Recognising, Assessing & Treating Pain in Dementia: The Experiences of Caregivers

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A thesis submitted in partial fulfilment of the requirements of the University of Greenwich for the Degree of Doctor of Philosophy

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DECLARATION

I certify that the work contained in this thesis, or any part of it, has not been accepted in substance for any previous degree awarded to me or any other person, and is not concurrently being submitted for any other degree other than that of Degree of Doctor of Philosophy which has been studied at the University of Greenwich, London, UK.

I also declare that the work contained in this thesis is the result of my own investigations, except where otherwise identified and acknowledged by references. I further declare that no aspects of the contents of this thesis are the outcome of any form of research misconduct.

I declare any personal, sensitive or confidential information/data has been removed or participants have been anonymised. I further declare that where any questionnaires, survey answers or other qualitative responses of participants are recorded/included in the appendices, all personal information has been removed or anonymised. Where University forms (such as those from the Research Ethics Committee) have been included in appendices, all handwritten/scanned signatures have been removed.

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ABSTRACT

Background & Aim: Pain presents a major challenge for people with dementia (PwD) and their caregivers. This thesis aimed to investigate the experiences of informal caregivers (IFCs) and care home (CH) staff supporting PwD, exploring how they recognise, assess, and treat pain among this population.

Method: This thesis is composed of two empirical studies. Study 1 undertook 18 interviews, exploring IFCs and CH staffs' experiences relating to pain among PwD. Study 2 implemented a mixed methods survey, expanding findings from Study 1, recruiting 115 IFCs, CH staff and nursing students. The survey consisted of open-ended questions exploring pain recognition and pain practices, and a quantitative component in the form of The Pain Knowledge and Beliefs Questionnaire (PKBQ) (Zwakhalen et al., 2007).

Findings: Qualitative data from Study 1 and 2 generated four main themes: *Deciphering Dementia; Relieving Suffering; Autonomy vs. Dependence;* and *The Pain of Caring.* Physical pain and its treatment were not a primary concern for caregivers. It was overshadowed by competing needs, normalised, and complicated by dementia-related changes, noncompliance, and uncertainty about pain medication. Pain was recognised and assessed informally, through individualised approaches, dyadic relationships, and interpretation of bodily narratives. A reliance on simple pain medication and non-drug approaches was described. Caregivers' roles, and responsibilities for pain identification and treatment were delineated by a hierarchy.

Quantitative findings from the PKBQ highlighted deficits in caregivers' understandings of pain medication use amongst older adults and PwD, and maladaptive beliefs.

Conclusion: This thesis provides an in-depth understanding into the recognition, assessment, and treatment of pain amongst community dwelling PwD, and those living in care homes, from the perspectives of caregivers in central, 'front-line' roles. These findings have implications for dementia care provision, pain practices, and caregiver training.

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LIST OF ABBREVIATIONS

CA- Care assistant
CH- Care home
CNA- Certified nursing assistant
CR- Critical realism
IFC- Informal caregiver
LPN- Licensed practical nurse
NA- Nursing assistant
NH- Nursing home
OPAT- Observational pain assessment tool
PAT- Pain assessment tool
PKBQ- The Pain Knowledge and Beliefs Questionnaire
PwD- People with dementia
RN- Registered nurse
RTA- Reflexive Thematic Analysis
ST-TA- Structured-Tabular Thematic Analysis
TA- Thematic Analysis

Chapter 1-Introduction: Contextual foundations of dementia & pain

1.1. Introduction

This chapter aims to situate this thesis within the wider literature, providing the reader with context for the empirical work presented in later chapters. To start with the broadest level of contextual foundations, the review commences with a discussion of the clinical construct of dementia and the practices of dementia care in the UK. This review brings into focus the provision of dementia care within the community, including care homes (CHs), and informal care, the latter most often being provided by informal caregivers (IFCs) who identify as primarily spouses or family members. The significant terms and concepts used throughout this thesis are explicated and defined.

Against this wider backdrop, pain as a pervasive issue for people with dementia (PwD) and their caregivers is discussed. The implications of untreated pain are explored, as are the developments and guideline recommendations focused on pain assessment and treatment. The practical challenges of applying these developments are explored, as is the evolving landscape of pain care in which increasingly CH staff and IFCs are becoming responsible for assessing and treating pain, alongside supporting, and advocating for PwD with pain relief. To conclude this chapter, an overview of the structure of this thesis and subsequent chapters are mapped out.

1.2. Dementia

The term ‘dementia’ refers to a progressive syndrome or cluster of symptoms that may include deterioration in memory, thinking, orientation, comprehension, calculation, language, judgement, and learning capacity (WHO, 2010). There is an estimated 850,000 people over the age of 65 living in the UK diagnosed with dementia, a figure estimated to increase to 1.6 million by 2040 (Wittenburg, Hu, Barraza-Araiza & Rehill, 2019a). Late-onset dementia is most common, with 95% of PwD affected over the age of 65 years (Prince, Bryce, Albanese, Wimo, Ribeiro & Ferri, 2013; Wittenburg et al., 2019a). Alzheimer's disease is the most common form of dementia, affecting two thirds of people living with the disease (National Institute for Health and Care Excellence (NICE), 2019). Vascular dementia is also common, with mixed diagnoses of Alzheimer's and vascular becoming increasingly prevalent (NICE, 2019). Alongside the symptoms of dementia, PwD are also functionally impaired. Declining cognitive status is associated with poorer mobility, frailty, weight loss and undernutrition (Albanese, Taylor, Sierco, Steward, Prince & Acosta, 2013; Tolea, Morris & Galvin, 2016;). Such can lead to increasing disability and mortality (Albanese et al., 2013). Psychological impairment is also an issue with an estimated 61% of PwD experiencing symptoms of depression, and 71% experiencing symptoms of anxiety (Enache, Winbald & Aarsland, 2014).

There is currently no cure for dementia, however symptoms can be managed, and evidence suggests it may be preventable (Prince et al., 2013; Livingston et al., 2017). Pharmacological treatments are available to slow disease progress for certain dementia conditions, alongside pharmacological and psychosocial interventions to manage behavioural, cognitive, and psychological issues. Research suggests that increasing childhood education and exercise, maintaining social engagement, reducing or smoking cessation, and the management of other conditions (such as depression, diabetes, hearing loss, hypertension and obesity) could prevent one-third of dementia cases (Livingston et al., 2017). Increasing age however, alongside ethnicity, are significant non-modifiable risk factors (Prince et al., 2013).

1.2.1 Evolving Perceptions of Dementia

The ‘standard paradigm’ (as termed by Kitwood, 1997), or biomedical model conceptualise dementia as disease of the brain, which can be controlled medically. The discourse of the biomedical model is diagnostic, curative and treatment orientated, as such a linear causal relationship between neuropathology and dementia is assumed. In recent years, conceptualisations of dementia, and dementia care correspondingly, have evolved. The biomedical model has been criticised for neglecting social and individual components of dementia, thereby having a negative effect on treatment approaches to dementia and the experiences of those living with dementia. Instead, broader frameworks of dementia which include neuropathology, alongside the role of social settings, relationships and personality have been developed. This has primarily encompassed the work of Kitwood (1990; 1997), and colleagues (e.g., Kitwood & Bredin, 1992; Brooker & Latham, 2016) and models of person-centred care (see 1.3.6). Through the concept of ‘personhood’ and models of person-centred care, the ethos of dementia care has shifted from a focus on treatment of patients with a *disease,* to *people living* with dementia, and approaches of care which support the latter.

An evolving view of dementia has also been mirrored in policy and public health initiatives. Over the last decade dementia has been increasingly recognised by both the UK and international policy as a public health priority (e.g., WHO Global action plan on the public health response to dementia 2017-2025). National dementia strategies[1] have seen health and social care policy increasing driven by

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[1] National policies relating to improving the care and lives of PwD. England (Department of Health, 2009; Prime Minister’s challenge on dementia, Department of Health, 2012); Scotland (The Scottish Government, 2010); Wales (Welsh Government, 2011); Northern Ireland (Department of Health, Social Services and Public Safety, 2011).

ambitions to improve access to dementia care and care provision. Dementia has also become more ‘visible’ against a backdrop of charity and policy initiatives to promote public awareness and understanding of the disease and create community and care contexts which are ‘dementia friendly’ (e.g., Alzheimer’s Society Dementia Friends and The Butterfly Scheme).

1.2.2 Dementia care provision in the UK

In the UK dementia care is primarily provided by care homes (CHs) and informal or formal care in the community. It is estimated in England approximately 251,000 of PwD live in CHs (Wittenburg et al., 2019b). A significant proportion (80%; 201,000) of the CH population have dementia, usually in the late stages where challenges in communication, continence and other long-term conditions are present (Thraves, 2016). As such, CHs play a significant role in the provision of dementia care, often supporting with the management of dementia symptoms, alongside complex comorbidities and increasing dependency. It is estimated a further 400,000 PwD live in the community in England (Wittenburg et al., 2019b). A small proportion (90,000) receive some paid care, most often in the form of visits from domiciliary carers (Wittenburg et al., 2019b). However, a large proportion (258,000) of those living in the community do not receive any paid care, relying on their own resources and primarily familial caregivers (Wittenburg et al., 2019b).

For staff working in CHs, and among family caregivers, supporting PwD presents unique challenges, due to the complex, unpredictable and progressive nature of the illness (Newbronner, Chamberlain, Borthwick, Baxter & Glendinning, 2013).

The following section will explore dementia care in these two contexts, touching on the experiences of those most central to dementia care within each.

1.2.2.1 Care homes

Care homes (CHs) are providers of formal long-term care, offering care and support in a residential setting, primarily to the ageing population (Luff, Ferriera, Meyer, 2011). The level of support provided in CHs may vary, including those that provide support with personal and basic care; those providing nursing care; and those defined as dementia-specialist care (Luff, Ferreira & Meyer, 2011). Although there is some variation in terms given to CHs that provide different levels of care (e.g., Nursing home (NH); Elderly Mentally Infirm NH), CHs serves an umbrella term in the UK. While PwD may often be hospitalised or utilise primary care, it is within CHs that every-day, long-term care is provided if community care is no longer an option.

Dementia care in CHs is delivered by a workforce of nurses and direct care staff, but primarily the latter who account for 82% of the workforce in the UK (The state of the adult social care sector and workforce in England, 2018). CHs which provide nursing care have registered nurses present consistently, whereas CHs providing residential care will receive visits from registered nurses (RNs) and primary care (General practitioners) (Department of Health, 2016). There has been a significant decrease in RNs working within health and social care contexts in the UK (Skills for Care, 2020). This, alongside the increased workloads among nurses and physicians, and reduced time with patients, means that the bulk of care for our ageing population is provided by direct care staff, with varying levels of preparation and training (Cavendish, 2013). In CHs therefore, direct care is most often provided by unregistered staff, including health care assistants (HCAs) (carers, care workers, nurse auxiliaries, healthcare support workers, and personal support workers), and senior carers (senior care workers, or senior care assistants). In the current works, the terms registered (nurses) and unregistered (e.g., healthcare assistants, senior carers) are adopted to delineate these roles among CH staff, and the associated differences in training and professional preparation required to undertake them. Other roles are also present in the CH setting, including management, domestic and wellbeing/activity coordinators. HCAs are responsible for providing personal care, maintaining patient hygiene, assisting with eating and toileting, providing social interaction, offering psychological support, and assisting with domestic duties (Cavendish, 2013). Senior carers work alongside HCAs, overseeing HCAs, and taking on more administrative and patient monitoring duties. With increasing demands on care from the growing ageing population, unregistered staff roles, have become central in CH settings. More recently and following the completion of this study, the nursing associate role has been introduced (since 2019) in the UK (Health Education England, 2015). This role aims to bridge the gap between HCAs and RNs, requiring 2 years of training and registration with the Nursing & Midwifery Council (2018). Collectively, these staff roles in CHs may all be considered formal caregivers, as opposed to informal caregivers who are not employed to provide care

The increasing provision of dementia care in CHs has placed considerable demands on the skills and training of the workforce, as has increasing pressure to improve dementia care arising from public expectations, regulatory requirements and media coverage highlighting examples of poor care. Such has led to growing recognition that CH providers must upskill and train workforces, so they are prepared to meet the needs of this population (e.g., Department of Health, 2014. Living well with dementia: a National Dementia Strategy). The introduction of The Care

Certificate in 2015, alongside the 13 fundamental requirements[2] of the Quality Care Commission (QCC), require that health and social care providers ensure all staff are suitably qualified and competent in the provision of basic, dignified care. Despite this, there are large variations in the training given to CH workforces and subsequently their competencies (Cavendish, 2013; Smith, Parveen, Sass, Drury, Oyebode & Surr, 2019). A recent review of the health and social care workforce found around two thirds (62%) of direct care staff, such as HCAs, had not engaged with or completed a Care Certificate and around half hold no qualifications relevant to social care (Skills for Care, 2019). Other training is more common in the workforce, with many more likely to have completed mandatory training in moving and handling (75%), safeguarding adults (71%) and health and safety (63%). More specific training relevant to dementia is a problem area. A report by the All-Party Parliamentary Group on Dementia (2009) concluded even CHs promoting themselves as ‘specialist dementia CHs’ have low training levels, and it is estimated a third of CH workers receive no dementia training at all (Alzheimer’s Society, 2016). Alongside poor availability of training, the quality of training is an issue. A review of training packages on person-centred care for CHs found of 27 forms, only 3 were evidence-based (Fossey, Masson, Stafford, Lawrence, Corbett & Ballard, 2014). The Dementia Training Standards Framework (Skills for Health, Health Education England & Skills for Care, 2015; 2018,) sets out essential learning outcomes for health and social care workforce to deliver successful dementia care. However, there is currently no mandated requirements for accredited dementia training in CHs (Smith et al., 2019). As such there no standardised approach to essential content for

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[2] QCC fundamentals standards are those which providers must not fail. They include person-centred care; dignity and respect; consent; safety; safeguarding from abuse; food and drink; premises and equipment; complaints; good governance; staffing; fit and proper staff; duty of candour; and display of QCC ratings. https://www.cqc.org.uk/what-we-do/how-we-do-our-job/fundamental-standards

dementia, nor any accreditation to provide assurance in the quality of training provided (Smith et al., 2019).

A lack of training and preparation for the demands of their role, the CH workforce must also negotiate other challenges. Unregistered staff receive relatively poor pay[3] and there is high staff turnover across the health and social care sector (Skills for Care, 2019). Such often leads to understaffing and increasing pressure on the remaining workforce. Those working in CHs and supporting PwD also experience high physical and psychological workloads, which can lead to symptoms of burnout, including emotional exhaustion, depersonalisation, and feelings of poor personal accomplishment or self-efficacy (Edvardsson, Sandman, Nay & Karlsson, 2008; Duffy, Ovebode & Allen, 2009; Brodaty, Draper & Low, 2003; Evers, Tomic, & Brouwers, 2001). Burnout, psychological distress, and low self-efficacy can have negative implications for staff in relation to the quality of dementia care provided, and their attitudes towards ageing and dementia (von Dras, Flittner, Malcore & Pouliot, 2009: Tadd et al., 2011). However, the CH workforce also recognises the importance of their role in landscape of dementia care. HCAs acknowledge the emotional, ethical, and moral challenges of their role, yet also describe personal commitment and a sense of purpose and reward (Law, Patterson & Muers, 2019). Care staff in CHs have described their role as one of unique understanding, in which they become attuned to the needs and perspectives of those they care for (Coates & Fossey, 2016). They form close relationships which are seen to act as a protective

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[3] CH workforce is predominantly unskilled or professionally unprepared. Staff receive relatively poor pay (a healthcare assistant will receive between £8.21- £9.81 per hour) and there is high staff turnover (39.5%) (Skills for Care, 2019). Around half of the workforce is employed as full time, on average staff spend 4.5 years working within one role and 9.2 years working in the social care sector. Around 84% of workers in care only home services were female, and the average worker was 43 years old. The nationality of the workforce is predominately British (85%), the remaining being 7% EU (non-British) and 8% non-EU

mechanism, allowing staff to see the person, not the disease, while managing the more negative or potentially challenging aspects of their work (Tablot & Brewer, 2015; Schneider, Scales, Bailey & Lloyd, 2010).

1.2.2.2 Informal care in the community

Community dwelling is defined as PwD who live in private residents, not nursing or care home settings (Hunt et al., 2015). A large proportion of PwD, 63.5%, remain living in private households within the community, and therefore their support needs are often the responsibility of family members or informal caregivers (IFCs) (Alzheimer's Society, 2007; Wittenburg et al., 2019a). IFCs are defined as people who look family members, friends, or others in a non-professional/informal capacity because of long-term physical or mental ill-health/disability or care needs arising from old age (Department of Health and Social Care, 2016).

There are 700,000 IFCs supporting PwD in the UK[4], they are predominantly female, retired and over the age of 65 (Lewis, Karlsburg, Sussex, O'Neil & Cockcroft, 2014). The reliance on this 'invisible workforce' of unpaid carers has been underpinned by several factors, including increasing pressure on health and social care services (Department of Health, 2015: *Delivering major improvements in dementia care and research*); older peoples' preferences for, 'ageing in place'; and the increasing 'professionalisation' of the role of IFCs (Glasby & Thomas, 2019). As a result of these changes many PwD who might have previously been supported in CHs remain in the community (Glasby & Thomas, 2019). Alongside relieving the

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[4] This group is predominately female (70%) and spends more than 100 hours per week caring (Lewis et al., 2014; Survey of Adult Carers in England, 2016-17 (SACE)). Unsurprising given the time dedicated to caring, 63% of IFCs are retired and a further 15% indicate they are unable to work due to their caring commitments (SACE, 2016-2017). For many (30%) they have been a carer for a person with dementia for 5-10 years, another 22% have been a carer for over 10 years (SACE, 2016-2017). IFCs in the UK are providing care to the value of £13.9 billion a year, saving the state over 60% of the costs (Wittenburg et al., 2019a; Wittenburg et al., 2019b).

pressure on services and providing significant cost savings to the state (Wittenburg et al., 2019), PwD supported by a family member are less likely to be hospitalised or moved into residential care and have better quality of life compared to those living in residential care (Mittleman, Hayley, Clay & Roth, 2006; Hoe, Katona, Orrell & Livingston, 2007).

There is increasing recognition in UK policy and dementia guidance that recognises that IFCs provide a substantial body of care to PwD (Department of Health, 2009; National Institute for Care & Excellence, 2018). As such, IFCs should receive the necessary support to enable them to assist PwD to live as well as possible. This encompasses evaluating the support needs of IFCs and including them within care decisions and care planning (NICE, 2018). Support for IFCs may be offered through the state, self-funded or charitable organisations and delivered via respite care, day-centre care, domiciliary care visits and support groups. However, in practice obtaining support for themselves and their cared-for can be challenging. Only half of carers report having their needs accessed; a third report having no access to respite care; and a further fifth report being offered unsuitable respite care (Newbronner et al., 2013). Furthermore, IFCs report experiencing structural stigma and inequality in health and social care in which they are confronted with services which are challenging to access, providers who lack dementia knowledge or information, and significant delayed diagnosis of their cared-for (Knapp & Prince, 2007; Stokes, Combes & Stokes, 2014; Werner, Goldstein &Buchbinder, 2010; Speechly, Bridges-Web & Passmore, 2008).

Alongside these systemic challenges IFCs negotiate their own health and wellbeing related challenges. IFCs often neglect their own needs and are more likely to experience a catalogue of physical and psychological issues leading to burnout

(Etters, Goodall & Harrison, 2008; McCabe et al., 2016), such as depression (31% prevalence), increased stress hormones, compromised immune response, greater medication use and greater cognitive decline (Collins & Kishita, 2019; Mahoney, Regan, Katona & Livingston, 2005; Vitaliano, Young & Zhang, 2004). Stress and poor health among spousal caregivers can be a crucial factor underlying decisions to move spouses with dementia into long-term care (Umberson, Williams, Powers, Liu & Needham, 2006).

From the perspective of IFCs, supporting a PwD can be challenging. While the role can be seen fulfilling a duty, IFCs express feelings of inadequacy about their ability to provide the care needed (Werner et al., 2010). There are also feelings of disloyalty, as their role requires having to push the person, they support into confronting their symptoms and diagnosis (Werner et al., 2010). Deterioration of communicative and comprehensive ability also leads to frustration among caregivers, particularly so for spousal caregivers who express increasingly negative perceptions of relationship quality with the PwD supported (Clare et al., 2012; Davies et al., 2010; Massimo, Evans & Benner, 2013). For spousal caregivers the qualitative shift in the relationship requires them to adapt to evolving demands and changes to the spousal relational context, including identities (as a couple and individuals), shared life plans, routines, and interactions (Pozzebon, Douglas & Ames, 2016). They describe their change in identity to that of carer or a parental figure (Oyebode, Bradley & Allen, 2013).

It is clear that providing support for a PwD can be challenging, and there has been an overwhelming focus on the negative aspects of this role (Semiatin & O’Connor, 2012). However, caregivers recognise there are benefits, such a sense of spiritual and personal growth, gratification, feelings of mutuality in the dyadic relationship, a sense of family cohesion and functionality, and a sense of purpose in life (Sanders, 2005; Yu, Cheng & Wang, 2018). The negotiation of their role appears to relate to IFCs self-efficacy or their perceived ability to manage the demands of their role (Semiatin & O'Connor, 2012). Similarly, to the CH workforce, self-efficacy is an important buffer in protecting IFCs, with it being related to reduced depressive symptoms (Gilliam & Steffen, 2004).

1.3 Pain in people with dementia

The concept of pain varies in its definition. A widely used definition in the field of pain management and a touch stone for many clinicians and care providers alike is that provided by McCaffery (1979). McCaffery (1979, p.14) stated that *"Pain is whatever the person says it is, and always exists when a person says it does".* A further frequently used definition of pain comes from the International Society for the Study of Pain (IASP): *"Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage"* (Merskey & Bogduk, 1994, p. 209). These definitions have been widely accepted and often guide clinicians and care providers in their assessments of pain, injury and the extent of impairment. However, these definitions need to be considered judiciously. While they capture the subjective physical and emotive aspects of the experience, they imply a necessity for pain to be expressed or communicated, and such, may not be applicable to those with cognitive and communicative impairment and those with a diagnosis of dementia. Acknowledging this shortfall, the IASP the following notes to the definition:

> *"Pain is always subjective. Each individual learns the application of the word through experiences related to injury early in life." (*Merskey & Bogduk, 1994, p. 210)
>
> *"The inability to communicate verbally does not negate the possibility that an individual is experiencing pain and is in need of appropriate pain-relieving treatment." (*Merskey & Bogduk, 1994, p. 210)

This more inclusive definition is now accepted and has been used as the foundation for subsequent worldwide definitions.

Pain can be classified in several ways. It may be classified by temporal domains of acute and chronic. There is some variation in the time continuum, which is used to distinguish temporal domains of pain, commonly chronic pain is classified as that which persists for more than 3 months, continuing past normal healing time (Merskey & Bogduk, 1994). Chronic pain may further be defined by epidemiology, including (but not limited to), chronic cancer pain and chronic post-surgical or post-traumatic pain (Treede et al., 2015). While chronic pain commonly presents following injury or disease, it is not only an accompanying symptom, but has been described as a condition in its own right (Mills, Nicolson & Smith, 2019). Acute pain is that which is more transient and diminishes following tissue healing. Pain may further be classified by its intensity, including mild, moderate, and severe.

Pain in the context of this thesis carries a myriad of definitions, academically it subscribes to that accepted globally from IASP, with its latter additions, but in a practical sense it subscribes to much more. Pain is experience which is subjective, individually unique and may take on many manifestations and meanings to those who live it (Coghill, 2010). Pain is conceptualised and responded to through an interplay of multiple experiences and meanings. Personal, historical, and experiential conceptualisations of pain can affect how we interpret its presence and manifestation in others (Orgeta, Orrell, Edwards, Hounsome & Woods, 2015). Culture too may influence how pain is communicated by a sufferer, their pain beliefs and coping strategies, and the responses of others to pain in another (Sharma, Abbott & Jensen, 2018). It is important to acknowledge this subjectivity and potential source of bias in the assessments we make relating to others pain. Conceptualisations of pain and pain assessment have reflected on the biopsychosocial and multidimensional nature of pain as an experience for a sufferer, and as experience interpreted by an observer (Snow et al., 2004; Hadjistavropoulos et al., 2002). These frameworks acknowledge the intrinsic, intrapersonal, and contextual factors which may shape how pain may be experienced, communicated, and observed/understood by others (Snow et al., 2004; Hadjistavropoulos et al., 2002).

1.3.1 Prevalence of pain in older people

Older adults have the highest rates of surgery, hospitalisation, injury, and disease, and thus are particularly vulnerable to pain (Gibson & Lussier, 2012). Research exploring the prevalence of current pain indicates pain to be present in 20-46% of older adults living in the community (Bergh et al., 2003; Lichtenstein, Dhanda, Cornell, Escalante & Hazuda, 1998). For those living in CHs, perhaps unsurprising due to anticipated greater health issues, prevalence is higher ranging from 20-73% (Weiner, Peterson, Ladd, McConnell & Keefe, 1999: McClean & Higginbotham, 2002; Tsai, Tsai, Lai & Chu, 2004; Asghari, Ghaderi & Ashory, 2006; Boerlage, van Dijk, Stronks, de Wit & van der Rijt, 2008; Dos Reis, de Vasconcelos Torres & Dos Reis, 2008). For pain which is persistent, it is estimated to affect between 25-76% of older adults living in the community (Bergh et al., 2003; Elliot, Smith, Penny, Smith &

Chambers, 1999; Blyth, March, Brnabic, Jorm, Williamson & Cousins, 2001; Blay, Andreoli & Gasta, 2007; Yu, Tang, Kuo, Yu, 2006; Sa, Baptista, Matos & Lessa, 2008; McCarthy, Bigal, Katz, Derby & Lipton, 2009), and 83-93% of older adults living in CHs (Boerlage, et al., 2008; Weiner et al., 1999; Zanocchi, et al., 2008). These wide-ranging estimates reflect the difficulty in determining comparative figures of prevalence in studies using diverse definitions of pain, populations and methods of measurement (Abdulla et al., 2013). While these figures should be interpreted with caution and within their methodological limitations, it remains reasonable even within the lower estimations of pain to suggest at least a fifth of older adults are living with pain (Abdulla et al., 2013).

1.3.2 Prevalence of pain in dementia

95% of the UK dementia population are over the age of 65 years (Prince et al., 2013). In light of pain prevalence figures for older people, it is likely PwD similarly often live with persistent pain, if not more considering the presence of significant comorbidities and issues in communication within this group (Achterberg et al., 2013). Prevalence figures of 19.8% (Achterberg et al., 2010), 48% (Barry, Parsons, Passmore & Hughes, 2015) and 67.6% (Lukas et al., 2013) have been found among PwD. More recent estimations from the UK indicate just over a third of PwD in CHs are living in pain (Rajkumar et al., 2017). A survey of 100 UK CHs found a slightly lower figure, with 37% of CHs indicating 25% or less of their dementia residents were affected by pain, and 31% indicating between a quarter to half (Napp Pharmaceuticals, 2014). For PwD living in the community prevalence figures are higher (63.5%) (Hunt et al., 2015), as are for those in acute settings (57%) (Sampson et al., 2015). This lack of consensus in relation to prevalence is likely underscored by methodological disparities across studies (Rajkumar et al., 2017). Caution should be taken in interpreting figures for a population that is known to experience communication challenges and exhibit behaviours which can mask pain. However, leading authors and researchers maintain that pain is a significant issue for PwD and estimate it impacts around 50% of this population (Corbett et al., 2012; Achterberg et al., 2013).

1.3.3 Causes of pain among older people & people with dementia

Older people and PwD are at increased risk of the development of painful conditions and comorbidities. For older people common pain complaints include osteoarthritic back pain (65%); musculoskeletal pain (40%); peripheral neuropathic pain commonly related to diabetes or postherpetic neuralgia (35%); and chronic joint pain (15-25%) (Denard, Holton, Miller, Fink, Kado, & Marshall, 2010). Likewise, comorbidities are a source of significant pain, 91.8% of older adults with dementia have twice as many comorbidities as those older adults without dementia (Browne, Edwards, Rhodes, Brimicombe & Payne, 2017; Pablador-Plou et al., 2014). Common comorbidities among older people and those with dementia include hypertension; stroke; diabetes; visual impairment; pressure ulcers; gastrointestinal infection; gastrointestinal complications such as peptic ulcers, intestinal obstruction, and peritonitis; cardiac issues like ischemia and myocardial infarct, and issues relating to the skin (Horn et al., 2002; Black et al., 2006; Corbett et al., 2012; Bunn et al., 2014; Browne et al., 2017). PwD are also vulnerable to poorer recovery outcomes following surgery, and preventable conditions, including fractures and infections (Kassahun, 2018; Scrutton & Brancati, 2016).

Pain may further arise from substandard care or poor access to services. Reports reveal that PwD receive the poorest quality care in several areas, pain being among a myriad on unmet needs (Alzheimer’s Society, 2016b; Alzheimer’s Society, 2018). While equitable access to NHS services for all are enshrined in the NHS constitution[5], PwD often receive inadequate or timely access to primary, secondary and mental health care services (Alzheimer’s Society, 2016a; 2016b). Access to vital areas of services including GPs, dentistry, and physiotherapy, can lead to ongoing unmet needs in many areas and escalation of illness or conditions.

1.3.4 Impact of dementia on pain experience & expression

Dementia can impact an individuals’ ability to express pain. While it is thought that PwD perceive painful stimulus as others do, their ability to remember, interpret and respond to pain is altered by the neuropathological changes of the syndrome (Benedetti, Arduino, Vighetti, Asteggiano, Tarenzi, & Rainero, 2004). This may result in loss of semantic memory, in which PwD are no longer able to identify painful situations or describe what pain means (Oosterman et al., 2014). Similarly, due to cognitive and communicative decline, PwD may not be able to express their pain verbally, necessitating behavioural and non-verbal communication, such as agitation, combativeness, aggression, grimacing, wandering and social withdrawal (Closs, Cash, Barr, & Briggs, 2005). These changes may have significant implications not only in terms of how pain is expressed or understood, but also for how pain is assessed and treated.

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[5] The NHS Constitution for England 2015 https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england

A body of experimental studies have investigated if neurodegenerative changes associated with dementia impact pain processing pathways and experience (across forms of dementia). A recent meta-analysis examined sensory pain experience among those with and without dementia (Stubbs et al., 2016). Whilst no significant differences were present for threshold, tolerance, heart rate response or intensity ratings, PwD had significantly raised facial expression scores. This suggested a potential amplified experience of pain. Research too suggests affective and cognitive components of pain may be subtlety different for PwD, compared to those without (Gagliese, Gauthier, Narain & Freedman, 2018). Evidence exploring different forms of dementia suggest that pain may also vary based on the form of dementia and associated differentiating neuropathological changes. Pain reflex and fMRI studies find that responses to painful stimulus among people with Alzheimer's disease are more pronounced, compared to those without dementia (Defrin et al., 2015). Those with Vascular dementia appear to have similar pain intensity to those without dementia, however, those with Alzheimer's Disease appear to suffer more from the pain (Scherder et al., 2015). Frontal temporal dementia may on the other lead to an increase in tolerance of pain and pain threshold (Bathgate, Snowden, Varma, Balckshaw, & Neary, 2001). Thus, dementia and different subtypes, may impact pain experience. However, further research is needed given the methodological limitations of current studies to fully understand and interpret the impact of dementia on pain experience (Corbett et al., 2012; Defrin et al., 2015).

1.3.5 Impact of pain on behavioural & psychological symptoms of dementia & wellbeing

Behavioural and psychological symptoms of dementia, including behavioural disturbances, psychological problems, and the deterioration of social behaviour, emotional control and motivation affect up to 90% of PwD (Achterberg et al., 2013; Feast, Orrell & Moniz-Cook, 2016). These symptoms may be experienced as agitation, aggression, calling out repeatedly, sleep-disturbance, resistance to care, wandering and apathy (Achterberg et al., 2013). Behavioural and psychological symptoms of dementia have a clinically significant impact, reducing quality of life for those with dementia and often triggering institutional care (Feast, Orrell & Moniz-Cook, 2016; Brodaty, Connors, Xu, Woodward & Ames, 2014). They are also the primary cause of caregiver burden, leading to depressive symptoms and health issues among caregivers (Pinquart & Sörensen, 2007). For formal or professional caregivers' aggressive behaviours resulting from behavioural and psychological symptoms of dementia are perceived to be one of the most complex aspects of care, increasing staff stress and burnout (Brodaty, Draper & Low, 2003). For IFCs and family members, behaviours associated to behavioural and psychological symptoms of dementia are seen as transgressing social norms, causing embarrassment and confirming a loss of 'personhood' or identity (Feast et al., 2016). To protect themselves and those they support from perceived degradation and stigmatisation, IFCs may choose to ignore symptoms or conceal them from the outside world through social distancing (Croog, Burleson, Sudilovsky & Baume, 2006; Lopez, Rose, Kenney, Sanborn & Davis, 2019). Through this IFCs may deny themselves peer support and access to services, increasing their burden (Werner & Heinik, 2008).

The aetiology of behavioural and psychological symptoms of dementia are multifactorial and complex. It is unclear if behavioural and psychological symptoms of dementia can be attributed as a symptom of dementia, or if behavioural and psychological symptoms of dementia are an expression of an alternative underlying cause (Flo, Gulla & Husebo, 2014). Theoretical models of dementia behaviour, including the unmet needs model and dementia-compromised behaviour model, have proposed that behavioural and psychological symptoms of dementia and ‘challenging’ behaviours may be a sign or expression of an unmet need among PwD (Algase et al., 1996; Cohen-Mansfield, 2000; Kovach, Noonan, Schlidt & Wells, 2005). These models indicate that pain is one such unmet need. It is also proposed that if these symptoms are unrecognised or misdiagnosed, this may lead to a cascading effect of new needs and behavioural symptoms, exacerbating primary needs and giving rise to secondary needs (Kovach et al., 2005). For example, arthritic knee pain gives rise to a primary need for analgesia and rest. Behaviourally this need may manifest as attempts to exit a place of care/care situation, which may result in a fall and fracture risk (an outcome). A secondary need will then develop, requiring analgesia, decompression of the fracture and increased assistance need with activities of daily living. A secondary outcome will be decreased appetite and increasing incontinence (Kovach et al., 2005). This proposed reciprocal relationship between pain and behavioural and psychological symptoms of dementia is supported by the literature (Corbett et al., 2012). A review of the literature investigating the link between pain and this cluster of symptoms, concluded there is an association between unmet pain and behavioural and psychological symptoms of dementia in people with dementia (Flo et al., 2014).

The relationships between pain and behavioural and psychological symptoms of dementia is concerning given that research suggests symptoms of agitation, and aggression arising from pain may be frequently inappropriately managed using antipsychotic medications among UK CH residents experiencing pain (Barry et al., 2014). Antipsychotics can have dangerous side-effects including increased mortality, cerebrovascular events, and an increased risk of falls (Briesacher et al., 2005; Ballard, Smith, Aarsland & Corbett, 2011). Pain relief may be a more appropriate intervention, with evidence finding that pain relief reduces agitation and behavioural and psychological symptoms of dementia, the use of psychotropics, and caregiver distress (Ballard, Smith, Corbett, Husebo & Aarsland, 2011; Aasmul, Husebo & Flo, 2016). UK policy recommendations indicate that pain should be considered as a potential driver for behavioural and psychological symptoms of dementia, in line with a push to reduce the unnecessary prescription of anti-psychotics for PwD (Department of Health, 2015).

Pain among PwD can also cause distress and discomfort, and is associated to declining cognitive impairment, depression, malnutrition, falls, sleep disturbance, and reduced social and functional activity among PwD (Herr, 2011; Corbett et al., 2012; van der Leeuw et al., 2016). This culmination can impact upon their ability to carry out daily tasks, thereby rendering PwD into dependency on caregivers and complicating care needs (Cipher & Clifford, 2004). For caregivers, the suffering of an individual they are supporting is both emotionally and mentally distressing to witness (Givens, Givens, Prigerson, Jones, & Mitchell, 2011). Evidence suggests among all symptoms experienced by PwD pain is reflected on by both PwD themselves and family caregivers as most distressing and bothersome (Murray, Sachs, Stocking & Shega, 2012). These implications, alongside the role of pain in aggravating behavioural and psychological symptoms of dementia, imply a real need for pain to be addressed appropriately among this vulnerable population.

1.3.6 Responding to pain in dementia care

Untreated pain will cause significant suffering, behavioural disturbance, and poorer quality of life, for both PwD and their caregivers. Responding to pain is this vulnerable group is imperative. Alongside the ethical tenets of beneficence and non-maleficence which oblige health care providers to respond to pain and suffering (Herr et al., 2011), the need to provide comfort, and respect and dignity are fundamental tenets of the NHS constitution and the Quality Care Commission[6] in the UK. Further, national clinical guidelines for the provision of dementia care highlight the centrality of needs assessment, which includes pain. The National Institute for Health and Care Excellence (NICE, 2012; 2018) highlight that not only should staff receive training relating to pain, but that structured observational pain assessment should be carried for those presenting with behavioural disturbance. These guidelines also advocate that assessment should be repeated for those suspected of having pain and following the administration of analgesia. Further in the quality standards for care in people with dementia, the management of distress, including pain, is highlighted as an area for quality improvement (NICE, 2010; updated 2019).

Pain also forms an important consideration of person-centred, or patient-centred care. Advocated as best practice in dementia (QCC[2]; NICE, 2018), and now synonymous with ‘good’ dementia care, person-centred care is that which is needs

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[6] QCC fundamentals standards are those which providers must not fail. They include person-centred care; dignity and respect; consent; safety; safeguarding from abuse; food and drink; premises and equipment; complaints; good governance; staffing; fit and proper staff; duty of candour; and display of QCC ratings. https://www.cqc.org.uk/what-we-do/how-we-do-our-job/fundamental-standards

driven, aiming to understand and meet individual needs. The incorporation of person-centred care into national policy documents for care services has been a key driver for improvements to care for this population (NHS, 2017). Person-centred care has been used as a composite term; the ethos has been incorporated into many proliferations in dementia care. As a framework, person-centred care in dementia care is primarily associated with the of Tom Kitwood (1997). Kitwood believed that in dementia, impairment, dissolving consciousness of thought and discontinuity of memory, can be interpreted a loss of a ‘core self’ by others, threatening the personhood of PwD (Kitwood & Bredin, 1992). Kitwood described personhood as *‘a standing or status bestowed upon human beings by others, in the context of relationships and social being’* (Kitwood, 1997, p. 8). If personhood is not acknowledged, or perceived as lost, those with dementia may not be treated as individuals. Personhood is bestowed by others through mutually trusting relationships and social interactions. Relationships and environments are central to maintaining it, just as they can erode it through depersonalisation (e.g., disempowerment, infantilism, and objectification) (Kitwood, 1990).

Kitwood (1997) emphasised the need to consciously adopt the patient’s perspective, and in his discussions around interpersonal processes discussed care as a meeting between persons. This meeting can be initiated by the PwD through a behaviour or a verbalisation which then requires another to recognise and respond. Through observation caregivers can recognise physical behaviours and emotional states as a ‘*reaching out into the social world’* despite cognitive or communicative decline (Kitwood, 1993, p. 214). Observation also allows caregivers to distinguish between states of well or ill-being. A state of wellbeing may be fostered by exploring what a person needs; the centre of all need is love, followed by comfort, attachment, inclusion, occupation, and identity (Kitwood, 1997).

In practice, person-centred care encourages those providing care to focus on the recipient of care and respond to their needs, rather than delivering care as a task-based routine activity (Kitwood, 1997). This encompasses attending to unmet basic needs, such as pain, and attending to how unmet needs may be communicated. Certainly Kitwood (1997) indicated that those striving to provide person-centred care should not neglect pain as a need, especially given that pain or discomfort is an indicator of ill-being (Bradford Dementia Group, 1997). Models of person-centred care proliferated from Kitwood’s (1997) work for use in practice have also advocated the centrality of acknowledging and responding to pain. The VIPS framework distils Kitwood’s (1997) approach into 4 core elements, including valuing (V) PwD and those who provide care for them; treating PwD as individuals (I); seeing the perspective of PwD (P); and positive social environment promoting wellbeing (S) (Brooker, 2004; 2006; Brooker & Latham, 2016). This approach highlights the importance of vigilance and responsiveness to changing physical wellbeing and the impact of physical environment. This entails staff understanding individual signs of pain among those being supported and potential triggers and causes for pain within the physical environment. More practically it involves a response, including assessing pain and observing PwD behaviours during care where discomfort or pain may be come to light (Brooker & Latham, 2016). Buron (2008) similarly presented a model of person-centred care which emphasises that to acknowledge someone at their most basic biological level, we must attend to pain as a universal experience of all sentient beings. In a similar vein, Hicks (2000) presented a patient-focused model of the ethical care for older people living in nursing homes. Hicks (2000) indicates that care given which disregards pain is unethical care, and care which erodes trust in provided-patient relationships and devalues patients. Care which is person or patient centred may therefore be seen as a holistic ethos to care that involves fulfilling basic needs, alongside supporting psychosocial needs.

1.4 Pain assessment in dementia

For pain to be appropriately treated, it must first be assessed, so that the possible causes and the severity of pain being experienced can be established (Achterberg et al., 2013). Pain assessment is also a concern for the ongoing monitoring of pain and for determining if a treatment has been effective in reducing pain (Corbett et al., 2012). The assessment of pain in PwD has clear challenges, given the decline in cognitive function, communication difficulties, and possible changes in pain expression associated with dementia. Assessment may involve differing processes, both formal and informal. The formal route will involve the use of standardised self-report or observational pain assessment tool (PAT). Alongside the national broader guidelines relating to dementia which highlight pain in relation to needs assessment, several pain specific guidelines and evidenced-based position statements[7] have been developed. These offer recommendations regarding the best practice approaches to identify and assess pain amongst ageing and cognitively impaired populations. The following highlights some of the core practice recommendations which should be considered when approaching pain assessment in dementia care.

Self-report methods of assessing pain are considered the first step of pain assessment and may be elicited through asking directly about pain or asking a

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[7] Royal College of Physicians, British Geriatrics Society & British Pain Society, 2007, The Assessment of Pain in Older People: National Guidelines; Schofield et al., 2018, The Assessment of Pain in Older People: UK National Guidelines; Herr et al., 2006; 2011; 2019, Pain assessment in the nonverbal patient: Position Statement with Clinical Practice Recommendations.

patient to complete a self-report PAT (British Pain Society & British Geriatric Society, 2007). While self-report can be complicated by cognitive impairment, it can still be reliable and accurate where pain recognition and verbalisation remains (Pautex, Herrman, Michel & Gold, 2007; Snow et al., 2009). Several studies have examined the use of common self-report rating scales in dementia, including the verbal rating scale (VRS), faces scale and numerical rating scale (NRS). It has been found 61% of patients with severe or late-stage dementia can understand at least one of these scales and identify positions for no pain and extreme pain (Pautex et al., 2006). For the VRS, around of a third of those with severe dementia are still able to provide a response (Closs, Barr, Briggs, Cash & Seers, 2004; Pautex et al., 2006). Other scales, such as the NRS and faces scale which require more discrimination between numerical and pictorial representations of pain, have been found to be less reliable among those with cognitive impairment (Pautex et al., 2006; Kaasalainen & Crook, 2004; Stolee et al., 2005).

As dementia progresses, the use of self-report can be less reliable, and some evidence suggests that around a quarter of CH residents in the UK are not able to provide a self-report of their pain (Cohen-Mansfield, 2002; Barry et al., 2014). This is not to say however, that those older adults with moderate to severe cognitive impairment should not be invited to self-report, using formal or informal means. Both national and international guidelines, and evidence-based recommendations for the assessment of pain among older people and non-verbal patients, recommend an approach to pain assessment that integrates self-report, alongside observations of pain behaviour (Royal College of Physicians, British Geriatrics Society & British Pain Society, 2007; Schofield et al., 2018; Herr et al., 2006; Australian Pain Society, 2019).

When self-report is not possible in dementia, or the accuracy of self-report is uncertain, observational methods can be used. While observational assessment may occur informally, standardised observational PATs have been developed for populations with communication problems or cognitive impairment (Herr, Coyne, McCaffery, Manworren & Merkel, 2011). Observational or behavioural PATs have been developed on the basis that they are universal behaviours and verbalisations from which it is possible to determine the presence of pain (Achterberg et al., 2013). These behaviours and verbalisations can include, but are not limited to: facial expressions (e.g. grimacing, closed eyes); verbalisations (e.g. moaning, shouting, loud breathing); bodily movements (e.g. fidgeting, pacing, restricted movement); changes in activities or behaviour (e.g. changes in appetite, disruptive behaviour, increased wondering); and changes to mental status (e.g. confusion, distress, irritability) (American Geriatric Society Panel on Persistent Pain in Older Persons, 2002). Observational tools or scales require an observer to rate the presence/absence of pain based on the intensity and frequency of these behaviours and verbalisations to provide a score or indication of likely pain (Herr et al., 2011).

A large number of observational PATs are available for use in dementia which vary in structure and content (Husebo et al., 2012). Several leading authors have dedicated critical discussion to the current evidence base supporting the use of observational pain assessment tools (e.g., Achterberg et al., 2013; Corbett et al., 2012; Lautenbacher, 2014). UK guidelines, and within international guidelines and research, have highlighted observational PATs which have the strongest conceptual and psychometric support, and clinical utility in dementia care (e.g., Royal College of Physicians, British Geriatrics Society & British Pain Society, 2007; Schofield et al., 2018; Litcher et al., 2014; Herr et al., 2006; Australian Pain Society, 2019). Those commonly recommended based upon available evidence of validation, include: The Abbey scale (Abbey et al., 2004), The Pain Assessment in Advanced Dementia Scale (PAINAD) (Warden, Hurley & Volicer, 2003), Doloplus (Lefebre-Chapiro, & The Doloplus Group, 2001) and The Pain Assessment Scale for Seniors with Severe Dementia (PACSLAC) (Fuchs-Lacelle & Hadjistavropoulos, 2004). At current due to a varying and under-developed evidence-base, no single PAT is currently recommended as sufficiently valid or reliable for broad adoption across dementia care (Herr et al., 2006; Schofield et al., 2018). Recent developments have produced a meta-tool, identifying the best items from across observation tools that may be most relevant for pain in dementia (Kunz et al., 2020).

Although no single tool is recommended, guidelines and position statements maintain that the most suitable (and validated where possible) tool for the level of patient impairment and clinical setting should be implemented (Royal College of Physicians, British Geriatrics Society & British Pain Society, 2007; Schofield et al., 2018; Herr et al., 2006, 2011; 2019). This tool should be completed or contributed to by an individual who is familiar with the patient and their unique behaviour and history (British Pain Society & British Geriatric Society, 2007). The latter is due to the large variability in pain expression and behaviours across individuals, thus familiarity with a dementia patient will help to identify behavioural indicators of pain to facilitate accurate and prompt interpretations of pain (British Pain Society & British Geriatric Society, 2007; Schofield et al., 2018).

The comprehensive assessment of pain is not only contingent on formal or informal methods of assessment. Assessment must be multimodal, performed along a hierarchy, which considers self-report where possible, identification of potential causes of pain and examination, patient history, observation of behaviour, and obtains proxy-reporting from family members/consistent caregivers (Herr et al., 2006; Herr, Coyne, McCaffery, Manworren & Merkel, 2011; Royal College of Physicians, British Geriatrics Society & British Pain Society, 2007; Schofield et al., 2018). It must further be documented so it can be communicated amongst different healthcare providers, monitored, and treated individually (Royal College of Physicians, British Geriatrics Society & British Pain Society, 2007; Schofield et al., 2018).

1.5 Pain treatment in dementia

The evidence base informing the effective treatment of different types of pain and specific forms of analgesia among the dementia population is incomplete. This is due to largely to the exclusion of both older people and PwD in clinical trials and pain treatment studies, which has limited our understanding of the pharmacodynamics of medication for this group (Atcherberg et al., 2013). The treatment of pain for PwD therefore tends to be informed by clinician experience, rather than the evidence per se (Atcherberg et al., 2013; Atcherberg et al., 2020). Guidelines[8] developed for the treatment of pain among older adults offers some insight as to how pain should be addressed among PwD. In addition, several authors have provided reviews of the limited evidence base to underpin recommendations for pain treatment in dementia (e.g., Corbett et al., 2012; Atcherberg et al., 2013; Atcherberg et al., 2020; Dunham et al., 2020). The following draws out the core considerations from these sources which should be made when managing pain in older adults (with or without dementia).

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[8] Abdulla et al.,2013, *Guidance on the Management of Pain in Older People;* American Geriatric Society (AGS), 2002; 2009, *Pharmacological management of persistent pain in older persons*.

The treatment of pain in dementia needs to be considered in light of the changes related to ageing in body composition and the subsequent ability to metabolise drugs (Abdulla et al., 2013). These changes can result in hypersensitivity to particular analgesia and pose a greater risk of increased side-effects. As such, lower dosages should be trialled and titrated (Abdulla et al., 2013). Secondly, the choice of pharmacological treatment should be stepwise; that is less potent options should be prescribed before more powerful analgesics are used. Paracetamol should be trialled first, followed by non-steroid anti-inflammatory (NSAIDs), and then opioids for moderate to severe pain causing functional impairment or a reduced quality of life (Abdulla et al., 2013). The WHO analgesic pain stepladder provides a model to guide the slow introduction and titration of analgesic medication, commencing with simple non-opioid analgesics, with a progression to weak opioids, and then strong opioids (Ventafridda & Stjernsward, 1996). A scheduled approach to administration should be used, as opposed to ‘as needed’ or ‘as required’ to insure consistent and safe pain relief (AGS, 2002; 2009; Corbett et al., 2012). All treatments need to be individualised and monitored, in light of drug-interactions and individual reactions (AGS, 2002; 2009; Abdulla et al., 2013;).

UK guidelines (Abdulla et al., 2013), along with the American guidelines (AGS Panel, 2009), recommend a dual approach to manage pain; using a combination of non-pharmacological and pharmacological strategies. Non-drug treatments may include assistive devices, repositioning, heat/cold therapy, physical activity/exercise, and complimentary therapies. However, the evidence base surrounding best options for older or impaired populations in terms of non-drug options is limited (Abdulla et al., 2013).

1.6 Pain assessment & management in practice

Clinical guidelines and position statements, alongside national policy and regulatory bodies, advocate the need to assess and manage pain among those with dementia. However, in practice this may not occur. This section explores the implementation of these recommendations and practical considerations within the context of CHs and informal dementia care within the community. It further considers the roles of caregivers in recognising and assessing pain and supporting those with dementia to receive pain treatment.

1.6.1 Pain assessment & management within care homes

While guidelines and recommendations do exist in the UK, as it stands there is no unifying set of guidelines which leaves room for geographical inconsistency and variation in approaches to pain management in practice (Napp Pharmaceuticals, 2014; Corbett et al., 2016). Similarly, the availability of specific guidelines for the management of pain for PwD is an issue, which contributes to the challenges of optimally addressing pain treatment in this group (Corbett et al., 2016; Rajkumar et al., 2017). In a review of existing guidelines available in UK CHs to inform pain assessment and management among residents with dementia, 15 documents were identified, however only 3 were developed for PwD, and none were specific to CH settings (Corbett et al., 2016). There were further largely inaccessible for non-specialists working in these contexts and untrained caregivers. Such likely explains why in a survey of 100 CHs in the UK, 22% had no written guidelines in place for assessing pain among the cognitively impaired (Napp Pharmaceuticals, 2014). This indicates that current guidelines may be inaccessible to those who provide daily care for PwD, and they are poorly used in CH settings. Currently, the development of guidelines which can provide an appropriate resource for all caregivers, and which are evidence-based, will be difficult to achieve while other areas require further development to inform them.

There is also evidence to suggest that developed PATs have had limited impact upon practice (Torvik, Nordtug, Brenne & Rognstad, 2015; Achterberg, Lautenbacher, Husebo, Erdal & Herr, 2019). The value of PATs to practice depends on implementation, and evidence suggests among trained and untrained staff working in CHs, community care and hospitals across Europe and internationally, uptake is poor (Liu et al., 2011; Peisah et al., 2014; Zwakhalen et al., 2018). The practical application of PATs can too be challenging. Estimating a multi-dimensional and subjective experience of pain on behalf of another person can be unreliable, with evidence suggesting caregivers may either overestimate or underestimate pain experienced by PwD (Barry et al., 2014; Apinis, Tousignant, Arcand & Tousignant-Laflamme, 2014). Assessment may too be complicated by dementia, in which reports are only made at the point of experience (in the here and now) due to memory impairment, or it is expressed unexpectedly (e.g., stillness, quiet and withdrawnness) (Leong & Nuo, 2007; Kaasalainen, 2007). Some of these challenges can be overcome when assessment and interpretation of behaviour is carried out by a caregiver in daily contact with the person with dementia (Cohen-Mansfield & Lipson, 2008). However, time and opportunity for caregivers to develop close working relationships and carry out a thorough assessment integral to identifying pain may also be limited by environmental challenges. CH staff in particular report increasing competing demands on their time, staff shortages, increasing paperwork and reduced time with patients (Coates & Fossey, 2016; Talbot & Brewer, 2015).

Further, PATs have primarily been developed with engagement with doctors, expert panels, nurses, and other caregivers (Corbett et al., 2012). There are questions therefore about the whether these scales are user-friendly to all caregivers, or all levels of training and education (Corbett et al., 2012). While some have included those caregivers without professional preparation in their development (e.g., Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC), Fuches-Lacelle & Hadjistavropoulos, 2004), they have primarily been developed from the viewpoint of clinicians. While pain assessment (informal and formal) and treatment has typically been seen as the responsibility of professional caregivers, with an emphasis on the experiences of nurses (Holloway & McConigley, 2009), earlier discussions about those responsible for providing daily care in CHs and other contexts highlights the integral role of untrained and unregistered care staff, specifically HCAs and senior carers. The landscape of care has evolved, and responsibilities for pain need to be reconsidered in line with the workforce responsible for providing the bulk of dementia care (Andrews et al., 2019). In recognition of such, a PAT has been developed aiming to provide a simple, less cumbersome formal assessment for PwD which is accessible to unregistered staff working in long-term care settings (Certified Nursing Assistant Pain Assessment Tool (CPAT) (Cervo et al., 2007; Cervo, et al., 2009; 2012). Certainly, evidence suggests professionally untrained or unregistered CH staff are routinely assessing pain. A survey of 100 CHs across the UK found 46% report that untrained staff are responsible for assessing pain among PwD (Napp Pharmaceuticals, 2014). This assessment is likely to be informal however, given that untrained and unregistered staff, such as HCAs, do not receive training in formal pain assessment (De Witt Jansen et al., 2017a). It is unsurprising that unregistered staff roles are assuming responsibility for identifying pain. Daily care routines allow HCAs to develop close physical and social contact with PwD which provides them with a greater knowledge and understanding of the normal behaviour, routines, preferences, mood, appetite and disposition of those under their care (Wilson, Davies & Nolan, 2009; Morgan et al., 2016). Given that familiarity with a PwD is a central aspect of pain assessment and discriminating the meaning of behaviours, HCA and equivalent roles may be best placed to identify and assess pain (Herr et al., 2011). Certainly, evidence suggests that certified nursing assistants (CNAs) are sensitive to pain, and more so than other forms of assessment (Fisher et al., 2002). Fisher et al. (2002) advocated several years ago the inclusion of CNAs into the multimodal assessments of cognitively impaired nursing home residents.

An important side note of pain assessment is that its identification may not necessarily lead to action, and pain may not be regarded as a priority. A survey of nursing homes found that for many residents who reported being in pain, there is no history of pain recorded in their case notes (Achterberg, Pott, Scherder & Ribbe, 2007).

The treatment of pain in CHs has also been found to be ineffective. Studies worldwide have identified PwD receive significantly less pain treatment compared to cognitively intact older adults (Horgas & Tsai, 1998; Husebo, Strand, Moe-Nilssen, Borgehusebo, Aarsland & Ljunggren, 2008; Cornali, Franzoni, Gatti & Trabucchi 2006; de Souto, Lapeyre-Mestre, Vellas & Rolland, 2013), even for the same painful conditions (Morrison & Sui, 2000). For example, one study reported that despite similar rates of pain related conditions, 56% of nursing home residents with severe cognitive impairment received pain medications, compared to 80% of residents without cognitive impairment (Reynolds, Hanson, DeVellis, Henderston, &

Steinhauser, 2008). Survey data from the UK revealed that out of 100 CHs, 54% reported less than half their residents were currently taking analgesics (Napp Pharmaceuticals, 2014). A combined approach of non-drug and pharmacological strategies was also only used for 10% of PwD living in NHs (Liu & Leung, 2017), despite recommendations endorsing this as best practice.

In contrast, Haasum, Fastbom, Fratiglioni, Kåreholt and Johnell (2011) found an increased use of pain relief in the PwD comparative to cognitively intact older adults. A higher use of paracetamol among PwD was documented, but no differences in use of opioids or NSAIDs were observed. These findings have been interpreted as suggesting a growing awareness of pain among PwD (Haasum et al., 2011). However, they could equally suggest a willingness to administer paracetamol but not stronger drugs. A UK based study found that 88.1% of CH residents with dementia received one or more analgesics, most often paracetamol and codeine (Barry et al., 2014). However, other pain management options, such as opioids or drugs for neuropathic pain, and anti-inflammatory drugs, were less commonly used, with them prescribed 14.3%, 11.9% and 19% respectively (Barry et al., 2014). This would suggest that PwD may be in receipt of less powerful pain relief and that other drug options are not used frequently. In addition, just because PwD might be receiving more pain relief, it does not necessarily mean their pain is being treated appropriately. Pain relief may fall short of prescription recommendations. For opioid pain relief, PwD receive a third of the dosage compared to cognitively intact older adults (Morrison & Sui, 2000). Analgesia also tends to be given ‘as needed’ rather than according to a fixed scheduled in dementia (Barry et al., 2014), suggesting pain relief may not necessarily be timely. This body of evidence suggests that PwD are often being prescribed, administered, or taking sub-optimal pain treatment than necessary to provide effective relief.

While this body of evidence likely refers to the role of professional healthcare providers in the context of CHs and providing pain treatment, in line with the need to free up the time of registered nurses, HCA and senior carers can be delegated medicine administration (Spilsbury, Baker & Alldred, 2017). Registered nurses or general practitioners remain responsible for the prescription of medications and instructions on their use in CHs. HCAs, providing they are suitably trained and competent, can administer medicines, including those relating to pain (Department of Health, 2016). While an HCA may therefore not necessarily control dosage or scheduling (unless it is prescribed 'as needed', in which case they will need to use their clinical judgement), they can be involved in the process of pain treatment. It is recognised that older adults in CHs rely on staff to support with administration of prescribed medicines (Centre for Policy on Ageing, 2012). Responsibilities and guidelines for pain treatment and medications must therefore be reconsidered with those increasingly involved in medication administration for pain management.

1.6.2 Pain assessment & management within informal community care

Turning to pain assessment and treatment within informal dementia care and the role of IFCs, this is similarly an evolving situation given increasing numbers of community dwelling PwD. In terms of pain assessment, many will likely have no knowledge of formal pain assessment tools (PATs), however informally it is likely they have a central role in pain assessment. Similarly, to HCAs, due to their innate closeness to family members or friends they are supporting, IFCs are vital sources of knowledge (Nguh, 2013). This knowledge may play an integral role via two routes, firstly by informing their own caregiving behaviours (e.g., offer pain relief to their loved one or seek support from healthcare providers). Secondly, it might be used to improve pain care provided to their loved ones by others. Research indicates family involvement allows older adults living in long-term care to receive more timely and appropriate pain management than they otherwise might without family input (Alexander, Plank, Carlson, Hanson, Pickenx & Schwebke, 2005). Nurses refer to family to learn the life story of a PwD and how to interpret pain behaviours (Brorson, Plymouth, Örmon & Bolmsjö, 2014). This suggests that IFCs can offer vital information regarding the assessment of pain, and healthcare providers acknowledge such. Further evidence suggests that IFCs of PwD can discriminate pain using observational pain assessment tools developed for long-term care staff (Ammaturo, Hadjistavropoulos & Williams, 2017).

The role of IFCs is not only in pain assessment, but also within pain treatment through their responsibility in medication management. As dementia progresses, there is a transition from self-management of conditions to dependency. While strategies could be adopted to support self-management, such as memory aids and dosette boxes, over time these cease to be effective (Bunn et al., 2016). There is then a shift to increasing reliance on family caregivers or IFCs, as the risks of over medication, non-adherence and medication errors increase due to declining cognitive function (Bunn et al., 2016; Lim & Sharmeen, 2018). IFCs can become responsible for medication prescription ordering and acquisition, collection, dispensing into adherence aids, administration of medicines, prompting self-management, and monitoring of adherence (Lim & Sharmeen, 2018; Barry et al., 2020). These responsibilities can be complex, dependent on the complexity of the medication regime and the health literacy of the IFC (Lim & Sharmeen, 2018;

Gillespie, Mullan & Harrison, 2013), increasing the burden on caregivers (Maidment, Aston, Moutela, Fox & Hilton, 2017). IFCs become the decision maker about if and how much medication should be given, such might be based on their own assessments, or their understanding of conditions and medications (Lim & Sharmeen 2018; Gillespie et al., 2013). Often IFCs lack an understanding of medications, which is exacerbated by poor access to healthcare providers or poor relationships (Barry et al., 2020; Smith, Grijseels, Ryan & Tobiansky, 2015). A further challenge for IFCs within medication management is negotiating cognitive decline, while supporting loved one's decision making and their autonomy (Smith et al., 2015). Certainly, wider literature has captured the challenges IFCs encounter in making decisions on behalf of loved ones with dementia, and the resistance and refusal which may arise (Livingston et al., 2010).

IFCs may not only take on these roles due to declining capacity. A large-scale audit of primary care records for PwD living in the community highlighted that PwD are less likely to receive primary healthcare (Cooper et al., 2016). A lack of regular contact with healthcare professionals and support with the management of new or existing health conditions, may exacerbate the responsibilities of IFCs.

In culmination, this suggests that IFCs may be responsible for pain medication management and administering pain treatment, and therefore how effectively pain might be relieved in a PwD they are supporting. Interestingly, research finds usage of pain medication among those with dementia (33%) living in the community is lower than for older adults without cognitive impairment (47%) (Mäntyselkä, Hartikainen, Louhivuori-Laako, & Sulkava, 2004). Similarly, Landi et al. (2001) found one quarter of community dwelling older adults did not receive any analgesia despite reporting daily pain This figure further decreased when the older adult had cognitive impairment. A recent systematic review found 47.7% of PwD living in the community reporting pain did not use analgesic medication (Bullock et al., 2019). This suggests informal community care may too present challenges for effective pain treatment. The experiences of caregivers around general medication management described, also suggests that managing pain medication, and supporting with adherence and self-management may be a complex issue for IFCs.

1.7 Summary: From broader contexts to literature review

This chapter has provided the broader contextual foundations of this thesis, the key messages of which are:

- Dementia is a progressive syndrome which leads to cognitive and communicative impairment, and behavioural and psychological symptoms of dementia. Escalating needs and physical impairment associated with age, alongside the symptoms of dementia, lead to PwD becoming increasingly dependent on others as the syndrome progresses. PwD may be cared for in the community by IFCs, often spouses, but when their when their care needs become more complex, they may be placed into CH care. Both IFCs and CHs staff are on the frontline of care and face many challenges within their roles as primary advocates and carers (either informal or formal) for PwD.
- Comorbidities, age related issues, preventable conditions and injuries are common among those with dementia, and often contribute to pain. It is estimated 50% of PwD are living with pain. Pain presents a major challenge for PwD and their caregivers, leading to distress for both parties and behavioural disturbance among PwD. Clinical guidelines and position statements, national policy and

regulatory bodies, and best practice person-centred care approaches, advocate the necessity to assess needs, including pain among those with dementia.

- Guidelines and PATs have been developed to support caregivers in recognising and assessing pain and responding appropriately with treatment. However, as it stands there is no universally accessible guidelines for caregivers to refer to in supporting their assessment and treatment of pain among PwD. Similarly, no single PATs can be recommended to assess pain. At current the evidence-base regarding pharmaceutical and non-drug interventions for pain and validated PATs is underdeveloped to inform specific guidelines for dementia.
- In the CH context, existing guidelines and PATs have received poor uptake. The treatment of pain is also ineffective, PwD receiving less pain medication, smaller doses and sub optimal analgesia than older adults without cognitive impairment. The changing landscape of care provision in CHs has seen the responsibility for pain recognition, assessment and medication administration increasingly shift to unregistered direct care staff such as HCAs and senior carers. These roles may be considered experts by experience through the consistent close relationships they develop with PwD, such being integral to recognising pain when verbal communication is diminished.
- An increasing reliance on community informal care and growing ‘professionalisation’ of the role of IFCs mean they are now responsible for many aspects caring, inclusive of pain and its treatment. They may be responsible for medication management, and as such act as gatekeepers or administrators of pain relief. They may also act as experts by experience, recognising pain in the person they support and advocating this to a healthcare provider.

These key points have brought into focus several key issues, raising several points of consideration which have been used to underpin the literature review presenting in the following chapter:

- The role of informal caregivers and CH staff have been brought into focus in relation to pain in dementia as potential experts by experience, gatekeepers, and advocates. There is a need therefore to explore if these caregivers acknowledge a responsibility in relation to pain, and as to whether pain assessment and treatment is incorporated into their day-to-day caregiving and existing skillset. There is also a need to understand how this role and these responsibilities play out in context, to explore experiences and determine potential upskilling and support.
- There is a sense that pain may not be a priority, given the disparities in pain relief received by PwD and a lack of translation of guidelines and PATs into care home practice. There is a need to understand why these developments have failed to have a meaningful impact within dementia care. There is also a need to reflect on the importance of pain to caregivers, exploring competing or overriding demands, be those environmental, skills/training related, or patient related.

The following chapter picks up on these themes, presenting a critical review of the literature exploring the roles and experiences of CH staff and IFCs in the context of pain recognition, assessment, and management among PwD.

1.8 Charting a path forward: Thesis structure

This thesis is organised into 9 chapters. This current chapter positions the thesis within the broader landscape of dementia care provision in the UK, highlighting the roles of IFCs and CH staff in this context. It provides a contextualised statement of the problem of pain in dementia by drawing on the wider pain literature, and current pain guidelines and recommendations. Chapter 2 follows on with a more honed focus, exploring the problem of pain as experienced by informal caregivers supporting community dwelling PwD, and CH staff. This encompasses a review of existing literature exploring the experiences of these caregivers in relation to the recognition, assessment and treatment of pain among PwD. In chapter 3, the focus shifts to the methodological underpinnings of the thesis, through the lens of critical realism. A rationale for the pluralist approach adopted and an epistemological middle-way is explicated. Chapter 4 sets out the methods of both empirical studies undertaken, elucidating the qualitative approach of Study 1 and the mixed methods triangulation strategy of Study 2.

The focus of this thesis from chapter 5 shifts to the empirical findings. In chapter 5 and 6, the findings of Study 1 are reported, each chapter covering two overarching qualitative themes. Chapter 7 builds upon the former qualitative results chapters, presenting the qualitative survey results from Study 2 with reflection of how they expand and extend the findings of Study 1. In Chapter 8, the quantitative findings of the survey are reported and caregivers’ responses to the PKBQ explored and analysed, including analytical integration of qualitative survey responses. The final chapter of this thesis draws together the findings of both empirical studies in a discussion integrating existing literature. Here the contributions of this thesis are reflected upon, alongside the limitations, issues of validity and suggestions for future research.

Chapter 2- Recognising, Assessing & Treating Pain in Dementia: Exploring Caregiver Experiences through the Literature

2.1 Introduction

The previous chapter introduced pain in the context of dementia, identifying pain as a pervasive unmet need. The landscape of dementia care was discussed, in which the roles of informal caregivers (IFCs) and care home (CH) staff were brought into focus as primary caregivers and advocates for the needs of people with dementia (PwD). The purpose of the current chapter is to explore the experiences of these caregivers in relation to their roles in the identification, assessment, and treatment of pain. This is achieved through a narrative discussion of conceptual frameworks and literature from which caregivers' roles, experiences, challenges, and perceptions have been explored.

The literature has been synthesised into key themes, organised by their relevance to the conceptual domains of identification and assessment of pain among PwD, and the treatment of pain among PwD. Following a discussion of the literature, the gaps in current understandings are identified as a rationale for the aim and research questions developed to underpin this thesis. To begin, a brief overview of how the literature was gathered is provided, alongside the guiding review aim and objectives.

2.2 Gathering the literature

The aim of this literature review is to synthesise literature exploring the experiences and roles of those supporting those living with dementia, in relation to pain identification, assessment, and management. Initially, the identification of relevant literature was centrally concerned with that focusing on the recognition, assessment, and treatment of non-malignant pain among PwD in CH settings and informal care within the community; the settings of interest described in Chapter 1. Of particular interest was the role of unregistered and untrained caregivers in both these settings. Initial scoping of the literature however, highlighted a dearth of literature attending to these roles, particularly those involving IFCs. As a result, a more encompassing approach to the literature was taken, with the inclusion of key papers concerned with other care settings (acute and hospice), and end-of-life care, alongside more diverse caregiver roles providing direct care to people with dementia. Papers exploring the roles and experiences of non-direct care staff, such as physicians and pharmacists, however, have not been included. Caregivers has been utilised as a broad term in the following objectives and review, to include formal (paid or professional roles) and informal (familial or unpaid) roles.

The objectives of the literature review were to:

1. Explore literature regarding the experiences and roles of caregivers in relation to the identification of pain among PwD.
2. Explore literature regarding the experiences of caregivers in relation to the formal process of pain assessment (pain assessment tools).
3. Explore literature regarding the experiences and roles of caregivers in relation to pain management among PwD.

In line with these objectives, the literature search was conducted iteratively, to support with the identification of the most pertinent and recent publications throughout the duration of the thesis. Searches were undertaken to gather peer reviewed and published literature dating from 1980. Electronic databases were searched (Academic Search Premier; CINAHL; Education Research Complete; Humanities International Journals; Psychology and Behavioural Sciences

Collection; PsychINFO; PsychArticles; and MEDLINE), in addition to Google Scholar. Search terms were developed using a combination of key terms (Table 2.1), incorporating Boolean operators, MeSH headings and phrase searching (e.g., "*pain in dementia"*). A broad approach was taken in operationalisation of *experiences*, encompassing perceived barriers and facilitators, challenges, perceptions, understanding and beliefs. Literature was further identified via hand-searching of reference lists and searching for publications from known key authors. Throughout the duration of the thesis search alerts were set to flag new publications.

Table 2.1 Exemplar search terms

pain AND pain assessment OR pain scales OR identification OR recognition) AND (*pain management OR pain treatment OR drugs OR non-pharmacological OR pharmacological) AND* (e*xperiences OR values OR opinion* OR attitude* OR beliefs OR knowledge OR education OR qualif*) AND* (*cognitively impaired OR dementia OR Alzheimer's disease OR older* OR elder* OR 65 years*)

2.2.1. Review & literature development

As indicated, literature was identified iteratively and throughout the course of the thesis. The literature base has developed since the initial searches were carried out and the inception of the studies undertaken in the thesis. The following gives some reflection upon the development of the literature and how this has been considered in the presentation of the available literature.

The initial searches (completed 2016 prior to data collection) returned a limited literature base, centrally focused on registered nurses, or licenced roles in long-term care settings. These were primarily small qualitative works undertaken outside the UK (see section 2.2.2) (Kovach, Griffe, Munchka, Noonan & Weissman, 2000; Kenefick & Schulman-Green, 2004; Kaasalainen et al., 2007; Gilmore-Bykovksyi & Bowers, 2013). This qualitative stream of work focused broadly on informal pain identification and treatment. A small body of quantitative papers were also present, focused on exploring the knowledge and attitudes of formal caregivers in relation to pain, its management, and its assessment among those with dementia (Zwakhalen, Hamers, Rieneke, Peijnenburg & Berger, 2007; Barry, Parsons, Passmore & Hughes, 2012; Burns & McIlfatrick, 2015).

Throughout the duration of the thesis however, the literature base has developed. A cluster of more recent and larger qualitative and mixed methods studies were reported within UK care homes (e.g., Corbett et al., 2016) and acute settings (Lichtner et al., 2016). Beyond the UK, more recent papers also emerged from long-term care settings (Halifax, Miaskowski & Wallhagen, 2018; Andrews et al., 2019). The papers in this area have become more diversified in their methodologies, drawing on multiple sites of data collection (Corbett et al., 2016; Dowding et al., 2016) and exploring more diverse angles of the present issue, such as pain documentation processes in long-term care (Andrews et al., 2019) and experiences using formalised pain assessment tools (De Witt Jansen et al., 2018). Alongside this, studies acknowledging the roles of unregistered formal caregivers, such as healthcare assistants (HCAs) have also emerged (e.g., De Witt Jansen et al., 2017a; Hallifax et al., 2018), diversifying the perspectives represented in the literature.

The literature base did not significantly develop in all areas, however. The perspective and experiences of IFCs responsible for the direct care of people with dementia living in the community, has attracted little research attention since the initial searches. A paucity of papers could be found that focused on IFCs providing direct care to those with dementia living in the community (Fisher, Morris and Gellatly, 1997). Primarily papers have included family/relatives of nursing home (NH) residents within studies alongside formal caregivers, such as nurses and other nursing home staff (Mentes, Teer & Cadogan, 2005). While one paper has been published since initial searches to address this gap (Bullock, Chew-Graham, Bedson, Bartlam & Campbell, 2020), the literature base has remained sparse. As a result, papers relating to other contexts (e.g., hospice care- Tarter, Demiris, Pike, Washington & Oliver, 2016; cancer pain among older people- McPherson, Hadjistavropoulos, Devereaux & Lobchuk, 2014) were drawn upon in the following literature review to illuminate the views of IFCs in potentially relevant areas.

The developments in the literature have served to enhance the thesis and demonstrate a slow emerging recognition of the importance of the subject matter, which has evolved synchronously with the initial drivers of the studies conducted herein. Rather than excluding more recent papers after initial literature searches, they are included in the final literature review below, to provide an updated review of current knowledge and remaining gaps in knowledge. As a result of this inclusivity, the gaps in knowledge identified at the close of this chapter (Section 2.6.), and contributions to knowledge made within this thesis (Section 9.1.1.), can be discussed in the context of a holistic view of the body of knowledge in this specific area.

2.2.2. Overview of included studies & methodological quality

The literature review presented shortly has been informed by a broad approach to the literature. The review primarily draws on papers from long-term settings, such as nursing homes (n=25), acute care contexts (n=6), and end-of-life settings (n=6).

Papers relating to IFCs supporting community dwelling PwD are also included (n= 3). A brief overview of each of these body of literature are provided below.

Long-term care settings

The largest body of knowledge is this area comes from papers focused on pain among older adults, those with dementia and those with cognitive impairment, living in varying forms of long-term care settings (n=25). Varying terminology is used to describe these settings, delineated by origin of the study (e.g., UK- nursing home, Australia- aged care facility), size of the setting, level of care provided and type of staffing roles present. Much of this literature is qualitative in nature (n=20) and exploratory approaches using interview or focus groups methodology. One paper was mixed methods in its approach (Corbett et al., 2016). Three of the papers were orientated towards theory development using samples of registered nurses, one utilising concept analysis (Chang et al., 2011); and the other two focused on decision making processes (Kaasalainen et al., 2007; Gilmore Bykovskyi & Bowers, 2013).

Qualitative studies mainly originated from outside the UK (7 US; 4 Canada; 4 Australia; 2 China; 2 UK; 1 Sweden; 1 Korea). In terms of sampling, sample sizes varied (from 3 to 77), with almost half focused on registered, licensed, or certified roles (n= 9) (e.g., certified nursing assistants, registered nurses, licensed practical nurses), others sampled more diversly from mixed staff roles (n=9) (often unspecified), and less have focused on unregistered roles (n=3) (e.g., nursing assistants). Among these papers, a number (n=5) also included family/relatives of residents.

A smaller body of quantitative studies were identified focused on long-term care (n=4). These included three questionnaire studies and one document audit, originating from the UK (n=2), The Netherlands (n=1) and Australia (n=1). Samples ranged (from 33-to 123), with two questionnaire studies concerned with registered nurses, and one concerned with all staff.

End-of-life

A small cluster of papers (n=6) were included with a focus on end-of-life or hospice settings. These were directly focused on pain among those with cognitive impairment or dementia, so deemed to have potentially relevant findings for the review. Other reviews have opted to exclude these papers (Geddis-Regan, Stewart & Wassall, 2019), given the differences between pain during palliative and end-of-life, comparative to that arising from acute or chronic pain.

This group of papers were all qualitative, primarily interview studies. Most were focused on registered nurses (n=4), another (De Witt Jansen et al., 2017a) focused on unregistered roles (healthcare assistants), and one focused on the roles of IFCs (Tartar et al., 2016). A series of related papers were identified from the UK (n=3). The remaining papers were from Sweden (n=1), Norway (n=1) and US (n=1). The samples varied, from seven to fifty-one participants.

Acute care

Papers were also gathered from acute settings (n=6). These papers were either qualitative (n= 4), or mixed method (n=2). One study utilised ethnographic observation, alongside other forms of data collection to augment data collection (Lichtner et al., 2016; Dowding et al., 2016). Studies originated most often from Australia (n=2) and the UK (n=2). The remaining papers were from Finland (n=1) and Sweden (n=1).

Informal Caregivers

Alongside the papers including family members of those with dementia living in long-term care settings, two papers were identified exploring the experiences of family and informal caregivers supporting people with dementia living in the community. Both papers originate from the UK. A recent small interview study (Bullock, Chew-Graham, Bedson, Bartlam & Campbell, 2020) (n= 9) was identified and a larger scale national survey (n= 47) (Fisher, Morris and Gellatly, 1997). It should be noted however, this national survey was not specifically focused on the role or experiences of IFCs, rather the pain experience of those with Alzheimer’s disease. A further paper was identified that focused on the IFCs supporting older adults in the community with their cancer-related pain (McPherson, et al., 2014). While the focus of the review was not specific to cancer-related pain, the paper referred to cognitive impairment and related to care provided to community dwelling older adults, as such was deemed relevant to the review objectives.

Other

In terms of other papers identified, although intervention studies (such as training programmes) were excluded from the review, one UK intervention study was included (Petyaeva et al., 2017), given its origin. A single paper was identified as a European survey of pain assessment, guidelines and protocol use (Zwakhalen et al., 2018). One paper exploring home health for people with dementia in pain originated from Sweden (Karlsson et al., 2015) was also identified. Two meta-syntheses of existing literature were also included in the review, one drawing from literature across different settings (Geddis-Regan, Stewart & Wassall, 2019), and one focused on pain among nursing home residents (Vaismoradi, Skär, Sòderberg & Bondas, 2016).

Methodological quality

While the literature review included all potentially relevant literature, it is important to consider the quality of included studies given the relation to the development of themes in a review (Carroll & Booth, 2015), and moreover the quality of current literature on the topic area. The methodological quality of papers and quality of reporting of findings included in the review varies largely. Sample sizes vary, with many derived from small samples, including exploratory interview studies (Brorson et al., 2014, n= 7, De Witt Jansen et al., 2017a, n= 14), open-ended surveys (Peisah et al., 2014, n=20) and a mixed methods study present (Corbett et al., 2016, n=22). Exemplars of larger studies were also present (Lichtner et al., 2016, n=56, Fry et al., 2016, n=80), however fewer within long-term care settings and specifically within the UK, despite the use of multi-site sampling. Quantitative studies, while few, have obtained poor response rates in long-term care settings (39%, and 33% respectively, Barry et al., 2012; Burns & McIlfatrick, 2015), suggesting issues with the representativeness and potential bias in the findings reported.

2.3 Narrative review of the literature

The following section presents a narrative review of relevant literature gathered, clustered by common themes. While these themes are presented within the conceptual domains of pain identification and assessment, and treatment of pain, it is acknowledged themes may cross each domain, given that the recognition, assessment, and management of pain are intersecting processes. As noted, papers have most often reported the experiences of formal and IFCs within the same study, as such they are not separated in the forthcoming presentation of key themes. To delineate these views where is possible from the literature, the terms formal and informal are used. Among formal caregivers, particular roles are also separated where possible, including registered staff and unregistered staff (Section 1.2.2.1).

2.4 Pain identification & assessment

As discussed in the previous chapter (Section 1.4), it is important that pain is systematically assessed so that appropriate treatment can be provided. This is increasingly imperative among populations where communication and cognitive function are impaired (Herr et al., 2019). The consensus within the literature is that recognising pain, assessing the extent of pain, and diagnosing pain are challenging experiences for caregivers. A number of themes emerge indicative of these challenges, alongside a number of strategies described by caregivers to navigate these. These have been subdivided into those concerning pain prioritisation, communication, informal strategies of pain assessment, and formal pain assessment.

2.4.1. Communication & cognitive impairment

Across care settings, impaired communication, or an inability to express pain, has been a central barrier to the identification of pain among PwD and older adults described by informal and formal caregivers in the literature (Fox, Soloman, Raina & Jadad, 2004; Rantala, Kankkunen, Kvist & Hartikainen, 2012; Tarter, Demiris, Pike, Washington & Oliver, 2016). These challenges may be considered in light of how they may impair the ability of PwD to self-report their pain, or impact upon the experience/perception of pain among PwD.

2.4.1.1 Challenges of self-report

Survey data has found 91.7% of NH managers recognise the difficultly of pain assessment in PwD, with only 8.3% indicating PwD are accurately able to self-report their own pain (Barry, Parsons, Passmore & Hughes, 2012). However, those with more years' experience were more likely to believe accurate self-report was possible among those with dementia. While Barry et al. (2012) focused on those in management roles (n=96) who may not provide direct patient care, qualitative studies with wider caregiver samples mirror these concerns. NH staff reflect on whether PwD are able to provide accurate and reliable responses about their pain, or comprehend pain-related questions (Martin, Williams, Hadjistavropoulos, Hadjistavropoulos & MacLean, 2005). For IFC (n= 51) supporting PwD in a hospice setting, they have described the challenges of gathering pain information from their loved ones because of receptive and expressive aphasia (Tarter, Demiris, Pike, Washington & Parker Oliver, 2016). PwD have been likened to "*prisoners*" inside their own bodies (Tarter et al., 2016, p. 526) and as infants without verbal skills (Kenefick & Schulman-Green, 2004). Despite the challenges associated with self-report however, IFCs and NH staff have described verbalisation as the primary way in which pain was either communicated or came to their awareness (Martin et al., 2005). Without a self-report of pain, NH staff indicate they would assume pain is not present (Kaasalainen et al., 2007; Newton, Reeves, West & Schofield, 2014).

Without reliable communications from an individual with dementia, nurses indicate that traditional models of assessment, requiring patient feedback, cannot be used (Chang, Oh, Park, Myun & Yong Kil, 2009). An interview-based study exploring pain cues used by formal caregivers (n=65) and IFCs (n= 36) found a concomitant decline in the use of verbal and vocal pain cues used as severity of cognitive impairment among NH residents increases (Closs, Cash, Barr & Briggs, 2005). This implies an apparent lack of verbal or vocal indicators present, or a lack of attendance to these by caregivers in the presence of advancing dementia. Whilst the ability to verbally communicate pain may decline, studies do suggest the latter, that caregivers shift away from a communication-based pain assessment. Qualitative survey responses from hospital nurses (n=15) reflecting on self-report indicate there is “*no point in communicating”* with patients with dementia and that communication is “*impossible*” (Krupić et al., 2018, p. 78). Similarly, NH nurses’ distrust self-reports from PwD, as such did not even attempt self-reports, even before the initiation of an analgesic intervention (Gilmore-Bykovksyi & Bowers, 2013). This suggests a shift away from communication and patient-centred assessment, alongside an incongruence between practice and recommendations; the latter advocating self-report as part of the hierarchy of pain assessment (Section 1.4).

2.4.1.2 Supporting & integrating self-Report

A conflict is apparent in the literature regarding the role of self-report and communication in pain assessment. In a mixed method UK CH study, self-report was reflected on by staff (n= 28) and relatives (n= 10) of CH residents as the ‘most meaningful assessment route where possible’ (Corbett et al., 2016, p. 1357). In an exploratory qualitative study, registered nurses (RNs) and certified nursing assistants (CNAs) (n= 23) described the importance of communicating with PwD about their pain experience and trusting in their response as the foundation of assessment

(Karlsson, Ernsth Bravell, Ek & Bergh, 2015). Self-report was acknowledged as problematic; however, it was incorporated within explorative strategies which were centred on maintaining a collaborative approach that involved care recipients in their care (Karlsson et al., 2015). Self-report could be supported through simple questioning (Martin et al., 2005; Krupić et al., 2018), or more creatively through the translation of words into terms PwD could understand (Lichtner et al., 2016), and the creation of new languages (Tarter et al., 2016). Acute care staff and IFCs have described becoming skilled interpreters of disordered speech and metaphorical communications to identify pain (Lichtner et al., 2016; Tarter et al., 2016). This approach, in conflict to that described previously, sees PwD as active collaborators in their care and places the person at the centre of the care-planning process, more consistent to a wider person-centred care approach (Brooker & Latham, 2016), and pain assessment recommendations (Section 1.4).

2.4.1.3 Changing pain perception & experience

As discussed in Section 1.3.4, dementia may impact pain processing and experience. Some studies have suggested caregivers experience challenges in assessing pain due (actual or perceived) changes in pain experience, and it may lead them to further question the authenticity of pain complaints. Family caregivers question if the pain reported by the person with dementia, they were supporting really reflected the pain they were experiencing (Bullock, et al., 2020). Family members of cognitively impaired NH residents have described the pain reports of their relatives as dramatic (Mentes, et al., 2004), while IFCs have identified a change in pain perception leading to increased pain or increased complaining (Falls & Stevens, 2004). Conversely however, Fisher et al. (1997) undertook a small-scale national survey of predominantly IFCs (n=47). IFCs reported that despite caring for PwD who had experienced pain-related adverse advents, responses to pain were absent, despite intact emotional and verbal communication.

In an in-depth ethnographic study with NH nurses (n=3), participants described that the ability of those with cognitive impairment to respond and interpret sensory stimuli is changed (Kenefick-Shulman & Green, 2004). They described this may lead to perceptual and judgment errors in their perception and communication of pain. Survey studies have similarly found that most NH managers and nurses believe that dementia impacts upon physiological processing of pain (80.5% and 72%, respectively), with over a third believing that the perception of pain is different for those with cognitive impairment (55% and 38%, respectively) (Barry et al., 2012; Burns & McIlfatrick, 2015). The perceived directionality of this change is unclear from these studies. These findings cannot be extrapolated to reflect the pain experiences of PwD. They do, however, highlight a range of possible responses to pain among PwD, and that perceived or actual changes to pain processing or experience may be a barrier to caregivers' recognition or acknowledgement of pain.

2.4.2 Conceptualisations of pain

2.4.2.1 Stoicism & normalisation of pain

Some studies have found that older people, including those with dementia, have stoical attitudes towards pain (Mentes et al., 2004; Clark, Jones & Pennington, 2004). Stoicism is defined as "*illness behaviour characterised by silent endurance and lack of emotion"* (Moore, Grime, Campbell & Richardson, 2012, p.159). Stoical attitudes amongst older people and PwD have been described by formal and informal caregivers as impeding their ability to assess and manage pain (Clark et al., 2004; Mentes et al., 2005). In a large qualitative study across 12 NHs, residents were described as having adjusted to pain and reticent to disclose it (Clark et al., 2004). Staff expressed their sense of helplessness and frustration at such residents who did not want to ‘bother’ them to get help. Family members (n=16) of cognitively impaired NH residents have also described their relatives as minimising their pain, despite a sense that their pain was ‘most of the time’ (Mentes et al., 2004). Certainly, older people living in the community and NHs have expressed their reticence to seek help for their pain, perceiving that ‘nothing much’ could be done for age-related pain (Weiner & Rudy, 2002; Clarke et al., 2014). This may be a coping mechanism for older people, used to maintain a sense of control and independence (Gammons & Caswell, 2014). These challenges were also implicated in perceived trustworthiness of self-reports and whether pain complaints or denials could be taken ‘literally’ (Dowding et al., 2016). While PwD may choose not to communicate their pain, it is unclear at what point along a continuum of capacity an absence of pain complaints reflects their stoicism, rather than an inability to communicate pain.

Stoicism among PwD and older people may be reinforced by the NH environment. In a meta-synthesis of the literature, the NH environment has been described as perpetuating a culture of stoicism that ‘normalises suffering’ among residents and staff (Vaismoradi, Skär, Söderberg & Bondas, 2016). Pain arising from frailty and ageing was expected, becoming routine, “*unheard and hidden”* (Vaismoradi et al., 2016. p. 7). NH nurses have expressed their concern regarding the widespread pervasive myths about pain and ageing that may mean pain is not recognised by healthcare professionals (Kaaslainen et al., 2007). However, survey studies suggest NH staff do not endorse ageist views of pain. Over half of NH nurses and NH staff disagree that pain is natural consequence of ageing (Zwakhalen, Hamers, Rieneke, Peijnenburg & Berger, 2007; Barry et al., 2012).

2.4.2.2 Lack of awareness & consideration of pain

Awareness and consideration of pain in the literature varies, as does its saliency in the experiences of caregivers. Some studies have suggested a passive and dismissive approach to pain among formal caregivers (Kaasalainen et al., 2017; Holloway & McConigley, 2009; Corbett et al., 2016). In a survey, long-term care staff endorsed "*the extent to which pain is on our minds"* as an obstacle to pain relief among PwD (Peisah, Weaver, Wong & Strukovski, 2014, p. 1771). Focus groups with CH staff have revealed that pain is not high on the agenda, with few staff able to describe instances when pain has been a priority concern (Corbett et al., 2016). Relatives concurred with this, indicating awareness of pain among CH residents was low. Liu (2014) and De Witt Jansen et al. (2017a) found a subset of their samples (NAs and HCAs) took a passive and submissive approach to their work. As a result, they undertook only basic care, or task-orientated requirements of their role and did not actively seek out or respond to pain. While these findings may be related to the unregistered staff samples of these studies and a lack of preparedness, other studies suggest more senior staff share this passive attitude towards pain. Nurses and physicians also identified a lack of pain awareness and dismissal among colleagues as a barrier to effective pain management (Kaasalainen et al., 2007). Nursing assistants (NAs) (n=16) described having to 'nag' nurses for appropriate pain interventions to be provided, as pain was rarely prioritised (Halifax, Miaskowski & Wallhagen, 2018). This study further found NAs themselves differentiated types of pain to be prioritised. Everyday pain among NH residents was considered normal, expected and generally persistent. It was not reported and was managed using non-drug interventions (Halifax et al., 2018). New, reportable pain on the other hand was prioritised and reported. This differentiation may mean that chronic, known, or persistent pain issues may not be given consideration, nor escalated for treatment. Given that older people and those with cognitive impairment may only be encouraged to share their pain experience when they are actively asked (Closs et al., 2005), or feel ‘heard’ by healthcare professionals, a lack of consideration by healthcare professionals or awareness may have a cyclical impact which discourages help-seeking.

For those studies which have identified pain as priority concern, these have predominately been those exploring nurses and HCAs experiences during end-of-life care (De Witt Jansen et al., 2017a; De Witt Jansen et al., 2017b). During interviews with hospital nurses providing end-of-life care (n=7), all nurses agreed that any suffering should be alleviated to the extent possible among PwD dying (Brorson, Plymoth, Örmon & Bolmsjö, 2014). It appears that pain which is ‘lived with’, may not receive the same consideration as pain surrounding death and dying. While other studies have suggested that everyday pain is prioritised by NH staff, staff have provided contradictory reflections on this. Cohen-Mansfield and Creedon (2002) found NH staff indicated undetected pain was low in their workplaces, however simultaneously recounted episodes in which pain had gone unnoticed and the guilt they felt. A survey study from The Netherlands found most NH staff believed that pain receives much attention in their workplace, and that it was accessed and treated correctly (80%, 83% and 83%) (Zwakhalen et al., 2007). However, this study also identified knowledge deficits in relation to pain treatment, in conflict with the aforementioned beliefs. It has been suggested nurses lack self-reflection on their own abilities and how these impede effective pain practices (Gropelli & Sharer, 2013). Nurses tend to reflect primarily on the behaviour of colleagues, patients and environment to account for lack of prioritisation (Gropelli & Sharer, 2013).

2.4.2.3 Psychosocial & psychological pain

Pain was conceptualised as encompassing, and comingled with, psychosocial and psychological elements, which complicated the identification and prioritisation of physical pain. Qualitative studies have found pain is understood as relating to human suffering of both the mind and body (Karlsson et al., 2015; Vaismoradi et al., 2016). Vaismoradi et al. (2016) differentiated ‘life-bounded’ pain from ‘age bounded’ pain in the narratives of nursing home staff and residents. ‘Life-bounded’ pain encapsulated older people’s emotions and moods, and the major changes they had experienced. It both caused pain and was intertwined with physical pain. A cyclical relationship between pain and psychological and psychosocial was described by NH staff, older people and IFCs (Martin et al., 2005). Reduced social engagement and independence, led to withdrawal, isolation, and negative mood shifts which exacerbated pain. The existential aspects of dementia, such as depression and awareness of the dementing process, have also been described by home care staff as intensifying existential suffering (Karlsson et al., 2015).

Physical pain was viewed by formal caregivers as easier to detect and treat than the more emotive elements (Cohen-Mansfield & Creedon, 2002; Karlsson, Bravell, Ek & Bergh, 2013). However, because pain could be ‘heightened’ by distress and anxiety, acute care staff indicate it may be impossible to differentiate between physical aspects of pain, and those relating to emotional status, surroundings, and a person’s relations (Dowding et al., 2016). Such complicates both the assessment and treatment of pain, in which physical elements must be disentangled with non-physical elements.

Studies suggest that existential aspects of suffering elicit great concern and empathy from different formal caregiver groups, across NH and home care settings (Karlsson et al., 2013; Gilmore-Bykovskyi & Bowers, 2013; Karlsson et al., 2015). In a study examining how nurses treat pain among NH residents with dementia, Gilmore-Bykovksi & Bowers (2013) found although they did not prioritise the assessment and management of physical issues, they expressed a genuine concern for wellbeing. They attempted to support wellbeing by meeting a variety of needs, and considered numerous non-physical aetiologies for behavioural changes, such as psychosocial or environmental balance. The authors suggested this approach may reflect the care foci of NH environments, where the basis for care interactions is relational, between a resident and staff member, rather than a treatment foci more commonly seen in acute care contexts (Gilmore-Bykovksi & Bowers, 2013).

2.4.3 Informal strategies of pain assessment

2.4.3.1 Observing & interpreting behavioural indicators

Pain was most often identified through the observation of behaviour and behavioural change, it was relied on given the challenges of communication (Brorson et al, 2014, Chang et al., 2011; Corbett et al., 2016). By interpreting the symbolic meaning of behaviours, such as striking out, avoidance, grimacing, restlessness, and crying, nurses were able to identify issues of unrelieved pain (Kovach, Griffe, Munchka, Noonan & Weissman, 2000). Kovach et al. (2000) reflected that nurses appeared to follow a systematic and discernible approach to pain assessment through observation and interpretation of behaviour. A recent meta-review of studies showed that observable behavioural and psychological cues (irritability, vocalisation, grimacing, guarding, and rubbing the affected area) were important to ‘build a picture’ of pain for PwD (Geddis-Regan et al., 2019). Although rarely explored in the literature, it appears IFCs developed comparable observational mechanisms to formal caregivers, observing behavioural, psychological, and physical expressions and/or changes, in facial expressions, mood and body language (Bullock et al., 2020). The literature suggests, in line with the unmet needs model (Algase et al., 1996; Cohen Mansfield, 2000) and the dementia compromised behaviour model (Kovach et al., 2005), caregivers recognise behaviours indicative of behavioural and psychological symptoms of dementia as attempts to communicate distress. They further recognise that all “*behaviour has meaning”* (Brooker, 2007, p. 16), aligning to a person-centred framework of care.

Facial expressions have been identified as one of the most clinically relevant and frequently used behavioural indicators of pain in cross-sectional questionnaire with NH staff (n=77) (Liu, Briggs & Closs, 2011). CNAs have described paying special attention to the eyes and face to reveal states of ill health that cannot be verbally communicated (Mentes et al., 2004). Similarly, focusing on the eyes and mouth, the efficacy of pain relief could be examined. Facial expressions are a key behavioural indicator identified by practice guidelines (Section 1.4), and as a reflexive response to pain, these are increasingly important to identify pain for whom the ability to self-report is diminished (Hadjistavropoulos, & Craig, 2002).

Behavioural change has also been identified as one of the most salient identifiers of pain among NH residents and PwD (Clark et al., 2004; Peisah et al., 2014). Barry et al. (2012) found that majority (88.5%) of NH managers recognised that behavioural change is as a possible indication of pain. While NH staff reflect there is no universal pain cues which could be generalised, a change in behaviour was considered characteristic of pain among those with cognitive impairment and an alternative to verbal declaration (Parke, 1998). Behavioural change was also used to determine if pain relief was effective, in that a return to baseline behaviour suggested pain was relieved (Gilmore-Bykovskyi & Bowers, 2013; Monroe, Parish & Mion, 2015). This particular indicator of pain however, relied on a caregivers contextual understanding and familiarity of the individual with dementia, to be able to detect and interpret pain-related changes (Corbett et al., 2016) (Section 2.4.3.3).

Observational approaches described further encompassed physiological indicators of pain. In a UK questionnaire study, all NH nurses agreed that physiological indicators of pain (heart rate, blood pressure and temperature) were an important aspect of pain assessment for PwD (Burns & McIlfatrick, 2015). While this study reported a low sample and response rate (n= 32, 33%) suggesting it may not be representative of wider nursing approaches, qualitative research mirror these findings. Through interviews and surveys with NH staff members (n=72) Cohen-Mansfield and Creedon (2002) developed a list of indicators used staff to identify pain. Physical cues were used most often, with over half of the indicators identified being physiological indicators, such as skin discolouration, changes in vital signs, and swelling. Interview studies with nursing assistants (NAs) in NHs show that regular physical examination of a PwD during daily care tasks was considered important to identify physiological changes that might be indicative of pain (Karlsson, et al., 2013; De Witt Jansen et al., 2017a). This was an active and preventative approach that also accommodated known injury and pain (Karlsson et al., 2013). Despite the usefulness of examination, Chang et al. (2009) illuminated the difficulty of physical examination for PwD due to their ability to understand and a ‘lack of cooperation’. However, of concern is the potential use of physiological changes, which may not necessarily correlate to pain experienced by a person with dementia, particularly chronic pain (Herr et al., 2019). Correspondingly, an emphasis on vital signs is minimised in recent guidance on pain assessment among vulnerable populations unable to self-report (Herr et al., 2019).

2.4.3.2 Relationship-centred assessment: Knowing the person

This importance of knowing a person with dementia and developing relationship-centred assessment has been a central theme in the literature and expressed by caregivers of diverse training and roles. Adequate knowledge of the care recipient was highlighted by CNAs and RNs as vital to understand whether they are suffering pain and build *“an overall picture of the pain situation”* (Karlsson et al., 2015, p. 196). Staff continuity in care and the assessment situation was necessary to facilitate relationship-centred assessment (the creation of a relationship *with* a PwD), rather than constructing the care recipient as a casual acquaintance. Such an approach has been delineated in a meta-synthesis of NH literature as a ‘person-centred’ perspective, in contrast to a ‘care centred’ approach focused organisational routines (Vaismoradi et al., 2016). A person-centred perspective encapsulates not only individualised methods of pain assessment derived from knowing the NH resident, CH staff describe it also facilitates the alignment of pain needs to treatment (e.g., medication tolerance; difficulties swallowing) (Corbett et al., 2016). It may further encourage PwD to communicate their pain, given that acute care staff have recognised that relationships and trust are important for older patients to communicate their pain (Lichtner et al., 2016). There is a sense these relationships need to be reciprocal to support caregivers in identifying and responding to pain. NH staff described that emotional connectedness encourage more sensitive and empathetic approaches towards pain among NH residents (Cohen-Mansfield & Creedon, 2002).

Familiar relationships provide the context from which pain and pain behaviours can be distinguished from behavioural issues, such as boredom, fatigue, hunger and a demand for attention (Cohen-Mansfield & Creedon, 2002; De Witt Jansen et al., 2017a). However, NH staff and home care staff reflect that the creation of longstanding and affectionate relationships requires a slow tempo build up over years and repeated exposure (Parke, 1998; Karlsson et al., 2015). Contextual limitations in time (Section 2.2.1.3), may impede this for caregivers, particularly for roles without direct care responsibilities (e.g., nurses; management roles). A sense of connectedness, or challenges to this, may also impede the development of familiar relationships (Brorson et al., 2013). Hospital nurses providing end-of-care have reflected on the challenges of connecting with dementia patients given a loss of communicative abilities. Without connection, nurses found it increasingly hard to determine the nature of the pain. Malloy and Hadjistavropoulos (2004) proposed that the nature and authenticity of relationships between a person with dementia and their caregiver can underpin a caregiver's recognition and response to pain. They hypothesised how a caregiver relates to a person with dementia, and their personhood, will shape how they relate to the person with dementia, and their pain (Malloy & Hadjistavropoulos, 2004). Inauthentic relationships which undermine personhood and construct PwD as objects-of-care, may contribute to the undertreatment of pain. The emphasis on relational aspects of pain assessment in the literature support this conceptualisation of the undermanagement of pain as a dyadic issue.

The literature suggests IFCs may also use a relationship-centred approach to support them in identifying and treating pain. Interviews with family caregivers of NH residents reveal that they are very knowledgeable about the conditions of their relatives and provided exacting descriptions about how pain was expressed by them (Mentes et al., 2005). Despite no formal training, IFCs supporting PwD in hospice care drew on their personal histories with loved ones to gather information about pain, identifying pain through their loved one's movements and signals (Tarter et al., 2016). In a recent qualitative study, family caregivers (n= 9) caring for a person with dementia living in the community indicated their familiarity with the person or knowing them "*inside out"* aided their ability to identify pain (Bullock et al., 2020, p. 7). This study also highlighted the role of caregivers' familiarity as an important resource of by-proxy input to health providers also, with General Practitioners using information provided by family caregivers as a 'surrogate familiarity' (Bullock et al., 2020). In acute settings, where staff lack the opportunity of familiarising themselves with patients, family/carers have been described as a 'hidden workforce' (Fry, Chenoweth, MacGregor & Arendts, 2015) and as 'messengers', acting as pain advocates for PwD (Lichtner et al., 2016). In a qualitative study exploring emergency department nurses' (n= 80) perceptions of the role of family/carers in pain management, nurses described how family/carers supported their work (Fry et al., 2015). They took on an advocacy role, including communicating for patients, noticing subtle changes in behaviour which might otherwise be ignored, and managing behaviour which could interfere with treatment, such as anxiety and confusion. While not from the perspective of IFCs supporting PwD in the community, Fry et al.'s (2015) findings reinforce the salience of their role in pain management and emphasise the importance of considering pain from their perspective.

The importance of proxy input to support pain identification and assessment has also been reflected on by staff in long-term care. In focus groups with long-term care staff, Fox et al. (2004) found staff (n= 54) reflected on the family input as a facilitator to pain management among residents. Family could offer insight into residents' histories and behaviours which aided staff in identifying pain. In a UK CH study, staff have described close working relationships with residents' families (Corbett et al., 2016). However, family has also been described as interfering with pain identification and management (Monroe et al., 2015; Corbett et al., 2016). Long-term care nurses (n=29) participating in focus groups described conflict and ethical issues arising from the disparities between the needs of residents and the families wishes (Monroe et al., 2015). These could include families' perceptions that more or less pain relief should be provided. Such may explain the disparity between formal caregivers' emphasis on familial input, and what is observed and documented in their pain practices (Corbett et al., 2016; Lichtner et al., 2016). Family members of CH residents with dementia have expressed frustration at 'not being heard' by CH staff, with mixed experiences of contributing to the care of their relatives (Corbett et al., 2016). These findings suggest that while the input of by family or informal caregivers may be described as important by formal caregivers, this may not be mirrored in their actual pain assessment practices, nor the experiences of family caregivers. It also suggests that some formal caregivers may not be, as recommended (Section 1.4), utilising important information sources available to them to support their pain assessments. Lichtner et al. (2016) in their UK study of acute care recognised that relationship-centred care should be reframed so that family/carers are a part of the identify of a patient. This would shift the balance from information seeking from family/carers, to actively involving family/carers in the creation of information.

2.4.3.3 Intuitive & experiential approach

In addition to knowing a person with dementia to *know* their pain, the literature has identified a second route of knowing, knowing through experience and intuitive perception. In a qualitative study exploring how long-term care staff (n= 6) recognise pain among cognitively impaired older people, staff indicated they detect subtle changes in pain through an intuitive sense of knowing (Parke, 1998). Staff were unable to articulate this sense in words but did explain this perception was developed through recalling and learning from diverse clinical experiences/exposure with different cognitively impaired older people. Falls and Stevens (2004) found the majority of formal and informal (n=31) caregivers interviewed described (following onset of dementia) shifting to an intuitive approach. This same mechanism was used to determine when pain had dissipated. Caregivers were confident in this intuitive ability to realise pain, supported by an assured sense of connection and familiarity with the person/people they were supporting (Falls & Stevens, 2004). This intuitive sense was conceptualised by nurses as 'nurses' judgement' (Kenefick & Schulman-Green, 2004). Among NH residents with cognitive impairment nurses would use their own judgement in preference to patient history, family or colleague input, and the behaviours exhibited by residents.

More recent conceptualisations of pain assessment among acute care staff and NH nurses have also identified experiential and intuitive approaches (Chang et al., 2011; Dowding et al., 2016). From narratives of acute care staff, Dowding et al. (2016) conceptualised pain assessment as an intersection of type 1 thinking (including intuitive, subconscious, automatic processing) and type 2 thinking (controlled, reflexive, decision making) (Dowding et al., 2016). Through time, shared sense-making with colleagues, and experience, mental models of patients and their pain are developed iteratively to support staff to identify pain. Similarly, Chang et al. (2011), drawing from the literature and interviews with NH nurses (n=13), conceptualised pain assessment as a nurse-mediated process, relying on individual intuition, observation, and clinical experience working with PwD. As discussed in a review of the literature (McAuliffe, O'Donnell & Fetherstonhaugh, 2009), the emphasis within these conceptualisations on developing an intuitive sense through clinical diversity, seems in opposition to knowing through familiarity with individual people. In the current care climate in CHs, where staff turnover and agency staff may well be the reality, exposure to clinical diversity may be more opportune, as opposed to spending the time necessary to develop a relational approach.

Of note, is the disjunct between qualitative and quantitative findings regarding the role of clinical experience. While it is described above as an important mediator which supports caregivers' ability to identify and assess pain, this does not translate into greater levels of understanding about pain, its assessment and management. Quantitative studies exploring NH staff knowledge and beliefs regarding pain among PwD find that years' spent caring does not positively impact knowledge and beliefs (Zwkahalen et al., 2007; Barry et al, 2012; Burns & McIlfatrick, 2015). Therefore, greater experience does not relate to a more developed or accurate understanding of pain, or its assessment, as the narratives of caregivers imply (at least in a measurable way).

2.4.3.4 Uncertainty & misdiagnosis of pain

A common reflection among caregivers supporting PwD in the context of pain was uncertainty and a lack of confidence in their assessment of pain. Although caregivers from diverse formal roles could describe how they identified pain (Section 2.4.3), they did not take ownership of this or express confidence in their ability to correctly distinguish pain from other comorbidities, infection, delirium, or behavioural manifestations of dementia (Kovach et al., 2000; Chang et al., 2011; Corbett et al., 2016). NH nurses described the process of identifying pain among PwD as "*guessing game"* (Kovach et al., 2000, p. 218) and likened the pain assessment process to "*detective work"* (Monroe et al., 2015, p. 321). NH nurses describe their uncertainty piecing together a "*complex jigsaw puzzle"* of various information sources (including, patient, family, environment, medical record, and healthcare team) to determine the presence of pain (Monroe et al., 2015, p. 320). Interpreting the suffering of PwD was experienced as difficult by nurses, given that it was hard to know if their interpretation was correct (Midtbust, Alnes, Gjengedal & Lykkeslet, 2018).

As the severity of dementia or impairment increases, Closs et al. (2005) observed that the pain cues used by NH staff and NH residents' relatives to identify pain become increasingly imprecise, and generalised. Caregivers proposed hypotheses to explain behaviour they observed that required a considerable degree of interpretation or were contingent on knowing the NH resident (Closs et al., 2005). This may explain caregivers' sense of uncertainty, that as adjunctive information from a patient reduces, pain assessment becomes increasingly underpinned by allegorical explanations. This is consistent with the communications model of pain, which proposes that among those with declining cognitive and communicative ability, pain experiences are ‘encoded’ into increasingly more automated and reflexive responses (i.e., non-verbal vs. verbal) (Craig, 2009; Hadjistavropoulos et al., 2011). Interpreting these responses, or ‘decoding’ them is not a simple process, and it is contingent on caregivers’ appraisals, interpretations, experiences, interpersonal factors, and intrapersonal factors. This model emphasises the central role of caregivers in the process of pain communication and identification, given that encoded messages of pain from a sufferer are meaningless without an observer to interpret them.

Low levels of certainty about pain may lead to dismissal of pain complaints or behavioural expressions of pain, and inadequate interventions for PwD (Gilmore-Bykovskyi & Bowers, 2013). In a conceptual model developed to explore nurses pain management decisions, levels of certainty were dependent on patient and pain characteristics (Gilmore-Bykovskyi & Bowers, 2013). The presence of dementia and an absence of other confirmatory signs, such as an obvious cause, to substantiate the presence of pain, lead to deliberately delayed treatment, or no treatment being provided (Gilmore-Bykovskyi & Bowers, 2013). An identifiable cause of pain is relied upon by caregivers in the event of uncertainty to confirm caregivers’ assessments of pain, or indeed pain reported. Nurses are reluctant to respond to pain which have no clear indicators precipitating it, such as an event or a diagnosed condition, and may unduly focus on diagnosis as an explanatory model for patient behaviour (Cohen-Mansfield & Creedon, 2002). As a result of this ‘trained incapacity’, other explanations for behaviour or pain may be excluded. Similarly, IFCs supporting PwD in hospice care have reflected on the challenge of identifying the aetiology of pain, as if pain was definable by an ailment or injury (Tarter et al., 2016). A physiological cause allowed IFCs to “*differentiate between ‘‘real’’ and ‘‘imagined’’ pain”* (p. 526).

These experiences highlight how caregivers' uncertainty of pain, and their conceptualisations of pain as evidenced by diagnosis and discernible cause, may impede their recognition, assessment, and willingness to treat pain among PwD. Pain appears to be conceptualised through a biomedical lens, in which there is a predictable relationship between tissue damage or pathological cause and physical pain. Interestingly however, this emphasis on diagnosis is concordant with experiences of older people who express that without diagnosis they feel their pain is invisible, and they fear being seen as "*a fraud"* by healthcare professionals (Clarke et al., 2014, p. 4). It appears that the qualifying presence of a diagnosis and identifiable cause may be mutually affirmable for both older people and those providing care to them.

A significant cause of uncertainty, alongside an ability to confirm pain with an accurate self-report, was determining the cause of behavioural change and agitation (Kovach et al., 2000; Kaasalainen et al., 2007). It was believed psychosis or dementia itself could produce such, and consequently behavioural manifestations of pain were described as often ignored or mismanaged with psychotropic medications (Kovach et al., 2002; Peisah et al., 2014). Nurses reflected that in instances of behavioural disturbance, this was most often associated to psychological or psychiatric problems arising from dementia. Other causes were most often not investigated, and pain would be considered the last potential cause (Kovach et al. 2000; Kaasalainen et al., 2007). Consistent with this, analgesia was often only administered after treatment with psychotropic medications had been unsuccessful (Kovach et al., 2000). NH staff indicate that residents with behavioural issues are treated with less empathy (Cohen-Mansfield & Creedon, 2002), suggesting misdiagnosis of pain-related behaviours also impacts upon relational elements of care.

IFC have also described similar challenges distinguishing between pain-related behaviours and dementia-related behaviours. Those supporting PwD were able to determine when “*something else was going on”* through behavioural change, however, could not easily determine the cause of this (Bullock et al., 2020, p. 7). For those supporting older people, they reflected on the difficulties of discerning pain from other comorbidities (McPherson, et al., 2014). The uncertainty expressed by caregivers, and an emphasis on dementia, supports that a diagnosis of dementia may overshadow other potentially painful comorbid conditions (Tolman & Dening, 2018). It further suggests that caregivers are constrained by their own routine ways of conceptualising behavioural change and agitation as arising from dementia, and as a result may overlook pain as an underlying cause.

2.4.4 Communication & team collaboration

Communication and collaboration were emphasised as central to recognising, assessing, and treating pain among PwD, yet this could be challenging in the context of dementia and care settings. This encompassed verbal and non-verbal communication with PwD (Section 2.4.1), and communication between caregivers. Studies exploring facilitators of, and barriers to, optimal pain assessment and treatment among NH residents consistently identify the importance of multidisciplinary collaboration and communication (Fox et al., 2004; Kaasalainen et al., 2007; Monroe et al., 2015). Examples of effective collaboration included seeking advice from more experienced staff, respecting colleagues’ clinical opinions, and using the insights of others (Fox et al. 2004). In a series of recent papers exploring pain management in four UK hospitals, pain assessment was described as shared sense making in which several members of staff were involved in making sense of the overall picture of a patient's pain (Dowding et al., 2016; Lichtner et al., 2016). Information gathered by different members of staff could be fragmented however and it needed to be re-assembled, relying on a collective staff memory and *"mental computation"* (Lichtner et al., 2016, p. 11). The process in residential settings has been reflected on as similarly complex, with a "*laborious pain communication chain"* present to be traversed by staff (Peisah et al., 2014, p. 1771). In a survey among long-term care facilitates, staff (n=20) described variable interactions between junior staff and medical staff, with nurses acting as conduit. Medical staff, such as GPs, were described as discounting junior staff and care assistants pain reports (Peisah et al., 2014). Alongside the complexity of communication and information sharing with colleagues, a recent ethnographic study of acute care suggested that collaboration may further undermine pain practices through ineffective shared practices (Harmon, Summons & Higgins, 2019). Harmon et al. (2019) observed that shared and culturally mediated pain practices were developed between staff and a consensus emerged informing the how pain should be dealt with among older people. Some of these shared practices included a lack of pain documentation, a lack of input or inclusion of older people, and questioning the education and practices of colleagues (Harmon et al., 2019). They reflected that culturally shared or 'group think' practices may undermine person-centred care and evidence-based pain practices.

Communication breakdown and disparities between formal responsibilities, particularly between registered and unregistered care staff, is described as a significant barrier to collaborative care and optimal pain assessment and treatment. Corbett et al. (2016) found that pain was most often identified and reported to nurses by care assistants. However, care assistants reflected on their role as finite; unidirectional communication meant that nurses did not discuss treatment or outcomes with them. This contributed to a sense of devaluation of their input, which resulted in communication breakdown with more senior staff (Corbett et al., 2016). In another study by Liu (2013) exploring the roles of NAs (n= 49), a repetitive cycle of reporting was described in which NAs would report pain repeatedly to nurses before they would provide pain treatment. This culminated in delayed treatment for NH residents, and NA reluctance to report pain. In a recent UK study, HCAs described their frustration at being excluded from multidisciplinary team meetings and a lack of professionalism attached to their role, despite their in-depth patient knowledge (De Witt Jansen et al., 2017a). The dismissal described could be related to nurses' preference to perform their own assessments of pain, alongside colleagues' assessments (Kenefick & Schulman-Green, 2004).

Despite these challenges, the literature suggests that unregistered staff experience a sense of accountability to identify and communicate pain to senior staff (Karlsson et al., 2013). In an Australian study exploring the work role of NAs (n=6) supporting older people in long-term care, an overarching theme of 'perfectly positioned' emerged, encapsulating the central position of NAs in the pain communication and treatment process (Holloway & McConigley, 2009). NAs described themselves as being at the forefront of pain assessment, being able to identify pain through direct care and through their close emotional bonds with older people. They described their role as also encompassing monitoring the effectiveness of interventions provided by nurses, although they reflected on being expected to make clinical decisions without any formal training in pain. NAs worked together to problem solve, largely due to a lack of access to registered nurses. They expressed a sense of satisfaction at being able to help older people with their pain, although seeing those they felt connected to could also cause them distress (Holloway & McConigley, 2009). Other studies suggest these roles also adapting care to prevent triggering pain and promote comfort (Liu, 2013), and reflecting on possible causes of pain (Karlsson et al., 2013). These findings support that the role of unregistered staff has expanded, and a recent review of pain documentation in long-term care facilities indicate unregistered staff are involved at all stages of the process, including documentation, use of a PAT and documentation/evaluation of interventions (Andrews et al., 2019). Consistent with this, De Witt Jansen et al. (2017a) has emphasised a need to upskill and reconceptualise these roles, to empower those working within them, and the receptivity of colleagues. In contrast with these experiences however, home care nurses have reflected on formal expertise of NAs, given the consistent relationships they share with PwD (Karlsson et al., 2015). NAs were described as the *"eyes"* of nurses (p. 194), given that nurses were not as consistently present. The removal of nurses from direct patient care in UK CHs likely presents nurses with a similar reliance on unregistered staff.

2.4.5 Formal pain assessment

2.4.5.1 Non-use of pain assessment tools

Formal approaches to pain assessment, including standardised self-report and observational pain assessment tools, are reportedly not used by formal caregivers. In a survey study of long-term care facilities in Australia, staff reported that pain assessment was not routinely assessed using PATs, for the purposes of either measuring pain, or to determine the efficacy of treatment interventions (Peisah et al., 2014). Formal pain assessment was regulatory-driven, rather than patient-driven. A series of recent UK papers explored the use of observational PATs (OPATs) among physicians, nurses and HCAs working in hospice, hospital, and CHs supporting patients dying with advanced dementia (De Witt Jansen et al., 2017a; 2017b; 2018). Most (11/14) HCAs were not familiar with OPATs and their content, while a small subset had accompanied nurses in the use of the Abbey Pain Scale (De Witt Jansen et al., 2017a). Among nurses (n= 24), 11 reported using OPATs to comply with mandates and recommendations. The pain scores generated were undocumented and were not used to inform treatment decisions (De Witt Jansen et al., 2018). They were perceived as lacking clinical meaning and having "*no added value"* to their existing holistic approach to pain assessment that drew on contextual knowledge of the patient and other collateral sources (e.g., patients' families; clinical and physical examinations) (De Witt Jansen et al., 2018, p. 1347). In contrast with this view however, nurses simultaneously recognised the benefits of standardised pain assessment to identify pain severity, monitor treatment, supporting care continuity and improve pain reporting and recognition (De Witt Jansen et al., 2018). HCAs expressed an interest to learn more about using PATs (De Witt Jansen et al., 2017a), suggesting scope for upskilling in this area.

Practically the non-use of PATs may relate to a lack of awareness and environmental limitations. Most NH managers in a UK survey by Barry et al. (2012) with NH managers (n=96) were uncertain if pain assessment tools (PATs) for the cognitively intact could be used for those with dementia. Liu et al. (2014) examined the acceptability of OPATs among NH staff, while 72% scored highly on acceptability of OPATs, staff indicated these methods were time consuming and too burdensome to be used for regular and systematic use. They also reflected on the applicability in dementia, given that observable behaviours indicative of pain, could be indicative of several states (such as agitation, distress, and dementia). Self-report PATs have been reflected upon comparably. Home care staff highlighted the limitations of using the VAS among those with dementia due to memory impairment and inability to describe pain (Karlsson et al., 2015). The inability of patients with dementia to use numerical pain scores means that acute care staff will provide a score on behalf of a patient using “*some kind of judgement”* based on the patient’s body language and other cues (Lichtner et al., 2015, p.7). Given that these tools are developed to provide a standardised approach to assessment, the use of judgement runs counter to this purpose. The practical limitations raised are consistent with the view of Dowding et al. (2016) who proposed that PATs do not support the rapid creation of an overall picture of pain that healthcare providers base their assessments and decisions on. Also, PATs have been developed with a view of pain assessment as a sequential, linear process (type 2 thinking), rather than acknowledging more intuitive and experiential processes (type 1) (Dowding et al., 2016). Reflecting on how formal caregivers describe assessing pain informally (e.g., experientially, relationally, and intuitive), and the aspects of formal assessment consolidated into their daily practice (e.g., observation of behavioural change and physical examination), this is consistent with the view that pain assessment is a combination of type 1 and 2 processes.

For IFCs supporting PwD living in the community, without training in pain assessment and considering there being “*no guide”* to steer them, they used a ‘*common sense’* approach to assess pain (Bullock et al., 2020, p.7). However, the literature suggests IFCs who can observe PATs use in practice, can integrate this into their care provision. In a study exploring IFCs role in supporting older people with cancer-related pain, IFCs described using a 1-10 rating for their loved ones, as they have observed done by healthcare providers (McPherson et al., 2014).

2.4.5.2 Lack of documentation

The literature suggests that the pain documentation within care settings is often incomplete, or pain is not documented. Corbett et al. (2016) noted that during focus groups with CH staff, documentation, and communication of pain among residents was ad-hoc. There was no clear pathway described by staff that detailed if their reports were documented or any processes for this, with communications tending to be verbal (Corbett et al., 2016). In reviewing care plans, pain was also only included in half (2/4) of CHs recruited to take part in the study (Corbett et al., 2016), further emphasising documentation was inconsistent. In a retrospective documentation audit of four Australian long-term care facilities, Andrews et al. (2019) found that pain assessment and management documentation was incomplete. Around a third of pain documented had no information or explication, with the remainder not offering information on the nature or cause of pain (Andrews et al., 2019). In an audit of documentation and observational notes in acute hospital wards, Lichtner et al. (2016) found a disparity in the quality and accuracy of data recorded. Staff described undertaking documentation as an administrative rather than investigative exercise, due to the large amount of paperwork they are required to complete. This resulted in sparse information on pain being documented (Lichtner et al., 2016). These findings, alongside those already highlighted are increasingly concerning given that staff report that they tend to assume patients with dementia do not have pain if it is not recorded in their documents (Lichtner et al. 2016).

2.4.5.3 Lack of time to assess pain

The literature suggest that long-term and acute care environments may not be conducive to the prioritisation of pain, or its assessment. Consistently, a lack of time has been identified as a barrier to the identification and assessment of pain, which appears to undermine caregiver’s ability to consider and reflect on the pain expressed by PwD and manifested behaviourally (Cohen-Mansfield & Creedon, 2002; Martin et al., 2005; Kaasalainen et al., 2007; Karlsson et al., 2015). Survey results indicate that over half of NH managers identify a lack of time as a barrier to pain management among PwD (Barry et al., 2012), while the majority (91%) of NH nurses identify this as a primary barrier. A recent European survey exploring use of PATs found long-term care staff indicate that although these tools are easy to use, a lack of time was a barrier to their use (Zwakhalen et al., 2018).

Qualitative studies have found long-term care staff and NH nurses reflect with frustration on the demands of their role, and the administrative duties that prevent them to spend more time with patients (Fox et al., 2004; Kenefick & Schulman-Green, 2004). A heavy workload has been described as a daily challenge and finding time for pain management insurmountable (Kaasalainen et al., 2007). Bowers, Lauring and Jacobson (2001) studied how nurses manage their time and found that time pressures forced them to forego the should-do work to complete the must-do work. It appears that pain management may not be conceptualised as the latter, and the environmental and workload pressures of long-term care settings may reinforce this. Conversely however, pain may also not be prioritised given the added demand of assessing and managing it. Cohen-Mansfield and Creedon (2002) found NH staff described how residents calls for attention, when in pain, put added constraints on their already limited time to provide care.

Time is a requisite of both PwD and caregivers to provide the space and time necessary for pain to be communicated (Martin et al., 2005; Karlsson et al., 2015). Given the fluidity of cognitive status and pain experiences among those with dementia, home care staff described “*being in the moment in the particular situation”* when responding to a person with dementia (Karlsson et al., 2015, p. 196). Similarly, acute care staff have highlighted the importance of being present in the “*here and now”* to receive pain reports as PwD are unable to provide them (Dowding et al., 2015, p. 158). Due to time restrictions in the home care environment, staff described having to strike a balance between having time to make visits, whist maintaining the quality of care and being able to identify and assess pain during visits (Karlsson et al., 2015). These time constraints re-emphasise that time may force formal caregivers into choosing between care tasks to undertake (‘should-do’ vs. ‘must do’).

2.4.6 Pain identification & assessment: Key literature findings

With dementia, a range of challenges arose for caregivers from a reduced or altered ability to verbally communicate or self-report their pain. Dementia was viewed to have precipitated changes in either pain experience or perception, or communication, which contributed to a sense of distrust regarding pain reported. As a result, alternative strategies were described which did not rely on verbal communication of PwD per se or a self-report. These encompassed observation (behavioural change, verbal/non-verbal signs of pain, and physical indicators), relationship-centred assessment, and intuitive-experiential mechanisms. Self-report was not unanimously distrusted however, with some caregivers encouraging it and integrating it as a part of their assessment approach. The latter approach was more consistent with recommendations and a hierarchy approach to assessment which draws from multiple pain information sources (Section 1.4). Pain assessment tools were not used; they did not add anything to caregivers existing repertoire of assessment approaches and were described with cynicism.

The pressures of the care environment meant formal caregivers felt there was insufficient time or opportunity for pain assessment, or reflection on pain. The context of care further meant that pain assessment was dependent on a complex chain of communication between different ‘assessors’ of pain, with unregistered staff often most likely to identify and raise their concerns. In a similar capacity, family/IFCs could raise pain or provide insights to support pain identification. Family/IFCs however, could be omitted from care or dismissed, an experience relevant to unregistered staff also.

Pain was considered important in the context of existential and emotional suffering, and during end-of-life care by formal caregivers. Yet the literature suggests physical pain and pain arising from age-related conditions among PwD is otherwise not actively considered or monitored. Older people and PwD themselves were described as barriers to pain assessment with stoic views towards ageing and pain that prevented them reporting or seeking help. The NH environment further normalised a stoical approach to pain and ageing among residents and staff. These findings identify a myriad of potential challenges which caregivers must circumvent in identifying and assessing pain as a precursor before pain treatment can even be considered. They also highlight how caregivers’ understanding of pain and its assessment may present further challenges to the effective recognition and assessment.

2.5 Pain treatment

Pain may be managed through non-drug or drug (pharmacological) approaches, and ideally a combination of both approaches, as discussed in Section 1.5. As evident in the previous chapter, the treatment of pain and provision of pain relief is sub-optimal among those with dementia, despite comparable (or increasing) pain related conditions which cause significant pain issues. The following section explores caregivers' experiences within the conceptual domain of pain treatment among older, cognitively impaired, and demented populations to explore the underlying basis for this. The literature indicates an overwhelming sense of uncertainty around pain treatment and appropriate responses for these populations; the following clusters caregivers' reflections around this by emergent themes in the literature.

2.5.1. Drug approaches: reluctance, misunderstanding & beliefs

The literature suggests caregivers' experiences of treating pain using pharmacological strategies is characterised by ambiguity and reluctance. This appears to be underpinned by a lack of knowledge, and caregivers' beliefs and fears regarding different pain medications, side-effects, dosages, and scheduling among PwD. These deficits and their critical implications for pain practices and suboptimal treatment for PwD are further delineated below.

2.5.1.1 Simple analgesia: paracetamol & NSAIDS

Recommendations and the WHO pain ladder indicate that a stepwise approach to pain management should commence with simple analgesia (Section 1.5). Consistent with this, Corbett et al. (2016) found paracetamol was used as first-line response to treat pain. Nurses perceive paracetamol as the analgesic of choice for mild-to-moderate pain, reflecting upon the low side effect profile for older adults (Kovach et al., 2000). They did endorse the use of non-nonsteroidal anti-inflammatory drugs (NSAIDs) for musculoskeletal pain, however, were concerned about side effects for people with dementia, including possible bleeding and stomach problems (Kovach et al., 2000).

The literature suggests that there is a reliance on simple analgesic approaches, without escalation., Andrews et al. (2019) found all documented interventions in a sample of long- term care facilities were either simple analgesia or NSAIDs. IFCs have reflected on the relative safety of paracetamol considering the presence of co-morbid conditions and their associated treatments where other analgesics may be contraindicated (Bullock et al., 2020). This study also found GPs were reluctant to prescribe more than simple analgesia to PwD. This confirms the challenges described by NH nurses and staff who identify that physicians can be reluctant to prescribe stronger pain relief to older people and those with dementia (Section 2.5.1.2). This may be why simple analgesia are relied upon, because caregivers are unable to access or obtain prescriptions for stronger pain relief. It may also explain why studies find PwD are more likely to be prescribed and administered simple analgesia, rather than NSAIDS or opioids (Section 1.6.1).

Despite a preference for using paracetamol, in a questionnaire study many NH managers neither agreed nor disagreed that ‘paracetamol is the best analgesic to use in people with dementia who are experiencing chronic pain’ (29.2%) (Barry et al., 2012). This suggests an ambiguity surrounding appropriate analgesic choice in dementia which is mirrored in other questionnaire-based studies. Zwakhalen et al. (2007) explored nursing home staffs’ (n= 123) beliefs and knowledge regarding pain assessment and management among NH residents with dementia. A lack of consensus was present regarding pain management with staff frequently (30-40%) using ‘no opinion’ in response to items relating to risk of addiction and side effects for older adults, scheduling of medications, and efficacy of pain medication. Although differences in experience did not appear to resolve ambiguity for NH staff, education did with RNs with specialist training having significantly more understanding than both RNs and NAs (Zwakhalen et al., 2007). Although this study was undertaken over 10 years ago, and in The Netherlands, a more recent UK study with NH nurses found they were also unsure regarding analgesic choice and safety among PwD (Burns & MacIlfatrick, 2015). No recent studies have been identified that have explored understanding of analgesic use among more diverse staff roles, nor in relation to IFCs. However, the current evidence base suggests that pain treatment entails significant uncertainties for formal caregivers, which is likely increasingly so for those without training, such as unregistered staff, or IFCs.

2.5.1.2 Opioids: fear & reluctance

The literature indicates that among the elderly and those with dementia, the use of opioid analgesics, and associated side effects, caused formal caregivers significant concerns (Geddis-Regan et al., 2019). Qualitative studies find that CH staff believe that older people cannot tolerate opioid medications (Newton et al., 2014), and that NH nurses believe dementia is an additional ‘risk factor’ or complexity to be considered (Chang et al., 2009). Such are the concerns regarding risks, addiction and tolerance, opioids were described as a final treatment option by nurses and physicians, only used when all other options had failed (Kaasalainen et al., 2007). They indicated opioids were rarely used in dementia, as pain could not be confidently determined they are unwilling to risk opioid use. Opioids become more acceptable in the context of end-of-life, which suggests that acute pain or persistent pain is treated differently. Additionally, interviews with NH staff indicated a resistance (from family members, nurses, and care workers) for opioids to be used, even when they are prescribed to a resident with dementia (Peisah et al., 2014). Resistance reportedly remained even when alternative treatments were not effective (Martin et al., 2005). Uncertainty and fear may be reinforced by a lack of understanding regarding opioids. Barry et al. (2012) found NH managers frequently responded ‘neither agree or disagree’ regarding the safety of opioids in dementia (37.5%), risk of addiction (24%) and risk of side-effects (30.2%). However, those with more than 20 years’ experience were more likely to respond appropriately regarding opioids use. More recently a cross-sectional survey found hospital nurses (n= 267) have a good understanding of the potential adverse effects of strong and weak opioids among patients with dementia (Rantala et al., 2015). The age of nurses predicted levels of knowledge with younger nurses demonstrating the most accurate and informed understanding. This suggests that how recently a nurse qualified may shape their perspective on opioid use.

It was acknowledged however, that a reluctance to use opioids may result in the undermanagement of pain. Nurses reflected that while opioids were used for acute pain following surgery, or at end-of-life, these medications could be offered for relief of everyday pain (Kovach et al., 2000). While cognisant of side-effects like constipation and sedation, comfort was the primary concern. NH staff similarly highlighted that that cancer-related pain in particular may be undermanaged without the use of opioids (Martin et al., 2005). In both these studies, physician resistance to prescribe opioids was highlighted as a primary barrier to the use of opioids (Kovach et al., 2000; Martin et al., 2005). This relates to a wider theme in the literature relating to the nurse-physician relationship, and its characterisation as one of co-dependency and co-operation. Barry et al. (2012) and De Witt Jansen et al. (2017b) found CH nurses and managers described delays in prescriptions of analgesics, subtherapeutic prescriptions and reluctance to prescribe alternative forms of administrations among physicians. This gave rise to a sense of powerless among nurses (Brorson et al., 2014). While nurses described themselves as focused on patient comfort, physicians were described as concerned with addiction and risk of side-effects (Kaasalainen et al., 2007; Brorson et al., 2014). As such, a reluctance to escalate pain relief to opioids among PwD may reflect not only a caregivers' own anxieties, but further those responsible for prescribing opioids.

2.5.1.3 Dosage & scheduling

Consistent with recommendations (Section 1.5), a stepwise approach to analgesic use among older people and those with dementia has been observed across some studies. The majority of NH nurses and managers agree the drug treatment of pain in dementia should follow a stepwise approach (79.2%, 87.5%) (Barry et al., 2012; Burns & McIlfatrick, 2015). Interview studies with NH nurses mirror this, with nurses describing a process of beginning with a low category and dose of analgesic and using a systematic process to escalate the dosage (Kovach et al., 2000; Kaasalainen et al., 2007). This was referred to as a *"start low and go slow"* response (Kaasalainen et al., 2007, p. 571). Nurses delineated between categories of analgesia, from simple nonopioid analgesia, to opioids, such as morphine, and the types of pain and causes they had used each for (Kovach et al., 2000). However, nurses participating in this particular study were recruited having been identified as knowledgeable in regard to pain management for PwD and having received recent training. As such their understandings may not be representative of wider understandings of dosage and categories of analgesia.

A stepwise approach may not be guided by recommendations, as a result pain relief may not meet thresholds necessary to offer relief. A qualitative study exploring the wider challenges of caring for people with advanced dementia found one third of healthcare professionals (n=44) recruited described a reluctance to use appropriate amounts of analgesia with those living in long-term care facilities (Chang et al., 2009). Clinicians in acute care described using their own judgment in applying the analgesic pain ladder among PwD (Lichtner et al., 2015). Judging the level of titration, or the appropriate next step on the analgesic ladder relied on clinicians' knowledge or 'sense' of what the expected pain medication would be for a given medical condition (Lichtner et al., 2016). A reliance on healthcare providers own 'sense' is consistent with observations that pain management protocols or guidelines are not used by NH staff (Kovach et al., 2000; Martin et al., 2005). Only 60% of NH managers claim to use pain treatment guidelines within their nursing homes (Barry et al, 2012). As a result, pain management practices appear to be guided by caregivers' own judgements about medications and conditions, rather than guided by the resources available.

Disparate perspectives on the scheduling of pain treatment and the most optimal approach to treating pain were present among formal caregivers. While most (79.2%) NH managers disagreed with 'as needed' (pro re nata, PRN) pain treatment among residents with dementia (Barry et al., 2012), almost one third (31.3%) NH nurses were uncertain if scheduled analgesics provided the most optimal pain management for PwD (Burns & McIlfatrick, 2015). This preference appears to be mediated by specialist training. A study by Zwakhalen et al. (2007) found that while most NH staff agreed that ‘as needed’ scheduling should be used among PwD, all trainee nurse specialists disagreed. Qualitative and observational studies suggest in practice preferences appear to fall on the side of ‘as needed’ medicating, with long-term care staff and acute care staff deferring to this approach on an ad hoc basis (Peisah et al., 2014; Lichtner et al., 2016). ‘As needed’ also appears consummate to a ‘wait and see’ approach, used by IFCs and older people themselves to see if pain was tolerable before pain medication was used (McPherson et al., 2014). Long-term care staff report that ‘as needed’ medicating was triggered when a resident displayed observable pain indicators, such as calling out or facial expressions, and when behavioural change occurred (Peisah et al., 2014). ‘As needed’ medicating relies on the ability of a PwD to be able to communicate their need, where the same challenges identified earlier will be encountered (Section 2.4).

Despite an apparent preference for ‘as needed’ medicating, most NH staff disagree that pain medication should be delayed among those with dementia, so they received less pain medication (87%) (Zwakhalen et al., 2007). Moreover, most disagree that a person with dementia should first report pain before receiving their next dose of pain medication (70%) (Zwakhalen et al., 2007). This suggests ‘as needed’ medicating may not necessarily be related to a reluctancy to provide medication to those with dementia.

2.5.1.4 Balancing side-effects: Pain & comorbidities

Multifactorial concerns were considered by caregivers before offering drug-based treatment to PwD. During interviews with long-term care nurses, and focus groups with emergency nurses, treating pain was reflected upon as balancing act and a trade-off between pain and side-effects, polypharmacy and preserving cognitive function (Kaasalainen et al., 2007; Fry, Chenoweth & Arendts, 2016). Nurses perceived that analgesic options were restricted for older people with cognitive impairment because of these competing considerations (Fry et al., 2016). During end-of-life care, nurses have also reflected on having to balance their own anxieties about overdosing or harming a patient with dementia, alongside relieving the suffering of the patient (Brorson et al., 2014). The number of medications being taken by the person with dementia (due to their comorbidities) was another consideration among caregivers (Mentes et al., 2004; Martin et al., 2005). In a qualitative study, family caregivers of PwD were concerned about adding analgesia to their loved one's medication regimen, considering it to be "*over and above" t*he large number of medications already being taken for other conditions (Bullock et al., 2020, p. 9). The concerns of both formal and informal caregivers suggest that pain, in the presence of comorbidities and other medications, is unlikely to be prioritised. Qualitative research with older people suggests that they also perceive pain to be a lower order health concern, comparative to more important medication regimes (Sale, Gignac & Hawker, 2006; Makris et al., 2015). Older people accept their painful conditions as 'tolerable' and 'not life threatening' (Sale et al., 2006), striving to be pain-tolerant, rather than pain-free (McPherson et al., 2014). This aligns with a lack of consideration of pain (Section 2.4.2.2) and stoical tolerance of pain discussed already (Section 2.4.2.1).

2.5.2 Non-drug approaches

Non-drug methods broadly encompass any intervention which does not involve pharmacological drugs or medications, including simple approaches (repositioning; distraction), and psychosocial approaches to improve wellbeing and functioning (social activities; exercise programmes) (McDermott et al., 2018). In a recent qualitative meta-synthesis, formal and informal caregivers were both found to endorse non-drug strategies, largely due a reluctance to use analgesic medications among older people and those with have dementia (Geddis-Regan et al., 2019). Non-drug methods may therefore play a role in reducing the use of pain medications and pharmacological burden among PwD. However, they may also be used inappropriately as a substitute to pain medication. This is supported by the findings of Andrews et al. (2019) who found 67% of interventions documented following pain events among NH residents with dementia were non-drug approaches (Andrews et al., 2019).

Questionnaire studies indicate that most NH managers and nurses surveyed agree that non-drug approaches are useful in the management of pain among residents with dementia (51%, 91%) (Barry et al., 2012; McIlfatrick & Burns, 2015). In accordance with this, qualitative studies with nurses, nursing assistants, and family caregivers, describe a variety of non-drug approaches as effective in relieving pain and anxiety among PwD, including massage, reposition, hand holding/touch, music, physical therapy, distraction, and exercise (Kovach et al., 2000; Martin et al., 2005; Mentes et al., 2004; Midtburst et al., 2018). These approaches are described as complimentary to pharmacological approaches and adaptable to a patient’s life story or their ‘likes and dislikes’ (Liu, 2013; Brorson et al., 2014).

Although highlighted by diverse roles, non-drug approaches were typically employed by unregistered staff providing direct care, such as nursing assistants (Geddis-Regan et al., 2019). Karlsson et al. (2013) found CNAs described being present and involved as important for the alleviation of suffering among PwD. Nursing assistants recognised that iatrogenic pain and existing injuries could be triggered by daily care, as a result they used repositioning, gentility, distraction, and adapted approaches to prevent pain during personal care (Liu, 2013). This suggests these unregistered staff are involved in non-drug responses to pain, likely as a function of their everyday caregiving.

Family caregivers of PwD have also reflected positively on the use of non-drug approaches. Corbett et al. (2016) found family caregivers of CH residents with dementia expressed a preference for these methods, using heat/cold therapy, music, and massage. They conveyed that non-drug approaches should be a first-line response to pain. Among IFCs supporting PwD living in the community, most supported the use of non-drug strategies to manage pain, such as physiotherapy, exercise, and treatments providing warmth and comfort (Bullock et al., 2020). IFCs did reflect the benefits of these methods could be short-lived, and some were sceptical about alternative therapies. While not reflected on in these studies, as the ability of person with dementia to self-manage their conditions wanes (Bunn et al., 2016), IFCs are likely relied upon to lead on non-drug approaches to manage pain for the person they support. Considering this, it is positive there appears to be receptivity to these methods among informal and family caregivers.

In contrast to the above, UK CH staff indicated the use of non-drug approaches for pain management were not a part of their usual practice (Corbett et al., 2016). Staff recognised the value of these methods, however a reliance on medication to treat pain was a dominant theme. Descriptions of the use of non-drug approaches in practice also suggest their use in long-term settings are sporadic and non-systematic (Peisah et al., 2014). These methods have further been described by care assistants in a CH as time consuming and ineffective (Petyaeva et al., 2017). However, non-drug methods may be more amenable to PwD than pharmacological routes. Prior to entering a NH, PwD were described by their relatives as primarily using non-drug approaches to manage their pain, such as laying down, relaxation or exercise (Mentes et al., 2004). During interviews, CH residents described using non-approaches such as hot baths and ‘rubbing the affected area’ as methods of self-management (Newton et al., 2014).

2.5.3 Trial-&-error treatment

Pain was not routinely responded to with pharmacological intervention, often related to the uncertainty associated with diagnosing pain (Gilmore-Bykovskyi & Bowers, 2013). Instead, NH nurses describe engaging in a trial-and-error process to manage pain and eliminate behavioural changes. The process commenced with non-drug strategies and such as toileting, repositioning, and checking for signs of infection (Gilmore-Bykovskyi & Bowers, 2013). It then shifted to pharmacological strategies, with the objective being to return a resident with dementia back to their baseline behaviour, rather than the identification of a cause of pain. Trial-and-error could span 2-3 shifts, or 1-2 days, until the issue would be escalated, significantly delaying pain medication or resolution (Gilmore-Bykovskyi & Bowers, 2013). Acute care staff describe that once pain is suspected they tested ‘guesses’, trying to link events and treatments over the period of a patients stay (Dowding et al., 2016). This trial-and-error process required that staff assimilate information from the initial sign of pain to the resolution of pain. Chang et al. (2011) developed a conceptual model outlining this process, drawing from nurse interviews and the wider literature. This model defines an active process that requires nurses to integrate expressional clues from patients after an intervention is trialled, comparing the patient’s response with their usual habitual expressive patterns, all while schematising responses based on stages and types of dementia (Chang et al., 2011). Although not an exacting or standardised process, the experiences of nurses indicate trial-and-error was a reasonably calculated and considered process, that draws diverse information sources.

2.5.4 Declining communicative & cognitive capacity

The treatment of pain requires the cooperation of PwD, however diminishing capacity is described as a barrier to this. PwD may refuse care, even though they are experiencing pain, which presents an ethical dilemma for nurses and CNAs (Karlsson et al., 2015). In interviews with nurses from acute, hospice and residential care, patient refusal of analgesia and aggressive resistance were a common experience (De Witt Jansen et al., 2017b). Nurses were unable to engage in a nurse-patient dialogue to allay patient fear and anxiety regarding medications, due to cognitive deficits. IFCs have also experience combative responses from those with dementia they support in response to pain medication or interventions (Tartar et al., 2016). They described the inability of those with dementia to make the causal connection between interventions being offered and the relief of their pain (Tarter et al., 2016). This combative resistance, alongside empathising with another's pain, contributed to 'secondary suffering' among IFCs. This reciprocal distress has also been described by Licensed practical nurses (LPNs) and RNs (n= 20) providing palliative care to those with severe dementia (Midtburst et al., 2018). They described distress and helplessness in situations where a person with dementia is experiencing pain, but aggressively rejects care and intervention. However, if nurses could succeed by finding the "*right buttons to push"*" with patients, there was a sense of positive accomplishment (Midtburst et al., 2018, p. 4)

Non-compliance was highlighted as exacerbating an already complex situation of pain treatment. In a hospital study exploring nurses perceived barriers to pain management following hip fracture, a bidirectional relationship was described between pain and confusion among those with dementia (Rantala et al., 2014). Pain exposes confusion, and confusion in turn can escalate painful situations and resistance to care (such as refusing medication or ignoring instructions regarding walking). To further complicate this situation, nurses indicate older people with cognitive impairment may not recall what medication they have already taken (Fry et al., 2016). Thus, treatment may be prohibited by cognitive impairment.

It is unclear from the literature if, and how, caregivers negotiate issues of non-compliance or a lack of cooperation. One study suggests that patient refusal of analgesia is rarely prioritised (Peisah et al., 2014). Long-term care staff indicated non-compliance to psychotropic medications and other physical care medications is viewed as a more significant concern, due to patient safety. This reinforces suggestions that managing behavioural aspects of dementia and comorbidities are the main preoccupation that can detract the prioritisation of pain (Section 2.4.3.5; Section 4.2.2.1).

Caregivers highlight that non-compliance was further compounded by practical administrative challenges. Older people and those with dementia are described as resistant to pain medication, preferring not to seek help or accept relief (Fox et al., 2004). This was identified as related both to their stoic attitudes towards pain (Section 2.4.2.1), their fears regarding medications, and administrative challenges. Bullock et al. (2020) found that many PwD and their caregivers were reluctant to use analgesia, referring to it as ‘poison’. As a result, PwD and older people have described a preference for non-drug interventions, preferring to be in pain, rather than experiencing negative side-effects (Schofield, 2006; McPherson et al., 2015; Bullock et al., 2020). Moreover, among those with advanced dementia, nurses identify the problems with oral administration due to challenges swallowing (De Witt Jansen et al., 2016b). Alternative approaches, such as syringe drivers and intravenous administration were also problematic due to a lack of body fat and patient fears. As a result, nurses have expressed a preference for transdermal patches as a lower risk alternative and less invasive approach for those whom compliance and administration may be challenging (Martin et al., 2005; De Witt Jansen et al. 2015b). However, alternative routes of administration may not be easily accessible with physicians unwilling to prescribe such.

2.5.5 Medication managers & advocates: role of informal caregiver & unregistered care home staff

The experiences regarding pain treatment thus far have overwhelmingly reflected that of registered, certified, or licensed roles. However, the literature does provide some insight (albeit sparsely) into the actual, and potential roles of unregistered staff providing direct care and IFC. NAs have described a supporting role in pain treatment, reporting pain to nurses and working under the supervision of nurses during drug administration (Liu, 2014). However, in another study, personal care workers identified that access to a registered nurse can be an obstacle to pain relief for long-term care residents with dementia (Peisah et al., 2014). This suggests that unregistered staff may be impeded in their roles by a lack of registered staff to oversee drug administration or escalate patient complaints to. It is plausible that similar experiences may be present in UK CHs for senior carers and HCA roles, where a RN may not be present consistently (Section 1.2.2.1). Liu (2014) suggests that there may also be further scope for unregistered staff to act as re-assessors of pain and evaluators of medication effectiveness. Given that NAs often identify pain, Liu (2014) suggests they would therefore be best positioned to determine if pain was alleviated and to monitor patient status.

The position of IFCs as proxies, information sources and advocates in the context of pain assessment has been discussed (Section 2.4.3.2), their role in relation to pain treatment could be comparably significant. It is recognised in the wider literature that IFCs become increasingly responsible for managing conditions and medications among those with dementia, and that this may be an onerous task (Section 1.6.2). In considering the management of pain more specifically, it is likely pain presents its own unique challenges to those of other conditions. Pain is an emotive topic, particularly so when the person suffering may be a spouse or close family member. As such, it will be different to the management of everyday conditions which do not cause immediate suffering. Further, the management of some conditions will likely be supported by known diagnosis, known prescribed medications, with known outcomes of treatment. Pain on the other hand can be challenging in terms of its origin, severity, and treatment responses.

Few papers have explored the role of IFCs in the management of pain. One paper by Bullock et al. (2020) however, does provide some insight into this. During interviews, IFCs described being responsible for administering and managing analgesia, and non-drug approaches. This entailed simple approaches like prompting those with dementia to take analgesia. It also entailed more complex responsibilities, including monitoring the status of a loved one and their compliance to medication regimes, and feeding this back to healthcare providers (Bullock et al., 2020). IFCs supporting hospice patients with dementia, have reflected however, upon a lack of guidance from healthcare providers in preparing them for the responsibilities of managing pain among relatives (Tarter et al., 2016).

A study exploring the experiences of family caregivers of older adults indicates that increasing cognitive impairment leads to family caregivers becoming more active in assessing and controlling the pain of loved ones (McPherson et al., 2014). This was especially so as self-management becomes more concerning. Active involvement entailed communicating with healthcare providers on behalf of a loved one, being responsible for another's' pain, choosing the right medication and dosage, and resolving any arising side-effects (McPherson et al., 2014). This was described as exhausting and challenging, given tensions arising from shifting relationship boundaries and older adults' reluctance to discuss their pain (McPherson et al., 2014). This study, while not specific to dementia, suggests that IFCs do become increasingly involved in the management of pain and pain-related conditions as cognitive impairment increases.

2.5.6 Lack of understanding & training

As is evident throughout the key themes drawn from the literature encompassing pain identification and assessment, and pain treatment, caregivers expressed uncertainties, misunderstanding and a lack of preparedness. This is acknowledged by caregivers, with a perceived lack of understanding and training consistently highlighted as a barrier to pain assessment and management, and an expressed emphasis being placed on the need for upskilling and training across registered and unregistered staff (Kovach et al., 2000; Chang et al., 2009; Kaasalainen et al., 2007; Liu, 2014). A significant proportion of NH managers and nurses had not received any training on pain in PwD (63.4%, 37%) in two UK questionnaire studies (Barry et al., 2012; Burns & McIlfatrick, 2015). Nurses indicated that training was most often related to palliative care, suggesting this may not prepare nurses for issues of persistent or acute pain arising in day-to-day care provision. Almost all (81%) NH managers identified a lack of education or knowledge among staff about pain management among PwD as a barrier to optimal pain management (Barry et al., 2012). Qualitatively, a lack of specific training has been a strong message arising from focus groups with CH staff (Corbett et al., 2016). Staff, except for nurses, had not received any training in pain, and there was a lack of confidence in taking ownership for identifying and managing pain among junior staff. The consensus was that training and more leadership within the CHs would encourage staff to take more responsibility for pain (Corbett et al., 2016). This fits with wider discussions around the disparity of dementia training provided to CH staff (Section 1.2.2.1).

For unregistered staff, a lack of training appeared in conflict with their expanding roles. Despite acting as a pain assessor and reporter to nursing, NAs described receiving limited training in pain management and limited supervision by nurses (Liu, 2013). Upskilling was highlighted as a critical element among HCAs in a study by De Witt Jansen et al. (2017a), almost all (13/15) identified a need for responsive and continued training for them. They were particularly interested in more involvement in using pain assessment tools. This suggests greater scope to include unregistered staff in formalised pain assessment processes. A need for continued formal developed has also been expressed by nurses working across hospital, hospice, and NH care (De Witt Jansen et al., 2017b). Nurses suggested that mentoring, shadowing or ‘learning by example’ could support their formal development.

A small cluster of quantitative studies have been carried out to specifically examine levels of knowledge and attitudes/beliefs towards pain assessment and treatment in dementia among NH staff (Zwkahalen et al., 2007; Barry et al., 2012; Burns & McIlfatrick, 2015). These studies confirm qualitative suggestions that formal caregivers need training to support in developing their understanding, awareness, and beliefs about pain in dementia, with particular attention to elements of pain assessment (self-report and PATs), and drug approaches to pain treatment. These studies also confirm that training is an important mediator of optimal pain practices, by way of supporting more accurate beliefs and understandings relating to pain. While educational level itself does not significantly improve understanding and beliefs (Barry et al., 2012), specific training on pain in dementia does relate to greater understanding and more appropriate beliefs regarding pain in dementia, and its assessment and management (Zwakhalen et al. 2007; Burns & McIlfatrick, 2015).

2.5.7 Pain Treatment: Key Literature Findings

Treating pain in dementia is reflected upon in the literature as a complex process, requiring multifaceted considerations. Age, comorbid conditions, potential side-effects, and polypharmacy are significant concerns that result in a reluctance to escalate pain treatment into opioid categories. Prescribed opioids were difficult to obtain from physicians, which left nurses unable to provide optimal relief from suffering.

There is an apparent reliance on simple analgesia, and non-drug approaches. Paracetamol was perceived as safer option, considering the populations vulnerability. Treating pain followed a trial-and-error approach and was most often focused on returning a person with dementia back to baseline behaviour, rather than the relief of pain. This reflected a preoccupation with managing behaviour change as a symptom of dementia, rather than managing pain. The process ultimately delayed (or prevented) drug-based treatment being initiated. Scheduling of drug-based relief tended towards ‘as needed’, despite an awareness that PwD may not be able to verbalise when they next required pain relief.

Caregivers reflected on the challenges of treating pain when PwD may be non-compliant (through administrative challenges or cognitive impairment) with medication regimes. Non-compliance did not appear to be prioritised however, with pain medication being considered a lower-order priority than the management of other conditions. IFCs appeared to adopt a role of medication manager and advocate, however the literature suggests they feel inadequately prepared for this role. Overwhelmingly, a lack of understanding in relation to pain treatment was present among formal caregivers, and there was self-confessed need for greater knowledge and training in this area.

Non-drug responses to relieve discomfort and pain were often described by family caregivers and appeared preferable to older people and PwD. Unregistered staff tended to lead on non-drug methods in nursing and care homes, having incorporated these into their daily care interactions. These approaches were not consistently supported however, with their use unsystematic.

2.6 Reflecting on the literature: identifying gaps & developing a rationale

This review provides an overview of pain identification, assessment, and treatment for people with dementia, as described, experienced, and understood by formal and informal caregivers in the literature. The experiences of caregivers described, and themes generated indicate substantial challenges are present, with misunderstandings and uncertainty across both conceptual domains of identification/assessment and treatment. The literature indicates caregivers have developed mechanisms to circumvent these challenges. These, however, do not appear consistently effective or consistent with recommended or optimal practices (for assessment or treatment). This builds upon the previous chapter, providing a contextualised understanding of pain identification, assessment, and treatment inadequacies, from the viewpoint of formal and informal caregivers directly involved in supporting PwD with their pain. However, some limitations are present with the current literature that can be critically reflected upon to develop a rationale for empirical work undertaken in this thesis.

The body of literature exploring caregivers' experiences identifying, assessing, and treating pain among PwD primarily originates from varying forms of long-term care settings. This review has subsequently provided a cohesive understanding of aspects of pain assessment and treatment within this context. However, a large body of this literature does not originate from the UK (see Section 2.2.2). These settings within other countries will vary in their organisation, capacity, level of care provided, funding, and staff structure, to that represented in the UK (Ribbe et al., 1997; Robertson, Gregory & Jabbal, 2014). As such, while there are likely shared challenges and themes across countries, the UK care home context will have its own unique environmental constraints, workforce structure, and regulatory requirements, that are not represented within papers derived from other countries.

There is a domineering focus among the literature discussed on registered, certified, and licensed nursing staff. As explicated in Chapter 1 (Section 1.1.6), increasingly direct care is provided by unregistered staff, not registered nurses, in the UK and beyond (Andrews et al., 2019; Halifax, Miaskowski & Wallhagen, 2018).

A lack of consideration of these roles within the literature has been underscored by the assumption that pain assessment and treatment are duties that fall within the domain of nurses and physicians (Liu, 2014). It may also be underscored by a lack of UK care home papers discussed above, and as such its workforce representation. There has been in recent years some recognition of the changing landscape of nursing and care home workforces, with some papers taking a specific focus on unregistered (or unlicensed/uncertified) staff in the context of pain assessment among PwD, such as nursing assistants and HCAs (Holloway & McConigley, 2009; Lui, 2014; De Witt Jansen et al., 2017a). As found in the current chapter, these studies suggest that unregistered staff are involved in pain assessment as reporters and advocates, and pain management using drug (as supervised by registered staff) and most often using non-drug methods. This emphasises the importance of continued development of the literature base inclusive of their view. While the views of registered staff, specifically RNs, are important, so too are those of HCAs, and other roles such as senior carers, and management, who are likely are drawn into pain assessment and treatment process.

The primary focus of the current literature has been role specific, with few papers in the last decade taking an encompassing approach to recruitment of different roles (Liu et al., 2011; Peisah et al., 2014; Corbett et al., 2016). Although studies focused on specific roles provide in-depth perspectival insight, the findings are limited to one perspective alone. This has been reflected upon, and calls have been made for studies which elucidate different roles, the interaction between different roles, and the outcomes of such for pain assessment and management (De Witt Jansen et al. 2017b). This is particularly important considering the findings of this review that pain assessment and management appears to be shared and collaborative activity between different staff. Further work is needed to build upon current findings and establish how pain management functions in real-life settings, engaging the spectrum of key stakeholders involved in dementia care in CHs (Corbett et al., 2016). This can be achieved by exploring the landscape of pain recognition, assessment, *and* management with a holistic, encompassing view on *all* staff roles.

Diverse papers were included in this review for the purposes of an encompassing view of relevant, and potentially relevant studies. However, some reflections are made regarding the representativeness papers from different care settings to the focus of the review. A number the papers reviewed concerned pain among people with advanced dementia during end-of-life care in long-term care settings, hospitals, and hospices (Brorson et al., 2014; Tarter et al., 2016; De Witt Jansen 2017a, 2017b, 2018; Midtbust et al., 2018). As identified in this review, end-of-life pain appears to be approached and considered differently from other forms/causes of pain (Section 2.4.2.2). Given the incidence of pain-related comorbidities, chronic pain conditions and incidence of injuries (e.g., falls) among PwD (Section 1.3.3), it is more likely that issues of chronic and acute pain are encountered most often by CH staff and IFCs, rather than those relating to end-of-life. While these papers are an important contribution that likely raise shared challenges, conceptualisations of pain during end-of-life may not necessarily reflect more everyday issues of pain encountered by the caregivers of interest in this thesis. Similarly, several papers from acute settings are also discussed (Fry et al., 2015; Rantala et al., 2015; Dowding et al., 2016; Lichtner et al., 2016). Acute care is a contextually different environment to CHs, with a focus on treatment and intervention, rather than on daily care and interactions, as in a CH. Within acute care, pain is also likely to be acute in nature arising from injury or post-operatively (Fry et al., 2015). Access to healthcare providers to support with pain assessment, prescription of pain treatment, and administration will be more readily available in acute care than in a CH setting. While again, comparable challenges will be present, they may be heightened in CH settings where they will be unique contextual factors that relate to the environment and processes within it.

As noted by others (Kankkunen & Välimäki, 2014; Bullock et al., 2020), a dearth of literature from the viewpoint of family or informal caregivers is present. Most studies in the area of pain in dementia have included IFCs to compare concordance between patient and proxy pain reports (e.g., Barry et al., 2015), rather than exploring if and how IFCs identify or recognise pain. The omission of IFC in the literature may be explained comparably to the omission of unregistered formal roles; that perhaps pain is seen as outside the remit of family or informal caregivers. However, the limited literature which could be gathered regarding pain (e.g., Martin et al., 2005; Tarter et al., 2016; Bullock et al., 2020) and within the wider literature on medication management (Section 1.6.2) indicate that IFCs are supporting with aspects of pain identification and treatment.

Family caregivers have been included in studies within residential settings, exploring their perspectives on residents’ pain (e.g., Mentes et al., 2004; Corbett et al., 2016). In such settings, care and support is provided by a team of staff, where residents with dementia and their family caregivers will have support with pain-related care. Therefore, it is unlikely that family caregivers of PwD in residential settings will be primarily responsible for pain-related care, in the same way, those supporting a community-dwelling PwD would be. As such, literature exploring the viewpoints of family and relatives of PwD living in residential settings may not fully encompass the responsibilities and challenges experienced by primary caregivers to PwD living in the community. Considering the amount of PwD living in the community (Wittenburg et al., 2019a) and the amount being supported by IFCs (Lewis et al., 2014), this viewpoint a significant omission from the literature base. The involvement of family caregivers in the pain assessment and management process is recognised to result in more individualised and more effective pain management (Schofield et al., 2018; Dunham et al., 2020). The significance of family and informal caregiver involvement is also recognised in relation to wider dementia care and support (NICE, 2012; 2018). An oversight of IFCs within the literature is therefore inconsistent with an integrated approach between formal and informal caregivers that combines their expertise to the benefit of those with dementia. This suggest further empirical studies are necessary to explore the viewpoints of IFCs (Kankkunen & Välimäki, 2014).

The review of the literature indicates that some caregivers may have a limited understanding of pain in dementia, with respect to some aspects of identification and treatment. However, this has primarily been reported upon or inferred from qualitative studies, this being the dominant approach of the literature. A small cluster of studies has, however, aimed to measure formal caregivers' understandings by way of cross-sectional studies exploring levels of knowledge and beliefs relating to pain, assessment, and management (Zwkahalen et al., 2007; Barry et al., 2012; Burns & McIlfatrick, 2015; Rantala et al., 2015). These studies have provided a means from which knowledge and beliefs can be measured (rather than inferred), identifying potential support and training needs. Within these studies, however, again, few have sampled outside of nurses (except, Zwkahalen et al., 2007), and none have included IFCs. Limited knowledge and inappropriate beliefs about pain can perpetuate ineffectual pain assessment and treatment practices for those with dementia (Geddis-Regan et al., 2019; May & Scammell, 2020; Jonsdottir & Gunnarsson, 2021). As such it is imperative that the paucity of literature exploring this potential barrier to pain assessment and management quantitatively, and from different perspectives, is addressed.

These gaps highlight key areas in which contributions can be made to the body of literature exploring how pain is identified, assessed, and treated among PwD living in CHs and in the community. It specifically identifies the scope for further work that takes a more encompassing view, both in respect to the inclusion of IFCs and all CH staff roles, and in respect to method. The body of literature is primarily qualitative, which lends itself to the experiential aspects of pain recognition, assessment, and treatment. However, it does not lend itself as effectively to more measurable aspects, such as what caregivers understand and know about pain, its assessment and treatment. As such, a mixed-method approach may offer a methodologically diversified viewpoint. This would provide an in-depth understanding of caregivers' experiences and roles, while also examining the extent of their understanding of pain, its assessment and treatment in dementia. The latter seemingly an important mediator of caregivers' decisions, challenges and likely their pain practices.

It is imperative to understand the relative contributions of both CH staff and IFCs within the context of pain, to recognise the evolving roles of those on 'front line' of dementia. Further work in this area will inform a legacy work that can be used in line with this, to inform future practice development and improvement. This will be by way of representing the current landscape and challenges of pain assessment and management for PwD in UK CHs and the community, alongside identifying support and training needs among caregivers. Such findings can be used to inform support interventions and training directed at increasing caregivers' capabilities to recognise and negotiate pain within their daily care provision. The ultimate endeavour of this being to improve pain practices, alleviating the negative implications of pain on the quality of life of PwD (Rajkumar et al., 2017); the incidence of pain-related behavioural and psychological symptoms of dementia (Flo et al., 2014); caregiver burden and distress (Murray et al., 2012); reduced cognitive function (van der Leeuw et al., 2016); and the inappropriate prescription of anti-psychotic medications to those with dementia in pain (Ballard et al., 2012). This has the potential to contribute towards UK recommendations and policy centred on improving the lives of PwD and their care, supporting family caregivers, and appropriately training formal caregivers to provide compassionate dementia care (Department of Health, 2015; NICE, 2018).

2.7 Aim & research questions

The over-arching aim of the thesis was to examine the experiences of informal caregivers (IFCs) and care home (CH) staff supporting people with dementia (PwD), exploring how they recognise, assess, and treat pain among this population. This aim encapsulated four research questions, developed from the gaps in the literature identified in the previous section. These research questions are as follows:

1) What are the experiences and processes underpinning how caregivers (IFCs and CH staff) recognise, assess, and treat pain among PwD?

2) To what extent is pain a consideration within the everyday care roles of caregivers within CH contexts and IFCs supporting community dwelling PwD?

3) What are the contextual and broader challenges arising for CH staff and IFCs regarding the recognition, assessment, and treatment of pain among PwD?

4) What are caregivers (informal and CH staff) understandings of pain, its assessment, and its treatment among PwD?

2.10 Summary

This chapter reviewed literature exploring the recognition, assessment, and treatment of pain among PwD, from the perspectives of formal and informal caregivers. From the critical discussion of the literature, gaps in current understanding were identified and a rationale developed for the investigation undertaken in this thesis. The overarching aim and research questions developed from the findings of the literature review have been explicated. The following chapters provide details of the epistemological framework (Chapter 3) and mixed-method approach of underpinning this thesis (Chapter 4).

Chapter 3- Methodology: A pluralist & critical realist approach

3.1 Introduction

The previous chapter explored the experiences of caregivers in supporting people with dementia (PwD) who have pain, as captured by existing literature in the area. This critical discussion of this literature revealed that while current understandings acknowledge the clear challenges faced by caregivers within this capacity, there are gaps in the literature, particularly with regards to a lack of consideration of the role and experiences of frontline caregivers who have not received formal training. From these gaps an overarching aim was formulated to underpin this research, alongside four research questions devised to explore the working lives of CH staff, and caring lives of IFCs (Section 2.7).

This chapter aims to provide the epistemological framework underpinning the empirical work undertaken in this thesis and its pluralist approach to methods. To begin, the aim and research questions guiding this thesis, are set out. The potential epistemological standpoints to address these research questions are explored, as are the implications of methodology on methods. Firstly, positivist and constructivist approaches are highlighted, as are the debates around their epistemological and methodological incompatibility (quantitative vs. qualitative). The incommensurability of these paradigms and their affiliated prescription of a quantitative or qualitative imperative is challenged, and an argument made for the adoption of a research paradigm that offers methodological plurality.

Critical realism (CR) is then introduced as a third paradigm and that in which this research was located. CR as an epistemological middle-ground to positivist and constructivist philosophies is explored, alongside the ontological and epistemological synergies and diversions from these dominant paradigms. The approach of CR to explanation and exploration of social phenomenon is discussed, as are the implications to method.

3.2 Research Aims & Questions

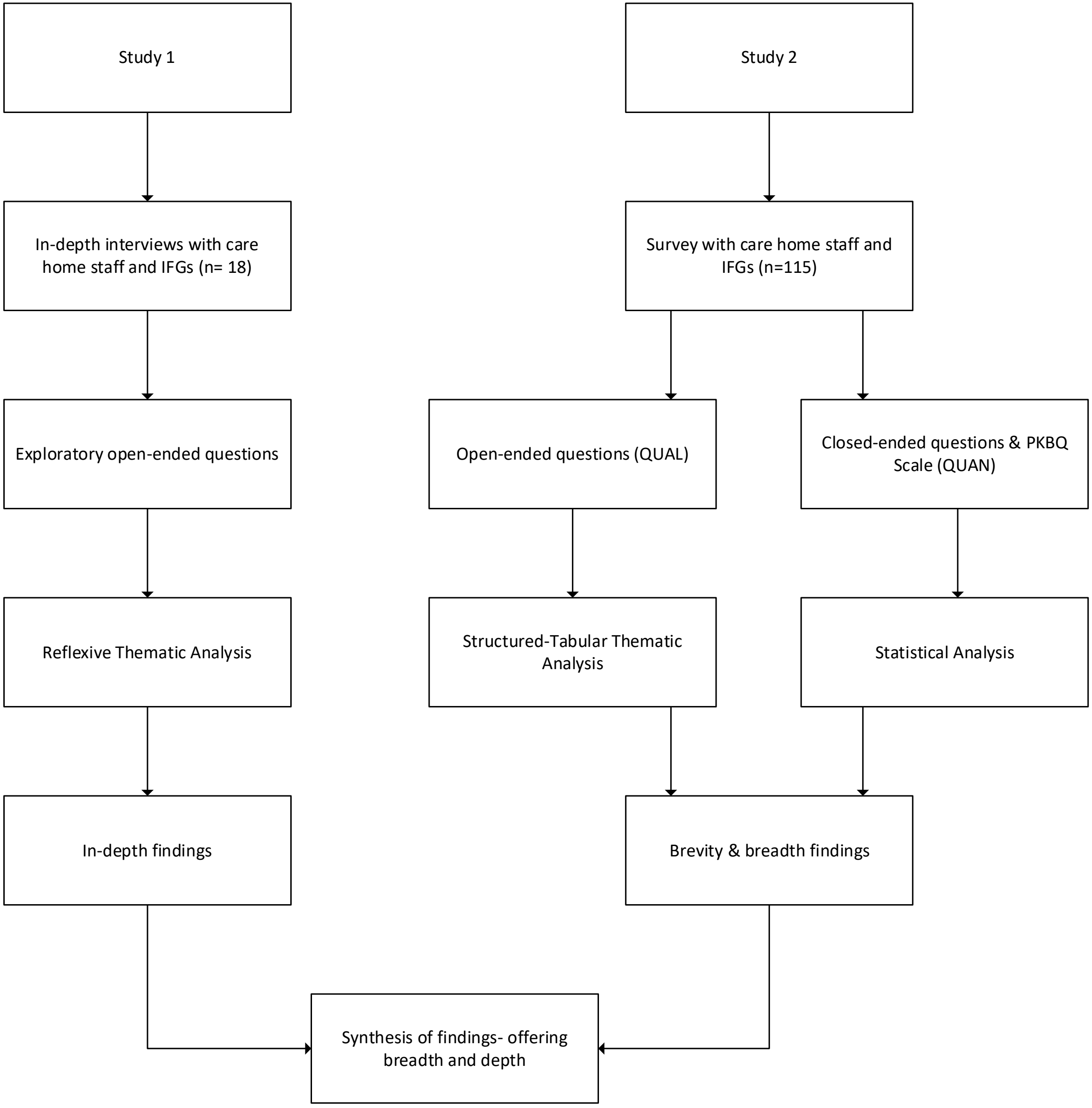
Two studies were carried out within this piece of research to address the research questions explicated in previous chapter (Section 2.9). The first study explored caregivers’ experiences through in-depth semi-structured interviews. It aimed to respond primarily to research questions 1, 2 and 3, while exploring contextual issues and providing case examples of the working and caring lives caregivers working in care homes and those taking on informal roles. The latter was essential to be cognisant and respectful of the broader situation of dementia care, which is complex, challenging, and nuanced (see Chapter 1). It was deemed likely that this broader situation would have some interplay or reflection in relation to how pain among PwD was encountered and negotiated, after all nothing occurs in a vacuum.

The second study built upon this by implementing a survey. It also sought to address research questions 1, 2 and 3, however the methods used were developed differently to accommodate recruitment and contextual challenges. A survey was used to provide a more measurable focus, particularly in the relation to research question 4. It served to explore reactions, courses of action, and processes in the caring activities of caregivers. The survey also included the Pain Beliefs and Knowledge Questionnaire (PKBQ, Zwakhalen et al., 2007), which was used to explore research question 4 and provide concrete insight (by way of scores indicating the level of understanding present) into caregivers understanding of pain as it occurs among PwD and appropriate treatment choices. Figure 3.1. provides an overview of these two studies.

3.3 Research Paradigms

A research paradigm may be defined as the shared beliefs among a research community that provide a framework for research (Kuhn, 1962). They express an epistemological stance and certain ontological assumptions (Blaikie, 2007). Ontological assumptions exist along a continuum and refer to the nature of what social reality is; how it appears; and what it is constituted of (Blaikie, 2007). These assumptions underpin our beliefs about reality, and whether we believe it exists as separate from human practices and understanding (Braun & Clarke, 2013). Epistemology is the theory of knowledge and how we can come to have that knowledge. It provides the philosophical underpinnings of how knowledge can be gained, or in the social sciences how social reality can be known (Blaikie, 2007). Within a paradigm applied to research, epistemology and ontology form the assumptive base from which we produce knowledge or uncover it with the prescription of appropriate methods of inquiry. Their importance is therefore paramount in the research process, as is the need to make explicit the research paradigm from which the researcher draws. The following section seeks to achieve this, exploring the dominant paradigms in psychology and the social sciences, discussing the tensions between paradigms, and resolutions (or middle ground) to be found within the critical realist approach taken in the current research.

Figure 3. 1 Overview of Study 1 and Study 2



3.3.1 Paradigm tensions- Positivism vs. Constructivism

Positivism and constructivism are frequently cited philosophical positions that appear across the social sciences and psychology. They are typically seen as conflicting research paradigms and many tensions exist between the two approaches, particularly in relation to the discovery (or creation) of knowledge (Wiggins, 2011). Positivism may be seen as aligned with quantitative or experimental methods of inquiry in the discovery of knowledge, whereas constructivism may be seen as aligned to qualitative methods, or at least this has been the traditional presentation (Wiggins, 2011). This dualistic presentation has served to proliferate and enforce paradigm conflicts and hostilities between qualitative and quantitative methods. The following will explore these tensions, and their relationships to the qualitative-quantitative (qual-qual) divide frequently imposed upon researchers.

3.3.1.2 Positivism

Positivism is one of the major philosophical positions in psychology, which up until the 1980s and the rise of constructivist approaches held a dominant presence, according to several writers on qualitative methods[9] (Howitt, 2019; Murray & Chamberlain, 1999). Ontologically speaking positivism is realist, sitting on one extreme of the ontology continuum in opposition of relativism. Realism dictates that there is a single reality or unitary real world that is knowable, and ‘things’ appear as they are independent of human ways of knowing or human bias (Madhill, Jordan & Shirley, 2000; Brinkmann, 2015). Positivism therefore dictates an observable, independent, and measurable singular reality, which can only be represented through ‘scientific’ methods (Madhill et al., 2000; Braun & Clarke, 2013). ‘Scientific’ methods are viewed synonymous to measurement and experimentation, and measurement is a necessary part of ‘science’[10] (Mitchell, 2003a). This ontological position is usually associated with quantitative approaches of inquiry (Braun & Clarke, 2013), as mathematical and statistical approaches reduce the potential for researcher input and thus for bias. Epistemologically speaking then, positivism is

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[9] Positivism is most often associated to psychology by qualitative advocates aiming to critique the emphasis on quantitative methods within the discipline (Mitchell, 2003a), rather than by psychologists themselves. The emphasis on a quantitative imperative within psychology is not necessarily underscored by positivism, as discussed later in this chapter. Psychology has been most influenced by the work of Karl Popper (1959), rather than positivism. Positivism is therefore described with the aim to highlight this position as disparate from psychology and quantitative methods.

[10] The use of quotations is to illustrate that the association of measurement, or a quantitative imperative, as qualifiers for science and scientific methods is a debated issue (e.g., Mitchell, 2004). As is the idea that positivism implements science and scientific approaches and is therefore inherently quantitative. Non-quantitative methods are not pre-scientific and can be used within a positivist framework (see discussion later in this chapter).

realist, in which there is an assumption that the ‘truth’ or ‘facts’ about the social world and human experience can be discovered through research (Braun & Clarke, 2013).

Positivism in its classical form was founded as a philosophy by the sociologist August Comte (1853/1974) during the 19th century. It was a progressive and radical reaction to religious dogma and metaphysics and their regimes of ‘truth’ which had served to perpetuate society’s acceptance of knowledge derived from religion and speculation (Stainton Rogers & Willig, 2017). Positivism called for a return to observable data, and knowledge as drawn from this (Brinkmann & Kvale, 2015). Comte proposed that to explain and isolate the fundamental forces guiding the operation of society, we must refer to abstract theories, not ideologies or personal biases (Turner et al., 2011). Furthermore, theories must be explicitly and systematically tested against the empirical world, science being the vehicle by which this is carried out (Turner et al., 2011). Abiding by these methods and applying science would allow objective and undisputable ‘facts’ to be discovered.

Positivism has since evolved from Comte’s ideas through logical positivism and postpositivism. In the 20th century logical positivism emerged through the work of philosophers such as Schlick and Carnap (Brinkmann, 2015; Brinkmann & Kvale, 2015). This form of positivism was perhaps less influential in the field of psychology, given that it had become increasingly dogmatic and prescriptive, aligning strictly with scientific objectives. Logical positivism proposed that the truth or reality is ‘out there’ and as such it can be known through objective study (Stainton Rogers & Willig, 2017; Lyons, 1999). It proposed a reductionist view of the world and human experience, describing it in terms of measurable variables, hypotheses, reliability, and replicability (Charmaz, 2008). This focus led to a strong association, or methodological bureaucracy, for quantitative methods which could allow for generalisable ‘truths’ to be studied and discovered (Lyons, 1999; Kvale, 2008).

Postpositivism emerged from the critiques of logical positivism and the methodologies of the social sciences which were occurring from 1950-1970s (e.g., Karl Popper, 1959). Practically, and logically, positivism was challenged on the basis of whether an observer-free reality as conveyed through scientific methods is epistemologically and ontologically sound. As descriptions and observation are necessarily selective and filtered through the signs and symbols of language, perception of reality or ‘facts’ can only be partial. As such postpositivism includes a range of perspectives that reject the ideas of (a) that knowledge can reflect reality ‘as it is’, and (b) that observation is the only appropriate method to achieve this. Postpositivism acknowledges that reality can only be approximated and cannot be fully known (Lyons, 1999). It too acknowledges that ‘truths’ will be laden with theory and bias, as they are influenced by researcher and context. It has been suggested that postpositivism provides the foundation from which qualitative and quantitative methods can be utilised, and without conflict from ideas such as ‘science’ (Mitchell, 2004).

3.3.1.3 Popper- Hypothetico-deductive model

Karl Popper (1959) was one of major critics of the positivist approach, and became a major influence in psychology, arguably more so than positivism, given that Popper’s hypothetico-deductive approach to science is now almost ubiquitous across quantitative psychology, and positivism is now confined to a few behaviourist journals such as the *Journal of the Experimental Analysis of Behavior*. Popper (1959) argued that scientific theory or ‘facts’ can never be unequivocally or indisputably true, there is always an exception, and assertions of fact are always provisional, never final. The problem with positivism was a reliance on induction to create theory and verification to ‘prove’ a theory conclusive (Willig, 2008). Popper (1959) instead proposed deduction and falsification through his hypothetico-deductive model. This model proposed that a hypothesis should be derived from theory and then tested using experiments and observations. The aim of this testing is to reject a theory, or to retain it until it falsified or disproven. Such an approach will allow a researcher to claim what is probably the case, but never conclusively what is factual (Willig, 2008).

Popper’s hypothetic-deductive method still underpins many of the protocols of quantitative designs in psychology research, including hypothesis-testing, hypothetico-deductive logic, probabilistic statements, statistical representation, and analysis of groups of people, that appear widely in psychological research. Popper’s model however is not without its assumptive issues, and there are obvious limitations to its application to research problems which reflect historical, social, and cultural factors. Also, if hypotheses must be generated from theory, then the generation of new theory or hypotheses is somewhat inhibited by this approach. Knowledge does not always evolve in this way, nor does it evolve gradually with each hypothesis that is rejected, it develops in leaps from anomalies and inconsistency (Kuhn, 1962). Similarly, to generate hypotheses from theory requires knowledge and familiarity of theory and the systems from which they are derived. This precludes the outsider researcher, or the ‘unenlightened’ from contributing to knowledge generation (Willig, 2008). There are clear pitfalls in Popper’s approach to how knowledge might be discovered, particularly new knowledge without an existing theory to weigh it down. However, it is key to emphasise that it places a clear emphasis on the limits of human knowing that provide a bridge between quantitative psychology and qualitative methodologies.

3.3.1.4 Constructivism

In the 1920s-1930s constructivism emerged from the Chicago School, however it was not until the 1960s-1970s when it emerged more prominently in the social sciences arena (Broom & Willis, 2007). Its emergence was underpinned by criticisms of positivism. Anti-positivism from a constructivist perspective hinged on several points of tension. The treatment of data as facts and the proposal of a singular and objective reality accessible free from observer bias was challenged (Murray & Chamberlain, 1999). Secondly, dissatisfaction regarding its monistic approach to science, and deductive inferences challenged not only the positivist assumptions, but also its reliance on quantitative methods. Of the back of these criticisms, approaches such as grounded theory, symbolic interactionism, phenomenology, and ethnography, and more recently poststructuralism and postmodernism, rose. These approaches in different ways rejected positivism, theorising reality, or knowledge as theory laden, and created and constructed through interaction (Braun & Clarke, 2013).

Constructivist approaches refocused the social sciences upon meaning, language, and discourses. Methods were developed by constructivists to access subjective reality, human experience and meaning, proposing radical ways of re-conceptualising research (Broom & Willis, 2007; Chamberlain & Murray, 2008). Ontologically and epistemologically speaking, these approaches take a relativist standpoint, as such they propose that multiple ‘truths’ exist, which are not universal and knowing them is dependent on where and how knowledge is generated (Braun

& Clarke, 2013). As such there are no absolute ‘truths’, reality is experientially based and specific, so knowledge is perspectival (Guba & Lincoln, 1994). Constructivist approaches also hold that the search for knowledge is not one of discovery, realities are not ‘out there’, rather they are constructed or produced through discourse, and interactivity between the research and the researcher (Guba & Lincoln, 1994). The emphasis on the construction and co-construction of reality places the researcher as a tool for data collection (Brinkmann, 2015). To facilitate this researcher position, constructivist epistemologies favour methods which enable researchers to interact with people in open, discursive, and naturalistic ways. This facilitated a re-emergence of qualitative methods which had been otherwise marginalised until the 1980s when constructivist approaches took an affinity to them. Alongside the role of the researcher in constructivist approaches, is the ownership of subjectivity and interpretation. This not to say that within constructivist positions any interpretation will lead to knowledge or that such approaches are lax in their development of knowledge. The knowledge produced in these approaches must still be heavily grounded in data and a sophisticated consensus of understanding must be derived (Braun & Clarke, 2013; Guba & Lincoln, 1994).

There are some challenges for constructivist approaches, the first is their diversity. This diversity has led to in-house debate about appropriate methods to explore constructed realities, and problems with disparate and sometimes conflicting debates (Danziger, 1997). A second issue, and one most fundamental, is at the level of ontology. Although experience is our primary reality, explaining all phenomena as socially or culturally constructed is problematic. This is particularly so when related to technologies and medical products that have been developed based on strong assumptions of a reality that sits beyond human interpretation, and the importance of taking recourse to that reality when assessing truth claims. On the technological side, this includes the internet, computers, and electricity, and on the medical side, this includes vaccines and painkillers. These were all developed based on science that assumes a lawful physical reality and moral facts that transcends any individual human interpretation or discourse. Similarly, the discursive focus of constructivism also obscures other significant aspects of human life, experience and social construction will be limited by the body, the material world, and the power of the systems in which we live. With language as the sole constructor, constructivism reduces the human body to talking and discursive traces, ignoring the significance of functional, physiological, hormonal, anatomical and phenomenological aspects and how they may shape reality (Cromby & Nightingale, 1999). Constructivist approaches also tend not to regard the constraints which arise from the material world and the influence of power from systems and institutions which act in our everyday being (Cromby & Nightingale, 1999). There are constraints in our everyday life which exist beyond our construction or interpretation of them, often already having shaped reality and what is possible.

3.3.2 Paradigm Tensions- quantitative vs. qualitative

As already alluded, the epistemological divide which is seen to exist between positivism and constructivism has fed into beliefs that qualitative and quantitative methods inhabit incommensurable paradigms, and therefore are rooted in antithesis (the incompatibility thesis- and incompatibilist's argument) (Howe, 1988). As such, they are in opposition and should be used in separation, fuelling the qualitative-quantitative (qual-quan) divide which continues to proliferate research and academia. However, there are paradigmatic ways of conceiving qualitative and qualitative methods that view them both as rooted in pluralistic webs of assumptions, which overlap (e.g., Creswell & Plano Clark, 2007; Teddlie & Tashakkori, 2003). As this research mixes qualitative and quantitative methods, it is essential that the incompatibility thesis is unravelled, and the key challenges to it discussed as the underpinning rationale for the acceptability (and desirability) of plurality. The following section explores some of key tensions suggested between qual-quan methods, and the rebuttals from supporters of plurality.

3.3.2.1 Pluralistic foundations of quantitative psychology

To consider the roots of quantitative methods within psychology provides a challenge to the qual-quan divide. Several authors have bridged this supposed epistemological chasm by proposing that qual-quan methods are compatible on the basis that quantitative methods within psychology are not derived from the positivist paradigm (e.g., Howe, 1988; Michell 2003a; Robinson, 2014). It is conceded that while a quantitative imperative in psychology has been endorsed and marginalised qualitative methods for many decades, there is no conceptual link between quantitative methods and positivism (they are in fact nonpositivist in many respects) (Mitchell, 2003a; Howe, 1988).

Quantitative methods are often construed as positivist given the deference to statistical analysis of large groups. The individual is at the heart of the qualitative paradigm, and thus a tension arises. However, quantitative methods can be individual, it depends on the application of the method. As Robinson (2014) highlights, historically, and even to date, psychology has used numerical analysis of small sample case studies to provide case intensive and personal approaches to research problems. Therefore, numerical analysis does not negate the in-depth analysis of individuals, nor does it place it at odds with qualitative methods or in allegiance with positivism (Robinson, 2014). Further, when considering quantitative data or analysis, it is assumed that this process objectifies a concept and divests it of its qualitative ontological dimensions, such as its intentionality (incorporating values and beliefs) and the individual or “insider” perspective (Howe, 1988). Yet as Howe (1988) comments “*But by what sort of magic does this divesture occur”’* (p. 11). If we measure the same thing using qualitative data or quantitative data, Howe (1988) questions if we are measuring something ontologically different, or the same. If we consider them to be the same, this then implies quantification is not a source of incompatibility among data which is qualitative in nature or quantitative.

Similarly, furthering illustrating the point of philosophical plurality in the quantitative method and compatibility of methods, is the presence of assumptions and interpretation, which are so heavily relied on in both methods. Often, and deceptively, within the design and analysis of the quantitative approach is suggestion that inferences made are objective and non-judgmental (Howe, 1988). This is a clear demarcation from the qualitative approach. However, quantitative designs and analysis are not value-free, they draw from background assumptions and make numerous judgements (e.g., how variables may be operationalised and measured; how can confounding variables be controlled; what statistical test is needed) (Howe, 1988). Equally, these assumptions feed into interpretation of results. Like the qualitative researcher, a quantitative one will construct an argument about their results from their own interpretation of them while pulling from a much larger landscape of knowledge. Therefore, a statistical or numerical result forms a part of a nuance of knowledge claims, assumptions, and interpretations (Howe, 1998). So, at the basis of analysis and data, qualitative and quantitative methods are intertwined, given that the latter shares markers which would be ascribed to qualitative methods.

The presence of non-positivist assumptions within quantitative methods is exemplified in use of questionnaires and psychometric tests in quantitative psychology (Robinson, 2014). These forms of data collection are widely used (and have been used in this research) and they demand introspection and interpretation on the part of a respondent. Positivism was focused on direct observation by researchers as the sole portal to accurate knowledge. Yet in self-report, there is no observation. The respondent must look inwards on the premise that accurate introspection of oneself can produce self-observed data. The respondent must also interpret not only the statement or question they need to respond to, but also the possible responses they can make (Robinson, 2014). They are many meanings, ideas, thoughts, feelings and so on which language (written and spoken) are laden with, the respondent will need to navigate these when responding to potentially abstract statements with vague predefined response options. The researcher must also interpret the responses given by the participant (Robinson, 2014). Therefore, there are many hermeneutic layers and interpretations which underlay self-report tools in quantitative methods and their outputs. If we consider this in the context of positivism, self-observed data is not viewed as a valid basis for science, nor is the use of theory-laden interpretations (Comte, 1853/1974), which distances quantitative methods further from the positivist approach, and more closely to qualitative methods.

The influence of pragmatism in quantitative psychology has also contributed to its medley of philosophical bases and can be seen to provide a basis for compatibility of diverse methods (Robinson, 2014). Pragmatism as a philosophy emerged from the work of William James (1909/1977), who coincidently was also a key figure in the development of empirical psychology. Pragmatism is orientated towards problem-solving within the real world, it is not hung up on assumptions of truth or knowledge. It is focused on whether a method produces meaningful knowledge and contributes positive outcomes (James, 1909/1977). This orientation means that knowledge may have different uses and because of this a pragmatist may employ diverse, or even conflicting, methods or theories, because knowledge is ultimately pluralist (Robinson, 2014). The influence of pragmatism upon psychology is reflected by the demand upon researchers now to justify their use of methods in applied terms of impact to public, patients, and groups- positive outcomes (Yardley & Bishop, 2008). It is also reflected in the recognition of the mixed methods movement, or mixed methods research, as a ‘third paradigm’ or methodology. Pragmatism has been the epistemological basis drawn upon by many mixed methods researchers (e.g., Johnson & Onwuegbuzie, 2004) and hailed as ending the paradigm wars (Yardley & Bishop, 2008).

This discussion on the basis of the quantitative method demonstrates that (within psychology at least) it is actually founded on pluralist philosophical approaches that encompass elements of individualism, subjectivity, introspection, interpretation and pragmatism. As such, quantitative methods are not inherently in conflict with qualitative methods or wedded to a positivist approach, which provides a possibility for plurality of methods.

3.3.2.2 Positivism & non-quantitative methods

The opposition of qual-qual methods is rooted in the argument that positivism underlies quantitative methods and constructivism underlies qualitative methods, and therefore the two methods are incompatible (Howe, 1988). However, positivism does not dismiss the possibility of non-quantitative methods or demand a quantitative imperative (Mitchell, 2003a). Classical positivism from the work of Comte (1853/1974) was not explicitly antagonistic about the use of non-quantitative methods, it was in its original form complex and tolerant (Mitchell, 2003a). In fact, Comte regarded that beyond the physical sciences quantification was not the only appropriate approach to scientific inquiry (Howitt, 2019; Brinkmann, 2015). It was logical positivism which equated Comte's focus on observable facts to quantitative or experimental methods only (Howitt, 2019).

Similarly, the emphasis in positivism on scientific enquiry does not negate the compatibility of methods. Qualitative and quantitative methods (and positivism and constructivism) can be seen in opposition by the misassumption that the latter holds the principles of scientific study, and the former does not (Stainton Rogers & Willig, 2017). The quantitative imperative within a positivist epistemology hinges on the idea that positivism is scientific, quantification is scientific, and therefore positivism is wedded to quantification for its scientific rigour. However, to consider what is meant by science is to reveal that qualitative methods do not threaten the scientific credentials of research, and that science is not purely quantitative or positivist it is approach (Mitchell, 2004). Science as a term is often ambiguously positioned next to qualitative methodology (Stainton Rogers & Willig, 2017), yet the term itself does not imply a prescription of methods or impose an opposition to non-quantitative methods. As Brickman (1980, p. 10) states:

> *"Science is a question of aim, not method. Science is an effort to make accurate observations and valid causal inferences, and to assemble these observations in a compact and coherent way."*

In this view, science is treated with malleability, and as an approach - not a predefined method- it provides room for methodological flexibility (Mitchell, 2004). Furthermore, as Mitchell (2003b) indicates, methods should be judged by their contribution to gaining relevant knowledge, as this is the central concern of science. On this basis and using this as the criterion by which methods should be evaluated, there are no scientific grounds on which we can rule out the use of qualitative methods or make demands about a quantitative necessity in science- or positivism (Mitchell, 2004). Mitchell (2004) has further argued that maintaining a divide between qual-quan approaches is counterproductive to advancing qualitative methods. Equally, it may serve to enforce an idea of qualitative research as a complementary approach to quantitative methods. Therefore, in recognising that positivism is not anti-qualitative, nor solely quantitative, this ebbs away at the centre of the incomparability thesis. The use of terms such as ‘science’ within positivism to reinforce a divide or apparent distinction between qual-quan methods is misplaced and may serve only to marginalise the qualitative method.

3.3.2.3 Real-world research

The previous discussion has highlighted a pluralist basis for the compatibility of qualitative and quantitative methods. This approach suggests that the incompatibility thesis is an overly dualistic way of conceiving qualitative and quantitative methods. Furthermore, the qual-quan divide is being challenged on a practical level by real-world research conducted in applied branches of psychology such as health psychology and sport psychology, where the contribution of *both* qualitative and quantitative has proved to be essential to understanding a range of phenomena and solving a range of problems which cannot be explored without accessibility to both methods. In psychology, to understand the complexity of the human condition and experience is not only advantageous, but necessary to draw across the divide (Yardley & Bishop, 2008). This is the essential premise of much mixed methods research, which affirms that the use of both methods overcomes the inherent weakness of either method (e.g., broad vs. deep; generalizable vs. individualised), and opens up the possibility of triangulation and convergence of data (Johnson & Onwuegbuzie, 2004). Practically then, the incompatibility of methods becomes somewhat immaterial or practically challenging to abide by in real-world research.

3.3.4 Locating a middle ground through Critical Realism

The previous section has established the tenuous and impractical position of the incompatibility thesis. There are however methodological ramifications in combining methods, which bring a need to locate a paradigm that allows for the compatibility of methods. Critical realism (CR) is one such paradigm and has formed the methodological basis of this research. Critical realism emerged from the paradigm wars in the 1970s-1980s primarily from the work of Roy Bhaskar (e.g., 1978; 1989). It draws from both positivist and constructivist schools and presents a middle ground between these, while showing some similarities to Popper’s approach. The following will explore key concepts and ideologies of CR, its diversions from positivism and constructivism, and its openness to a plurality of methods.

The most influential figure associated with critical realism is Roy Bhaskar (e.g., 1978), who was responsible for a return to realism in the 1970s-1980s (Fleetwood, 2014). Bhaskar built upon the earlier work in realist philosophy of science, specifically the work of Rom Harré (e.g., 1986). CR realism has continued to be developed by authors such as Archer, Collier, Lawson, Norrie, Sayer and

Fleetwood (e.g., Archer, Bhaskar, Collier, Lawson & Norrie, 1998; Sayer, 1992; Fleetwood, 1999) from domains of the social sciences to economics. The distinctive feature of the work of Bhaskar's work in contrast to others, is that his vision of CR was developed as a meta-theory for social science in general, distinguishing his approach from those who applied realism to specific issues (Fleetwood, 2014).

The most salient feature of CR is the differentiation of ontology and epistemology. CR holds that ontology (what is real) cannot be reduced to epistemology (our knowledge of reality), given that our *knowledge* of reality can only capture a snippet of the vastness of reality as a whole (Fletcher, 2017). This was a criticism that Bhaskar (1998) levelled at empiricism and positivism as the 'epistemic fallacy'. The epistemic fallacy is the reduction of ontology to epistemology; within positivism it was the limiting of reality to what can be empirically known. Similarly, constructivist approaches typically equate reality with that which is known in discourse, thereby making a reductionism of reality to human knowledge (Fletcher, 2007). Bhaskar (1979) called this the linguistic fallacy, in which ontology of being is reduced to narrative and discourse.

CR refers to a single reality, within which there are entities which are real in different 'modes', including those which are: materially real (material or physical entities, e.g., oceans); ideally real (conceptual entities, e.g., language); socially real (social structures and organisations, e.g., employment); and artefactually real (synthesis of the other 3 modes, e.g., computers). Entities may be straddled across these modes, and modes may undergo evolution in which entities my shift between modes (Fleetwood, 2014).

CR also describes a double-sided view of knowledge, distinguishing between transitive and intransitive objects of knowledge (Bhaskar, 1998). On the one hand there exists a reality which exists independently of us (the intransitive domain) (Archer et al., 1998). On the other side is the transitive domain in which reality or knowledge is created through human thought and action, such as theory, established facts and methods of study. This distinction of knowledge allows for epistemological relativism, in which knowledge can be seen as shifting and imperfect, and entangled with, or relevant to, specific contexts. While we can explore reality through philosophy or social science, knowledge produced will be fallible and some knowledge or theories of reality might be closer to the actual reality than others. Knowledge and theories can be produced which are more or less the truth- but never ultimate truth- and through this closeness to truth we can attempt to explore the causal mechanisms driving phenomena and the presentation of reality (Danermaker et al., 2002). This critical stance towards factual truth, whist maintaining that a reality exists independent of human perception, is similar to the stance of Popper's Hypothetico-deductive Model (1959).

In CR ontology, reality includes domains of the *empirical*, the *actual* and the *real*. At the *empirical* level is human experience and what we perceive to be the case, as such events or objects can be measured empirically. Because at this level events are as we experience them, they will be mediated through the lens of human experience and interpretation. Quantitative researchers often operate in the empirical domain, using observation to investigate linear causality. At the *actual* level, events occur in space and time, as such there is no filter from human experience or interpretation. This means that events at this level might differ to what is observed at the empirical level (Danermaker Ekström, Jackobsen & Karlsson, 2002). Finally, in the stratified conception of ontology is the *real*. The domain of the real includes objects and structures with inherent causal powers that lead to events (Fletcher, 2007).

Within this stratified conception of causation, the three levels are not separate, and none are any less ‘real’ than others; they are all a part of the same reality and therefore interact (Fletcher, 2007). The stratified reality illustrates that even though there is one reality, we cannot access it all immediately. A CR position accepts the empirical and actual, but also aims to identify the causal mechanisms which given rise to social events. Causality is seen as generative, rather than successionist as in positivism or in purely experimental methods. In other words, causes actually *make* something happen rather than just come before them sequentially. An example of this would be a divorce – finding out that signing the divorce papers always precedes a divorce does not lead meaningfully to assertions about the divorce papers *causing* the divorce. The cause of the divorce lies in the motives of the individuals concerned that led to the end of the marriage.

To investigate causal mechanisms Bhaskar (1989) proposed retroduction (also called abductive reasoning). Together with inductive and deductive methods of enquiry, retroduction is necessary to make observations and devise theory to explain them. Retroduction takes a set of observations and aims to identify an explanation for that based on causal mechanism (Fletcher, 2017). It is the central mode of inference in CR and involves arguing backwords, from the abstract to the concrete, and back again to develop an explanation (not prediction) and causal account (Fleetwood, 2014). Akin to Popper’s Hypothetico-deductive Model (1959), theory or explanations are always open to revision, given that as discussed, knowledge is fallible. Theories or explanations which have the greatest explanatory power, not predicative power, will be favoured (Sayer, 2002).

In summary, CR presents a view of a single reality in which social phenomena are, like most natural phenomena, the product of a plurality of structures operating in multifactorial and open systems. Reality is more than what we can observe, this is because some entities exist independent of their identification because they are not constructed from discourse – they are extra-discursive. The focus of CR is explanatory, in which generative logic is used to explore the interplay between structure and human agency to determine generative mechanisms which give rise to events. Knowledge may be derived from causal mechanisms, which can be explored using theory developed through retroduction. Through deductive, inductive and retroductive methods we can explain social phenomena, however our explanations and theory will never be precise and are open to revision.

3.3.4.1 Methodological plurality in CR

In terms of methods, CR is not affiliated with a particular set of methods (Fletcher, 2017). The choice of methods in CR is driven by the nature of the research problem and ontological concerns. Because of this, and because it overcomes the dichotomy of objectivity/subjectivity and qual-quan divides, it is methodically pluralist and inclusive (Sayer, 2000). CR is not specifically nomothetic (law finding) or idiographic (individualistic), and therefore can provide a way of combining naturalism with the necessity of the interpretive understanding of meaning in social life (Sayer, 2000). This openness allows for CR to be a viable paradigm for research in a variety of disciplines, utilising qualitative, quantitative, and mixed methods. It is the way in which methods are used within CR, which is important, as opposed to the methods themselves (McEvoy & Richards, 2003).

In addition to being an approach which allows for plurality of methods, CR's explanatory focus arguably requires a pluralistic approach. The focus on causation, and the interplay between social structures and human agency, requires adoption of broader and triangulated methods (Archer, Sharp, Stones & Woodiwiss, 1999). As Bhaskar and Danermark (2006, p. 294) indicate from an ontological perspective CR is the "*least restrictive perspective, insofar as it is maximally inclusive as to causally relevant levels of reality",* it therefore allows and demands a variety of approaches to be used to explore phenomena. Practically then with a CR approach, reality can be quantified, while acknowledging that not all of reality can be reduced to quantity (Schiller, 2016). Similarly, reality can be explored qualitatively, without claiming that all knowledge is centred on discursive or experiential processes. In this sense, all data may be seen as accounts of reality, or different levels of the stratified ontology (albeit none of it seen as representing actual reality), meaning that data drawn from qualitative or quantitative methods may be treated as equally as valid in contribution to an understanding of a singular reality.

Using CR as a paradigm for plurality of methods also overcomes some challenges typically associated with mixed methods research. One challenge for using multiple methods is the weighting given to either the qualitative or quantitative element. If one is weighted more than the other, the inference of such is that one method contributes a better understanding than another. CR allows for a more level playing field in which methods are not set against each other in hierarchy. Another criticism of mixed-methods approaches is that qualitative and quantitative methods are not compatible at the level of assumptions (Wiggins, 2011). By locating research within a critical realist stance, qualitative and quantitative research can both be seen to be limited attempts to access information about a phenomenon. Both use aspects of language and symbol to do so, both lead to tentative statements about social reality rather than certain laws, and both require considerable interpretation to function (Robinson, 2014).

3.4 Summary: From paradigm tensions to a pluralist Critical Realist methodology

This chapter has discussed the core research paradigms underpinning inquiry in the social sciences and psychology, locating this thesis within a critical realist approach and a pluralist approach to method. The key messages of this chapter and points of discussion include:

- Positivism and constructivism are two dominant philosophies which have typically been construed as conflicting research paradigms. Positivism dictates a single observable reality, which can only be represented through ‘scientific’ methods. Quantitative methods are often, although not wholly appropriately, viewed as synonymous to the positivist approach. The practical and logical challenges of key tenets of the positivist approach have been challenged by authors such as Karl Popper (1959) and the constructivist movement. As a result, postpositivist thinking has emerged.
- Constructivism encompasses a range of perspectives, at the core of these is the rejection of positivism and the view that multiple, theory laden realities are created and constructed through interaction and discourse. The qualitative method with an emphasis on subjective experience has typically been affiliated with constructivist approaches. The challenge of the experiential and discursive focus of constructivism is that it reduces all phenomena to that which is socially

and culturally constructed, yet there are physical realities and universal facts which transcend human interpretation or discourse.

- Constructivism and positivism are seen as incommensurable paradigms, as such their affiliated methods (qual vs. quan) are seen as rooted in antithesis. This thesis of incompatibility has proliferated research and fuelled a divide in which qualitative and qualitative methods should be used in segregation and for wholly different purposes. However, there are paradigmatic ways of conceiving qualitative and qualitative methods that view them both as rooted in pluralistic webs of assumptions which open up their cohesive use. These arguments around compatibility highlight that a qual-quan divide is bridgeable, and indeed desirable for research.
- There are methodological ramifications of combining methods, which need to be accommodated for a research paradigm. Critical realism (CR) has been introduced as a third paradigm which offers an epistemological middle-ground and forms the assumptive base of the research undertaken in this thesis. CR views reality as singular, yet complex and multifactorial. Reality cannot be observed in its totality and cannot be fully apprehended by the researcher, as such, we create explanations which are fallible and open to revision. CR is a paradigm that offers both exploration and explanation of social phenomena, and shifts away from dichotomies, embracing plurality of methods.

The following chapter follows this discussion of methodology, with that of method. The implications of CR and the research questions set out early in this chapter in relation to the methods of data collection for the empirical studies presented in this thesis are discussed.

Chapter 4- Methods: Study 1 & 2: A pluralist mixing of methods

4.1 Introduction

The previous chapter provided an overview of the critical realist methodological approach taken. As discussed, critical realism (CR) is not affiliated with specific methods, achieving metatheoretical unity and plurality by acknowledging facets of both positivist and constructivist approaches (Price & Martin, 2018). Choices relating to methods in CR are therefore centred on responding appropriately to research problems or questions (McEvoy & Richards, 2003). The choice of methods discussed within this chapter not only reflect those most suitable for these purposes, but also those which could negotiate practical limitations presented by samples and contexts. The result was 2 sequential studies which drew from qualitative and quantitative methods (Figure 4.1). The dual study approach used, and use of qualitative and quantitative methods, can be seen as a melding of both intensive and extensive methods (Sayer, 2000). From a critical realist stance, the former deals with in-depth interpretative data, generally drawn from qualitative methods (Study 1); the latter explores regularities and patterns, usually through statistical and survey data (Study 2).

The purpose of this chapter is to provide an overview of the each of these studies, providing practical justifications of the methods of data collection and analytic strategies employed in each study. To begin this chapter and provide the basis for forthcoming discussions of each study, considerations made in relation to aspects of the methods which were consistent across both empirical studies are discussed, including ethical and sample considerations. The specifics of Study 1 are explored first, and the use of Reflexive Thematic Analysis (RTA) (Braun & Clarke, 2019) to interpret the narratives of interviewees. A discussion of Study 2 follows, outlining the survey developed for the purposes of this study, and analysis using the Structured-Tabular approach to Thematic Analysis (ST-TA) (Robinson, 2021). The discussion of both studies also considers the alignment of methods and analytic strategies with the critical realist stance taken. Throughout the chapter, considerations made in relation to ethics, and contextual and recruitment challenges are highlighted.

4.2 Ethical considerations

Ethical concerns were considered at all stages of the research process, protecting, and respecting the wellbeing of both participants and the researcher. Prior to any data collection in either study departmental ethical approval was sought (UREC/14.2.5.8) and reference was made to the British Psychological Society Code of Ethics and Conduct (2009, revised 2018), and Code of Human Research Ethics (2014) as a basis for best ethical practice. Study 1 and 2 took into consideration the following points:

1. Approval to recruit care homes (CHs) (and staff within) was required from the Local Authority Council. Similarly, approval was needed by the carer support organisations before any data collection could occur with informal caregivers (IFCs) utilising support provided. Gatekeeper approval was also required from individual CHs involved to permit recruitment of staff, this approval came from either the direct CH manager, or from middle management in CHs attached to larger organisational chains.
2. All participants were provided with an information sheet prior to providing written consent to take part.

3. Participants were informed of their right to withdraw themselves at any time during data collection and their data up to 2 weeks following their participation. They were also assured they could decline to respond to any questions they considered too distressing or sensitive.
4. The voluntary nature of the studies was emphasised. Participants were assured their engagement (or if they choose to decline) would not affect their employment (CH staff) or support received (IFCs).
5. Confidentially and anonymity was maintained throughout both studies, all data (audio recordings and survey responses) was saved on a password encrypted computer and paper copies of surveys were kept in a locked filing cabinet. All personal identifiers were removed from data collected and pseudonyms used.
6. Audio recording was conducted only as agreed by the participant during interviews.
7. Debriefing was carried out; participants were provided with a debriefing sheet consisting of the researcher's contact information and counselling services (appropriate to the participant group).
8. All materials were developed with feedback from lay representatives of caregivers to insure appropriate, sensitive, and inclusive content.

4.3 Sample

Several adaptive strategies were employed for sampling and recruitment for both Study 1 and 2. Where possible strategies were informed by theoretical and analytical concerns, however pragmatically they were developed to negotiate known challenges relating to the people and places of interest. They also evolved reactively to overcome challenges which emerged relating to gatekeeper organisations and recruitment of caregivers. The following sections will explore choices made in relation to selecting sample universe; sample size; sample strategy; and sample sourcing.

4.3.1 Sample universe

The sample universe for both studies was people caring for PwD in the Southeast of England. This included those working in CHs providing care for those with dementia, nursing students with experience caring for those with dementia, and IFCs supporting a person with dementia. This represented a diverse and heterogeneous group, particularly with the CH workforce who are diverse in age and nationality (Skills for Care, 2019).

In the region in which this research was conducted there were a total of 297 registered care and nursing homes listed by the council, of which 131 were registered as dementia specialist. Recruitment was open to any of these care or nursing homes, whether dementia specialist or not, given that many provide care for residents with dementia (diagnosed & undiagnosed) despite not being registered as dementia specialist (Luff et al., 2011). CHs which identified themselves as having no residents with dementia or cognitive complaints were self-excluding.

CHs are a unique, complex, and heterogeneous. They differ substantially in their funding and workforce, with some run as independent business and fewer funded by Local Authority (Luff, Laybourne, Ferreira & Meyer, 2015). The level of care provided in CHs also differs, distinguishable by those which provide support with day-to-day living (e.g., personal care), those which are dementia specialist (also known as ‘dementia friendly’ or EMI, elderly and mentally impaired) and those which provide nursing care (Luff, Ferreira & Meyer, 2011). The sample universe also included all those individuals working in these CHs and IFCs supporting people with dementia (PwD) across the same region.

To focus on those individuals with lived experiences most relevant to the research question, and to contexts which offered most relevance, inclusion and exclusion criteria were applied. These criteria were applied to create a more accessible and homogenous sample in relation to graphical homogeneity and to some extent life history (i.e., caregivers experience supporting a PwD). Although for the latter there were unique characteristics in relation to this and demographics which remained within the sample, such being important for diversity and meaning in data (Robinson, 2013).

4.3.1.1 Inclusion/exclusion criteria

CH staff: CH staff of any role, providing consistent and regular contact with PwD, were included. If an individual had been in their job for less than one month, they were excluded from participating.

Nursing students: A small cohort of nursing students with experience of PwD were invited to take part. All had completed a 10-week work placement with older adults and those with dementia, most had jobs as healthcare assistants as care in the community or in CHs.

Informal caregivers in the community: IFCs supporting a person with dementia living in the community of any age, any relation to the PwD, and any professional or employment background were invited to take part. IFCs who have previously been supporting a PwD who was now deceased were included, providing they were not bereaved within the last 6 months. IFCs supporting a person with dementia who were now living in a care or nursing home were excluded, as were IFCs supporting older adults with other conditions not related to dementia or memory complaints. Those supporting a person with and without formal dementia diagnosis were included, given challenges there may be obtaining a diagnosis. One of the support groups from which IFCs were recruited offered training on dementia, IFCs were included whether they choose to attend training or not.

4.3.2 Sample size

Although sample requirements varied between Study 1 and 2 and there were unique attributes of each to consider, there were consistent practical considerations in relation to sample size that needed to be accommodated in both. Pragmatically, it was acknowledged from the outset there would be limits in sample size possibilities. For CH samples across Study 1 and 2, accessibility was dependent on gatekeeper approvals from managers (and sometimes higher management). Research accessibility in these contexts has been recognised to be challenging, such as distrust of an outsider (who might not represent the care and service provided), lack of capacity to engage due to limitations of time and staffing, and lack of prioritisation given to research (Lam et al., 2018). For IFCs similar issues had to be practically considered. IFCs negotiate personal issues such as a lack of time and lack of social engagement, potentially a barrier to recruitment opportunities and participation. Alongside this, a researcher must negotiate potential mistrust of scientific communities and institutions, that can make engaging this group in research challenging (Leslie et al., 2019).

4.3.2.1 Study 1

Qualitative research generally favours depth over breadth and therefore leans towards smaller sample sizes (Braun & Clarke, 2013), an orientation which Study 1 aligned with. A provisional lower and upper sample size was estimated: a minimum of 10 interviews, and a maximum of 20. Ideally it was aimed that interviewees should equally (or very near to) represent CH staff and IFCs. These estimates reflected consideration of the research questions of Study 1, the theoretical stance of the research, and the practicalities of data collection, all of which supporting a discrete sample size. The research questions of Study 1 inferred a smaller more case study approach would be most appropriate. Idiographic focused research which aims to generate intensive analysis of individual cases typically requires sufficiently small sample sizes to ensure participant voices do not become subsumed into the larger whole (Robinson, 2013). Theoretically critical realist approaches utilising intensive methods of data collection and hermeneutically focused should centre their focus on the study of individual agents in their causal contexts (Sayer, 2000). Finally, as the groups being targeted often have little time, there might be limits on opportunities for caregivers to take part in interviews.

While being cognisant of the practical need to determine a sample size in advance of Study 1, it was acknowledged this would be object to in-situ considerations. When approaching research reflexively and utilising an analytic strategy that emphasises this (Reflexive Thematic Analysis, Braun & Clarke, 2019b) as Study 1 did, meaning is generated through interpretation and the reflexive process. Therefore, estimations made in advance about how much data is enough, might not be useful. As Braun & Clarke (2019b, p. 10) have discussed, "*we conceptualise research as a situated, reflexive and theoretically embedded practice* *of knowledge generation or construction, rather than discovery, there is always the potential for new understandings or insights*". The estimates were therefore developed on the proviso that in-situ revisions might need to be made based the adequacy of data collected (Braun & Clarke, 2019b).

4.3.2.2 Study 2

Sample size in Study 2 was predominantly determined by the quantitative element of the survey (PKBQ Scale, Zwakhalen et al., 2007) and the number of participants required to complete statistical analysis. It was not possible to accurately ascertain the population of the sample (amount of CH staff or IFCs in the region) so the following formula was used to generate sample size estimation:

$$\text{Necessary sample size} = {(\text{Z-Score})}^2 \times \text{StdDev}\,(1-\text{StdDev}) / (\text{Margin of error})^2$$

Margin of Error (Confidence Interval) = +/-10%

Confidence Level = 95% (Z-Score= 1.96)

Standard Deviation = 0.5

$$\text{Necessary sample size} = {(1.96)}^2 \times 0.5\,(0.5) / (0.10)^2$$

$= 96.04$

= 96 necessary sample size Study 2.

4.3.1 Sourcing & recruiting sample

The strategies employed for recruitment in Study 1 and 2 were responsive to improve recruitment opportunities as the research progressed and in the field experiences.

4.3.1.1 Care homes

For Study 1, attempts to source the CH sample was initially sought through Local Authority in the region of the Southeast in which recruitment took place. The Local Authority electronically promoted the study via email, contacting CHs within its region. The email contained a participant information sheet detailing Study 1, and the researchers contact information. Managers were to contact the researcher direct to engage with the research. Only one email response was received from a manager of CH (this was to inform the researcher they did not accept admissions from older adults with dementia, so did not fit the study criteria).

To follow up the researcher then emailed a total of 44 CHs who's direct (and valid) emails were listed on the Local Authority website, the researcher also called a significant number via telephone. This contact led to responses from 9 CHs: 2 CHs agreed to meet to discuss further; 2 indicated they were not registered to care for older people with dementia; 2 already had research ongoing and did not have capacity to undertake further; 1 was interested but was unable to engage without approval from head of care (which was not forthcoming); and 1 was undergoing a change of manager (the previous manager having requested further information). 3 CHs were recruited, however 1 CH that provided written consent to take part then declined (the member of staff supporting the researcher left the CH).

Anticipating that a lack of interest or possible mistrust might be preventing recruitment, attempts were made to connect with CHs via a dementia support and training organisation known to the researcher. Acting a point of trust this organisation introduced the researcher to several CHs electronically. This led to the recruitment of a further 2 CHs for Study 1.

At the point at which 4 CHs had agreed to take part in Study 1, data collection began. It was clear on completing 1 interview in each of the CHs that there were going to be practical challenges in recruiting a handful of staff from each CH (see Section 4.4.1.4). Reacting to this, and the clear engagement challenges which could be anticipated in recruited a new set of CHs for Study 2, CHs recruited for Study 1 were then approached about Study 2. All 4 agreed to take part in Study 2. The researcher then recruited a further 2 CHs for Study 2 through their connection to a dementia support and training organisation. A total of 6 CHs agreed to take part in Study 2.

4.3.3.2 Care home staff

Recruitment of CH staff took several routes. Initially, recognising CH managers as research partners as a strategy to engage them and staff (Lam et al., 2018), managers were asked to champion the research and provide time for staff willing to take part firstly in Study 1, and later Study 2. To recruit for Study 1, the researcher visited each of the 4 CHs and was introduced to staff by the manager. Given that interviews could take up to an hour, the manager at each CH made recommendations about which staff would be able to dedicate the time necessary. This does raise issues around bias, however without management support, staff would not be able to take part during shift time, given competing demands on workloads. The researcher then approached staff members at each CH for an interview.

Recruitment for Study 2 took similar routes, however required a more time-intensive process, in part underscored by the drivers of adequate sampling. Firstly, the manager of each of the 6 CHs made their staff aware of the survey, and to ensure all staff had the opportunity to take part (e.g., those on night shifts) paper copies were left for them to complete during their shifts. The researcher also visited each home on several occasions to promote the survey at staff meetings and provide paper copies directly to staff. It was intended that staff would complete the surveys independently during or after work and return them back to the CH manager or researcher at a scheduled return visit. However, it became apparent early on this was not effective in engaging staff, with a meagre response rate. Previous survey studies in UK CHs have typically returned low response rates, even with the use of postal surveys (39%, and 33% respectively, Barry et al., 2012; Burns & McIlfatrick, 2015). A ‘sit-in’ approach became relied upon, to opportunely recruit staff who became available during their shift and to allow staff time to acclimatise to the researcher’s presence. It is important that data collection within CHs is sensitive and adaptive to established routines (Luff et al., 2015). As such, the researcher was present for recruitment between 10am- 12pm, 1.30pm- 4 pm on each visit. These periods, post breakfast and post lunch, were less busy for staff, and given that most opted to complete the survey with the researcher during their shift, adequate time was necessary. Sampling often snowballed, where a participating member of staff would suggest to a colleague, they take part, or would recommend colleagues potentially available/interested to take part.

The challenges experienced during field work in CHs and recruitment described in the current section, and later (Section 4.3.1.1) reflect those described in the literature on CH research (e.g., Luff et al., 2015). However, these were new experiences for the researcher, who having spent significant time volunteering in CHs was acclimated to the environment and the staff within. The researcher experienced a sense of change from being ‘familiar’ with the environment and to those within it, to a ‘stranger’ regarded with what appeared at times to be slight apprehension. As such, the diverse strategies described were necessary to engage CHs and develop rapport with staff to facilitate data collection. These strategies were in part informed by approaches proposed by the literature (Luff et al., 2015; Lam et al., 2018), alongside an experiential learning in the field of what would ‘work’ in this setting.

4.3.3.3 Informal caregivers

The most effective strategy to recruit IFCs is support groups, as these provide a trusted point of outreach, overcoming issues of mistrust and social isolation (Leslie et al., 2019). The researcher therefore obtained gatekeeper approval from 3 caregiver support organisations to attend their support sessions for recruitment purposes (2 were dementia related and 1 provided support to any IFC). The researcher briefly presented at some groups where invited to do so by the group facilitator and used a participant information sheet to approach attendees. Recruitment for Study 1 and 2 were the same, however were not concurrent. Following recruitment of 14 IFCs interviewees for Study 1, recruitment for Study 2 commenced using the same support group organisations.

For Study 1 and 2 some participated during support group time, however most either took a survey to return at the next session or provided contact information to arrange an interview. It often took several visits to support groups for IFCs to familiarise themselves with the researcher, and often recruitment was precipitated by a recommendation from another caregiver. To diversify the sample and recruit those who were not attending support groups, advertisements via social media was used for both studies. A brief description of the research was provided on local news pages in the Southeast region. In addition, one of the support organisations also recruited for Study 2 by providing surveys and researcher contact information to IFCs not attending support groups but being visited by the organisation.

4.3.3.4 Nursing students

A small cohort of 25 nursing students were approached to take part in Study 2 during a seminar session. This cohort had just completed a 10-week placement working with older adults and those with dementia, which provided them with relevant and recent experience. Surveys were distributed to those interested, a small number elected to complete the survey online and an email copy was sent to them.

4.3.2 Sample strategy & bias

A combination of convenience and snowball sampling was used for both Study 1 and 2. Participants were self-selecting and volunteered to take part. Alternative sampling strategies, such as stratified, may have reduced the potential self-selection bias (particularly in Study 2 where statistical analysis is being performed). However, the sample under study presents its own limitations to recruitment opportunities. Self-selection bias is an inescapable ethical necessity, and the resolution is only awareness of its potential biases (Robinson, 2013). On an individual level, self-selection bias will mean the sample recruited present with certain traits which those who do not opt to take part do not have. They are likely to be more open to self-disclosure and more interested in the topic of the research (Robinson, 2013). At the level of gatekeeper organisations, self-selection is a potentially troublesome issue. Like at the level of an individual participant it is unescapable, as gatekeeper organisations must provide approval for recruitment of their employees or those utilising their services. Should a particular gatekeeper decline to take part in research, this then prevents those working or utilising services within the organisations the opportunity to take part. Steps were taken to circumvent this, through social media advertisements, however given that gatekeepers were necessary to access relevant participants it could only be avoided in a limited capacity. The other challenge around gatekeepers self-selecting is the bias of the type of CHs likely to engage with research. With the understanding that there are challenges such mistrust of the research community or lack of time/resources/staffing to support research in CH recruitment (Luff et al., 2015), it is likely those CHs that responded would be different from those who did not. It is likely those who responded had more capacity for research, so perhaps good levels of staffing, were more conscious of the importance of research, and were confident in the care and services being offered. It can be imagined those who did not respond were concerned about the potential for judgements to be made relating to staffing (e.g., training) and quality of care provided.

The final bias which is likely to have been present from the outset of sampling and recruitment is the researchers own biases, and their presence within CHs and support groups as a recruitment strategy. The process of sourcing and recruiting the sample was time intensive in both studies, much of sourcing and recruitment of the sample was contingent on trust, established from in-situ familiarity. In the interests of transparency regarding researcher bias, a reflexive statement has been provided (see Appendix G: Reflexive Account).

Sample biases do impinge on the representativeness of Study 1 and 2 samples; therefore, findings must be acknowledged as contextualised and local (Robinson, 2013). In recognition of such, findings are situated, case studies provided, and the characteristics of participants explored in relation to common characteristics of caregiver groups in the UK.

4.4 Study 1: A Qualitative interview-based approach

The first phase of this research was exploratory, reflexive, interpretative and in-depth, at its centre was *experiences*. It aimed to explore the experiences of caregivers supporting PwD who have pain, both within the CH context and within the community. The research questions under enquiry in this phase included 1-3 (Section 3.2). These research questions were concerned with experiences, roles, environment, and contexts. To respond to these research questions a qualitative approach was most appropriate, the following sections distinguish this approach and provides a rationale for its relevance to these research questions.

4.4.1 Distinguishing the qualitative approach

Research from a qualitative orientation attempts to transform the naturalistic and lived experience into visual, audio and written materials to generate ‘thick descriptions’ of social phenomena (Denzin & Lincoln, 2005). Study 1 was concerned with the working and caring lives as experienced by caregivers, while being conscious of wider contextual issues which came to light in Chapter 1. The generation of ‘thick descriptions’ to provide the context of people’s behaviour and experiences (Geertz, 1973), and a window into their reality (Denzin & Lincoln, 2005; Howitt, 2019) aligned with this concern.

An open, experientially focused, and situated approach was necessitated in Study 1, considering both the research questions and sample under investigation. Study 1 therefore took a big Q approach (as distinguished from small q; Kidder and

Fine, 1987). A big Q approach employs open-ended inductive methods aiming to explore meaning (Willig, 2008). The collection and interpretation of data is reflexive and fluid (Harper & Thompson, 2012), consisting of a *"continually changing set of questions without a structured design" (*Kidder & Fine, 1987, p. 59). Alongside this, Study 1 also took an experiential approach to language (as distinguished from discursive; Reicher, 2000). Experiential approaches aim to gain a better understanding of what participants think or feel through their use of language, as language is seen to reflect reality (Reicher, 2000). Language provides a window into internal categories held by people, and as such can be read as what people think or have experienced (Reicher, 2000; Terry, Hayfield & Clarke, 2017). An experiential approach provides perspectival reality which holds onto the participants own framing, prioritising the participant voice and interpretation over that of the researcher (Terry et al., 2017; Braun & Clarke, 2013). Given that the caregiver groups targeted in this research have been largely omitted from what literature has been identified in Chapter 2, it was essential that an approach to language supported participants' voices to be represented Study 1.

4.4.1.1 Interviews

In using conversation, our most basic mode of human interaction, interviews aim to provide a space for people to share their lived experience, in their own words (Kvale & Brinkmann, 2009). Research from a critical realist stance often begins research from an intensive approach, deferring to hermeneutic methods like interviews (Price & Martin, 2018). This is because language provides an 'inside' or 'interior' to social life which cannot be accessed without initial hermeneutic engagement (Bhaskar 2016). As method interviews are best suited to respond to research questions which are experientially based and are particularly well suited when trying to engage people with sensitive topics (Braun & Clarke, 2013). Such made interviews aptly suited to the research questions in Study 1, which were framed around life/work narratives on what could be envisioned as potentially difficult subject matter (dementia; pain; caring; dependence).

Semi-structured interviews were used, consisting of pre-prepared open-ended questions. While semi-structures allow for a clear focus and schedule within interviews, they remain sufficiently open and responsive to participant responses (Braun & Clarke, 2013). The interview schedule was developed as an iterative process, using existing literature, feedback sought from lay representatives within caregiving roles, and evolving responses during actual interviews (see Table 4.1). One of the key issues which arose during interviews was focusing caregivers on pain, among the myriad of other issues they were negotiating in their caregiver roles and subsequently prioritising in their narratives (see Section 4.4.1.4). This necessitated an increasingly honed interview schedule to provide caregivers with more steer towards discussions relevant to the research questions. As an illustrative example, the first iteration of the interview guide consisted of the question ‘How do you know if the person you care for is in pain?’. A follow up question was later added to elicit more concrete examples or considerations from caregivers, ‘What behaviours, noises, or signs do you look out for?’.

4.4.1.2 Interview sample

Study 1 aimed to recruit a maximum of 20 interviewees, a total of 18 were recruited. While total interviewees were not far off this maximum guideline, a desired balanced mixed of IFCs (n= 14) and CH staff (n= 4) was not achieved. The decision to cease recruitment of CH staff for interviews was based on several factors. The first was in-situ assessments of the adequacy of data collected, which is provided for in a reflexive approach to research and analysis (Braun & Clarke, 2019b). Certainly, compromises had to be made (see Section 4.4.1.4) in relation to the interviews carried out. However, these were balanced against interviews from CH staff and IFCs which in combination provided rich, complex, and nuanced accounts relevant to research questions. As transcription of interview audio began after the first interview, the researcher was able to audit the depth of data being gathered, which served to guide when sufficient data was present.

The second factor was Study 2. The decision to collect qualitative data in Study 2 meant interviewees were not the only source of qualitative data, any issues not covered expansively in interviews were therefore likely to be picked up by Study 2. Practically, it also meant a larger volume of qualitative data, the researcher only being able to synthesise and analyse thoroughly a certain amount of qualitative data independently. The final in-situ consideration was contextual challenges in CH recruitment, which limited the number of interviews a CH could accommodate (see Section 4.3.3.2).

Table 4.1 Overview of key domains of interview guide for care home staff and Informal caregivers

Domain	Key areas relating to caregiver	Key areas relating to person/PwD being supported
Demographic & personal characteristics	*CH staff:* Demographics and life history, including age; nationality; job title and years' experience; and training received in relating to older adults, dementia and/or pain. *IFCs:* Demographics and life history, including relation to PwD supported; previous work or life experience as caregiver; support received; duration as caregiver; any training received)	*CH staff:* Frequency supporting CH residents with dementia/cognitive impairment. *IFCs:* PwD characteristics, including duration of symptoms, diagnosis, and form.
Pain in dementia	*CH staff:* Consideration of pain in day-to-day role. *IFCs:* Consideration of pain in day-to-day role.	*CH staff:* Pain related conditions or injuries they encounter supporting PwD; Medications they are aware off for aforementioned; responses of PwD to pain. *IFCs:* Pain related conditions or incidents in PwD supported; response to pain in PwD.

Pain assessment	*CH staff: Questions or reactions to PwD in pain; challenges experienced trying to find out when pain is present.* *IFCs:* Their questions or reactions to pain in person they support; challenges experienced trying to find out when pain is present.	*CH staff:* signs of pain among PwD supported; familiarity with Pain Assessment Tools (and thoughts if any on their use). *IFCs:* signs of pain in PwD supported; familiarity with Pain Assessment Tools (and thoughts if any on their use).
Pain management	*CH staff:* response/action to pain; use of pain medications (and thoughts on their use); use of any non-drug methods to relieve pain (and thoughts on their use); response of other healthcare providers. *IFCs*: response/action to pain; use of pain medications (and thoughts on their use); use of any non-drug methods to relieve pain (and thoughts on their use); visits to healthcare providers.	*IFCs*: visits to healthcare providers relating to pain.
Perceived barriers	*CH staff:* feelings about supporting PwD with pain; response to statement ‘There is some suggestion that	

	pain might go unnoticed and untreated in people with dementia'; suggestions for improving how pain is noticed to treating among PwD. *IFCs*: feelings about supporting a PwD with pain; response to statement 'There is some suggestion that pain might go unnoticed and untreated in people with dementia'; suggestions for improving how pain is noticed to treating among PwD.

4.4.1.3 Interviewee Characteristics

An overview of the characteristics of interviewees is provided in Table 4.2., more detailed case studies of interviewees can be found the appendices. Of CHs recruited all had a considerable dementia population, all having mixed older adult populations, with 3 registered as dementia specialist (A, B, D). A member of staff was recruited to represent each of the CHs. CH staff recruited were representative of the archetypal 'staff' found in the UK care sector[11]. All were White British women, ranging from 30-66 years of age (mean= 41.5 years) and had been working in the sector from 6 months to 30 years (mean= 16.9 years). CH staff consisted of two healthcare assistants, one senior carer and one duty manager (previously a senior carer).

The IFCs recruited represented predominately wife-husband dyads, most commonly with the wife acting as primary caregiver (n= 6) (Table 4.2). It is estimated 60-70% of carers for PwD in the UK are women[12]. This sample fitted well within such estimates. However, in line with growing figures of women living with dementia this sample too included 4 husbands supporting their wives and 4 daughters supporting their mothers/mother-in-law. IFCs varied in age from 44 to 84 years (mean= 66.4 years). Most (10/14) were over the age of 65. IFCs' time as a carer varied, ranging from 6 months to 7 years and for some it was not only dementia which had precipitated this shift to a caring role, but other comorbidities. Those with dementia being supported by IFCs recruited were all over the age of 65, and half (7/14) were over the age of 80 years.

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[11] Report: The state of the adult social care sector and workforce in England. (September 2018). 82% of the CH workforce in the UK is female and untrained. Average age of joining workforce is 35 and average workforce age is 44. The workforce is predominantly White British. As the workforce ages retention of staff increases, those aged 20 have the worst retention and are unlikely to remain in the sector. On average workforce have 8 years' experience and 71% have been working for 3 years of more in the sector.

[12] Women and Dementia: A Marginalised Majority by Alzheimer's Research UK. (2015).

Table 4.2 Study 1 interview characteristics

Int	Pseudonym	Gender	Role	Years' Experience	CH
1	Jane	F	Healthcare Assistant	6 months	A
2	Ceri	F	Manager	27 years	B
3	Elaine	F	Senior Carer	10 years	C
4	Clare	F	Healthcare Assistant	30 years	D

Int	Pseudonym	Gender	Supports	Years Supporting	Additional Support
5	Mary	Female	Mother	18 months	Yes
6	John	Male	Wife	5 years	Yes
7	Emma	Female	Mother	7 years	Yes
8	Derek	Male	Wife	7 years	Yes
9	Caroline	Female	Mother-in-law	6 months	Yes
10	Rose	Female	Husband	5 years	No
11	Donna	Female	Husband	6 years	Yes
12	Tom	Male	Wife	1 year	No
13	Anne	Female	Husband (Deceased)	>5 years	No
14	Joyce	Female	Husband	6 months	Yes
15	Eric	Male	Wife	18 months	Yes

16	Irene	Female	Mother	18 months	Yes
17	Lyn	Female	Husband	5 years	Yes
18	Betty	Female	Husband	Unknown	No

4.4.1.4 Interviews in Context

Interviews were conducted by the researcher. All were audio recorded and most often occurred within the CH (for CH staff) or within participants own homes (for IFCs). On two occasions an IFC opted to be interviewed during their attendance at a support group, and another two at a café. All CH staff opted to be interviewed at their workplace.

CH interviews were most challenging in respect to recruitment (Section 4.3.1.1, Section 4.3.3.2) and actual practicalities of conducting interviews. All four CH interviewees were consistently interrupted, and interviewees were engaged in other activities during interviews. Both interviewee 3 and 4 answered the phone on multiple occasions; interviewee 4 also had several interactions with residents, as did interviewee 1. Interviewee 2 completed her interviewee while doing paperwork and eating her lunch. The result of disturbances were often shorter interviews than desired (e.g., interviewee 4 was disturbed so frequently the interview lasted less than 30 minutes) and loss of fluidity in the interview narrative. Such reflected the demand on participants’ time and implied a need to explore alternative forms of data collection which would comply with the environmental limitations that CH staff were experiencing.

Similar challenges were present for IFCs who took part in interviews. Most interviewees were the primary caregiver, as such would often need to interrupt interviews to check on the person with dementia being supported, or some would be accompanied by them.

For both groups' interviews were challenging in respect to subject matter. As is explored further in analysis (Chapter 5 & 6), pain was not an easy topic to negotiate during recruitment or interviews. For those interviewed pain was disassociated from their caregiving roles and the experiences of the PwD being supported. In interviews it was challenging to elicit narratives about pain, this resulted in more honed interview questions as data collection progressed and added to the rationale that a structured survey method might be more accessible (in respect to focused responses on pain).

For those IFCs who did not participate, they cited 'paperwork' as a common reason for their reluctance to engage, bureaucratic form filling and sharing of information had left them disillusioned with what an interview could offer to them. It is possible there were other reasons at work with those who choose not to take part, such as stigma associated with dementia and overwhelming demands of their role (as disclosed in interviews, see Chapter 6). The problematic nature of pain as subject matter also underlay why some IFCs declined to take part, they would often indicate that (a) they did not know anything about pain (the researcher would attempt to assure them this was about experiences); and (b) the person with dementia they were supporting did not have any pain (the researcher would assure them they could still take part, by describing the ways in which they knew this). This was likely comparable for some CH staff who opted not to take part.

4.5 Analysis of Interviews

Reflexive Thematic Analysis (RTA), as developed by Braun & Clarke (e.g., 2006; 2019a), was used to guide the analysis of qualitative data from interviews. The following sections provide an overview of RTA, with consideration of its utility in relation to the research questions of Study 1 and theoretical orientation of the research. It then follows on with a detailed discussion of the practical application of RTA to guide the analytic approach to interviews.

4.5.1 Reflexive Thematic Analysis (RTA)

Reflexive Thematic Analysis (RTA) emerged from the work of Braun & Clarke (2006). Previously termed simply Thematic Analysis, it has recently been re-named to distinguish the approach from other thematic methods and highlight its emphasis on reflexivity in the analytic process (Braun & Clarke, 2019). RTA is a flexible version of thematic analysis (TA), which provides a systematic framework for identifying patterns in qualitative data and interpreting data deliberately, reflectively, and thoroughly (Braun & Clarke, 2014). Demarking it from other TA approaches which are theoretically driven, such as those which locate TA implicitly or explicitly in realist-post-positivist paradigms (e.g., Boyatzis, 1998; Joffe, 2011; Guest, MacQueen, & Namey, 2012), RTA is detached from methodological anchors, and it is the researcher who chooses how they engage with the data (Braun & Clarke, 2006). As such it can be used across the epistemological and ontological spectrum, from a [critical] realist or constructionist methodology (Braun & Clarke, 2014). That being said, RTA sits most comfortably with big Q qualitative research approaches (Kiddler & Fine, 1987), i.e., those which apply qualitative techniques within a qualitative paradigm (Braun, Clarke & Weate, 2016).

RTA was the analytic guide chosen for several reasons, relating to theoretical foundations and research questions. It was necessary to adopt some framework for analysis, given a lack of development to practical application of CR in empirical research, and the abstract descriptions given to the application of concepts such as retroduction (Ackroyd & Karlson, 2014; Fletcher, 2016). The choice of analytic approach needed to meld with key aspects of CR. In considering more structured approaches to TA, such Boyatzis, these were not appropriate given their realist approach. Such approaches view that an accurate reality can be found within data. However, while CR indicates a single reality, it is seen to be stratified and more than what can be observed discursively (Bhaskar, 1978).

Other authors have engaged grounded theory in their analysis of CR research (e.g., Oliver, 2012), however this research took the position that this was not appropriate either. Grounded theory, while engaging with existing theory or literature as a guide, it avoids active engagement with theory during analysis (Glaser & Strauss, 1967). In contrast CR engages with existing theory and knowledge for the purpose of finding best explanation of social phenomena (Fletcher, 2016). Utilising RTA was able to facilitate the latter, acknowledging that analysis is drawn from disciplinary knowledge and theoretical assumptions, alongside a myriad of other influences (Braun et al., 2016).

While CR engages with what is known it is acknowledges that our understanding will be fallible and therefore remains open to the re-vision of ideas and theory (Fletcher, 2016). In this sense it is reflexive, providing space for critique of our assumptions and the possibility to re-visit and revaluate. The relevance of reflexivity to CR is also related to the necessity of hermeneutic engagement to explore language and the insights it provides to social life (Price & Martin, 2018).

Similarly, to these conceptualisations, RTA approaches research as a reflexive and embedded practice in which knowledge can be generated, but always with the potential for new insights (Braun & Clarke, 2019). RTA further allowed CR to inform analysis on several levels, in that the concepts of demi-regularities, abduction and retroduction could be weaved into the analytic approach.

In relation to research questions, RTA was also well serving for the purposes of exploring experiences and roles. RTA aims to derive patterns with the possibility of providing analyses of people's experiences; processes underlying behaviours or practices; and providing perspectival insights (Clarke & Braun, 2014; Braun et al., 2016). Given that RTA seeks experiences across a sample (not just the individual), is not theoretically driven, and is well suited to heterogeneous convenience samples (Braun & Clarke, 2020b), it further suited the overarching aim of this thesis and approach to recruitment.

4.5.2 Reflexive Thematic Analysis in Practice

In practice RTA is guided by a six-phase model (Braun & Clarke, 2006; 2019a), the phases of which were used to underpin analysis of interviews. It is important to emphasise that these phases are not linear, and although described below for clarity as distinct steps in the analytic process, thorough RTA involves a recursive and reflective moving back and forth between phases (Braun et al., 2016). It too is important to emphasise that these phases act as guidance not prescription, and the researcher must actively and consciously make choices at each phase (Braun et al., 2016). Analysis is produced through the *"intersection of your theoretical assumptions, disciplinary knowledge, research skills and experience, and the content of the data."* (Braun et al., 2016, p. 196). As Braun & Clarke (e.g., Terry, Hayfield, Clarke & Braun, 2017; Braun & Clarke, 2019a) have keenly clarified in later writings on their method, analysis is not in the data, themes do not simply “emerge” through a search, they are generated. Because themes do not passively sit within the data RTA requires reflexivity, theoretical knowingness, and transparency (Braun & Clarke, 2019a).

4.5.2.1 Phase 1: Familiarisation

Phase 1 of RTA is centred on developing an intimate familiarity with the data, which is achieved through immersion in, and critical engagement with, the data (Braun & Clarke, 2006; Clarke & Braun, 2014). Familiarisation of the data began with transcription, which the researcher carried out. A verbatim account of all verbal utterances was transformed into written text (transcripts). It then continued with repeat listening to interview audio. Notations were taken during this time to record initial ideas, analytic observations and nuances about each interviewee or the environment of data collection.

4.5.2.2 Phase 2: Generating Coding

Phase 2 began by thorough and systematic tagging, or coding, of the data. Codes capture the features of data which are most relevant to the research questions in brief phrases (Clarke & Braun, 2014). These phrases should reflect the content of the data and sometimes the researcher’s interpretative lens (Braun & Clarke, 2006). Given that this analysis aimed to achieve a rich description of the whole data set, rather than a more detailed account of one particular aspect (Braun & Clarke, 2006), all interview data was coded. Coding was proceeded with openness, inclusivity, and flexibility, as recommended at this early analytic stage (Braun et al., 2016). Codes were explored at both the surface meaning of the data, albeit through the researcher’s interpretive lens (semantic level) and deeper into underlying systems of meaning (latent level) (Clarke & Braun, 2014). Coding also paid attention to demi-regularities and tendencies, which are semi-regularities or broken trends in the data (Fletcher, 2016). It was unproblematic in RTA to weave in this feature of critical realism, given that it too seeks to identify patterns.

4.5.2.3 Phase 3: Generating Candidate Themes

A theme represents some level of patterned response (Braun & Clarke, 2006). An overarching theme is used to house codes and associated data which can be clustered based on overlap and similarity (Clarke & Braun, 2014).

Table 4.3 Initial theme clusters generated by interview schedule

Frequency Encountering Pain	Pain Assessment Tools
Pain Response (PwD)	Response to Pain (Caregivers)
Detecting Pain	Treatment Challenges
Drug Pain Management	Improving Detection
Non-drug Pain Management	The Pain of Caring

The search for candidate themes and clustering of codes was initially loosely framed by the core categories of the interview guide as a starting point (Table 4.3) and were more domain orientated and theoretically driven. Domain themes serve to capture a shared topic within the data, presenting diversity in relation to that shared topic (Braun & Clarke, 2019a). The result of this initial clustering was 7 candidate themes for CH interviewees and 9 for IFCs.

Several shifts were then made, the first was the amalgamation of data sets from CH and IFC interviewees, given the developing similarities in experiences being captured by codes. A shift was also made to re-cluster codes in themes more inductively, returning to the codes, themes were then drawn from the data. This inductive shift leads to analysis, which is data driven, without preconceived categories, and more developed themes (Braun & Clarke, 2006). Themes were then formed from a central organising concept, which denotes a shared meaning or uniting core concept (Braun & Clarke, 2013). A more inductive approach allowed for a deeper identification of themes from the latent level, rather than the semantic. Identification of themes at the latent level means going beyond the surface content of the data, to explore underlying ideas, structures and so forth which shape the surface content (Braun & Clarke, 2006). A latent approach involves interpretation and is often aligned with constructivist approaches. However, it can equally be seen as relevant to the critical realist approach taken, in that CR assumes a reality that cannot readily and wholly be grasped by what is observable.

This re-exploring of codes and re-identifying candidate themes lead to 3 potential candidate themes emerging. However, it soon became clear this was too broad brush an approach which limited the depth of each theme, and 5 candidate themes were then generated for review in Phase 4.

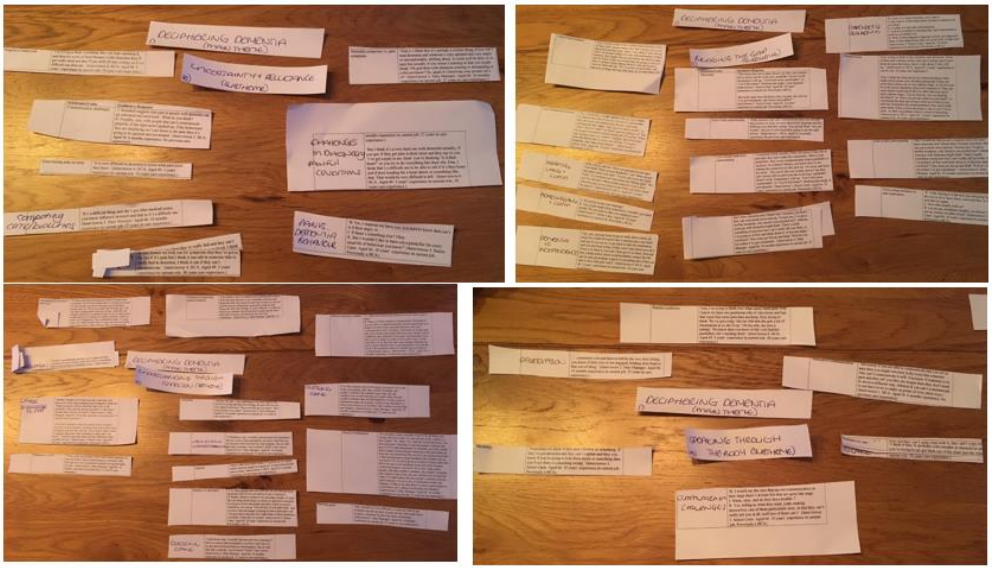
The importance of a theme, or whether a theme should be considered a theme, was decided on by its contribution or relevance to the research questions, as advised by Braun and Clarke (2006). Decisions about themes ultimately rest with the researcher in RTA, it is not necessarily something which can be guided by quantifiable measures such as its frequency across the data set (Braun & Clarke, 2006). Therefore, it is important notations are made throughout each phase to make transparent the choices made by researchers (see Appendix E).

4.5.2.4 Phase 4: Reviewing Themes

Candidate themes devised in Phase 2 were then reviewed. The first level at which themes were reviewed was within themes. This involves checking themes against coded data to determine if there is a good fit between the two. The second level at which themes were reviewed was in relation to the data set as a whole. Themes can intersect and share relationships, but they must hang together to tell a rich and complex story (Clarke & Braun, 2014). This phase highlighted some disconnect within themes and themes as a coherent whole, so it was necessarily to recursively revisit the codes and candidate themes.

To refine themes visual mapping of candidate themes and codes was used to construct a skeleton structure which could be shifted around (see Image 4). Initially CH and IFCs data was mapped separately, but only for the purposes of making visual mapping easier. The generation of themes was not a linear process; engaging in a constant reflective dialogue, the data, codes, and themes were dissected. After 4 iterations of the process, and a total shift the original clusters devised (see Table 4.4.), 4 final themes were conceptualised (Table 4.4.) (to follow this journey, see Theme Memos Appendix E). These themes offered distinction but remained interconnected as part of a holistic narrative.

Image 4.1 Example of visual mapping of themes



4.5.2.5 Phase 5: Defining & Naming Themes

Within Phase 5 there is a shift from a more summative position to a more interpretative orientation, in which a researcher makes sense of the patterns and diversity in the data (Terry et al., 2017). A part of this making sense requires naming final themes and providing them with definitions. Theme names which were punchy and impactful were conceptualised, and definitions provided to capture the essence of a theme, its relationship to other themes and to the research questions (as advised in Braun et al., 2016). Theme names were derived from a combination of the researcher's interpretive lens and the language of participants. Subthemes were also derived at this point, which serve to delineating specific points within themes, which sharing a central organising concept (shared meaning) (Terry et al., 2017).

Table 4.4 Final thematic analysis: themes and subthemes

Theme	Subtheme
1. Deciphering Dementia	A. Speaking Through the Body B. Understanding Through Connection C. Deteriorating Connections
2. Relieving Suffering	A. Lack of Prioritisation B. Existential Pain C. Striking a Balance
4. The Pain of Caring	A. Evolving Identity B. Grief & Loss C. Practical, Systemic & Societal Challenges
4. Autonomy vs. Dependence	A. Supporting Choice B. Assuming Control

4.5.2.6 Phase 6: Write Up

The final phase of RTA is writing up, the approach taken to write up was both descriptive and interpretative, and verbatim extracts were drawn on both illustratively and analytically (Braun & Clarke, 2013). Given that the generation of knowledge is seen part of a continued conversation in RTA (Braun, Clarke & Hayfield, 2019), write up also engaged with other research, so an accumulative broader story could be told. This approach fitted well with the CR concepts of abduction and retroduction, allowing them to be introduced into analysis during write-up and interpretation of data. Abduction involves the re-interpretation, re-description, and re-contextualisation of data to form connections that enable the researcher to discern relations which might not otherwise obvious (Danermark, Ekström, Jakobsen &

Karlsson, 2002). It shows what something might be, going beyond description of what it is. Retroduction is a contextualised form of reasoning which aims to identify the necessary conditions under which a particular causal mechanism functions and causes the observed effect (Fletcher, 2017). It is the central mode of inference in CR and involves arguing backwords, from the abstract to the concrete, and back again to develop an explanation (not prediction) or a causal account of what we observe in the here and now (Fleetwood, 2014). Practically, in write up this took the form of exploring and reasoning why things happen in the data.

4.6 Quality Evaluation: Interviews

A composite approach was taken to the criteria explored to support quality in Study 1. This was necessary, because as recognised by others (e.g., Reicher, 2000), qualitative research is not a singular entity, as such a prescriptive ‘one-size fits all’ methodological criteria was not appropriate to assess the approach taken. The composite quality criteria consisted of guidance relating to quality in Thematic Analysis and Reflexive Thematic Analysis (Braun & Clarke, 2006; 2019b; 2020a), and generic criteria for assessing quality in qualitative research drawn from the Yardley’s quality principles (2000; 2008). The former guidance relates to ensuring quality in undertaking, processes, and outputs of TA, while the latter relates to wider processes and impacts of qualitative research. The following will explore the criteria used.

4.6.1 Checklist for Reflexive Thematic Analysis

Braun and Clarke (e.g., 2019b; 2020a) have offered some guidance regarding how to appraise quality in research utilising their approach. This has predominantly taken the form of discussing concepts which while might be applied in other qualitative criteria, or other forms of TA, are not suitable for RTA. The first of these concepts is data saturation, which is often used as a rationale to support sample sizes and as a concept aligned with validity (e.g., Critical Appraisals Skills Programme 10 item checklist for Qualitative research). Braun & Clarke (2019b) have discussed that data saturation is not necessarily a concept which sits well within their RTA or big Q approaches, given that meaning is generated through interpretation and the reflexive process:

> *"When we conceptualise research as a situated, reflexive and theoretically embedded practice of knowledge generation or construction, rather than discovery, there is always the potential for new understandings or insights (Braun & Clarke, 2019, p. 10)."*

As such, when data saturation is achieved, will be dependent on the researcher. Similarly, this is why concepts such as inter-rater reliability or coding reliability measures are not appropriate for RTA (Braun, Clarke & Hayfield, 2019). These may be relevant to structured forms of TA where accuracy is a concern (e.g., Boyatzis, 1998). However, they are not relevant to approaches which are contextual and subjective, because different insights about the same experience can be generated from different people (Madhill et al., 2000). That being said, analysis must still be grounded in the data to form coherent and plausible analysis (Braun and Clarke, 2013).

Several resources are available specifically for RTA which could be referred to during analysis and write up. These include a 15-point checklist of ‘good’ TA to support researchers to engage in a thorough, reflexive, and systematic process at each phase of analysis (see Table 4.5). They also include a recently developed checklist for editors and reviewers of TA manuscripts (Clarke & Braun, 2019), and a 20-point tool for evaluating the use of TA (Braun & Clarke, 2020a). From the 15-point checklist items relating to 1-5 were centred on thorough coding (see Appendix E), and the development of coherent and data supported themes. Items 6-11 were relevant to analysis and write up (Chapter 5-6), and items 12-15 were centred on offering an explicit and transparent account of the research process (see Appendix E; Theme Memos and Appendix G; Reflective Account). From the more recently developed resources (Clarke & Braun, 2019; Braun & Clarke, 2020a), these focus on assessment of adequate choice of explanation of methods and methodology (encompassing the current chapter and the previous), and a well-developed and justified analysis (Chapter 5-6). Key to accessing the quality of the use of any form of TA approach, is evidence of deliberate and reflexive engagement with TA as method and practice (Braun & Clarke, 2020a). Braun et al. (2016) acknowledge that their checklist acts only as a guide, and therefore Yardley’s quality principles (2000; 2008) were also drawn on.

Table 4.5 15-point checklist for a good TA (table from: Braun & Clarke, 2006. p. 96)

Process	Criteria
Transcription	1. Data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for “accuracy.”
Coding	2. Each data item has been given equal attention in the coding process. 3. Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive. 4. All relevant extracts for all each theme have been collated. 5. Themes have been checked against each other and back to the original dataset. 6. Themes are internally coherent, consistent, and distinctive.
Analysis	7. Data have been analysed – interpreted, made sense of – rather than just paraphrased or described. 8. Analysis and data match each other – the extracts illustrate the analytic claims. 9. Analysis tells a convincing and well-organized story about the data and topic. 10. A good balance between analytic narrative and illustrative extracts is provided.

Overall	11. Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a light once-over.
Written report	12. The assumptions about, and specific approach to, thematic analysis is clearly explicated. 14. There is a good fit between what you claim you do, and what you show you have done – i.e., described method and reported analysis are consistent. 14. The language and concepts used in the report are consistent with the epistemological position of the analysis. 15. The researcher is positioned as active in the research process; themes do not just “emerge.”

4.6.2. Yardley’s Quality Principles (2000; 2008)

Yardley (2000; 2008) developed a set of 4 criteria by which qualitative research from any orientation can be accessed. This criteria is open and each criterion can be demonstrated in different ways, as appropriate to the methods employed, equally not all criteria will apply to all qualitative research. Table 4.6 provides an overview of each criterion and illustrative examples of how they can be demonstrated in research.

Table 4.6 Criteria for assessing qualitative research (Table from: Yardley, 2000. pp 219)

Essential Qualities	Examples
Sensitivity to context	Theoretical; relevant to literature; empirical data; sociocultural settings; participants' perspectives; ethical issues
Commitment & rigour	In-depth engagement with topic, methodological competence and skill; thorough data collection; depth/breadth of analysis
Transparency & coherence	Clarity and power of description/argument; transparent methods and data presentation; fit between theory and methods; reflexivity
Impact & importance	Theoretical (enriching understanding); sociocultural; practical (for community, policy makers, health workers)

4.6.2.1 Sensitivity to context

Yardley (2000) indicates that a researcher must have awareness of context on different levels. The first is at the level of the understanding created by previous investigators. This can be demonstrated by engagement with knowledge of the field, but also by seeking out new knowledge which may not fit into existing theoretical notions or understandings. The second is at the level of socio-cultural context of the research, which can be demonstrated by exploring what participants' contexts are and how this might be implicated in accounts they describe. The third level is with the perspective of participants', demonstrating that during data collection (via open-ended questions) and during analysis the researcher did not impose their own meaning (Yardley, 2008). The final level of sensitivity is ethically responding to the stories of those who might be vulnerable or marginalised. Ethically, it is also about considering social context of the relationship between researchers and participants, for example balances of power (Yardley, 2000).

4.6.2.2 Commitment & rigour

Commitment and rigour must be demonstrated at the level of data collection, analysis, and engagement with the topic. Commitment encompasses extensive engagement with the topic, participants and data, and the development of methodological skill and theoretically knowing (Yardley, 2000). Rigour refers to the completeness of data and analysis. Data collection should be thorough, and analysis should offer both depth and breadth (Yardley, 2008). Equally, the sample used should be justifiable by relevance to the research question, not necessarily by sample size, but by adequacy to provide a comprehensive analysis (Yardley, 2000). To support rigour and completeness triangulation may be employed, using different sources or methods to achieve a rounded, multilayer understanding. As Madhill et al. (2000) highlight, triangulation can be used to explore the differences in people's accounts, however not for the purposes of confirmation, rather completeness of a more nuanced understanding.

4.6.2.3 Coherence & transparency

The coherence of research is determined by the quality of the narrative, the extent to which it forms a whole and alignment of aims, research questions, theoretical basis, data collection and so forth (Yardley, 2000; 2008). It is about presenting a united front and offering compelling argument. Transparency refers to the extent to which research details every phase/process of data collection and analysis. It can be demonstrated by offering textual data which can be assessed independently, and by disclosure of all relevant aspects of the research process. For the latter this may take the form of reflexivity that explicitly considers of the influence of the researcher in the research process (Yardley, 2000).

4.6.2.4 Impact & importance

The impact and importance of research may be theoretical, or it may provide a new understanding of something. Theoretical worth may be demonstrated through drawing on empirical data to provide ideas which challenge understanding (Yardley, 2000). Importance and impact may be practical, in which communities, providers and policy makers can find use for findings for real-word change (Yardley, 2008). It may too be gauged by sociocultural impact, and how research can serve to alter experiences and discourses (Yardley, 2000).

4.6 Reflexive considerations

The role of reflexivity has been highlighted in the context of analytic approach (e.g., Braun & Clarke, 2006; 2019a) and as prerequisite for determining quality in qualitative research, specifically supporting transparency and coherence (Yardley, 2000; 2008). Elliot, Fisher & Rennie (1999) indicate that is necessary for a researcher to make clear the impact of their own experiences and beliefs upon how data has been interpreted. In owning their own active position through the course of research, a reflexive approach can be used as a tool for supporting the integrity of qualitative research, and permit opportunities for the reader to construct alternative interpretations (Eliot et al., 1993). Reflexivity has also been highlighted particularly important for researchers involved in CH research (Dewing 2009; Luff et al., 2015). Careful consideration needs to be given to those living and working in the CH, given that CHs are both a home and workplace (Luff et al., 2015). Further, careful reflection should be given to the how residents and staff view the researcher and research (Luff et al., 2015).

In light of importance of reflexive consideration, a reflexive account has been provided to locate the perspectival and experiential position of the researcher within the context and construction of this research (Appendix G).

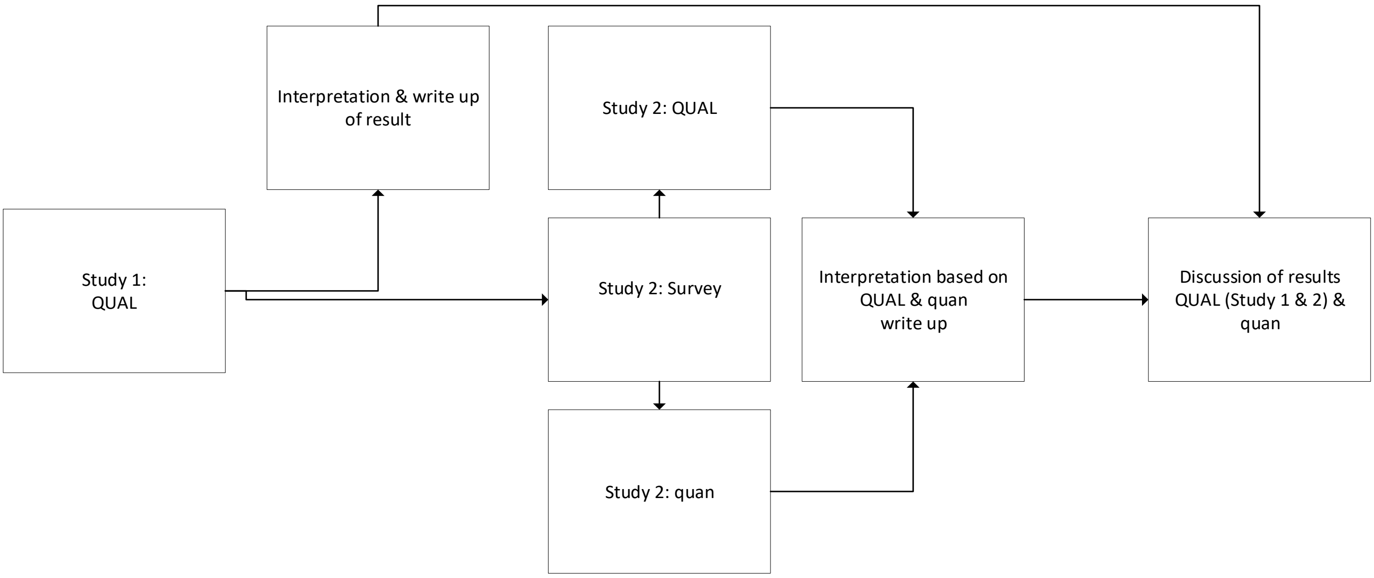
4.7 Study 2: A mixed-methods approach: survey

Study 2 was sequential to Study 1. It aimed to extend, triangulate, and compliment the findings of Study 1, exploring the experiences of further caregivers in regard to pain recognition, assessment and management among PwD, and caregivers' understandings of such. It employed a survey formalised for the purposes of responding specifically to research question 4, centred on exploring understanding among caregivers, while also building on interviewee insights (Study 1) to research questions 1, 2 and 3 (Section 3.2).

Study 2, in contrast to Study 1, took a small q approach, embedding open-ended survey items alongside closed-ended questions and scale responses (Kidder & Fine, 1987). The use of surveys to collect qualitative participant generated textual data and quantitative data concurrently is a popular approach in mixed-methods research in psychology and the social sciences (Robinson, 2021). It is often used for the purposes of triangulation in which different data sources can be compared to understand nuances and contradictions in the data (Creswell & Plano Clark, 2010). Taking a triangulation strategy to data collection allows for two different methods to be used to corroborate, cross-validate, and confirm findings within a single study (Creswell, Plano Clark, Gutmann & Hanson, 2003). The integration of methods in this way offered Study 2 breadth, being able to reach out to more participants than interviews, whilst retaining some depth by the inclusion of open-ended responses. It too allowed for analysis in Study 2 (see Chapter 7 & 8) to draw from different data sets produces a richer, more comprehensive understanding (Creswell & Plano Clarke, 2010).

Alongside the benefits of integrating a qualitative element in Study 2 via open-ended survey items, this inclusion also permitted a deeper understanding through with-in method plurality. In seeking to understand the complexity of social phenomena psychologists are increasingly recognising the need to turn to pluralism of qualitative methods, data sources, theories, and researcher interpretation (Frost & Nolas, 2011). In using brief data (Study 2: survey) alongside depth data (Study 1: interviews) more qualitative data can be generated for systematic and meaningful analysis, which can enhance the applicability and transparency of qualitative research (Frost, Nolas, Brooks-Gordon, Esin, Holt, Mehdizadeh et al., 2010). The use of different within method approaches and frameworks also offers diversity of insights, which can facilitate a greater understanding of the complexity of the world and the variety of human expression (Frost & Nolas, 2011). Thus, plurality of methods within Study 2, and across both studies in union, offered benefits to the totality of findings and enabled triangulation of findings within Study 1, and across both studies. Figure 4.1 presents an overview of how Study 1 and 2 are interrelated, and the following provides a detailed discussion of survey development and implementation in Study 2.

Figure 4.1 Mixing of methods in Study 1 and Study 2



4.7.1 Survey development & content

The survey developed consisted of qualitative and quantitative aspects, including 22 open, and closed ended questions, followed by 17 statements of the PKBQ Scale (Zwakhalen et al., 2007) (Table F1 and F2, Appendix F).

As a method in practice, surveys are accessible and can be used to reach a wide range of people and viewpoints, while providing a structured and focused approach to data collected (Braun & Clarke, 2013). This can be advantageous to qualitative studies in supporting inductive claims about populations from which the sample is taken (Robinson, 2021). Surveys can be used to gather data on participant experiences, understandings, perceptions, and practices/behaviours (Braun & Clarke, 2013), which made them particularly appropriate for the research questions. They are also appropriate when dealing with sensitive issues or reluctant participants, allowing a participant to have more control over the information shared (Terry & Braun, 2017). In considering the challenges of Study 1 regarding recruitment, surveys offered the flexibility and sensitivity needed to negotiate this and reach harder to engage participants.

4.7.1.1 Open-ended questions

Open-ended questions were developed through 2 primary sources: interview data (Study 1) and previous literature. They aimed to respond to the same research questions (1-3) as Study 1 (given the purpose was to expand upon and compliment findings of Study 1). While Study 1 had illuminated much relating to the research questions, interview data picked out some key areas which needed to be explored further (particularly relating to the CH context), and previous literature helped to identify areas which interviewees had not broached in open discussion but had emerged in previous research. These areas primarily related to processes and responses. Questions were therefore developed to elicit responses from caregivers about how they actually assessed pain, what course of action they take, and what treatment (if any) is offered, either by them or relevant healthcare providers (Appendix F, Table F1) to attempt to explore experiences, processes and challenges (research questions 1-3). The survey consisted of 6 sections with 22 questions (not including sub questions). Section 1 explored demographic and contextual information (Q1-9). Section 2 explored caregivers’ reflections of the experience of pain among PwD (Q10-13). Section 3 captured how caregivers were identifying pain among PwD (Q13-14). Section 4 explored caregivers’ reported familiarity and use of pain assessment tools in their practice, or by healthcare providers (Q16-17). Section 5 explored caregivers approaches to treating pain using drug and non-drug methods (Q18-22).

The qualitative items generated for the survey were piloted with a small group of lay representatives and a leading academic in the field, who provided feedback on terms used, structure and relevance of content. This led to minor changes in wording and question phrasing for clarity. It also led to the inclusion of a description of pain within the survey instructions and a description of pain assessment tools within Section 3 (Appendix F, Table F1).

4.7.1.2. Quantitative questions

Quantitative items were included to respond to research question 4, which sought to explore caregivers understanding. To explore this, Section 6 of the survey consisted of closed-ended questions relating to participant demographics and characteristics (Appendix F, Table F2) and the Pain Beliefs & Knowledge Questionnaire (PKBQ, Zwakhalen et al., 2007).

The PKBQ (Zwakhalen et al., 2007) was identified during a review of the literature review (Chandler, Zwakhalen, Docking, Bruneau & Schofield, 2017). It was included within the survey given that if offered a concrete means to explore the understanding of caregivers in relation to pain among older people and those with dementia, and how pain should be treated in these groups (Appendix F, Table F2). The scale has been validated (Zwakhalen et al., 2007; Ghandehari, Hadjistavropoulos, Williams, Thorpe, Alfano & Dal Bello-Haas et al., 2013) with unregistered NH staff and registered nurses which made it accessible to the diversity in training within the sample. Given that the scale is brief it could easily be incorporated into the survey without increasing administrative burden. Other authors have used the PKBQ to similarly evaluate understanding among special care aids (equivalent to UK healthcare assistant role) and nurses in long-term care settings

(Ghandehari et al., 2013). Comparative to other scales identified in a review of the literature (Chandler et al., 2017), including the Acceptability of Pain Observational Methods Questionnaire (Liu, Briggs & Closs, 2011), The Geriatric Pain Knowledge Assessment (Swafford, Miller, Herr, Forcucci, Kelly & Bakerjian, 2014) and the Tool for Evaluating the Ways Nurses Assess Pain (Ng, Brammer, Creedy & Klainin-Yobas, 2014), the PKBQ was the only to measure knowledge in relation to pain, its assessment and its treatment among older people and PwD within one scale. It was further the simplest to undertake for diverse audiences of caregivers and least burdensome. More generic measures of knowledge regarding pain more widely are available (e.g., The Nurses Knowledge and Attitude Survey Regarding Pain, Ferrell & McCaffery, 1987; 2012), and those with are specific to pain the elderly (e.g., The Pain in the Elderly Questionnaire, Sloman, Ahern, Wright & Brown 2001), however these do not include items directed specifically at the population of interest.

The PKBQ includes 17 items across 4 domains and has been found to be valid and internally consistent (Cronbach's alpha = 0.78). The first domain (statement 1-3) is pain assessment and treatment in context. Domain 2 (statement 4-9) is pain experience of younger people compared to younger people. The third domain (statement 10-12) is pain treatment among older people. The final domain is pain medication (statement 13-17). Throughout the domains, although there is a dominance of older adult questions, there are 5 statements specific to PwD (Statement 3, 8-9, 16-17). Given that most PwD are older adults, items relating to pain in the context of ageing were equally of interest.

Statements in each domain of the PKBQ are responded to on a 5-point Likert scale of agreement (strongly agree- strongly disagree). For more information on how the PKBQ was scored and minor changes made, please see Appendix I.

4.5.1.3 Survey sample

A total of 118 responses were obtained from the survey. The sample is described in detailed in section 7.2. In terms of sample adequacy for statistical analysis of quantitative items, surveys returned exceeded the sample estimations made (N= 96). More specifically, the sample was adequate for statistical analysis via one-way ANOVA and T-Tests (see Appendix I). The sample was also adequate for Structured-Tabular Thematic Analysis (ST-TA) (Robinson, 2021) of qualitative survey items, and allowed for ample exploration of frequencies of themes across the data set.

4.7.2 Surveys in context

Surveys took on average 30 minutes to complete. Most CH staff completed their surveys during shift time, either with the researcher acting as a scribe, or independently. Most IFC took a survey away to complete and would return them at the following weeks support group. Alternatively, they would arrange for the researcher to collect it from their homes. Reflecting on this method in practice, and considering their use was in part to overcome recruitment challenges, surveys certainly served their purpose to engage more caregivers in discussions. CH staff in particular were more receptive to surveys. It is however, acknowledged that recruitment and collection of data was still time-intensive and a sit-in approach at both CHs and carer support groups still necessary to encourage participation. Disturbances were still frequent within CHs, similar to interviews, but were more easily negotiable as surveys could be started and returned to for completion.

4.8 Analysis of survey

Analysis of qualitative and quantitative survey data was carried out in segregation, but later incorporated in the discussion of findings (Figure 4.2).

4.8.1 Analysis of PKBQ responses

To explore understanding of pain and its treatment in PwD among caregiver groups (research question 4), statistical analysis was performed on PKBQ scores alongside other caregiver characteristics. Descriptives were also used. Two hypotheses were derived to explore difference in understanding across the sample, based on training, role, and years' experience. Previous literature indicates that professional caregivers with training demonstrate a greater understanding and more appropriate beliefs about pain, its assessment, and its treatment among PwD, than those without (e.g., Zwakhalen et al., 2007; Barry et al., 2012; Burns & McIlfatrick, 2015). The level of training that a professional caregiver receives may be delineated by their level of education and their role. In contrast, the literature suggests that years' experience may not have an impact upon caregivers understanding (Zwakhalen et al., 2007; Barry et al, 2012; Burns & McIlfatrick, 2015). However qualitatively, experience is identified as key ingredient that mediates caregivers' assessment of pain and treatment choices (e.g., Falls & Stevens, 2004; Chang et al., 2011). Based on this, 2 hypotheses were formulated:

Hypothesis 1: The first hypothesis (H1) predicted that caregiver roles indicative of training/professional preparation would perform more optimally on the PKBQ, scoring less and demonstrating more understanding and appropriate beliefs. Those roles that do not require professional preparation or registration (unregistered staff, e.g., HCAs) will have the least understanding and endorse maladaptive beliefs (as indicated by higher PKBQ scores), comparative to caregiver’s whose roles require professional preparation and registration (e.g., nurses). It was anticipated that IFCs would have the highest PKBQ scores, given that most are not trained healthcare providers.

Hypothesis 2: H2 predicted that those with increasing years’ experience as a caregiver would score more optimally on the PKBQ, again scoring less and demonstrating more understanding and appropriate beliefs.

4.8.1.1 Statistical analysis

To test the hypotheses results from the PKBQ were explored using analysis of variation (ANOVA) and T-Testing facilitated by the IMB SPSS software (v26). A rationale for the use of these statistical tests and a detailed breakdown of statistical outputs are provided in Appendix I(A) and I(B). In summary, ANOVA allows comparison of mean scores on a dependent variable (DV) (PKBQ scores) across levels (caregiver roles and categories of years’ experience) of an independent variable (IV) to determine the presence of any significant differences in mean scores. Two one-way ANOVAs were preformed, one exploring the means scores based on caregiver roles (testing H1; Appendix I(A)) and one exploring mean scores based on years’ experience (testing H2; Appendix I(B)). A T-Test was also undertaken to explore H1, to explore the difference in mean PKBQ scores (DV) between those who had received dementia training (IV) or not (testing H1; Appendix I(A)). T-tests can be used to determine if there is a significant difference between the means (PKBQ scores) between two groups (dementia training vs. no dementia training). Prior to undertaking statistical testing, all assumptions relating to normality, sample size and heterogeneity were checked and suitably satisfied (Appendix I(A), I(B)).

4.8.2 Analysis of qualitative survey data

A hybrid variant of Structured-Tabular Thematic Analysis (ST-TA), as developed by Robinson (2021), was used to guide the analysis of qualitative survey data. The following sections provide an overview of ST-TA, with consideration of its utility in relation to the research questions and theoretical orientation of the research. It then follows on with a detailed discussion of the practical application of ST-TA to guide the analytic approach to textual survey data.

4.8.3 Integrated ST-TA & PKBQ analysis

For the purposes of analytical integration, and to explore relationships between qualitative survey responses (via ST-TA themes) and quantitative responses (performance on the PKBQ), a series of exploratory T-Tests were undertaken. To facilitate analytical integration of these two data sets and T-Testing, differentiating themes were selected from ST-TA results and were quantified into a nominal variable. This allowed for their presence (demarked by 1) or absence (demarked by 0) to be explored in relation to mean PKBQ scores. An open-ended research question was generated to explore *'How does caregivers' performance on the PKBQ, relate to their qualitative responses within the survey'?* Before T-Tests were undertaken, relevant assumption testing was carried out (Appendix I(D). The process of integration is further explained in Appendix I(D), and in Chapter 8.

4.8.4 Structured-Tabular Thematic Analysis

Structured-Tabular Thematic Analysis (ST-TA) is a recent methodological injunction developed explicitly to provide a flexible and appropriate technique to analyse brief texts (Robinson, 2021). Typical of thematic analysis (TA) approaches, ST-TA aims to explore patterns in qualitative data, but additionally it provides a process for exploring the frequency of patterns (or themes) for the purposes of cross-checking data and establishing reliability (Robinson, 2021). Because of the latter, ST-TA is particularly suited to working with larger samples, than typically might be associated with qualitative analytic approaches. This made ST-TA particularly relevant for dealing with the sample size in Study 2, as did the emphasis on patterned data and the frequency of patterns in respect to the research questions. Considering the research questions aimed to explore experiences; approaches to recognising pain and responses; relation of pain in caregiving roles; and caregiver understanding, the ability to derive patterns in such and the potential inferences of this to wider caregiving practices was of value.

TA incorporates aspects of RTA (Braun & Clarke, 2006; 2019a) and the work by Boyatzis (1998). Both these TA approaches offer flexibility in relation to underpinning epistemology and embrace inductive and deductive approaches. ST-TA retains this flexibility in terms of methodology and methods. Adopting the reflective injunctions of RTA (Braun & Clarke, 2006; 2019a), ST-TA acknowledges the role of researcher subjectivity in the interpretation of data, however it also aims to create patterns in data which are testable and replicable across different researchers and context. This pluralistic blend of analytic approaches and use of arguably epistemological oppositional concepts (reflexivity vs. reliability), fitted well with the pluralist ethos of critical realism, and that adopted in the approach to this research.

4.8.5 Structured-Tabular Thematic Analysis in practice

ST-TA provides a six-phase approach to guide analysis, which is drawn from the steps developed by Braun & Clarke (2006; 2019a) (Phase 1-4 & 6) and influenced by Boyztis (1998) (Phase 4-5). A hybrid approach to ST-TA was used, which encompasses both inductive and deductive injunctions in the generation of themes. A deductive approach entails applying a prior set of themes to a new domain or sample, themes generated in Study 1 in this case. This objective of this approach is to replicate an existing TA study or develop, extend, or test an existing TA framework (Robinson, 2021). A deductive approach was relevant to the analysis of survey data given that its contents had been derived from Study 1, as the basis from which Study 2 could actively build incrementally on the analysis from Study 1. This interconnection and use of the same sample universe meant a deductive approach could offer further synthesis of findings across both studies and support the applicability of Study 1's core themes in a wider sample. However, in the process deductively applying prior themes from Study 1, it was apparent that new themes were also necessary. As such, an inductive approach was used in tandem, generating new themes for data which did not align with prior themes. A hybrid approach allowed for analysis to build on Study 1's findings and extend them. The following provides a detailed discussion of the application of a hybrid ST-TA approach to survey data.

4.8.5.1 Immersion in the data

This phase of ST-TA is the same as that prescribed by RTA (Braun & Clarke, 2006; 2019a) and centres on immersion within the data. This was first achieved with the initial reading and inputting of survey data (qualitative and participant characteristics) into an Excel spreadsheet. Following repeat reading of the data, initial ideas for codes and notations were then recorded within the spreadsheet.

4.8.5.2 A Priori Theme development & coding

The process commenced with the deployment of existing themes generated from Study 1 (Table 4.4). A priori themes serve to orientate analysis, coding and theme generation is guided by these, however they can be modified if the data does not fit the scheme (Robinson, 2021). During the inductive generation of codes to account for new themes which did not fit with those from Study 1, 4 new subthemes emerged (see Table 7.4).

4.8.5.3 Tabulating themes against data chunks & checking inter-analyst agreement

This phase involves assigning data segments to the predefined themes and subthemes, facilitated by a duplicate spreadsheet. This process allows for the relationship between themes and data to be visually presented via the spreadsheet (Robinson, 2021). At this point inter-analyst agreement was also explored. A second analyst (OR), using the spreadsheet prepared in Phase 1 and using the pre-defined themes from Study 2, tabulated themes against data chunks (from 30 survey participants) independent of the researcher. Thematising agreement was then determined by comparing agreement across the same 30 survey respondents. The percentage of agreement was 92.22%. This was considered adequate following guidance by Miles and Huberman (1994) who suggested a level of 80% agreement among analysts was appropriate for qualitative appraisal.

4.8.5.4 Exploring theme frequencies

With final themes established and with inter-analyst agreement supporting the thematic structure and its coherence with the data, theme frequencies can be explored. The purpose of this is to provide concrete statements about the salience of a theme within a data set or its importance to the phenomenon being studied (Robinson, 2021). As will be discussed in the following Quality Appraisal section (Section 4.9), this helps to support transparency.

Exploring theme frequencies also allows the frequency of themes across participant groups to be explored, or in relation to other variables, such as a score on a psychometric scale. This was particularly useful to research question 4 of Study 2, given that performance on the PKBQ (Zwakhalen et al., 2007) could be explored in relation to, and integrated with, qualitative survey responses (see Integrated ST-TA & PKBQ Analysis). The use of theme frequency and inter-analyst agreement distinguishes ST-TA from Braun and Clarke's (2006; 2019a) RTA, as does its underpinning meta-assumption that qualitative and quantitative data can be used validly together. Braun and Clarke (2006) argue that prevalence of a theme does not indicate its relevance. They further argue that processes for checking analysts' agreement of coding and themes are inherently positivist, as such dilutes qualitative research, and denying the contextualised subjectivity of it (Braun & Clarke, 2019a). While ST-TA shares the view that theme prevalence does not necessarily communicate theme salience, it also approaches theme frequency as a marker of transparency and maintains that quantity does convey important messages about qualitative findings (Robinson, 2021).

4.8.4.5. Producing the report & theme mapping

Producing the report, or the write up of analysis in ST-TA varies based on the data being drawn from. Study 2 drew from quantitative and qualitative survey items, therefore results from both aspects were discussed and interpreted in combination (Chapter 6-7). However, given that depth qualitative data was also sought in Study 1, and fed into Study 2, an integrative discussion to systematically compare the brevity-and-breadth findings of the ST-TA approach with the length-and-depth findings of the RTA of interviews was also used to discuss both study results in conjunction (Chapter 9). A visual theme map of emergent themes was created (Figure 7.1), integrating themes into a model of emergent findings.

4.9 Quality Appraisal: Surveys

To appraise the quality of qualitative analysis of survey data a number of points were considered, drawing from criteria developed by Yardley (2000; 2008), the 15-point checklist from Braun and Clarke (2006), and inter-analyst agreement (Robinson, 2021). Similarly, to appraisal of interview analysis, a composite analysis criterion was pulled from relevant sources to suit the analytic approach taken. An important meta-assumption of ST-TA is that qualitative and quantitative data can be validly combined, traversing traditionally conceived qual-quan dividers, such reflexivity vs. inter-analyst agreement and the quantification of theme frequency (Robinson, 2021). The quality criteria therefore needed to attend to this pluralistic approach in appraisal of survey data.

4.9.1 Checklist for Reflexive Thematic Analysis

As already discussed, Braun and Clarke (2006) offered some guidance regarding the process and criteria for carrying out TA. While ST-TA is only in part informed by Braun and Clarke (2006) approach, their 15-point checklist (see Table 4.5) was referred to support during analysis of survey data. The 15-point checklist resonates with most thematic approaches, for example the accuracy of transcription, the fit of themes to data, and the support of analytic claims with illustrative extracts. These points were equally as relevant to ST-TA, as RTA of interviews.

4.9.2 Yardley's Quality Principles, inter-analyst agreement & theme frequencies

Yardley's core four quality principles for qualitative research are outlined in Table 4.6. These criteria were referred to in the appraisal of analysis of survey data, alongside inter-analyst agreement and theme frequency which support transparency, coherence, and rigour.

The process of ST-TA supports both reflexivity and inter-analyst agreement (Robinson, 2021). Drawing from the reflective injections of Braun and Clarke (2006), and concepts of consensus and reliability advocated by Boyatzis (1998), ST-TA acknowledges subjectivity and researcher situatedness, while maintaining some inter-analyst agreement. Inter-analyst agreement refers to the intersubjective consensus established by two researchers regarding the internal coherency and consistency of a thematic framework. Not only does inter-analyst agreement imply that the findings are relevant to others, trustworthy and conceptually solid, it also supports Yardley's (2000; 2008) quality criteria of transparency, rigour, and coherence. Similarly, these concepts are supported using statements about theme frequency. In facilitating the generation of theme frequencies, ST-TA allows statements about the importance of themes to be supported by concrete affirmations.

4.10 Summary: two empirical studies encompassing interview & survey Methods

This chapter has presented the methods and analytic strategies implemented in the two empirical studies presented in this thesis. The key messages relating to sample, methods and analysis are as follows:

- The sample of CH staff and IFCs for both Study 1 and 2 was drawn from the Southeast of England. CH staff were recruited from 6 CHs and engagement with IFCs primarily occurred within community support groups. The sample and context presented challenges which needed to be negotiated both in responsive recruitment strategies and methods of data collection.
- Study 1 was developed to explore research questions 1, 2 and 3, taking an in-depth and exploratory approach with semi-structured interviews. Interviews were conducted with 18 caregivers supporting PwD living in the community and within CHs. Interviews were analysed using Reflexive Thematic Analysis (RTA) from Braun & Clarke (2006; 2018). RTA provided a flexible yet systematic framework for interpreting and identifying patterns in interviewee narratives, and lead to the generation of 4 themes with subthemes.
- Study 2 was developed to explored research question 4, while building on the other research questions. The methods of Study 2 were informed by the results of Study 1, alongside recruitment and contextual challenges encountered. A survey was developed as a more accessible medium for caregivers to share experiences. The survey consisted of qualitative and quantitative items, and the

Pain Knowledge and Beliefs Questionnaire (Zwakhalen et al., 2007). The combining of methods within a survey is common derivative of mixed methods of research and a reachable means of collecting simultaneously intensive (interpretative) and extensive (patterned) forms of data.

The survey was developed from Study 1's findings, the literature and lay representative feedback. Quantitative data was analysed using appropriate statistical analysis to determine any differences across caregivers in their understanding of pain, its assessment, and its treatment among those with dementia. Qualitative data was analysed using Structured-Tabular Thematic analysis (ST-TA) (Robinson, 2021). A hybrid approach to ST-TA was used, in which themes generated in Study 1 through RTA were applied to qualitative survey data deductively, and new themes generated inductively. ST-TA allowed for theme frequencies and patterns in the survey data to be explored.

- The purpose of the two separate empirical studies was to respond to different, yet interconnected research questions. In using breadth qualitative data from interviews (Study 1), brief qualitative data from open-ended survey items (Study 2), and quantitative data from PKBQ scale responses (Study 2) it is possible to systematically compare and triangulate the brevity-and-breadth findings with length-and-depth findings, offering a more holistic response to the research questions under enquiry. As an approach this plurality of methods within Study 2, and across both studies in combination, fitted well within the CR orientation towards exploration and explanation and emphasis on social phenomena as layered, complex, and multi-faceted.

Moving from method to results, the following chapter presents the results of Study 1. It explores the themes generated from Reflexive Thematic Analysis which serve to animate the experiences and roles of interviewees through their narratives.

Chapter 5- Study 1 interview findings- Exploring caregiver experiences: Deciphering Dementia & Relieving Suffering

5.1 Introduction

The previous chapter provided an overview of the methods used in Study 1 and 2 to explore the central aim of this thesis and guiding research questions. Study 1 took an in-depth and exploratory approach, implementing semi-structured interviews. Four main themes were generated from interviewee narratives; this chapter presents two of these themes, *Deciphering Dementia* and *Relieving Suffering*. These themes are centred on pain, and reveal caregivers understanding of pain, their experiences of its manifestations, and their responses and negotiations of it in their day-to-day caregiver roles. Each of these themes is discussed in turn and illustrative quotations pulled from interviewee narratives to exemplify meaning. This then leads into a summary that draws together these themes.

5.2 Brief background

This section provides a brief overview of the caregivers who took part in interviews. In addition to the outlining the key characteristics of interviewees, this section also provides a snapshot of pain in the context of interviewees day-to-day roles. At the commence of interviews, caregivers were asked to reflect on how often they encountered pain among those being supported and the kinds of conditions or injuries which were precipitating these encounters. Caregivers were asked to reflect on this to offer some context for forthcoming discussions, and it is relayed here for the same purposes ahead of a discussion of themes developed from interviews.

18 caregivers took part in interviews. A member of care home (CH) staff was recruited as a case study of 4 different CHs. CH interviewees represented more

senior members of staff (Senior Carer; Duty Manager) and less senior members of staff, with experience ranging from 6 months to 30 years. This offered a good mix of skills and experiences and allowed dynamics between senior and less senior roles to be considered. Of the 14 informal caregivers (IFCs) who took part, most were spouse dyads (n= 11) or child-parent dyads, as such their interviews reflected in-depth knowledge and understanding of loved ones. For further detail on interviewees, case study notes for each CH and IFCs are provided in Appendix F. In addition, Table 4.2 in the previous chapter provides an overview of interviewee characteristics.

In terms of the presence of pain and conditions precipitating pain among people with dementia (PwD) interviewees were supporting, interviewees experiences varied. Most IFCs (n=10) explained that their loved ones suffered from one or more conditions which could give rise to discomfort. They conveyed these conditions as causing their loved ones enduring pain, using descriptors such as *“constant”* (Caroline) “*most of the time”* (Eric) and *“always”* (Mary) to describe the frequency with which pain was lived with. A small segment (n= 4) described their loved ones as having no pain at present. While they did describe acute incidents such as falls or headaches that precipitated pain in the past, they indicated their loved ones were at current in good health and mobility.

For CH staff they referred to broader acute injuries as causes of pain for those with dementia being supported, such as sores and falls. They referred little to underlying long-term conditions, although did mention sciatica, arthritis and rheumatism did afflict some of those they supported. They tended to reflect on individual residents to describe causes of pain, for example Jane explained *“we’ve got one gentleman who’s having to have the District Nurse out a lot as he’s having* *dressings and things done",* and Clare indicated "*we have one gentleman who it's his knees and legs that cause him more pain than anything... We've got a lady, like her left arm she gets a lot of rheumatism..."* Ceri more broadly reflected on pain among the residents *indicating "Most of these people have dementia but they also have age-related illness, you know like arthritis and things like that, you know sciatica and that. I'd say at least 10, probably, about 10 have pain."*

The frequency with which pain was encountered by CH staff varied, Jane indicated it was only "*Once a week"*. Clare described it more frequently *"they haven't had their medication that's when they tend to complain…there might be the odd time that they'll feel pain in the evening, at the end of the day when they're getting tired, and things start playing up...".*

These varied experiences and interactions with pain both within caregiver groups and across them fed into themes developed from diverse perspectives. Caregivers were negotiating both chronic pain in their everyday support of PwD and responding to acute incidents. They represented reflections on different scenarios: those for whom pain was more prominent in their roles and those who had to confront it as and when it arose.

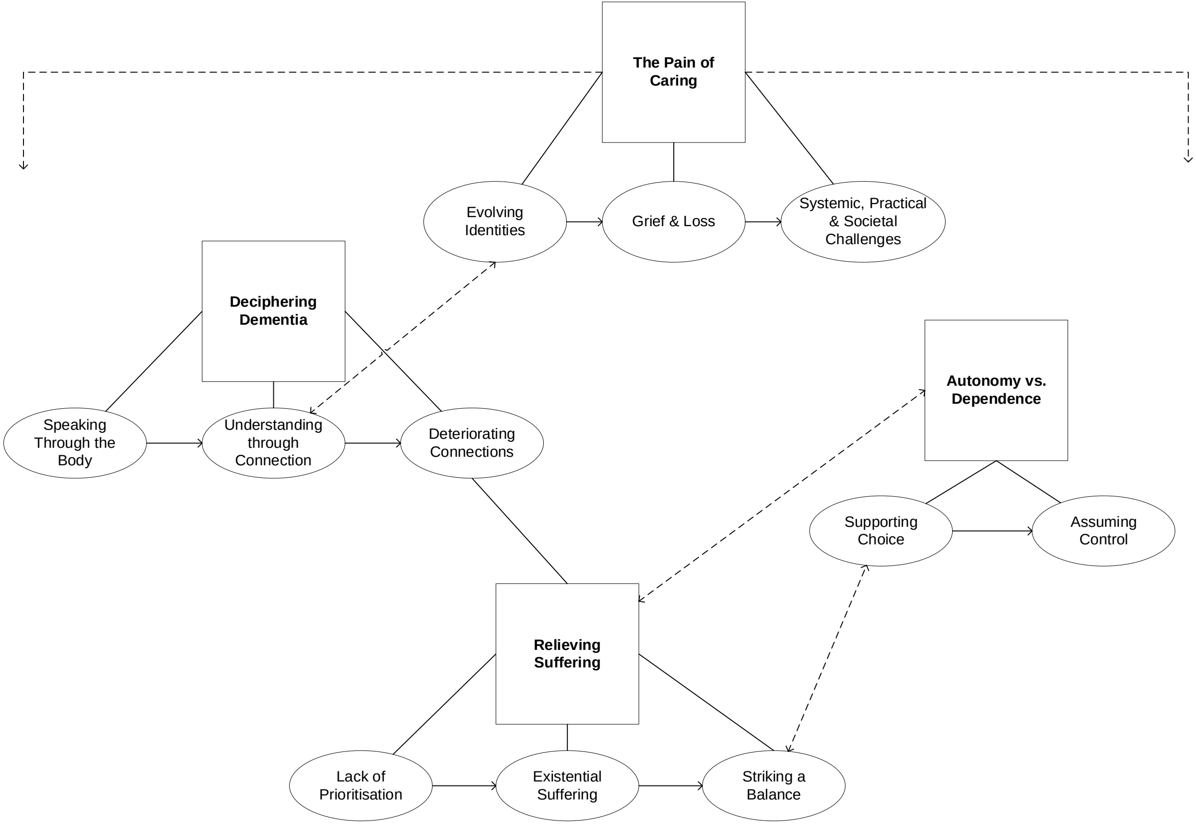
5.3 Results of Reflexive Thematic Analysis- *Deciphering Dementia* & *Relieving Suffering*

The four main themes generated from RTA (Braun & Clarke, 2006; 2019a) and the interrelations between themes are presented in Figure 5.1. Table 5.1 provides an overview of the two themes presented in this chapter and the frequency with which each theme and subtheme had relevance to interviewees. The purpose of providing the frequency of themes is not to indicate salience of themes (Braun & Clarke, 2006), rather their commonality.

Table 5.1 Frequency of Themes 1 and 2

Theme	Frequency	Subtheme	Frequency
1. Deciphering Dementia	16/18	A. Speaking Through the Body	12/18
		B. Understanding Through Connection	14/18
		C. Bridging the Gap	12/18
2. Relieving Suffering	16/18	A. Lack of Prioritisation	14/18
		B. Existential Suffering	10/18
		C. Striking a Balance	15/18

Figure 5. 1 Interview analysis: main themes and subthemes



5.3.1 Theme 1: Deciphering Dementia

The first theme presented is *Deciphering Dementia.* This theme encompasses the challenges of identifying pain in the presence of a disease process, which has an all-encompassing influence on communication, cognitive function, and behaviour. Deciphering dementia and pain hinged on an understanding and navigation of these changes, and a piecing together of puzzle pieces drawn from the bodily narratives of pain conveyed by PwD (*Speaking through the Body),* in-depth understandings of the uniqueness of PwD (U*nderstanding through Connection) and* adaption to declining capacity and memory (*Deteriorating Connections*). Both interviewees working with the CHs and IFCs could relate to this theme (n=14).

5.3.1.2 Subtheme A: Speaking through the Body

Speaking through the Body refers to interviewees (n=12) descriptions of the physical, behavioural, and verbal manifestations of pain they encounter and consciously study among PwD. With deteriorating capacity to verbally articulate needs, PwD are described as using their body and behaviour as an alternative means to convey their pain and emotions.

IFCs recognised the importance of observing and acknowledging symbolic behaviours as indicators of pain. In preference to verbal communication, they described it was necessary in dementia to refer to body language. The body and its communication are described as offering a window into the experience of a PwD, even when they may not be consciously aware of the message their body is sending. The body is seen to reveal secrets or resolve mysteries, which the symptoms of dementia otherwise serve to hide. It was further a means to understand another’s experience, an experience removed from oneself. As Donna describes:

> *"I think you have to be much more aware when the person is in that state or in the state of dementia, or the level they're at. You look out for things, erm because you are conscious all the time that they mightn't be aware of it, and that's hard to do that when its' not happening to you, it's happening to somebody else. It's not always easy to do it but you've got to keep on looking out and watching what they do and how they do it…. And you, you see it by their actions rather than [words], so what would I say to that? Erm...Yes, you've got to watch them continually and analyse continually." (Donna. Carer for Husband.)*

The constancy with which Donna describes observing and interpreting her husband behaviour was echoed by others. For example, John and Betty described having to *"assess from what I can see"* (John) and *"watch him carefully" (*Betty) when describing how they recognised pain in their loved ones. It seemed that while many IFCs clung to an idea that their loved one would still be able to communicate pain verbally if they choose to, on another level they deployed observation as a protective mechanism vigilant to diminishing ability to understand or communicate needs. Observation of their loved ones was described as an almost exhaustive exercise, a constant awareness and reflection on the meaning of the behaviour. Eric communicated this watchful scrutiny:

> *"I do it two ways. I ask her to see if you know she can give me answer because she can't always give me clear answer, but I also go with observation, her body actions, her demeanour, everything about her." (Eric. Carer for Wife)*

The omnipresent mindfulness, which IFCs described, was automated; they were automatically observing and reflecting on potential indicators of need, using this to interpret and analyse.CH interviewees too described a vigilance to bodily and behavioural communication, recognising this as a serving a communicative function for PwD and a source of information for them. Their responses tended to be more reactive, than proactive. CH staff responses tended to be triggered by overt behaviours of PwD. Jane described how body language and behaviour change, could be used by PwD to call attention to a need:

> *"If you know if someone is in pain and they tell you they are in pain, then they don't need to act in a different way, whereas if you can't communicate it you have to try to make us aware of it by other ways…If they are not able to communicate properly its body language, the way, the way their acting, if they are in pain then the things they are doing are going to be out of character and their going to be not normal for them…." (Jane. HCA)*

Other CH staff also emphasised deviations from patterned or purposed activities as an indicator of pain, describing behaviour as *"out of character…not normal"* (Elaine) and "*just not her at all"* (Ceri). Changes to behaviour were also observed in relation to emotional and reactive volatility. CH staff described how PwD could lash out or resist intervention to convey their pain, their mood and behaviour externally reflecting their internal state:

> *"I think if they're probably a bit irritable in themselves and you're trying to say get them out of the chair into the wheelchair and they can't quite cope with it, they can't cope with it and yet they can't quite understand what's wrong…. we've got*

> *certain residents' downstairs who find it difficult because they don't understand what you're trying to do and that you're trying to help them." (Clare. HCA)*

CH staff viewed volatility as commingled with fear, confusion, and frustration, arising from a sense of vulnerability and defensiveness. Changes to behaviour and resulting volatility were therefore approached with empathy and acknowledged as a mechanism of self-protection and communication. CH staff were able to distance these responses from the identity of residents and disassociate them from residents (e.g., "*it's just not her"* Ceri, Duty manager; "*they're going to be not normal"* Jane, HCA*),* rather than ascribing these expressions to problematic behaviour.

IFCs were also familiar with how pain could manifest as volatility. As such IFCs paired both a proactive mindfulness of pain, with a reactiveness to the direct signals from loved ones. Eric reflected on how pain precipitated a shift in his wife's mood:

> *"She's not aggressive person by any means but erm, she gets impatient and lazy when she's in pain- as we all do. That's just human nature, isn't it?" (Eric. Carer for Wife)*

While some appeared to be sensitive to the relationship between mood and pain, other IFCs responded quite differently. Mary and Irene were aware that mood and behaviour could communicate pain; they understood their mothers' volatile responses relayed messages. However, this cognisance did not prevent them interpreting their mothers' responses as unnecessary, dramatised, and difficult. Irene drew on childlike descriptors, such as "*paddy", "kicks off"* and *"stroppy",* to describe the shift in her mother's mood:

> *“I have noticed her mood changes if, if she’s got pain then I’ll notice it may trigger her to have a bit of a paddy or a bit of a, erm a bit of a moment and I have noticed that like if she is in pain and maybe I don’t know, it’s because she thinks we’re ignoring her and then she sort of kicks off a bit.” (Irene. Carer for Mother.)*

Mary used similar descriptors to talk about her mother’s resistive behaviours when in pain, expressing *“she kicked up a fuss”, “we dread it!*” and “*but anyone would think that they were trying to amputate a toe*”, when recalling how her mother had responded previously. Perhaps due to their closeness to their loved ones, and their ability to juxtaposition these responses to how pain was negotiated before dementia, Mary and Irene were not able to approach these responses with separation (this is pain; this is my mother; this is dementia) and appeared to lack empathy.

Interviewees continued to describe how the body conveys a message of pain, often through movement or restricted movement. As everyday movements become less fluid, caregivers described how this revealed potential issues relating to pain. IFCs often described slowness, stiffness, and poor mobility among those they were supporting. CH staff also highlighted poor mobility, particularly that noticed during personal care. Elaine provided an indicative comment:

> *“Sometimes we know if they aren’t mobile or something. If they’ve got dementia and they can’t explain and they you know if you’re trying to help them move or something, then you’ll see there is something wrong.” (Elaine. Senior Carer)*

These movements acted as an unspoken indicator of potential issues, which allowed caregivers insight, particularly when there was a reluctance or inability to express pain. John described his wife's communication as limited; as such, he used her movements to extract information. He observed "*I could see her rubbing it* [her hand]"' and *"I mean quite often she will be sitting like this (places hand on side of jaw), and I think has she got toothache?".* Similarly, other IFCs referred to movement when their loved ones were reluctant to discuss pain or stoic. Donna stated "*Very, very rarely [complains]…You can see that he's struggling sometimes."* Betty described how her husband's movements revealed suffering:

> *"He's very good at concealing it... [He] puts his hand on his head and I say to him "Are you alright love?" "Have you got a bad head?", "No, no. I'm alight"'." (Betty. Carer for Husband)*

IFCs also identified that body communicated pain through obvious signs of physical injuries. John, Joyce, and Emma described how an absence of physical signs assured them their loved ones were free from physical suffering. John said *"…but there is nothing physically, nothing visually that I could put down that is really giving her trouble".* Joyce added *"He doesn't seem to be in pain at all, I don't think so…A broken arm, a broken leg, yes, but to be in pain in some other way, no".* While it was positive that there was attentiveness to physical injury as indicator of pain, it suggested that pain to these caregivers meant something visible or tangible.

Throughout this subtheme, caregivers describe their familiarity with messages of pain conveyed by the body and identify some universality to how pain is communicated, and thereby recognised (such as deviation from norms, volatility, and impaired movement). However, both IFCs and CH staff also reflected on the uniqueness and individuality of pain. As Elaine commented "*The thing is, it is different for everyone".* Individuality mediates how pain might be expressed; as such it is a unique and only partly accessible experience to those who are not experiencing it.

5.3.1.3 Subtheme B: Understanding through Connection

Understanding through Connection shares a reciprocal relationship with *Speaking through the body.* When meaning cannot be made or understood from the narratives told by the body of PwD, interviewees described drawing on their own intuition, familiarity, and connectedness to PwD to understand when pain was present. Almost all (n= 14) caregivers could relate to this subtheme, deriving connection through interpersonal relationships, familiarity, and repeated interactions.

For IFCs, many described an intuitive sense of understanding that allowed them to recognise pain among their loved ones, even when it is not verbally communicated. This intuitive sense of knowing stemmed from the mutually intimate and long-term relationship they shared with their loved ones. Rose described this intuition as a *"sense":*

> *"I just sort of look and I can just see. You've like got that, sort of sense that there's something wrong there…. We've been married 49 years, and sort of if you don't know someone after 49 years (laughs) there's something very wrong! But I mean I think that's what it is, you know." (Rose. Carer for Husband)*

Other IFCs described this intuitive ability to understand the needs of their loved ones. Emma commented *"because obviously I know my mum, I would know if she was in pain*". John mirrored a similar response, indicating, *"I know when she's in pain and when you live with someone that long you just know automatically when, you know, they're not right".*

It appeared that IFCs engaged in a form of relationship-centred assessment, drawing upon intuitive familiarity and unique understandings of their loved ones to assess their needs. This provided context and a point of reference for IFCs, against which they could establish if intervention was necessary and the severity (and authenticity) of loved one's pain. Rose commented "Y*ou have to gauge it; you have to put it into context I find sometimes with him, to know how bad he is actually".* Mary similarly said:

> *"I mean she was in genuine pain, right across her head, I could see that she was in pain, it wasn't just an ordinary headache… I think I know when she really is in pain and when it's just something "Oh well a paracetamol will cure that" you know." (Mary. Carer for Mother)*

Intuitive familiarity was described as immersive and relationship-centred assessment contingent on a consistent and in-depth relationship within the carer-caree dyad. As Donna describes below, an understanding of an individual and their pain is developed with time, and through a shared life:

> *"Yes, and living with it because unless you watch on a daily basis… See if you're only around for an hour and you're not going to pick up on everything are you? And pain is a funny thing to pick up on because err, you know it doesn't always show or somebody doesn't want to show you they're in pain they can hide it for a long time. So, pain is a very difficult, I would think that is the most difficult thing to pick up on…" (Donna. Carer for Husband)*

CH staff also described a sense of familiarity and understanding unique to each resident with dementia they supported. Elaine described "*getting to* *know"'* residents, and similarly using this as a form of relationship-centred assessment:

> *"It's just the one thing about being in a home as opposed to hospital is you get to know the people and that's when you know sometimes you can go "Oh well they're not right today" and you have that advantage of getting to know them that well. You just know someone isn't right today or then sometimes you think "Yeah, they're in pain". (Elaine. Senior Carer)*

Jane identified this familiarity as enabling her to advocate for residents. She described negotiating between residents with dementia and more senior staff to communicate their needs:

> *"There's also been times where I've picked up on signals where someone might be in pain, so I've also informed the nurse of that…. We spend the most time with the resident so it's us that pick up on it." (Jane. HCA)*

For more senior CH staff interviewed (Ceri- management; Elaine- senior carer), they described drawing on the established relationships of HCAs to inform their assessments about residents' pain. Ceri explained:

> *"And like the lady I was explaining to you that came to me, you know crying and that sort of thing, the girls [HCAs] are very tuned in and were "This is not like her you know", that sort of sticks in my mind…. Another example is if I was to go into a new job, you know next week, and something was to happen I would say "Right you know, tell me about this lady, how is she normally?*

> *How does she present her pain?” to the carers’ because they’d know, you know?”. (Ceri. Duty Manager)*

CH interviewees conveyed a shared responsibility and team approach to understanding pain. While connectedness to PwD is significant, there comments indicate that trusting working relationships are just as significant. Positive staff relationships will empower all staff to inform patient care and clinical judgements.

Such was the emphasis on familiarity and connectedness to determine pain, Ceri further conveyed that using an informal relationship-centred assessment of pain or personal judgement was preferable to formal assessment. She explained:

> *“But I would say it (PAINAD) is rarely used because it just comes to the point now where we are aware, and we know the residents so well… I’d say trust your gut; I know that’s probably not a good thing to teach.” (Ceri. Duty Manager)*

This notion of “*trust your gut”* is resonant to the intuitive sense described by IFCs. Ceri herself recognises the limitations of this, likely understanding this approach relies on caregivers having the experiential or intuitive reference to inform their decision-making.

Both caregiver groups explained that understanding and connectedness allowed them to decipher the nuanced and individual ways in which pain might be expressed. They described how it could demystify and challenge misassumptions about the meaning of behaviour. Caroline explained:

> *“If you don’t know the person you can completely misinterpret, either by hearing lots of noise and thinking they’re in pain, or the other way they are quiet and they*

> *might be in pain but you're not picking up on it". (Caroline. Carer to Mother).*

An understanding of dementia was seen to be another stratum to be navigated to understand pain. As much as the person's unique ways and identity fed into their behaviours, mirroring this their dementia identity also fed in. These identities intersected and caregivers understood that an individual's expressions of pain, such as through unusual behaviour or agitation, at times overlapped with the behaviours of dementia. In tandem, with an in-depth understanding of the individual, and an understanding of dementia at the forefront of exchanges, caregivers could attempt to unpick overlapping behaviours. Ceri illustrates this almost layer approached, describing accommodating for dementia, alongside the person:

> *"You've got to know your people and you've got to know dementia to a certain extent you know! If you can't read dementia and someone's very agitated and very angry or uncomfortable, shifting about, it could well be they're in pain but actually if you weren't trained in that you might think "Oh god their a bit attention seeking or demanding or a bit, you know?". (Ceri. Duty Manager)*

As Ceri highlights, a lack of understanding of both dementia and an individual may lead to signals of pain being misinterpreted, or as Jane described dismissed "*if the behaviours they are displaying isn't put down to the pain, then it's going to be ignored and not treated" (Jane. HCA).*

There seemed to be some conflict for caregivers; understanding was conflicted with uncertainty and ambiguity. Dementia created uncertainty, by its very presence, and in the ways it progressively altered people's ability to convey their needs. Despite all that caregivers understood, dementia cast a shadow. Elaine captured this uncertainty wholly in a brief response. She reflected on the challenge of decoding the meaning of behaviour in those with dementia, a situation marked with uncertainty:

> *“It is hard to know then isn’t it if their angry? Or if there’s something else. But I wouldn’t like to give out a painkiller for every usual bit of behaviour, you know?”. (Elaine. Senior Carer)*

As Elaine highlights, in the mist of dementia and other causes of behavioural changes, she would not feel inclined to offer pain relief. This suggests the same as Jane’s earlier comment: where symptoms of dementia overlap with indicators of pain, pain can go untreated.

IFCs also shared this conflict, expressing some uncertainty about the causes of loved one’s behaviour, and sometimes idiosyncratic gestures. Joyce summarised “*I think a lot of it is guess work now...”.*

Caregivers did attempt to circumvent uncertainty and regain understanding. While their understanding allowed them to notice uncharacteristic behaviour and interpret this as a communication of unmet need, it did not always illuminate the exact message behind the behaviours. When such occurred caregivers deferred to a process of elimination or trial and error, to determine potential causes. This was especially so for those who’s communicative ability prevented them providing reliable verbal information to aid in explanation. Eric commented: *“She somehow conveys that things aren’t right, and I have to observe and test and etcetera etcetera”.* Rose similarly expressed “*I mean you sort of work out don’t you, whether somebody has pain or whether they need anything*”. For CH staff, they described this process of elimination as a complex exercise. As Ceri illustrates below:

> *“For example, a lady yesterday came to me all shaky and crying, she never cries, it’s just not her at all, couldn’t, is she is pain? “No”, then “Yes” and she’d hold her head, very just, you know? And then it was her tummy, well has she got a UTI? Is she dehydrated? So literally, give her a drink and a couple of paracetamols, which she took and within an hour, she was absolutely fine. So, all I can surmise from that is that she had quite a nasty headache and couldn’t tell us, you know? It is a bit of guess work to be honest, you know? It is a bit. Yeah, some people, this lady couldn’t verbalise, she couldn’t verbalise she wanted a cup of tea, she can verbalise lots of stuff but none of it makes sense, but she couldn‘t verbalise that she had headache, it was a case of elimination really and hoping. I’d like to say that there’s a more exact science to it, but there isn’t…I wouldn’t just presume but sometimes I have to come to that assumption, and I have to try the pain relief and then see what happens...” (Ceri. Duty Manager)*

Ceri talks about her negotiation of this process as an inexact science and “*guess work”* and yet she negotiates the complex interplay between reading body language, understanding the unique behaviours and norms of the resident, navigating the diminishing capacity of the resident, responding with suggestions and solutions, and observing the outcome of such. She is attentive to the queues, verbal, non-verbal and behavioural, of the resident and uses these as an information to determine pain was the issue.

The approach described by caregivers to determine when pain is present is one of connectedness and demonstrates their sensitivity to the uniqueness of individuals, and nuances of pain and dementia. Caregivers demonstrate their dedication to understand PwD, leveraging this understanding to enrich the care and support they provide. However, there is a sense it acts as a double-edged sword. Caregivers described acting on their intuitive judgement (as informed by relational connectedness or familiarity), placing their sense of understanding and *knowing* at the core of decision-making. While likely an altruistic and at times necessary response given unreciprocated communication, this could lead caregivers to disregard other important information or the accounts of PwD themselves.

5.3.1.4 Subtheme C: Deteriorating Connections

Deteriorating Connections captures interviewees' experiences and negotiations with dementia, and associated impacts to memory, understanding and verbal communication. Deterioration of these faculties, and an apparent alteration in the ways in which PwD interpreted and experienced pain, culminated in gaps in both the ability of caregivers to understand PwD and recognise their pain, and the ability of those with dementia to convey their suffering. Interviews described their attempts to negotiate this changing terrain and bridge these increasing gaps. Two-thirds (n=12) of caregivers resonated with this subtheme.

Pain was approached by many caregivers, both informal and CH, with uncertainty in the context of dementia and its disease process. While they recognised that cognitive and communicative decline was an obvious barrier to PwD communicating their suffering, they questioned the cognisance of PwD to pain and reflected on an apparent dulling of human response. A comment from Rose summarised IFCs reflections, she stated *“At the moment he’s a bit slower in letting me know that he’s got pain… whether he’s not with it enough to realise he’s got pain, I don’t know”.* They openly questioned in interviews if comprehension or sensory experience could be affected by dementia. CH staff mirrored the sense that awareness of pain had slipped away for residents with dementia, and increasingly so for those with more advanced symptoms. Ceri referred to connections in the brain, deducing that a link in the chain of consciousness had been broken for those with dementia. She indicated:

> *“People without dementia complain more than people with dementia, and that may well be because they can’t verbalise it or they can’t make that connection in the brain, they know that they feel uncomfortable but there not, I know they still feel pain, but do you know what I mean? They can’t...”. (Ceri. Duty Manager)*

Caregivers also observed changes in capacity to understand the semantic meaning of words and use words appropriately. There was a sense that while PwD had some comprehension of what they wished to communicate, they lacked the ability to choose the appropriate words to make this inner dialogue face outward. Jane stated “*They can’t really quite think of the word in the brain to say to you ‘I’m in pain. So that’s a problem when it comes to knowing”.* Irene too reflected on this narrowing of vocabulary with her mother. She explained that while her mother could communicate sufficiently to engage in conversation, words and fluidity of speech were slipping away from her:

> *“Yeah, even though she can have, you can have conversation with her and everything, she hasn’t lost that ability, but she*

> *struggles with certain words, but yeah she can't, she can't communicate like you, or I could". (Irene. Carer for Mother)*

Caregivers regarded this loss of words and their meaning as indicating the communications of PwD should be interpreted with caution. They described the inconsistency with which PwD could respond to questions about pain, resulting in responses that caregivers distrusted. Jane commented *"You can ask them "Are you in pain?"' but you're not necessarily going to get the right answer"* and John echoed about his wife *"She might say yes and two seconds later say no, so I don't really know ....".* Fading memory further compounded this, in which pain reports were inconsistent or forgotten. Clare indicated, "*It's very difficult to know because of their memory, they might tell you one minute that there in pain...".* Mary shared this experience, grappling with what appeared to be a fleeting awareness or memory of pain. She reflected on how her mother often expressed having a headache, yet it was forgotten soon after and her preoccupation shifted to another pain complaint. She further reflected on her mother's transitory memory of the event that had precipitated pain, the experience of pain having outlived all else in her consciousness:

> *"Most mornings actually she wakes up with a headache and I will give her paracetamol, but she will only have to take one paracetamol and that's it, the pain has gone, she doesn't complain about it anymore, and she will forget that she has had a headache or complain about her toe. When you have got a really bad headache you have to take at least two don't you to get rid of it, no she has the one and that's alright…. They can remember things from way back but something that happened*

> *half an hour ago ... I mean this incident with her feet, she kicked up a fuss but an hour later she didn't even know that it had been done. She just kept saying to me "my toe ain't half hurting" she said today, and I said to her "The chiropodist came this morning", "When? I don't remember that!" But that's what it does, the Alzheimer's, it's what it does, stops you from remembering, in a way it's good, it's good that she didn't remember…. she can forget these things that have happened, horrible little things anyway". (Mary. Carer for Mother)*

It was not only pain that seemed to live within memory for a brief time, but also resolution of it. CH staff described residents who would return to request tablets, despite having already received them, and those who would become repetitive about their pain. IFCs described similar incidents, for example Irene relayed the following:

> *"She forgets that we had gone to the doctor, and they had investigated and sort of get the hump with us thinking that we're ignoring her and thinking that her pain doesn't matter….". (Irene. Carer for Mother)*

Caregivers could offer many examples of the inconsistency with which pain, and associated communications and memories, would appear to come and go from the consciousness of those they supported. The fleetingness with which it would rear itself left caregivers in state of uncertainty. For CH interviewees they attempted to bridge the disconnection, simplifying their language and approach in the hope of triggering an understanding among PwD. Jane described listing areas of the body and waiting for a flicker of recognition, a response demonstrating patience and perseverance:

> *“Have you got pain in your legs? Your back? Have you got headache?’ erm ‘Have you got any pains down your arm?’ You try and cover the whole body, ‘Is it around your chest area your feeling tight?’ We just try and talk to them calmly and sort of give them direction and one at a time, to see if they can think where the pain is”. (Jane. HCA)*

Elaine provided a further example, in which she attempts to accommodate varying levels of comprehension in her approach:

> *“Sometimes I will say “You’ll feel more comfortable?” or “You’ll feel better?” thinking that might [work], it just depends, it just might click somewhere, I wouldn’t go round saying “Do you want to take your analgesia now?”. (Elaine. Senior Carer)*

There was a subset (n=4) of IFCs who while struggling with dissolving memory and capacity, also negotiated increasingly reactive responses to pain among their loved ones. Following dementia, their loved ones had become increasingly anxious, fixated and irrationally responsive to pain. Mary described this in her mother:

> *“We think my mum's pain level is very low, everything hurts you know. Whether it's more so in her, I don’t know. I mean she had the chiropodist come this morning and they were just cutting her nails, but anyone would think that they were trying to amputate a toe because she just was crying in the end by the time ... I have never known her to be like that before, she's never been like it*

> *when she was younger, you know, you have babies and things like that and you can seem to put up with child birth, I mean that's painful…But you know I mean she had us three so she must have been able to put up with a certain amount of pain but now it's just, the pain level is nothing, zilch sort of thing."* (Mary. Carer for Mother)

The result of this increasing reactivity to pain could be resistance to intervention among PwD, and frustration among IFCs. IFCs grappled to reconcile these changing responses among their loved ones, drawing comparisons to their loved ones once familiar ways to these uncharacteristic behaviours. Irene commented "*It's really weird and my mums never been like that but this last year I've sort of noticed that she gets... It's all very sort of dramatized…".* This seemed to cause disconnect between caregivers and their loved ones, their expectations of their loved one's behaviour (developed through long-term familiarity) and actual behaviour seeming to be conflict. This resulted in behaviours being assumed to be exaggerative and disproportion to the pain those with dementia were experiencing. Joyce commented how her husband "*makes a big deal of it…That's where I don't do well!"*. IFCs who observed this increasing sensitivity or responsiveness did not seem to question whether their loved ones were actually experiencing more acute or increased pain.

5.4 Theme 2: Relieving Suffering

The previous theme explored how caregivers come to know and recognise pain among PwD. Following on from this, *Relieving Suffering* captures a cluster of subthemes which explore how caregivers respond to pain, its prioritisation in their day-to-day caregiving, and negotiation of its amelioration. This theme was developed drawing from both CH and IFC narratives (n= 15). There was a reciprocal relationship between *Deciphering Dementia* and *Relieving Suffering* (Figure 5.1), in which the challenges in identifying pain and a preoccupation with dementia, minimised the importance of pain, and exacerbated uncertainty about its treatment.

5.4.1 Subtheme A: Lack of Prioritisation

This subtheme captures caregivers (n=14) encounters with pain and their consideration of it within the context of their day-to-day roles. Most often pain was not at the forefront of caregivers' minds, which was underscored by competing demands on their time and their own stoic approaches to pain that served to normalise the suffering of those being supported.

Caregivers in their day-to-day roles often did not reflect upon pain. For CH staff, as discussed in *Speaking through the Body*, they tended to reactively respond to indicators of pain from the behaviour of PwD, rather than having a proactive consciousness of it in their day-to-day caregiving. Their descriptions of pain supported this further and implied little consideration for pain. Pain tended to be associated to specific residents with known conditions, or otherwise vaguely described, as Jane's responses illustrates:

> *"General stuff really, erm, sores, things like that, where they're prone to falls, things like that, especially at the moment we've got one gentleman who's having to have the District Nurse out a lot as he's having dressings and things done so, things like that. If they fall over and hurt themselves". (Jane. HCA)*

Clare and Ceri also struggled to identify causes of pain among those they were supporting replying *"Erm, I'm trying to think now what causes them pain. Erm, I know we have one gentleman who it's his knees and legs that cause him more pain…We've got a lady, like her left arm she gets a lot of rheumatism in…" (Clare),* and *"They all have a lot of conditions but anything pain related?" (Ceri).* While these descriptions highlight CH staffs' unique knowledge of specific residents in their care (resonating well with the sensitivity to the individual demonstrated in Theme 1), overall, they reveal a lack of cognisance of pain or precipitating conditions.

CH interviewees described their time and responsibilities as consumed by supporting with personal care and managing comorbidities and dementia. As a result, pain was approached as separate and additional challenge to be overcome, after these superordinate needs had been met. A response from Ceri captured this best. She acknowledged herself the lack of priority given to pain at the CH, describing the overwhelming task of negotiating pain, among a miasma of other additional issues:

> "*They all have a lot of conditions …I would say perhaps it's not as massive concern as it should be, because you're dealing with so many issues." (Ceri. Duty Manager)*

Ceri latter further reflected on the lack of priority placed on pain and reconsidered its meaning. She conceded that "*I probably don't always compute when you say that [pain]… I suppose everyone is in a certain amount of pain*". Alongside competing comorbidities, pain was also secondary to task-orientated care, such as personal care, toileting and feeding. This became most apparent as CH interviewees reflected on the responsibilities and expectations of their roles. Pain was distinguished as something that did not lay within the normal remit of care; it was an aside which occasionally crept into CH staffs' awareness during their day-to-day. Jane distinguished this, separating her role in the "*care side"* from pain (the role of nurses):

> *"'No, I mean the care side of it for healthcare assistants is the main, is our main priority, making sure they are okay in that way. But the pain is still as aspect of that and if we notice something it's then our responsibility to mention it to the nurse. I wouldn't say it's a priority, but it's definitely there". (Jane. HCA)*

The care of the person was treated as separate from the care of pain. While there is an acknowledgement of responsibility to report pain or act as an advocate, this only extends to pain that arises directly to them when completing the "*care side"* of the role. Like Jane, another HCA Clare, described her role to be one of supporting with general wellbeing and welfare. She described how pain could surface within this capacity or "*crop up",* but again there was a detachment between pain and the meeting of wider care needs:

> *"I mean the residents who can communicate you ask them generally how they are feeling, if everything's okay and that. If they are prescribed painkillers, it would then be more the nurse that would say "Are you in pain?" "Where is it?", you know things like that. But it would normally crop up when we are asking them how they are". (Clare. HCA)*

Beyond reporting pain to a nurse, interviewees did not describe further engagement with pain. Elaine, a senior carer, also did the same, stating "*We learnt about pain management and assessment, but that's more what the nurses do than us".* This shifting of responsibility for assessment seems a missed opportunity, particularly for those in HCAs role. HCAs are described as experts by experience by more senior staff, having intuitive and familiar understanding of residents and their pain (Theme 1b). It therefore seems apt for HCAs to be involved in assessment, even that which is informal and engages residents in simple dialogues (such as that which Clare describes).

IFCs also did not approach physical suffering as a priority. This seemed to be in conflict with their awareness of the conditions their loved ones had (10 identified long-term conditions), and their understanding their loved ones were often living in pain. An exchange between Derek and Emma, a father and daughter duo supporting the same loved one, captured the nonchalance which pain could be discussed by IFCs:

> *"Emma: Don't suppose she would know if she had a headache.*
>
> *Derek: Well, she would, she said she had one yesterday… but it was nothing exciting.*
>
> *Emma: So, did you give her any tablets for that? You didn't give her any ibuprofen tablets or painkillers?*
>
> *Derek: No. But the carer asked me for some paracetamol, if we had a paracetamol…I told her they were in the box out there. But whether she actually took one I don't know. But she was talking about having a headache."*

Derek's indifference to his wife's complaint appeared to be wedded to his interpretation of it as "*nothing exciting"*, to his mind this complaint did not warrant a response from him. Other IFCs shared a similar approach of dismissiveness; it was directed at their loved ones and others more widely. IFCs seemed to expect tolerance of pain, as Mary commented:

> *“It's in the back of my mind, you know we don't let it rule our lives, I'd say to her “Look come on you have got to be brave; this has got to be done to you, that's got to be done to you”. (Mary. Carer for Mother)*

There was a sense that life proceeds irrelevant of pain, and activities of daily life must continue. There was some overt condemnation of intolerance to pain, Caroline commented “*But for somebody that I do know, that just makes a big fuss, mostly their men, I am not very sympathetic. I think “Oh well just get on with it, if I can cope you can cope”.* Joyce similarly stated, *“I am very intolerant to illness”.* Mirroring this, and again reinforcing an expectation of tolerance, IFCs spoke encouragingly of stoic responses to pain among their loved ones. They made comments such as “*He’s never succumbed to pain”* (Betty), “*He’s got a very good temperament, he doesn’t get fussed over anything”’ (Rose), and “She is just a person who bears pain well and doesn’t make a fuss” (Caroline).* Living with pain, or enduring suffering was appraised positively; the opposite was described with terms that implied weakness (“*succumb*”) and dramatisation *(“fuss”*).

The flippancy with which pain was approached seemed interrelated to caregivers own, and of those being supported, stoic attitudes. Both groups of interviewees considered pain and declining health as an inevitable by-product of ageing. This served to normalise physical suffering and supported their dismissiveness. John commented *“I think it’s just one of those old age things possibly as I sort of get sometimes, we all do when you get older, things start aching...”.* Elaine, a senior carer similarly indicated *“I suppose you do start to get creaky when things aren’t working so well…so it’s a bit of a vicious cycle and circle isn’t it?”.*

Those being supported shared caregivers' expectations to tolerate pain alongside ageing. IFCs were not able to prioritise pain as long as their loved ones were content in their suffering of it. PwD were described as stoic and reluctant to disclose their pain and accept relief. This aspect is further picked up in Theme 3 *Autonomy vs. Dependence*.

5.4.2 Subtheme B: Existential Pain

This subtheme is centred on interviewees' (n=10) descriptions of existential suffering among PwD. It primarily reflects the experiences of IFCs, for whom negotiating dementia and relieving existential suffering precipitated by it was fundamental to their roles.

As observed in the previous subtheme (*Lack of Prioritisation*), pain is eclipsed by the management of other issues. It is not that caregivers are insensitive to the needs of those being supported, but there is a sense of hierarchy to those which are more important. For IFCs negotiating dementia and all it entails was the consumptive concern in their everyday caregiving roles. For them dementia was at the forefront, they described emotively how the disease had eroded consciousness and independence. In reflecting on this loss, and the suffering caused for both them and their loved one, physical pain was inconsequential:

> *"I think her daily, erm how she is feeling on a daily basis overtakes my concerns more, as to whether she's in a lot of pain or not. It's more the mental side of things". (Mary. Carer for Mother)*
>
> *"Her mind going is the worst thing easily, that's the worst thing. It's awful". (Tom. Carer for Wife)*

IFCs also described practical concerns as overshadowing pain, anticipating spiralling dependency their focus was on assuring their loved ones were able to manage with the day-to-day. Joyce commented "*It just making sure he knows where he is going, what the day planned is...".* Caroline similarly reflected on her apprehensions about how her mother-in-law would negotiate life alongside declining independence and deteriorating faculties:

> *"I don't really think much about her pain. I think much more about her dementia, how she is going to cope, and how she and her husband are going to cope in the future". (Caroline. Carer for Mother-in-law)*.

Dementia was not only a consumptive concern; IFCs recognised it as causing psychological suffering for their loved ones. They were acutely sensitive to this pain. IFCs described their loved one's threads of memory as unravelling, and as a result they were losing familiarity of place and their sense of security. Emma commented "[*She] barely knows where she is. I mean she's really only comfortable here. And even then, sometimes she's not that familiar with where she is now. It is hard".'* IFCs were in tune with how this loss of familiarity could cause distress and confusion, being expressed through mood. Irene described this as "*trigger"* for her mother*, "That is her trigger, is that she doesn't think the house she's in now, even though she's live there for like 37 years, it's not her home...".*

IFCs too described the existential pain their loved ones experienced because of their awareness of the changes within themselves. A transition in self-perception and declining abilities lead to frustration. As Donna describes, her husband struggles to reconcile the limitations of his current capabilities, with those he once possessed:

> *"Ralph has become more irritable with himself rather than me, although you know it's always focused on me, but it's with himself when I think about it - because he knows he can't do somethings that he used to do, and he's frustrated" (Donna. Carer for Husband).*

Betty described similar with her husband, "*It's gradually got worse and again he gets over frustrated because he's led an active life...but yes, it really gets to him".* Caroline also commented on her mother in laws "*complete lack of confidence",* precipitated by her sense of inability to function independently. John added *"Some of the people I have met do know they have got it and do get annoyed by it because they can't remember this, and they can't do this".*

Declining independence and competence were not only frustrating for those being supported; it also precipitated a shift in roles which was traumatic for all involved. PwD were cognisant of a shift from independent to dependent, such as that from husband to cared for, or mother to caree. Mary described this poignantly, explaining her mother's resistance to the changing dynamic of their mother-daughter relationship, resulting in anger, blame and her denial of diminishing independence:

> *"If there is something gone wrong in the house it's got to be my fault! It's not her…... as far as she is concerned, I am still her little girl you know, even though I am 60, and she rules the roost. She is always saying to me "I used to be able to do this before you came up here to live, I could do that before you came up here to live", and in her head she can still do all these things, but in reality she can't, even simple things like putting the washing machine on, she can't remember how to use the*

> *washing machine anymore and putting washing out, and going shopping, she still thinks she does all these things, but she doesn't. That's the dementia you know the way it affects you". (Mary. Carer for Mother).*

Other IFCs highlighted the denial that Mary describes. They recognised denial as a response stemming from pain and internal conflict as PwD tried to reconcile changing statuses. It led to increasing demand on caregivers, as their loved ones refused to accept dementia and themselves, and thus help available. Tom described his wife's total rejection of dementia and assistance commenting:

> *"We had someone come round to see how we were getting on and she sort of said "Well I don't need any help anymore, I'm alright, I can wash myself etc. etc.", and that was the end of it really. I would have preferred it if we had kept the help…But you could do more for her, but she just blanks anything to do with Alzheimer's, she really does unfortunately". (Tom. Carer to Wife)*

IFCs attempted to shield their loved ones from confronting dementia, realising facing their denial would cause them further anguish. They described their loved ones as isolating themselves from others with dementia, which they understood to be self-protection. Betty described having to be *"careful"* to encourage social interaction with others with dementia, through fear of exposing her husband to those with more progressive symptoms:

> *"I have to be very careful...I have thought about taking him to clubs…but he doesn't seem bad enough to put him with people who've lost it, he'd wonder why he was there. I couldn't do that*

> *at this moment to him, it might be wrong but that’s how I feel”.*
>
> *(Betty. Carer for Husband)*

Irene described a similar distancing from dementia with her mother or from *“other people the same as her”:*

> *“I said to her “We’ll go and sort of check out all the coffee mornings and things like that”’ and she said she just weren’t up for that whatsoever. She doesn’t like being around other people who are the same as her, so yeah we did try to push it, but I didn’t want to obviously upset her more by sort of forcing her to go.”*
>
> *(Irene. Carer for Mother)*

This subtheme primarily related to the experiences of IFCs, however CH interviewees did reflect on existential suffering in a few incidences. PwD were recognised as sometimes delicate in their sense of familiarity with place, memory, and inability to communicate. CH staff felt this caused them confusion and distress, which required a sensitive, and understanding, approach. Ceri draw on a powerful example to highlight needs for comfort, security, and companionship:

> *“When somebody cries for their mother they’re actually not crying for their mother, you know? Because you do get those people who say “Oh no your mum died 50 years ago” “‘Oh my God! (Impersonates someone crying)”. What they are actually asking for is comfort, because if you’ve had a good mother then you’re asking for comfort and that’s what you want. So, it changed my view of dementia totally. I’ve met some very elderly people who’ve come up to me and asked where their mum is, and I will say “She’s not here at the moment, is there anything I*

> *can do for you?" and normally it is that they want comfort, they want comforting, they want to talk, you know?". (Ceri. Duty Manager).*

5.4.3 Subtheme C: Striking a Balance

This subtheme describes caregivers' (n=15) approaches to relieving physical suffering using drug and non-drug approaches. Interviewees described relieving pain among those with dementia as a balancing act. It was a complex task involving weighing risks against the need for relief, advocating for the needs of those being supported, and negotiating individual needs and their own reservations.

Across CH interviewees, there was some variation in their familiarity with pain medications and their roles in the use of medications to relieve pain among residents. Jane, as an HCA, stated she did not have a role in medicating, while the other CH staff had received medication training and did administer pain relief. Elaine seemed unsure of the medications used within the home to address pain, indicating vaguely "*Quite a bit, yeah quite a few".* Both these interviewees deferred responsibility for medicating to nurses. Clare and Ceri on the other hand described using a wide range of pain medications among residents with dementia, using varying routes of delivery, including paracetamol, co-dydramol, fentanyl patches, anti-inflammatory tablets, liquid paracetamol, butrans patches, ibuprofen rub, oramorph, tramadol and co-codamol.

For IFCs some (n=8) described their loved ones as having pain medication prescribed, however few (n=3) inferred it was routinely given (Irene; Mary; Tom). IFCs highlighted a mix of medications, including paracetamol; morphine patches; ibuprofen; co-dydramol; and codeine phosphate. Most PwD were also prescribed medications to manage comorbidities, and anti-depressants and anti-psychotics to address behavioural and psychological symptoms of dementia.

Interviewees described relieving pain as a complex process, which required protecting against side-effects, balancing the risk of harm with the severity of pain, negotiating individual differences, and compensating for dementia. In light of the complexity of this, most caregivers opted for what they perceived was the safest option, paracetamol. It was perceived as a safest option for those with dementia, which would not exacerbate symptoms, such as confusion, or underlying comorbidities. Caregivers were comfortable to use it in moderation if needed, as Mary described:

> *"'I know that you can take them quite safely can't you without them affecting you. Because with my mum, because of her condition you know, we don't want anything to aggravate that sort of thing or send her off into another world you know!". (Mary. Carer for Mother).*

Elaine described paracetamol as not only the first line response but as complementary to other forms of pain relief to increase efficacy. She described how paracetamol could be used alongside other forms of pain relief for a more individualised approach to relieving pain:

> *"We always try paracetamol and then maybe they're perhaps have it twice a day and then if it's not working, we will try two four times a day…We always try paracetamol first and we try to yeah, because it doesn't have so many side-effects, but I mean we have got a lady who has paracetamol and co-dydramol because her legs are so painful. We've got another lady who has*

> *paracetamol, and she has a patch, you know matrifen patches? Erm, but even that’s not enough”. (Elaine. Senior Carer)*

While it was not overtly discussed by caregivers, it appeared some were informally approaching pain from a stepwise approach, commencing with scheduled doses of paracetamol, and then incorporating stronger medications. There was a sense however, that caregivers could be reluctant to progress to stronger pain relief. As Elaine highlights, it might be perceived as the safest option, however not always the most effective for meeting a person’s needs. Several IFCs qualified that they would only use paracetamol, Emma indicated *“That is probably would be the only thing I would give her. Erm, I wouldn’t give her anything else.... It’s that, that’s all I would take myself. So that is all I would give out”.* This preference was also shared by GPs, who Ceri described as being risk-adverse in prescribing anything stronger for those with dementia. She described being in the challenging position of mediating the needs of the resident with the fears of the GP:

> *“GPs are obviously very reluctant to prescribe anything stronger unless you’ve tried paracetamol for quite some time, which I can understand you know but because of that I think it’s quite easy for the paracetamol regime drift on and drift on. For example, the lady upstairs and she’s in a lot of pain at the moment, she’s had a clot in her leg, they think it’s gone but I don’t know, she’s in pain in her leg and her arm… You can’t just ring up and say ‘Oh I think she needs a morphine patch; you know? She’s in terrible pain!’. It’s a difficult thing and she’s got other medical issues; you know*

> *inflamed stomach and that so it's a difficult one". (Ceri. Duty Manager)*

As Ceri reflects, relieving pain also requires negotiation of comorbidities and individual circumstances. This was something IFCs too negotiated, Donna commented that paracetamol was the only safe route for her husband with other issues "*Well, err, only paracetamol because with his stomach in the past, and you couldn't take anything because it would affect the stomach"* and Joyce indicated *"He's got so much wrong with him, he's reluctant to have anything else".*

Relieving pain was further complicated by side-effects, from both paracetamol and other forms of pain relief. While stronger forms of pain relief were needed to relieve pain fully, they could cause negative side-effects. This made caregivers responsible for deciding which was the lesser of the evils between suffering pain and experiencing side effects. It was a considered approach which caregivers described, weighing up themselves (often without extensive experience with medications) what would be the best outcome for those being supported. For IFCs in particular, they had to make as best-informed choices as they had capacity to do. As Tom described, he had to consider his own anxieties, sedation as a side effect and relief for his wife:

> *"Ibuprofen is excellent. It knocks her out, but it does relax the muscles. So erm, I am worried about, I don't want to make her a vegetable and be sedated all the time, but you know, erm you don't want her in too much pain, so it's a balance you have to work out". (Tom. Carer for Wife)*

This process of weighing up lead some caregivers to advocate for pain relief which was not as effective but had less side-effects for them and those being supported to manage. As Tom described, *“The GP gave us something else, Solpadol or something…it didn’t agree with her, made her feel a bit sick so we went back onto paracetamol”.* Ceri was also familiar which this process of weighing up relief vs. side-effects, explaining she had advocated for paracetamol considering lesser side-effects:

> *“One lady’s had quite a bit of pain in her legs and the doctor gave her co-codamol but she’s been really drowsy with it… not with it really and so we said ‘Can we not give her paracetamol four times a day instead of co-codamol?’ so she’s changed back”. (Ceri. Duty Manager)*

Caregivers were compassionate and practical in their approaches; they wanted to offer relief but there were many considerations to be made. They were not only responsible for providing pain relief that had been prescribed to those supported, but also determining if it was effective. While follow-up was never explicitly described, caregivers reflected on the challenge on knowing if relief provided was effective. The only available indicator that conveyed pain had been relieved was a lack of pain complaints. As Elaine commented, *“It is very difficult in dementia to know what pain level they have…so you do what you can…We think it is [effective] with this lady, she hasn’t complained”.* Caroline similarly indicated “*I assume the medication works. I don’t actually know how often she takes painkillers…she doesn’t really complain of pain*”.

To add to their caregiver’s tasks and the myriad of considerations involving in relieving pain, they were also often responsible for providing the context which informed how pain should be relieved. Given that those prescribing pain relief did not share the unique understanding of individuals being supported, it appeared interviewees were the keystone, providing history, context, and championing needs. Ceri provided an example of this from perspective of an advocate:

> *"I had a lady that had bad back pain, hideous back pain and erm the doctor decided to take her off Tramadol because you know although it was massively effective for her pain it was highly addictive you know? She was 98, I don't care if she's addicted to Tramadol, she's got to live for a year with pain". (Ceri. Duty Manager)*

Ceri passionately defended the right of the resident to be pain free in the above quotation, she further reflected *"But if someone was taking say 8 paracetamol for 24 hours on a regular basis…I would pretty soon get in touch with the doctor and say, "Well there's obviously a pain issue here, they are asking for them regularly, we need to up the strength".* Others, like Elaine, described reporting side-effects to a GP to have a resident's treatment reviewed, "*The doctor had tried doing a higher strength patch but that made her really drowsy, so he's not going to do that again, we will give her Oramorph".* IFCs did the same, acting as gatekeepers to important information. Mary recalled:

> *"My mum was prescribed some medicines by the doctor I think which had Codeine in them and it ended up making her really poorly, so now we have to say she is allergic to the Codeine in some drugs that they give for her. It made her bleed from the bowel actually..". (Mary. Carer for Mother)*

Caregivers also described administrative challenges among those with dementia. These challenges seem to be behavioural, as Elaine commented about one resident “*She won’t take them and she’s very, very challenging and resistant to taking them”.* Clare similarity said *“They’re not aware of what’s happening so you don’t want to give them a tablet if they don’t want it. Erm, I’d say that’s the problem… it’s if they will take it the pain relief”.* The challenges also seemed to be physical, Jane indicated “*The actual taking of the medicine… we’ve got certain residents’ downstairs who find it difficult”.*

To negotiate administrative challenges CH staff tended to seek liquid forms or patches of pain relief, Clare commented “*Senior carers would probably contact the GP and try and get perhaps a patch or something like if they are able to have that pain relief”* (Clare. HCA). Ceri echoed this, *“If we do have problems with them taking tablets, we’d contact the GP and see if you know ideally syrup form, so you know it’s simple for them”.*

IFCs were also familiar with administrative challenges. Emma commented on the more behavioural aspect she had encountered with her mother indicating *“When she takes her tablets... she chews them. So, you literally have to watch her- and that’s even if it’s gone in her mouth because otherwise, she’ll try to hide them”.* Tom commented on the practical challenges, “*Tablets sometimes are a pain to take, some of the big ones… eventually we get over it, but she does lose her rag doing it…. you have to, you have to cajole, you have to persuade, I’ve learnt, you have to talk her round to it…”.*

For IFCs it was not as simple as requesting alternative forms of pain relief to overcome these issues. They had to be more inventive and encouraging with their loved ones to circumvent challenges. John described *“I have to crush hers* *and feed them to her with her muesli in the morning and anything else would have to go with food".* Mary took a simpler approach*, "These (co-dydramol) are so big, and she has trouble getting them down, yes, and I normally give her paracetamol capsules, they are easier to get down they slide down, so that's why we start with them".*

Another issue to be negotiated was caregivers' own reluctances about pain medication, for both older people and those with dementia. CH staff seemed to approach providing pain relief with some hesitation, Elaine indicated "*We ask, we don't just want to give, if they've got a long-term condition we do"*. Clare similarly said, "*I would say that if they're really expressing the pain, then I would say yeah they've got to have it really".* Their comments seem to imply they were seeking some kind of affirmation of pain from residents with dementia, before pain relief would justifiably be given (i.e., a long-term condition, a self-report or an overt expression).

IFCs were resistant, referring to age and the increasing number of other medications loved ones were taking as causes of concern. Mary commented "*I mean some painkillers are not good for elderly people".* Drug interaction appeared a prominent concern for IFCs, Caroline indicated "*All of her medications need to work together, don't they? Because if you're taking one thing, you're not supposed to take another thing".* This was also a concern of Donna's, who relayed this as an escalating vicious circle:

> *"Well, I have the feeling that every pill has a side-effect and I think that sometimes if you take a lot of medication it will work against each other… you're given a pill for what you've got wrong*

> *with you and then you're given a pill to protect you from that pill. And it can get terribly out of hand". (Donna. Carer for Husband)*

IFCs' reluctant approaches towards pain medication was also underscored by their own ideas about pain and how it should be approached. As discussed in the subtheme *Lack of Prioritisation*, IFCs' stoicism often resulted in an approach to pain which could be dismissive. This spilled over into their approaches to pain medication too, in which they viewed medication as reserved for which could otherwise not be coped with. IFCs' attitudes towards pain and their appraisal of its severity mediated their willingness to offer relief. As Rose indicated about pain relief "*I don't think he needs it".* Mary described gauging the severity of her mother's pain and using this to determine if relief is required:

> *"If she's in a lot of pain then obviously I can give her some paracetamol but erm, you don't want to sort of give her constant paracetamol if it really is just a niggle and she's just voicing the fact that it's annoying her rather an actual "Ow! I can't stand this pain" sort of thing". (Mary. Carer for Mother).*

Donna reflected on how a cultural shift had precipitated a more relaxed view towards pain medication, something that is alien to herself and her husband. She distinguished between pain which can be lived with, and that which justifies intervention:

> *"When we were young and in our middle years, we never took pills of any sort. You know people will sometimes for the slightest things "Oh I've got a bit of a headache', you know? 'I'll take a pill". We've never been like that. So erm, I suppose really, it's become a bit of shock to us later in life….*

> *You know you put up with the pain, you thought "Oh I'll have a sleep and it will be gone by tomorrow" or whatever, and you know, you would focus on something else don't you, but then there are conditions where the pain becomes so bad that you can't focus". (Donna. Carer for Husband)*

Pain medication was not only used to relieve suffering, but it also too served to balance out other issues. Caregivers indicated that often providing pain medication offered psychological reassurance, almost as if there was some kind of placebo effect. Elaine indicated how for many regular pain medications was long-standing habit and whether needed, it provided the comfort associated with normality:

> *"We have got some with regular pain killers who come in and say "Oh I haven't had my painkillers today" they always had had them, and they can't bear to be without them, and it seems to be that's what they've always done and it seems keeps them comfortable you know? We keep that up". (Elaine. Senior Carer)*

For other caregivers' pain medication was used to address behavioural issues, both those arising from pain and those arising from dementia and reduce caregiver burden arising from managing such. Jane commented *"If they are shouting or their being aggressive, anything like that because they're in pain, obviously having the pain relief is hopefully going to help with that and calm the situation down".* Tom, a carer to his wife, similarly used pain medication as a method to manage his wife's behaviours, particularly during the night:

> *"Ibuprofen nightly, erm, give her some co-codamol which helps you know sedates her…I have to give her tablets to get her to*

> *bed, she struggled up the stairs and she's constantly "Is it time to get up?" I say "No, we've only just going to bed. No, no" and then eventually she'll kick the blankets down…So you have to cajole her, sit there with her, sometimes it can be an hour and a half, two hours getting her to bed and then she'll get up six or seven times…So you'd get two or three sleepless nights. So, the third night you really drug her so you can get some sleep, because you can't just go on like that". (Tom. Carer to Wife)*

Pain was not only approached using pain medication, caregivers also described the use of topical treatments and non-drug methods, to varying degrees of success. For many IFCs (n=10) non-drug approaches balanced out the negative side effects they associated with medication. They likened medication to chemicals poisoning the body and deferred to other strategies to provide comfort. Irene commented *"I hate the whole popping pill thing so I'm always up for looking at different ways".* Mary echoed this, indicating "*It stops you pumping things into your body, doesn't it? And if you are going to get the same effect yes, I am up for it".* IFCs used these approaches as a first response, before engaging healthcare providers or medications, John indicated *"I think before you start putting chemicals into your body if you can do it in that sort of way then yes, I would certainly go that way, and for myself come to that".* Approaches like rubs, heat and touch were simple and easy to individualise to preference of those being supported. As Joyce indicates:

> *"I mean some people rely on paracetamol…for us we've got what I call magic cream which works on most things. Erm, the old winter green…I'll put on that and if it doesn't work on that then I*

> *will take him [to the doctor], but we will always try that first. I mean if he's rolling around in pain then obviously, I'll take him, but no we will try that first. He's always played sport, so he reacts to that much better than paracetamol…. He had a bad back and rather than go to the doctor we just used, I used a hot pad and ice, and if that doesn't cure it in a few days I know it's a doctor". (Joyce. Carer for Husband)*

IFCs also described using distraction, Emma described "*Trying to stop the pain, or trying to get her mind off of it",* Donna too described *"do something to take his mind off it, his odd little jobs".* Others described using heat "*You know what works? Hot water bottle, good old fashioned hot water bottle, me massaging her neck or hot water bottle" (*Tom), Lyn too described this "*Well we have a hot water bottle at night. You have it on your back don't you [to husband]?".*

IFCs recognised that while these non-drug methods might not relieve pain fully, they could improve physical and psychological states through their cyclical relationship. They offered comfort through positive feeling:

> *"Even if, I mean it probably doesn't do any good, it makes her feel better, it makes her feel nice". (Emma. Carer for Mother)*
>
> *"Comfort really, to ease the pain let's say and for you know, you know given a bit more comfort…Psychologically as well, because if you've got heat around you, it's cold and you've got heat around you and your you know, psychologically it's a big boast to have some heat. You know because very often when I've used something like myself, I've thought "This is nice". It hasn't made*

> *the pain go, but you just think it’s, it’s nice because it’s easing the pain”. (Donna. Carer for Husband)*

CH staff did not overly discuss the use of non-drug methods to relieve pain. Ceri reflected on the reliance on medication to relieve suffering commenting *“You know if somebody had tummy ache and they wanted some warmth on it I probably would do that, but I do think we tend to switch to medication straight away rather than look at the alternatives to be honest”.* That being said however, it was apparent from CH narratives non-drug methods in an informal sense were incorporated into daily care and interactions. For example, Ceri indicated used of repositioning and pressure relief to ease pain “*They have very vulnerable scrotums and things like that, their prone to sores that we have to care for and alleviate by sitting them on pressure cushions”.* Ceri also commented *“We are very tactile when somethings painful we will give it a rub you know?”’* Jane commented that massage had been incorporated into daily activities “*We have done the odd massage if someone’s in pain. We’ve also done it as a pampering and as an activity we do sometimes”.* CH staff were sensitive to needs for reassurance, and understood pain overlapped with this need. They therefore described how touch and communication could comfort both physical and psychological pain. Elaine described her approach as one which incorporated topical pain medication, touch, reassurance, and dialogue:

> *“I know the gentleman with the legs he will go “Oh my legs, oh my legs!” and he’ll start rubbing them so you do what you can, you put pain relief on for him and try and make his legs comfortable and reassure him say “Now how does that feel?” or “Is it still aching?”. I think it’s a hard one that one with dementia”. (Elaine. Senior Carer)*

As with pain medication, non-drug methods had to be balanced against other issues. Caregivers recognised that these approaches had to be considered alongside dementia and the preferences of the individual. Jane suggested that PwD might not respond well to non-drug methods, but that this could be mediated by considering both their level of understanding and them as an individual:

> *"I think if they were not too bad in the dementia yeah, I think with somebody with extreme it would be difficult I think, but if they were mild, I think it could help some people. I think it's knowing how the temperament is, erm obviously if they're a lot more aggressive you couldn't do it really". (Jane. HCA)*

Rose indicated that due to her husband's dementia "*I don't think he would cope with anything like that".* Mary similarly felt her mother would not respond well to such methods:

> *"I don't think she'd but up for the sort of thing… Probably because it's something quite out of the ordinary you know?...Yeah, because it's just not her, she lives in her own ... the world of when she was younger and the newer things that have come out, she is not really willing to try".' (Mary. Carer for Mother)*

5.5 Summary: Theme 1 & 2

This chapter presented Theme 1: *Deciphering Dementia and* 2: *Relieving Suffering* generated from interviews. Together these themes reveal how caregivers identify pain among those with dementia, and how they negotiate its relief. Pain was primarily identified by caregivers through the study, observation, and interpretation of bodily, behavioural, and nonverbal manifestations of pain. A change in behaviour and volatility in mood were key indicators. Observations and interpretations were made within the context of close reciprocal relationships, and caregivers' familiarity of the PwD. Intuitive sense and a process of elimination augmented these other processes and were deployed when other approaches failed to identify pain. Dementia-related changes and impairments to communicative and cognitive ability were a significant barrier, impeding PwD ability to communicate pain and caregiver's ability to recognise it. Dementia was described as precipitating changing pain responses and expression, with caregivers highlighting extremes of over exaggerative and dulled responses among PwD. Caregivers attempted to bridge communicative or comprehensive disconnection arising from dementia by simplifying their language and approach to pain dialogues.

Relieving suffering was a complex issue for all caregivers, in which dementia and competing demands overshadowed pain and its treatment. Pain was not prioritised, undermined, and normalised by caregivers and PwD stoic and ageist views relating to ageing and pain. Emotional and psychological suffering arising from dementia, ill-health and change life circumstance was a more salient issue to be considered than physical suffering for caregivers. The treatment of pain was described as a balancing act, in which caregivers must weigh up the risk of potential harm vs. the need for relief, and administrative challenges (both getting medication prescribed and those relating to PwD). There was a reluctance surrounding drug approaches to treat pain, for both caregivers and PwD. Caregivers were afraid of the potential side-effects in dementia, with a lack of understanding of pain medications and stoic approaches to pain reinforcing a reluctance to medicate. As a result, there was a reliance on paracetamol among CH staff and on non-drug methods among IFCs to treat pain.

Chapter 6- Study 1 interview findings- Exploring caregiver experiences: Autonomy vs. Dependence & The Pain of Caring

6.1 Introduction

This chapter presents the two final themes from Study 1, Theme 3 *Autonomy vs. Dependence* and Theme 4 *The Pain of Caring*. These themes centre on broader issues of caring for those living with dementia. These wider issues intersect with how caregivers negotiate their caregiving roles and how they relate to the people they are supporting, and subsequently relate to their pain and suffering. Themes 3 and 4 are presented in turn and brought together with reflection on the research questions developed for Study 1. The chapter concludes with the implications of Study 1 to the development Study 2.

Table 6.1 Results of Reflexive Thematic Analysis- Autonomy vs. Dependence & The Pain of Caring

Theme	Frequency	Subtheme	Frequency
3. Autonomy vs. Dependence	12/18	A. Supporting Choice	12/18
		B. Assuming Control	6/18
4. The Pain of Caring	16/18	A. Shifting Relationships & Identities	9/18
		B. Grief & Loss	12/18
		C. Practical, Societal & Systemic Challenges	13/18

6.2 Theme 3: Autonomy vs. Dependence

This theme captures the tension caregivers experience in supporting people with dementia (PwD) to be independent in their management of pain, while negotiating diminishing capacity and assuming control and advocacy. *Autonomy vs. Dependence* was relevant as a standalone theme and as one which shared a reciprocal relationship with Theme 2*: Relieving Suffering.* In mapping out all themes (Figure 5.1.), there was some tension between these two. *Relieving Suffering* explores caregivers' attempts to address pain among those being supported, and the introspective challenges they experienced relating to such, including their own misunderstandings, fears and preconceived ideas about pain and its treatment. These challenges related primarily to the caregiver; they were *their* challenges to overcome. *Autonomy vs. Dependence* explores an intersecting yet different layer, the ability of PwD to act as decision makers regarding their treatment and endurance of suffering. This was a different challenge for caregivers to overcome, as it was tied up with issues around autonomy, capacity and the individual preferences of the individuals being supported. Caregivers could only relieve suffering (and put into practice the methods of relief observed in Theme 2), if this was the wish of those being supported or until such time control was relinquished following increasing dependency.

6.2.1 Subtheme A: Supporting Choice

This subtheme explores the choices PwD make in regard to the management of their pain. While caregivers acted as decision makers in many domains; caregivers (n=13) described supporting PwD to exercise control over their pain management, either by self-managing or by declining treatment. They acknowledged the fragility of choice, protectively they described trying to encourage PwD to make more informed choices about their pain without undermining them. Ultimately, caregivers honoured the right of PwD to choose and express their preferences (not to take medication), even if this resulted in suffering. Caregivers did, however, reflect on the tension between informed conscious choice and thinning capacity among PwD.

Caregivers described how PwD exercise choice and control in the context of pain. PwD often choose not to disclose their suffering. Mirroring the stoicism expressed by caregivers in Theme 2 *Relieving Suffering,* PwD approached pain with tolerance, making what was seen as conscious choices to live with it and refuse treatment. Betty described her husband as hiding and enduring his suffering, *"He's very good at concealing it".* Anne indicated similar about her husband, saying *"He wasn't a man to complain ever… even though you knew he was ill".* Donna reflected that despite her husband's daily pain he continued to maintain a façade, "*Everything with Ralph is "I'm fine" so he would say the same thing whatever happened...he doesn't like making a fuss about anything, he'd rather sort of go on not saying anything and you know being one of the boys as it were".* Ceri further commented more widely about residents under her care "*They just say "Oh no, I'm fine"…No! No, no I'm fine".*

While dementia progressively ebbs away at capacity to communicate pain, caregivers saw non-communication and tolerance as a coping mechanism among those being supported, a response they were accustomed to and accepted. This coping mechanism reflected a melange of stoicism, longstanding preferences, expectations about ageing, and pride. The challenge for caregivers was allowing loved ones to maintain control and instil their own preferences into their choices, but also support them to get suitable treatment. Mary illustrated this challenge, describing her mother’s resignation to pain and resistance to intervention:

> *“She just wants to be left alone, “Why don't you just leave me alone?” she says. She blames everything on her age “Well you expect to get these things because I am 90”’ or whatever. Everything she expects to have to put up with because of her age…. As far as my mum is concerned ... to me she could be pain free all the time, if only she was to take paracetamol regularly …but because of her stubbornness and her, the way she is with pills, she won't take them. She will take one and she will say “Oh I feel alright now” I say, “Yes but take another one in four hours mum and you can stay pain free” “Oh but I don't like taking too many pills!” It's because she can make that decision that she doesn't.” (Mary. Carer to Mother)*

This resistance to intervention, and particularly to pain medication, was commonly described by caregivers. While caregivers described offering pain relief that was prescribed to those being supported, they declined to accept it. Resistance to pain medication seemed to be in part underscored by the preferences of those being supported. Lyn commented about her husband *“He doesn’t like taking them”.* It was also in part related to fear and competing comorbidities. PwD had other conditions which were being managed with multiple medications, which lead to fears around safety and drug interactions. Betty described this with her husband *“It’s [pain] got to be very bad before he’ll have more [pain relief] … he has to have numerous tablets now for this skin conditions, but he’s loathed to take more, he really is”.*

Perhaps reflecting their stoicism to pain, pain was not something PwD themselves prioritised alongside other conditions which seemed to overwhelm and consume considerations. Joyce's described her husband's dismissal of pain in the context of his wider health challenges "*He's got so much wrong with him, he's reluctant to have anything else".*

Caregivers described how PwD would challenge them about their medications, seemingly trying to maintain a sense of control and understanding about medications that were being prescribed. PwD appeared to be rebalancing the power dynamic between themselves and caregivers, refusing to be placid recipients of medications they felt were otherwise unnecessary or unhelpful. Ceri described one particular resident's refusal of pain medication, "*She won't take the paracetamol "What's the point of taking them, they don't do anything", so it's sometimes quite hard to get through to someone.*" Rose responded similarly about her husband:

> *"Why am I taking all these pills? They're not doing me any good"…And he can't see the point because to him they are making no difference, and that's quite a struggle…" (Rose. Carer to Husband)*

As both Ceri and Rose indicate, this outright refusal and disillusionment regarding pain mediation was difficult to overcome. Caregivers usually accepted this refusal of pain medication, there was little which could be done to persuade PwD, aside from patience and communication. Clare describes trying to negotiate, reconciling that ultimately PwD have the freedom to refuse:

> *"You just keep trying to really talk to them, go away for a little bit maybe like 5 minutes and come back and see if you can try to*

> *get them to take the medication, and you just keep trying. If they won't take them, you can't force it on them, so you can't then give it to them". (Clare. HCA)*

As dementia progressed, refusal was increasingly problematic among PwD and escalated to physical aggression, such responses likely reflecting declining ability to verbally articulate needs. Ceri commented "*There are residents where I've been bitten given them medication you know? And their like "No" when I say, "I'll put it in your mouth" and then they'll grab you and bite you because they don't want them".* Elaine offered a similar experience:

> "I *mean we have a lady…she's very, very challenging and resistant to taking them but yesterday I went in and said "Hello, how are you? Would you like you pain relief?" "Oh, thank you!" and she takes them and yet another day she wouldn't take them, so it's very erratic." (Elaine. Senior carer)*

CH staff also reflected that for those with more marked impairment their resistance to medication might also reflect their diminishing capacity. As such, it was unclear at times what reflected conscious choice and what reflected diminishing capacity in refusal of pain medication. As Jane describes:

> *"We've got certain residents' downstairs who find it difficult because they don't understand what you're trying to do and that you're trying to help them. It's very hard to actually give them medication so that would agitate them, it would wind them up and maybe then cause more problems". (Jane. HCA)*

It appeared that supporting PwD to have choice over their pain medication was an ethical dilemma for caregivers. While there was an obligation to honour the choices of PwD, either morally or under assumption of capacity, caregivers reflected on whether PwD actually understood at times the choice they were making. This was a conflict for caregivers, they did not want to undermine freedom of choice among those being supported, however they understood it might result in PwD unknowingly choosing physical suffering. Ceri described her uncertainty about the choices particular residents make, and as to whether these are informed choices:

> "*I think there's a couple of people here who have paracetamol, it's very difficult because. you have to assume capacity in some way, you know just because they've got dementia doesn't mean they can't decide if they want a cup of tea but it's very difficult because there's a couple of people here, one lady in particular here I said to you about "Do you need any pain relief today? Are you in any pain?" they say "No, no I'm fine", and I'm not always sure they are". (Ceri. Duty Manager)*

Mary similarly reflected on the challenge of supporting her mother's choices, while knowing that these choices lead to unnecessary suffering. She described the fragility of her mother's independence and her protection of this:

> *"She still makes her own decisions for herself you know, and you can't undermine that really I suppose. She wants to keep that wants to be able to make her own decisions for as long as she can…There probably will come a time when I will have to just be the decision maker". (Mary. Carer to Mother)*

It appeared caregivers were more willing to accept suffering among those being supported, rather than challenge these choices or the capacity of PwD to make them.

In contrast to most IFCs whose role was offering prescribed pain relief to loved ones, a subset supported PwD to self-manage and have control over their pain medication entirely. Lyn was among those whose husband could access his pain medication whenever he required them, she indicated *“He never bothers…he just usually goes through it...I mean I never think about it, you know? He knows where they are in the cupboard”.* There were similar comments from Caroline and Irene. Irene indicated “*She was given paracetamol…so she has got it so if she needs it…but she doesn’t really take it on a regular basis”.* While Caroline said, *“I don’t actually know how often she takes pain killers… because I am not really involved in it…and she has the co-codamol there when she needs them, I stay out of it really”.*

These caregivers did not seem to reflect on the impact of dementia to their loved one’s ability to self-manage independently. From caregivers’ comments, they anticipated loved ones to recall where medication was stored, the correct medication to take, the dosage, when to take it, and so on. This seemed in total conflict with the earlier theme, *Deciphering Dementia*, when the impact of dementia to loved ones understanding and communication was so clearly acknowledged.

Caregivers supported PwD for the most part to have control and choice over their pain and its treatment. This appeared to have several bases. For many resistances to pain medication and tolerance of pain was a long-standing coping mechanism among those being supported and it was likely caregivers did not wish to challenge this or aggravate the situation. Caregivers were also cognisant of increasing frailty and diminishing control. It was suspected caregivers support of self-management of pain was part protective, as they could allow control in this domain without too many perceived risks (apart from suffering). Caregivers were also not overly concerned with pain, as seen in *Lack of Prioritisation* (Subtheme 2a). They likely choose not to challenge PwD in their tolerance and refusal of treatment, as such an approach fed into their own views about pain being a non-essential among a myriad of other issues.

6.2.2. Subtheme B: Assuming Control

This subtheme describes the shift among some caregivers (n=6) from supporters of self-management of pain, to controllers of pain medication. Reflecting concerns about safety and capacity, a subset of caregivers had assumed responsibility for their loved one's conditions and medications. This was a wider issue than pain, one which placed increasing pressure on caregivers and raised ethical issues.

For some IFCs they were in control of their loved one's pain medication, and they decided when to offer these medications (if at all). Dementia had been the precipitating reason for assuming control among caregivers; the diagnosis had provided the justification for caregivers and inferred an incompetence among PwD. Joyce described how dementia was the mechanism by which she could take control of her husband's medication "*He used to manage his pills for himself until he got the diagnosis, and by getting the diagnosis it allowed me to take over them".* Control provided these caregivers with the authority to decide when pain relief was needed, as Joyce continued "*He hasn't asked for it and I don't think he needs it".* Irene commented "She *was given paracetamol to the point where it was like coming out, falling out the cupboards she had so many rocking up on her repeat prescription, so*

I've cancelled it for now...". Both Joyce's and Irene's comment infer their sense superiority about their own assessment of their loved ones needs, yet their loved ones must have been prescribed pain medication as a healthcare professional deemed them necessary.

It was not only dementia and its associated diminishing capacity that gave rise to control, but also fear of risks. There were obvious concerns about accidentally over-medicating or drug interactions. Irene and Donna described their loved ones as being compromised both in terms of cognitive ability and psychologically, fearing potential overdose. They felt their loved ones were vulnerable and needed protection at times from harm they could possible self-inflict by taking too many tablets. Irene expressed this fear:

> *"I personally don't like them being in the house…because all mums medications are air packed and the paracetamol isn't so that has to sort of stay in the cupboard, but I don't know, if she was having a real down moment and she's got access to paracetamol …you could overdose. Yeah, I think that would be concern was if, see I'm not there all the time, that would be my concern, her overdosing." (Irene. Carer to Mother)*

For another IFC, this fear became a reality. Donna's husband had taken an overdose of paracetamol. As a result, her husband had been forced to relinquish control of his medication, and Donna forced to take on the responsibility:

> *"I was out, and he took a lot of paracetamols, and it was a hospital job. So now they've told him he's not allowed it anymore, so he really has to ask me…. I'd just gone out for a couple of hours that morning doing breakfast club and I come back to him taken 30*

> *tablets…he'd taken all those tablets because he wanted to get rid of the pain". (Donna. Carer for Husband)*

This subset of IFCs recognised their loved ones relied on them and it added pressure to their already demanding roles. It was a challenging task for caregivers, having to understand the dosages and schedules of different medications, including those for pain, and protect loved ones from risks. Caregivers held onto information about medications and their loved one's health when they could no longer do so reliably, as Betty commented *"He'll say, "When did I have some?" and I'll say "On the doctors advise you've had two tablets, two painkillers, in the morning after breakfast and then go on from there"…"* Joyce reflected on the task on managing her husband's many pills and being responsible for ensuring his comorbidities are managed. She described the weight of this task, "*In the morning he has 3 pills to take, an injection fine, in the evening he has 3 pills, injection fine, and he goes to bed and takes more pills and another injection, and I always go to bed before him, but I lay them out and stay awake until he comes up".*

Walking the fine line between control (and protection), and supporting PwD by assuming control, was part of a wider issue of autonomy which seemed to be a point of conflict between PwD and those supporting them. Caregivers had become accustomed to control and advocacy which they could struggle to relinquish. Mary conceded as the caregiver, "*It's difficult though to step back and let them do it".* Being the person in control was an ethical quandary. As caregivers they understood their role to be one of protector and an advocate for best interests, yet at times best interests could conflict with the wishes of PwD. In such circumstances it could be necessary for caregivers to circumvent around PwD, going against their wishes for their benefit. For IFCs, this could take the form pushing PwD to attend appointments or discussing issues with doctors without their loved ones being present. As Anne advised, *“Take things a bit further. Even against their own, I mean you don’t want to, but you’ve got to find a way round them”.* For CH staff this took the form of covert options to medicate PwD without their knowledge. This was only for those with dementia who lack mental capacity and refused to take essential medication (of which pain medication is not). Ceri described this method and the medley of issues that arise, including ethics, doctor resistance and resident resistance:

> *“There is also covert. It is difficult because the GPs never want to say “Yeah!”…because it’s the human rights thing, “Yes but this person, won’t take this and it’s quite important”…but it is a last resort to go through that. But to be honest, you know most of the time even covert if they’re not taking their medication because they’re suspicious, they’re not going to eat a yogurt you pop in front of them… they just have dementia they’re not silly. So, I don’t think that always particularly works anyway to be honest”. (Ceri. Duty Manager).*

It seems from this subset of caregivers, assuming control of medications and the management of conditions was often a poisoned chalice. While it protected PwD from potential self-harm and insured regular medication was adhered to, it put caregivers in the unenviable position of the decision-maker, responsible and accountable. This meant caregivers had to understand their loved one’s conditions and medications, placing increasing pressure on their already demanding roles. It also meant being in conflict at times with their own ethical principles, the preferences of those being supported, and their best intensions as caregivers.

6.3 Theme 4: The Pain of Caring

While much of interviewee narratives reflected the physical and existential pain of PwD, the challenges caregivers faced, and their own suffering was inescapable and came through poignantly (n=16). This theme captures this, consisting of a group of subthemes which explore the wider difficulties and demands caregivers encounter within their roles and environments. This theme is central, it wraps around the entirety of caregivers' experiences and thus the other themes generated from interviews. As the theme map illustrates (Figure 5.1), this theme envelops all and it is important to consider the other themes and pain, in light of the struggle's caregivers communicate within *The Pain of Caring.*

6.3.1 Subtheme A: Shifting Relationships & Identities

This subtheme relates to significant proportion of IFCs (n=9). It documents the changing nature of relationships IFCs share with their loved ones, and the resultant losses of familiar personhood and shifting identities experienced.

IFCs talked extensively about the ways dementia had changed their loved ones, particularly in their behaviours and personality. These changes were seen to slowly transforming loved ones from a person of familiarity, into a stranger. As Donna described, "*It's a most strange thing because the person you're living with is not the person you were living with...".* Dementia was described as drawing out ugliness, exacerbating the negative aspects of people and concealing the good. As Rose commented, "*I was told that's what happens with dementia, they revert back to how they used to be, the bad bits, not the good bits".* John reflected similarly on how his wife's once friendly demeanour had shifted, portraying her negatively to others and to himself. He indicated "*She'd do anything for anybody, particularly for me but* *now she will say no…She won't always say hello to anybody or goodbye, she just doesn't understand really the niceties”*. This apparent loss of human sensitivity seemed resonate with Mary who commented about her mother, “*She doesn't care what she says to us!”.*

This sense that dementia was transforming their loved ones was heart-rendering for caregivers, their closest and most familiar relationship were unravelling. PwD were described as emptied of their emotions and humanness. Emma conveyed her mother as being empty of love and attachment:

> *“It's just sad, sad really because the disease strips that person of their identity and that lovingness, that seems to have disappeared as well a little bit, she is very ... not very loving like she used to be. I’ll give her a cuddle and she sort of pulls away a bit you know, but that's ... I don't know, it's just the emotions seem to be taken away from her as well as everything else, you know, it's a horrible disease, Alzheimer’s”. (Emma)*

As a part of change, caregivers described how dementia led to previously out of character behaviour. This stirred feelings of shame and embarrassment for caregivers, as they observed loved ones conducting themselves in seemly abnormal or socially unacceptable ways. Sometimes this behaviour was obsessive compulsive in nature, Donna commented “*Ralphs got a thing about safety…he has a ritual”.* While this was frustrating for caregivers, uncharacteristic aggression caused the most concern. Irene described the increasing incidents of what she called “*episodes”’* in which her mother would become violent with her and paid domiciliary carers:

> *"My mums never been like it…she actually grabbed her [carer] by the clothes the other day and sort of held her like this (holds clothes under her neck) and was like being really threatening towards her. My mums a pussy cat she would never dream of being physical with anyone like that and it's crazy how it's just making her someone else and that scares me". (Irene. Carer to Mother)*

Irene was not alone in describing incidents in which loved ones had become increasingly verbally and physically hostile. For some being supported they were on medications to the control their emerging aggressive tendencies, as Tom described "*I give her is Phenergan and lorazepam in the morning because she does get some aggressive days. She's not an aggressive person but the condition she's going through makes her"*. These changes in behaviour, particularly that which was aggressive, lead to trepidation among caregivers, as they questioned how they would manage this as the severity of the disease progressed.

Caregivers also described their loved one's behaviour as becoming increasingly child-like. Both Mary and Irene used child-like references to describe their mothers' behaviours, referring to "*episodes"*, "*kicks off"* (Irene) and "*paddies"* (Mary). Child-like behaviours were hard for caregivers to negotiate and required patience and understanding. It was a strange dichotomy, the behaviours of an adult being similar to that of a child. As Donna indicated:

> *"I find often the behaviour is quite childlike, and now whereas with a child you can, erm, not force your point of view but you can distract a child or talk them round, you can't do that with an older person so consequently it is very difficult to persuade them to do*

> *what they don't want to do, and that's sometimes takes a lot of time". (Donna. Carer for Husband)*

Child-like behaviour led to infantilisation of PwD. This served to undermine their identity as adults, portraying them as challenging dependents on caregivers and vulnerable. It also served to reinforce the changing nature of relationships, in which caregivers felt increasingly responsible for the protection of their loved ones. There was a shift for caregivers at times into an almost parental identity, in which they described trying to control their loved one's behaviour. Tom described this, "*I thought you could sort of, not force her, but make her, discipline her, you can't. …erm it's sometimes hard to say or explain to her so you have to cajole her, humour her, leave it sometime, come back five minutes later, lots of things that you learn to adapt to".*

In total, for many IFCs, the perceived changes to behaviour and personality were seen by caregivers as a loss of personhood for their loved one. They could not reconcile this new person, to that of their familiar loved one. They were unable to relate to their loved ones and their usual behaviour as they once did. The shifting dynamics in the relationships IFCs shared with their loved ones and their own loss of personhood, made relating to PwD challenging also. This shift was painful as daughters, husbands and wives became 'carer', losing long-term identities. This shift in relationship was precipitated by increasing dependency and the slow decay of familiarity. Tom described his wife's increasing unfamiliarity with him as her husband:

> *"She remembers names, she remembers my name, she remembers her first husband, she remembers her family but she wouldn't recognise that it's me...She'll call out for Tom, and it's*

> *not good me saying “I am Tom” she won’t believe it... the names are in her head but they don’t mean anything”. (Tom. Carer for Wife)*

The sense from Tom and other IFCs was that they resented their loved ones and their loss of familiar affection. They felt they were not acknowledged within their significant roles (as husband, daughter), nor in their efforts to remain supportive and caring. Mary described the transition of her role, “*I am the carer rather than the daughter, you know, and it's so frustrating as well, frustrating for me…but I sometimes resent her….she looked after us but now we are having to look after her sort of thing”.* Anne similarly recounted *“The other heart-breaking bit which people don’t appreciate is you lose your identity, the carer does…. with dementia, people become people, but they can’t locate who they are to them”.* While caregivers went through the motions of explaining they understood this was the disease process, they none the less took to heart their loved one’s lack of recognition and detachment from them. Emma commented, *“No she doesn’t know who I am…I mean obviously it’s not her fault, but I do find it hurtful”.*

For some a shift in identity offered some self-protection. The carer role was one which was seen to be more distant, offering perspective and understanding. While there was the sting of loss, it allowed caregivers to cope with emotionally, physically, and mentally challenging circumstances. Irene described playing dual roles with her mother, *“Mentally as well, as to whether you can handle it…you’ve got to try and put yourself in the position of her carer rather than her daughter and you have to play two roles with her”.* Taking on dual roles allowed caregivers self-protection of their own personhood (as daughter, husband) and some extent to that of loved ones. The carer and the recipient of care could be separated from the wife-husband or daughter-mother dyad.

There was a sense that dementia, and the changing roles and identities it precipitated, created distance between IFCs and their loved ones. One caregiver described trying to negotiate this. Caroline described having to hold onto the identity of her mother-in-law and sought meaning and glimpses of recognition through the smallest of exchanges. She did not rely on her mother-in-law to reaffirm her identity; she placed the onus of "*hanging onto*" her on herself:

> *"We have to hang onto the fact that although you feel the person is gone or they've turned into someone different, that real person really is still there, but maybe you have to search and really look out for those, you know, those things that they do or that they say. Like my mother-in-law has a cheeky smile and she can still be very sarcastic, whereas some of the time when you're talking about things that maybe she can't quite understand...you think "Oh, I've lost her, she isn't there anymore" but I think we have to hang onto the fact that they really are there, the identity is still there, it's, we've got to spot it, really look for it". (Caroline. Carer for Mother-in-law)*

This subtheme reveals the discontinuity IFCs experience within their relationships with loved ones, and within their own identities and those being supported. This discontinuity appeared to lead to some unfamiliarity and detachment from loved ones (and loved ones with caregivers), dementia dissipating their ability to relate to loved ones. Considering the value placed on positive mutual relationships in relating to pain among PwD (2a *Understanding through Connection*), it is possible to see how a broader issue of shifting relationships and changing identities might more specifically influence pain. Caregivers who are no longer able to relate to their loves one, will struggle to relate to, and empathise with their pain. Equally, caregivers who perceive loved one's behaviour to be that of a stranger will not be able to relate to this behaviour via a point of familiarly and reconcile its meaning to be that of pain.

Caregivers perceived their loved ones as being emptied, emptied of human sensitivity, affection, love, and emotions. Thinking about such in the context of pain, for those that may be perceived as having lost essences of humanness through dementia, may not be acknowledged in the same way as feeling beings, or those capable of experiencing pain.

6.3.2 Subtheme B: Grief & Loss

This subtheme captures IFCs (n= 12) reflections on dementia and its all-encompassing impact to their shared lives with loved ones. Dementia was described as life changing and life restricting; caregivers were aggrieved in the many losses they suffered because of the disease and the demands of their role. It was a challenging adjustment for caregivers, but they ultimately accepted their role and their circumstances for the benefit of themselves and their loved ones.

Dementia was loss and grief for IFCs. They used powerful and emotive descriptors to convey this, such as "*an insidious thing" (*Anne), "*horrible, horrible thing"* (Caroline), "*very nasty illness"* (John), "*cruel disease"* and "*soul destroying"* (Derek). These descriptors conveyed in only a few words the overwhelming impact of dementia in their lives and their loves ones, and the cocktail of grief and loss that subsumed caregivers' reflections on the disease. Dementia was described as if an entity or *'thing'* external to their loved ones that had invaded them, their shared lives and taken over.

Dementia was overwhelming and caring for a person with dementia all consumptive. Dementia had altered life and changed retirement, leisure time, social engagement, careers, and shared plans for the future. Caregivers felt grief in the many losses they suffered because of the disease and expressed mourning. As Eric describes, dementia had altered his life wholly, spilling into every aspect from his psyche to his lifestyle and choices:

> *"To see somebody, break down in that way that you've known for 20 years is hard to take, completely, it's a complete life changer. Dementia is a complete life changer, everything changes, the silliest little things you wouldn't even think about if you didn't know dementia. Before I knew what it was, what dementia was, I'd read reports, we meet someone with it on holiday 10 years ago, and you know you think "Oh we can cope, it's just memory, so you forget a few things", but it encompasses everything, logical, she can't watch television, she can't read, she doesn't have the facility to do those things, I have to take her to the loo every time as she doesn't know where the loo is, erm, just lots of everyday small things that you wouldn't even consider err, that hadn't even come into the equation". (John. Carer for Wife)*

The role of a caregiver was 24 hour a day; they had to be omnipresent and perpetually aware. Irene described having left her job to accommodate the increasing demand on her in supporting her mother, "*We had two carers twice a day going in and it still wasn't really enough, erm so then I gave up my job and become* *her carer so I can sort of be there basically every day*". Mary described having moved in with her mother to provide daily support. For many they described being entrapped by their role as a caregiver; they were no longer able to engage simple tasks like food shopping. The risks of leaving their loved ones in the home alone were too great, as were the risks of trying to take them. Eric tried to negotiate this by taking his wife on shopping trips but leaving her in the car. This had its own risks; he described "*I just can't leave the house now unless she's with me. I can go to the local shop I put her in the car and hopefully she'll stay there, not always she will wander sometimes and do things but otherwise I'm 99% in the home".* John similarly reflected, *"Nothing is quite straightforward when you have got somebody to [consider] ... it's frustration at not being able to pop out somewhere…".*

Some caregivers tried to maintain some sense of continuity in themselves and their lifestyles, hobbies, or socialising. However, many had become isolated within their homes. Tom commented *"I can't leave the house"* and Donna indicated "*The amount of time is much more limited because I don't like to leave Ralph for too long" (Donna).* Alongside not being able to leave their homes freely, they indicated their time within the home was also restricted. They did not have time for self-reflection or to themselves, their loved ones being too vulnerable to be left alone, even within the home. Donna drew this example, "*Several times I have been in bed and he hasn't got a clue where I am…I was in bed one night and you'd [to husband] be down to the corner of the road because you thought I was out, and I wasn't back".* For other caregivers, their loves ones did not appreciate their need for space or the weight of demands on them, as Mary communicated:

> *"You know there have been lots of incidents where if I just want to go upstairs to get away sometimes for a bit, and she will come*

> *looking for me, and she is "I thought you was up here to keep me company?", and a couple of times she has come out with something like well "You might as well go, I don't know why you are here"…She can be a bit nasty at times. And then five minutes later she has forgotten, it never happened as far as she is concerned". (Mary. Carer for Mother)*

The transition to a fulltime caregiver, from the norms and expectations of their life previously, appeared to breed resentment. This was further amplified by a sense their sacrifices and the losses they were grieving were not acknowledged by their loved ones. They described how they tried to offer their best as a caregiver, even in spite of their own health challenges. Donna gave this simple example, "*Sometimes I'll struggle to make the meal, not always but I might get a bad day like I have today, so I might do something and then he'd say, "I'm not hungry I don't want to eat''*. Mary offered another example, "*I sometimes resent her because I try so hard to please her and do things for her, and make her life comfortable in her later years, but then there is no, she is not grateful for everything you do".*

While caregivers communicated an understanding of the nature of the disease, it was still a slow and painful realisation that their loved one would become increasingly dependent and their role increasingly demanding. This realisation and the creeping dependency of loved ones was a constant process of readjustment for caregivers. Tom described his ongoing realisation of his wife's progressive condition, while he could not accept the situation, he was had to cope with it:

> *"I've never get used to her being like this. I still can't believe that she's like this, in the early stages I used to think 'Oh, we'll wake up tomorrow, it's just a bad dream, it will be different', but it's not*

> *and it takes you a time to, what's the word, to adapt to the condition". (Tom. Carer for wife)*

This sense of adapting and re-adapting fluidly, to the changing way of life resonated with most caregivers. They appeared to counter some of their grief and loss by mind-set of resilience and acceptance. Donna described accepting the constant state of flux they lived in, while dementia ebbed away in the background of their life:

> *"In a way you become accepting of the situation and you don't analyse it too much…I don't think about it all the time because it becomes a way of life…because things crop up you see little changes on a regular basis, and you get to accept that that's the way it is…. I suppose I have learned to live with it now…I'm going to try my hardest to keep doing this…I think to myself "Come on Donna, don't let this get you down" you know? "You're just going to push on and fight it". It's easy to give in". (Donna. Carer for Husband)*

Caregivers persevered through the perceived hardships of their role and consoled themselves by offering their loved ones their best efforts. Joyce commented with humour, "*It's hard work but then living is hard work if you do properly with clout! We get there, yes. Housework doesn't get done though! (laughs)".* Emma reflected *"You just cope with it the best you can"*'.

For caregivers it was about also weighing up the positive, clinging to slitters of continuity and reflecting on good memories and shared experiences. Eric commented *"We have good days, and we have some bad days and some average* *days”.* Derek reflected on the years of shared happiness with his wife, this appeared to offset his grief:

> *“It is very difficult; you see somebody going downhill you know? But as the saying goes -what is to be will be. And I think we’ve just been dead lucky over all the years, because its only relatively recently that it’s really come to a head”. (Derek. Carer to Wife)*

John offered a further dimension to the role of a caregivers, that of duty and protection. He indicated *“So we have had 40 very good years, definitely…you know for a lot of people theirs is a lot shorter time.. It's part of my suffering I suppose that I have to endure and take on really”.* This suffering John referred to was a sense that caregivers absorbed the burdens of their roles and protected their loves ones from seeing their struggles. They did this out of love, loyalty, and duty to their loved ones with whom they shared their lives. Eric movingly conveyed this:

> *“I’m not a specialist in anything, I’m just a man trying to cope with err, dementia and it’s the fall of the dice, isn’t it?... When I was about 12 my mother said to me “You’re going to have some days that test you” at the time I said “What do you mean you’ll have days that’ll test you?” and these are the days that test you…You have some really dark days, you have to get through that…It doesn’t matter if you’re a person who’s got greater intellect or lesser intellect, it’s just common sense, patience, understanding and loving your wife”. (Eric. Carer for Husband)*

It was sometimes hard for caregivers to shield their loved ones from the emotional and other traumas they were experiencing. Mary reflected on how dementia offered her mother release from upset and sadness, and the memory of fraught exchanges and negative experiences. For Mary however, turmoil was not so easily overcome, and she could not always conceal it. She indicated *“I remember all the things that happen, and I can't just dismiss it like she can you know, I suppose yes it's a good thing that she can forget these things that have happened, horrible little things anyway”.* Donna similarly reflected on how at times her façade slipped, and she directed her frustration at her husband:

> *“You become inpatient and things like that, and I think the way to deal with it now is, not to shout at Ralph and say “For goodness sake”, you don’t, which I do now and again if I get frustrated, but is to go outside and sort of hammer on the washing machine or on whatever I’ve got to get rid of my frustration that way, so that he doesn’t hear it all”. (Donna. Carer for Husband)*

This subtheme reveals the many losses caregivers experience, and their sense of grief. The role of a caregiver was perceived an requiring sacrifice through life changes and commitment. Caregivers described negotiate the emotional fallout of this and adapting to new patterns of life. In considering the issue of pain, it is possible to question how the pain of another can emerge through an apparent veil of grief and loss, and when caregivers are negotiating their own existential pain and isolation.

6.3.3 Subtheme C: Practical, Societal & Systemic Challenges

While other subthemes within this theme relate to caregivers own internal conflicts and aguish arising from dementia, this subtheme explores the practical and extraneous issues that caregivers identify. It explores practical challenges they navigate in terms of their own understandings of dementia and ability to provide care.

It further explores issues confronted through societal interactions and interactions with healthcare systems and its providers. This subtheme relates to both caregiver groups (n=13/18), but predominantly IFCs.

For caregivers they were navigating practical challenges within their caregiving roles. At times, caregivers felt ill-equipped for dementia in terms of their understanding of the condition and therefore their ability to fulfil the support needs of PwD. Prior to taking on their caregiving roles (of employment and to loved ones), dementia had been at a distance and as such caregivers had much to learn about its complexity, its varying forms, and its unique progression. For CH staff, it appeared their environments did not always offer preparedness for dementia, and they were insufficient learning opportunities to address this. This came across when they reflected on the lack of training they received within their respective CHs. All CH staff described some training relating to dementia but made qualifications about how extensive or informative it had been. For example, Jane indicated "*Not a great deal"* when describing her training and Elaine commented "*I have had some training, I haven't had exceptional training"*. As a result, their learning had been experiential and their skills and understanding developed on the job. As Ceri described *"the rest of it is just hard worn experience"* (Ceri). For CH staff there was a yearning for greater understanding, particularly considering the increasing number of residents with dementia they were supporting. Elaine recognised the increasing pressure within the CH context on staff awareness of dementia, she commented "*There's been more dementia in the last four to five years…we are talking on much more with dementia and there seems to be more people with it".*

IFCs were navigating their own limited understanding of dementia. For most IFCs they had heard of dementia or encountered it, yet it had never struck close enough to home to resonate any meaning or understanding. John commented "*Until Lily had it, I really didn't know anybody who suffered from dementia, which is rather surprising considering how many people do but there is nobody in the family".* Being immersed in the care of their loved one meant IFCs had to navigate a steep learning curb to face up to dementia and their situation. Mary commented "*I am still sort of learning myself how to handle the situation...I have got to know her more now and her needs, and her likes and dislikes and how things work" (Mary).* They explained that preparedness and realisation of what dementia truly meant was part of a lived experience. Emma indicated "*Being involved with someone with dementia helps you to understand it. I think if you speak to people that haven't got a family member with dementia, they don't understand it".*

To understand dementia IFCs sought out and dedicated time to gathering information. For some they were self-sufficient, caregivers like Caroline and Irene described using books and online resources to improve their understanding. Others had taken advantage of training offered through carer support charities and the memory clinic. They attempted to plug the gaps in understanding to provide insights into the needs of their loved ones and into their shared future.

For IFCs, personally and practically, they were also battling with their own health conditions. Most were older and had experienced bouts of acute illness or injury, alongside long-term conditions, but had to place their loved ones needs at the centre of their world. Donna communicated her own escalating health challenges and the practicalities of supporting with all aspects of daily life, "*I do struggle with somethings...I have so much trouble myself, I mean I've cancer, I've got CPD, I've got kidney problems, I've got osteoarthritis …So I have quite a lot to put up with myself, but all of this has happened since, since Ralph has had the dementia".* This was a familiar quandary for some of the IFCs, who had to weigh up their self-care against the care of their loved ones. The result of this situation was wife's and husbands left struggling to provide daily care while being physically and emotionally fraught themselves. While this was hard for many, they continued to be sole caregivers feeling they would be failing their loved ones should they accept additional support. Emma described her father's reluctance to accept help in supporting his wife. She conveyed "*Dad [Derek] was very anti the carer's coming in at first, but now they do come in her likes it…I think it was change, and I think he felt like he was giving up, but obviously now he realises it's not, it's just added help".* Similarly, Betty, who described her own and her husband's escalating health needs, declined her husband's placement in a CH indicating "*I will look after him- all the time".*

Caregivers and those with dementia exist within social and familial structures that could at times present challenges. A key challenge that IFCs encountered during wider societal interactions was misunderstandings of dementia. IFCs described that while society was now becoming more progressive in its understanding of the condition, there were remnants of shame and judgement, which seemed to be a legacy of historic stigmatisation and institutionalisation of those with dementia. IFCs described encountering those who associated dementia with mental illness, which served to cause caregivers' shame. Anne described her experiences of this, reflecting on the slow emerging realisations of others and a new societal openness to address dementia:

> *"We are starting to break through from this "Oh he's away with the fairies, he's gaga", that there is a difference, because I had somebody say to me…said "Oh he's away with the fairies" and I could have thumped them. I get so angry with it…. Erm, so yeah,*

> *it’s like cancer, we talk about it now and now we are talking about dementia…You’ve got to break the barrier of “I’m his wife and his carer I can’t talk to other people because it’s embarrassing”. I found it embarrassing.” (Anne. Carer to Husband)*

IFCs described how dementia had been hidden, in part by the stigma and shame it gave rise to, but also in part by institutionalisation. They described how institutionalisation had served to reinforce stigma attached the condition and wider society misunderstanding, as dementia was not openly discussed or addressed. John commented “*You know Auntie Sarah's a bit doolally and then they'd disappear off into a care home, wouldn't they? And they're taken out of the community, and you wouldn't really see first-hand how the illness develops in people”*. Caroline echoed this sense of historic hiding, “*It is getting more and more recognised now, it wasn't spoken about I suppose is why maybe I didn't know many people with it”.* While there was a shift away from stigma and shame to openness, an associated to institutionalisation seemed to be more enduring. Many IFCs expressed both their own, and their loved one’s trepidation about it. For example, Mary described her mother’s fears, “*I say that is her worst ... she doesn't want to be put in a care home, or go into hospital, that's her two ... she is always saying that to me “As long as I don't end up in a care home and don't put me in hospital”.*

Alongside the wider, societal misunderstands of dementia, IFCs described the challenges within close relationships. They described how relationships with others, such as family and friends, were difficult because they did not understand the nature of dementia. IFCs felt that to the outside world and their family, dementia was not tangible and as a result, the weight of it upon them and loved ones unappreciated. For some IFCs this led to outright denial from family, who refused to accept dementia. Caroline reflected on how her father-in-law denied his wife's dementia "*He prefers to think that she has some memory problems, and "we're all getting older" "we all have problems with our memory''.* For other IFCs it had become a point of conflict almost, in which family would challenge them about the authenticity of their loved one's dementia. Joyce relayed her experiences of this:

> *"And relationships are hard. I know relations of mine query if he's got dementia because when they come…they can see nothing wrong with him because they are talking about the past. I find it hard, because he's got dementia but even some days, I think to myself "Well has he?", and I said that to the doctor and she said "Well he's had the scans and yes he has". Just other people can't see it because he remembers them, but they can remember the past better and of course he knows them, he knows their names from the past". (Joyce. Carer for Husband)*

For IFCs they felt those closest to them, and society more widely, at times could not relate to them, or to the person with dementia they were supporting which left them feeling isolated and misunderstood. To overcome this and re-establish some social support networks of understanding, many IFCs had opted to attend carer support groups. They described these groups as an invaluable safe place of mutual understanding in which they could get information and peer support. Being in the company of those who were on the same journey offered comfort in their struggles and provided companionship and escapism (opportunities for which often limited). Anne described "*They [caregivers] come in for the company just to sit and chat which is good, it doesn't matter, and that's their only chance sometimes to escape".* Eric echoed this sentiment indicating*:*

> *“First of all, I saw lots of people there who had similar problems and you know you’re not alone as it were and many experience the same problems…Some people might need places where you chat loads, I need just to get a break and my wife doesn’t want to sit down and have a, she’s not a chit chat person”. (Eric. Carer for Wife)*

These opportunities to gain accessible information and peer support appeared to become increasingly important for IFCs considering the support challenges they faced in relation to the healthcare system.

Caregivers described negotiating systematic structures and healthcare providers that were unprepared for dementia and unsympathetic to the role of caregivers. They described encounters with the system and healthcare providers as overwhelmingly negative for the most part. For IFCs their negative experiences began at the point of diagnosis, just as their journey into dementia was beginning. Most had struggled to get their loved one’s dementia recognised and diagnosed by healthcare providers. They felt unheard, many having to push for a diagnosis through repeated visits to doctors. Donna provided a response indicative of many of the IFCs, “*I felt it wasn’t being looking into…I had to fight for that diagnosis”.* Caroline similarly stated about her mother-in-law *“If I hadn’t pushed forward with the diagnosis she would have continued being undiagnosed”.*

IFCs felt healthcare providers dismissed their concerns about their loved one failing memory. Despite being the person who understood loved ones most intimately, they were disempowered. Anne commented “*I used to go with him to the doctor…I would say “His memory is going” “No he’s alright”.* Rose’s experience was similar, “*For a long time, 2 years before he was diagnosed, I was asking if he had* *dementia or anything or was it Parkinson's, they kept saying "*No, no, no*", now somebody must have known earlier…I could have been more prepared to cope with him when he was really bad".* They further expressed how they felt their loved ones were dismissed, their advancing years and dementia seemingly making them invisible and depersonalising them. Healthcare providers were described as treating them as passive recipients of care, not engaging with them directly and speaking through caregivers. Joyce described her experiences of this with her husband:

> *"It's getting people to listen…It's hard when we go to the doctor and he's sitting there "I've got a cough, I've got this, I've got that" and I have to say, "But doctor this has been going on for weeks, and you belittle him and he's there, and he's still got those feelings". (Joyce. Carer for Husband.)*

CH staff could also resonate with this, they felt that other healthcare providers disempowered them and dismissed their residents with dementia. Ceri commented, *"I've worked with GPs that have been fantastic and I've worked with doctors who really aren't listening to me, or the resident, you know who I see every single day".*

IFCs described battling against systemic ignorance of dementia. Healthcare providers were described as insensitive in their approach and being unaccommodating of unique needs (such as communication styles). Mary commented "*Well her doctor is, we are not that pleased about [him]…you know, he's not very sympathetic to her, the way she is and her needs".* They were too perceived as being unknowledgeable of dementia, as John indicated "*Unaware, yeah. Well, they're not clued up on it",* and preoccupied by competing demands. Rose commented on this "*I think it's partly dementia up until now, although they are* *becoming much more aware of it now, but I think it's becoming partly time limitations. I think they; they are so overwhelmed with all that they've got on their plates".*

Healthcare providers approach to IFCs, and their understanding of the needs of this group was much the same as those with dementia. They were conveyed as insensitive in their approach to the delivery of information or support of informal and family caregivers. IFCs described being bombarded with information about dementia and support groups. While there was some praise for the intention, IFCs also reflected on the challenges of absorbing and processing the weight of complex and often distressing information. John commented *"When she was first diagnosed the memory clinic gave us a five-week course for carers and we had all the information come…and a lot of it just went over my head because there are so many variations of the illness and it affected people in so many different ways".* General interactions with healthcare providers reflected a similar tactlessness, in which IFCs felt the exhaustive pressures of their role were unrecognised. Anne drew this example to illustrate, *"The doctor would say "Are you alright?" and I would say tired "Do you want some sleeping pills?". I was up and down all night, you don't want sleeping pills when you are a carer, so the GP hadn't a clue!".*

For IFCs there was an overwhelming sense of systemic abandonment and aloneness. Once their loved ones had received a diagnosis, caregivers described little follow up. They felt once a diagnosis had been given healthcare providers washed their hands of them and their loved ones. Loved ones became the responsibility of their families and spouses, and they were to cope with the new diagnosis and increasingly complex care needs. Tom described his experience of this:

> *"I found the diagnostic centre good when they diagnosed her but they're after sales is awful, it would have been nice not every day but once a month just to speak to them and say "Look how's things going? Have I got another tablet?" instead of saying once you're out the door and you've been diagnosed that's it, and I think that's a wrong…I think there's an issue there and I spoke to other carers at the five-week course I went to and they all felt the same. There was an issue there between who is responsible". (Tom. Carer to Wife)*

This lack of follow up seemed to reinforce caregivers sense their needs and the demands their role were unvalued, and the systems abandonment of them served to perpetuate more demand on them and further anxieties about the future. Abandonment was also expressed by a subset of IFCs (n=5) who's loved ones had been discharged from the memory clinic, and the medication to delay the progression of symptoms withdrawn. John's experience was similar to the other caregivers who discussed this, he stated *"I don't know quite why but then Lily was signed off…so I feel abandoned by that system…the people in the know, we can't do anything for you, out you go into the wide world basically".* While they understood their loved one's condition could not be cured, they felt discharge indicated a total hopelessness about the prospect of delaying their loved one's progression to more severe symptoms. Their descriptions conveyed their loved ones a lost cause. Irene indicated "*there was nothing else they could do"* and Emma relayed *"You get to a stage with dementia where the tablets won't help you anymore anyway".*

A sense of abandonment seemed further compounded by challenges in getting support and respite care. There seemed to be three challenges for caregivers in this area, the first was lack of domiciliary care and day centre care for loved ones. IFCs tried to maintain some continuity in their life during what time they had away from loved ones (during their day centre visits or visits from carers), however these breaks were limited. John described the relentless of his role and how he tried to balance some time for himself where possible:

> *"I am trying to lead a life, I would like more care but I can't see how to fit it into my life, I mean I do all the cleaning around here… Lily's out for two days a week, it's only about five hours a day, so I soon fill up those hours….I can't wait to May for respite, I haven't had a break since October so I have been going for the end of March". (John. Carer for Wife)*

The second challenge for IFCs was navigating the system. They described not understanding what support they were entitled to and the pathways to access it. Eric explained "*I've tried to gleam from the carers how the system works, how it operates, and they don't fully know"*. The third challenge seemed to be that support was only available when IFCs had reached the point of crisis and situations spiralled into disaster. Anne summarised this, "*I had no support until I collapsed of exhaustion".*

There was a sense that healthcare providers did not want to engage with dementia, this was particularly communicated through the diagnostic challenges and the dismissiveness caregivers described. It was likely this response was in part linked to societal misunderstandings already described, the healthcare system and its providers operating within societal structures that may stigmatise or misunderstand dementia. It also seemed in part related to the progressive and ultimately incurable nature of dementia. This came through in IFCs' sense of abandonment following diagnosis, and for some discharge from the memory clinic. There was nothing further healthcare providers could offer to slow the progression of the condition and so interaction appeared to be severed (or this is at least how caregivers expressed it). IFCs themselves offered further weight to this, reflecting on the nature of dementia and contrasting it to physical ailments. Physical ailments can be seen, understood more easily by their visibility and as such treated. Dementia was described as a different beast to master, it could be transient trickster who only appeared to those close enough to notice its imprints, it could equally render a person without speech. It was therefore uncertainty. Dementia is also incurable, and as such the capacity of healthcare providers to function as a restorative healer impossible. Caroline summed up the nuanced nature of dementia, and the challenges these nuances present to the healthcare provider:

> *"You can say "there is person with a broken leg", you can actually see it can't you? You can see what it's done to them can't you, you know it's going to be repaired, but with dementia it's like a slippery thing that you can't get hold of, and sometimes it doesn't even appear to be there. People can appear quite fine even though you know they've been diagnosed. They can talk complete sense and you think actually perhaps there is nothing wrong with them now, it sort of comes and go. It's very, very odd condition". (Caroline. Carer to Mother-in-law)*

This subtheme highlights a further layer of challenges that caregivers negotiate, alongside those which they described encountering in other subthemes.

There was an overwhelming sense that society and healthcare systems lack an understanding of dementia, and its impact upon those responsible for day-to-day care. This left caregivers feeling abandoned and increased the pressure of their role. It appeared there was a vicious circle in place, in which a lack of understanding, societal and healthcare provider misunderstandings, and systematic abandonment fed into each other. Caregivers were left to be self-sufficient, compensating for failures in the system and absorbing the bulk of are. Considering what caregivers described combatting throughout this subtheme, and its relevance to pain, it is likely that addressing the pain of those being supported would be difficult endeavour. Caregivers' interactions with healthcare providers were marked with limited understanding of dementia, insensitivity and dismissal and it is likely these experiences would extend to interactions relating to pain.

6.4 The intersection between caregiver context and pain

Two themes have been presented from Study 1, that centre on broader issues experienced by caregivers, supporting those living with dementia. These themes provide some indication, particularly among IFCs, of wider issues within the caregiver context that pose significant challenges in terms of support, preparedness to care for dementia and the emotion/psychosocial impact of a caregiver role.

Through a broader appreciation of the caregiver role and its challenges, an understanding of how caregivers relate to their role and to those being supported can be realised. Moreover, it is possible to see how such challenges may intersect with caregivers' ability to support or obtain support for those with dementia, and issues relating to pain. At a practical level, if a caregiver, whether a member of care home staff, or an informal caregiver, cannot obtain an appointment or support from a healthcare professional, how will they support with potential diagnosis and treatment of pain? Similarly, if a person with dementia refuses to attend an appointment with a healthcare provider, how can a caregiver expedite a diagnosis and appropriate treatment for an injury or condition that may be giving rise to pain? Moreover, if a caregiver feels unprepared to care for a person with dementia, as expressed by both IFCs and CH staff, correspondingly they may feel such unpreparedness in the context of caring for a person living with dementia who is pain.

The Pain of Caring conveys the significant challenges of IFCs, reflections are necessary about the impact of such to the ability of IFCs to consistently meet all care needs among those they support, including pain. For example, it a caregiver, as expressed by IFCs, have their own limiting health issues and medical appointments, how does this impact upon their ability to be a primary source of support to another? It is also possible to see where pain can be eclipsed and lost within the complexities of relationships, grief, and systemic challenges experienced. This may be particularly so where caregivers' ability to relate to those they are supporting, may impact upon their ability to relate to their pain, such as through perceived behavioural or perceptual changes to pain.

In the reflections made above, pain may be seen as an additional need, that can only be attended to after the negotiation of a superordinate issues that are more foundational and basic in premise, such as access to support, access to appointments and awareness of the care needs of those with dementia. As a result of the challenges of context, caregivers may be unable to provide the care and support necessary, to identify, recognise and treat pain, through the barriers that are presented more broadly.

6.5 Drawing together Study 1

This chapter, together with the previous chapter, present the findings from Study 1 and themes generated from interviews. The purpose of Study 1 was to explore the experiences of caregivers supporting PwD who have pain, both within the CH context and at home, responding to research question 1-3. This summary will draw together the themes discussed throughout this chapter, and those in the previous into a synopsis of key findings.

Interviews explored the role caregivers play in supporting PwD who have pain, including how caregivers recognise and respond to pain, and their understanding and consideration of pain in their day-to-day roles. Interviews revealed the experiences of caregivers were complex, their supportive roles of those with dementia posing many challenges to be negotiated. Caregivers played many roles in supporting those in pain. They acted as interpreter, recognising pain through bodily and behavioural communications, and harnessing their connectedness to overcome communicative and cognitive complications. They acted as protectors and advocates, responding to pain by offering pain relief, supporting PwD to appropriately self-manage and regulating medications for the protection of PwD. However, caregivers' responses to pain, and their consideration of it, were conflicted with their own, and those being supported, stoic approaches to pain and fears around medication, which served to normalise and perpetuate suffering. It was too conflicted with competing demands, managing the symptoms of dementia and meeting broader care needs overshadowing physical suffering. There were further wider contextual and environmental issues raised that served as an important backdrop against which to contextualise and fully appreciate the roles of caregivers, and the ripple effect upon how pain was perceived and prioritised.

These findings are revisited in the following chapter, with reflection on how qualitative survey findings (Study 2), builds upon and expand these findings.

Chapter 7- Study 2 survey results: Exploring caregiver experience through qualitative survey findings

7.1 Introduction

The findings of Study 1 presented in the preceding two chapters addressed aspects of research questions 1-3 set out in this thesis. This chapter is dedicated to exploring the findings of Study 2, the follow-on study, implemented to build upon Study 1, and address research questions 1-4.

The current study aimed to collect further data and reach more caregivers (particularly CH staff), for the purposes of extending, triangulating and compliment the findings of Study 1. Study 2 aimed to explore the experiences of further caregivers in regard to pain recognition, assessment and management among PwD, and caregivers' understandings of such. To meet this aim Study 2 took a triangulation mixed methods strategy to data collection (Creswell et al., 2003), implementing a survey. The survey was informed by the findings of Study 1 and relevant literature and incorporated a qualitative element using open-ended questions and a quantitative element in the form of the Pain Knowledge and Beliefs Questionnaire (PKBQ) (Zwakhalen et al., 2007).

Quantitative survey responses were analysed using appropriate statistical analysis, and qualitative responses were analysed using Structured Tabular Thematic Analysis (ST-TA) (Robinson, 2021). ST-TA was used as it has been explicitly developed to support the appropriate analysis of brief texts and the identification of patterns and themes in the data. Table H1 in Appendix H presents the results of this, distinguishing the commonness of particular themes and subthemes across distinct qualitative sections of the survey. ST-TA further allowed for a process of inter-analyst agreement of coding and theme development to be undertaken, for the purposes of cross-checking data, and establishing reliability and transparency (Robinson, 2021) (see Chapter 4: Method).

This chapter is dedicated to presenting the qualitative aspect of the survey, and results of ST-TA. These findings are considered in light of Study 1, and the ways in which qualitative survey data compliments Study 1 or contributes new understanding.

7.2 Survey Sample

A total of 118 caregivers responded to the survey, of which 115 responses were entered into survey analysis (CH staff 53%, NS 17%, IFCs 30%), with an average age of 47.67 years. Response rates varied across caregiver groups (IFCs 64%; CH staff 69.66%; nursing students 76%). A breakdown of each caregiver groups is provided below.

7.2.1 Care home staff

A total of 62 CH staff responded to the survey, all of whom were working within 6 different CHs across the Southeast of England. Responses from the 6 CHs varied, a maximum of 36% of responses were received from one CH, however the remaining 64% was more evenly distributed across the other 5 CHs. 55 (88.7%) respondents were female and 77.4% of the sample were White British. Ages varied from 19 years to 66, the average age being 39.94 years of age. Years' experience within current role varied from less than 6 months to over 10 years, with the largest majority of the sample working within their role for over 10 years (23%). There was a large variation in types of job title reported, the most common respondents were healthcare assistants (HCAs) (49%), followed by senior carers (15%). As a result, the sample reflected the typical UK CH workforce[1] structure (with a dominance of healthcare assistants) and also able to reveal staff interrelations, dynamics, and responsibilities. Only 11% were qualified nurses in the sample, a stark contrast to recruitment undertaken in previous research (e.g., Brorson et al., 2013; Kaasalainen et al., 2007; Kenefick & Schulman-Green, 2004; Kovach et al., 2000). Table 7.1 provides an overview of CH respondent characteristics.

All CH staff identified receiving some training, although it varied widely from basics such as moving and handling, to degree level among nurse respondents. Almost half (n=30) of respondents had undertaken a National Vocational Qualification in Health and Social Care at level 2 or above, to equip them with the necessary skills and knowledge required to care for others. More specifically to dementia, the majority (n=55) had received some dementia training, which varied in form (online training, in-house training and visiting trainers).

Table 7. 1 Overview of Study 2 care home respondents

Care home staff			
Job title	Frequency	Years' experience	Frequency
Healthcare Assistant	49%	6 months or less	23%
Senior Carer	15%	6 months- 1 year	18%

Administrator/Domestic	15%		10 years or more	16%
Nurse	11%		2-5 years	16%
Management/Director	11%		5-7 years	3%
			7-10 years	5%

7.2.2 Nursing students

A total of 19 nursing students completed the survey in full, 74.7% of whom were in year 2 of BSc Nursing and the remaining were completing their post graduate diploma in Nursing. Most were British (78.9%) and female (94.7%). Ages ranged from 23-47 years, with the average age being 36.10 years. A total of 65% of nursing students were currently employed as paid caregivers, the majority of which within HCA roles (63.5%), most often in CHs or as care assistants/support workers supporting vulnerable groups in the community (e.g., older people in the community; adults with learning disabilities). As such, they had been supporting older and vulnerable adults within both contexts of interest, the CH setting and within adults' own homes. All had further completed a placement supporting older adults in diverse contexts within the last 2 months as a part of their studies. Nursing students' employment and placement offered them a wealth of experiences in supporting individuals who may be cognitively or communicatively impaired.

Nursing students identified two sources of dementia training. Half (9/19) indicated they had attended a lecture on dementia, and due to undertaking their nursing training had not been required to complete further training in the area (aside from safety training, such as moving and handling). A further 6 identified undergoing, in addition to a lecture during their studies, workplace training on either dementia specifically (4/6) or NVQ training (2/6). The remaining nursing students did not provide information on their training. Nursing students reported varied experience within caregiving roles (see Table 7.2).

Table 7. 2 Years' experience among nursing student respondents

Nursing students	
Years' experience	Frequency
No experience	27.8%
1-2 years	22.2%
3-5 years	22.2%
10 years or more	16.7%
7-10 years	5.6%

7.2.3 Informal caregivers

A total of 34 IFCs responded to the survey. The age of IFCs ranged from 34- 81 years, average age being 65.8 years. All IFCs were White British and primarily female (88.2%). Years as caregiver varied from months to over 10 years, with 2-5 years being the average time spent as a caregiver (47%), a figure not dissimilar from UK estimations[13] (see Table 7.3).

A large proportion (79.4%) of IFCs had no experience as a healthcare professional before taking on their caring role. Over half were wives providing support for husbands (55.6%), in line with UK figures of unpaid carers for dementia[2]. A fifth were daughters providing support for a parent (20.6%) and the remaining were predominantly husbands supporting wives. The average age of the PwD being

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[13] 30% of IFCs have been supporting a person with dementia for 5-10 years, another 22% have been a carer for over 10 years (SACE, 2016-2017).

supported was 62 years of age and most (91.2%) had been experiencing symptoms of dementia for over 2 years before receiving a diagnosis. Duration of dementia diagnosis varied from less than 6 months to over 10 years, almost half had received a diagnosis 2-5 years ago (44%). Almost half of PwD were diagnosed with vascular dementia (47.1%), the remainder had Alzheimer's Disease (29.4%) or mixed diagnoses. Most (28/34) identified themselves as being the primary caregiver and providing the bulk of all care. Additional support was either not provided, not sought or sometimes not possible. A group (15/34) of IFCs had opted to learn more about dementia through dementia workshops and training offered by charities and the memory clinic. A further smaller group (5/34) had been in the caring profession so had some understanding of the condition already.

Table 7. 3 Informal caregivers' time spent supporting a person with dementia

IFCs	
Time spent Supporting	Frequency
2- 5 years	47%
10 years or more	14.7%
7-10 years	14.6%
5-7 years	11.7%
1-2 years	8.8%
0 months-1 year	2.9%

7.3 Qualitative survey results

The qualitative component of the survey consisted of five open-ended sections (Appendix F); (1) demographic and contextual information; (2) experiences of pain in people with dementia; (3) identifying pain; (3) pain assessment tools; and (4) treating pain in those with dementia. Responses within each of these sections were analysed using the hybrid approach of Structured Tabular Thematic analysis (ST-TA) (Robinson, 2021). The hybrid approach allowed for themes generated from Study 1 to be deductively applied to survey responses, and where necessary new themes to be generated inductively. Table 7.4. provides a summary of themes deductively applied and the new themes generated for Study 2, alongside their definitions. Overall themes deductively applied fitted well with the results of Study 2, with only four new subthemes having been inductively developed (Table H1 in Appendix H). Such indicates the experiences of survey respondents resonated comparably with those of interviewees.

Table 7. 4 Survey themes and definitions

<table>
<tr><th colspan="3">Theme 1: Deciphering Dementia</th></tr>
<tr><td colspan="3">Dementia gives rise to changes in behaviour, communication and expression, which impact upon how those with dementia may express pain and how caregivers might identify it. This theme captures a cluster of themes which describe these changes and the challenges they cause caregivers, and the methods by which caregivers attempt to circumvent these challenges.</td></tr>
<tr><th>Deductive/ Inductive</th><th>Subtheme</th><th>Definition</th></tr>
<tr><td>Deductive</td><td>a. Speaking through the body</td><td>How behavioural, emotional and movement issues relating to pain are communicated by the body. The conflict between caregiver's reliance on verbal communication, despite their awareness of bodily language as the overriding primary communication medium.</td></tr>
<tr><td>Deductive</td><td>b. Understanding through connection</td><td>Using relationship with patient or loved one including knowledge of their past to negotiate diminished capacity. Using Intuitive familiarity and knowledge to piece together the puzzle.</td></tr>
<tr><td>Deductive</td><td>c. Deteriorating Connections</td><td>Changes to pain experience and expression based on deterioration in memory, diminishing cognitive and communicative capacity, and underlying pathophysiology of the condition. Caregivers negotiate the disjunction caused by this to discover pain and reach PwD.</td></tr>
<tr><td>Inductive</td><td>d. Person-centred approach</td><td>Dementia and pain are individual, how either manifest is uniquely varied and idiosyncratic. To decipher pain and dementia, people must be approached as individuals and their treatment reflect their individual needs. There is no universal, all should be approached and treated equally.</td></tr>
<tr><td>Inductive</td><td>e. Informal vs. formal assessment</td><td>At the intersection between patient understanding, adaptive strategies in language, clinical experience, and intuitive understanding, informal pain assessment occurs. Informal methods to understand pain are incorporated into daily care activities and exchanges. Formalised assessment is of limited value.</td></tr>
</table>

Theme 2: Relieving Suffering		
Relieving suffering is a complex issue among those with dementia, requiring many considerations. This theme captures a cluster of themes which explore the considerations of caregivers, including how pain might be prioritisation in their day-to-day caregiving, and how caregivers negotiate of its amelioration.		
Deductive/ Inductive	Subtheme	Definition
Deductive	a. Lack of prioritisation	Flippant statements about pain and its authenticity. Pain is normalised as something that people should be living with, underscored by ageist and stoic attitudes. Competing health needs and managing the symptoms of dementia are higher in the hierarchy of caregivers concerns than pain.
Deductive	b. Striking a balance	Use of medication and non-drug therapies. Negotiating a balance between relieving pain and protection from risk and side effects. Contending with medication fears and resistance.
Deductive	c. Existential suffering	Emotional and psychological suffering precipitated by dementia and increasing frailty and dependence. Recognised as a higher priority than physical pain.
Inductive	d. Acute vs. chronic	There is an emphasis on changes to physical state, physical injury and acute conditions, as these indicate a deterioration in health that require immediate intervention. These incidents are associated with physical pain. Long-term or recognised health conditions are handled with insouciance, and the discomfort they give rise to disassociated from pain.
Inductive	e. Adhering to roles & responsibilities	Recognising pain, documenting it and reporting it, are encompassed by the caregiving role. Caregivers are cognisant of their responsibility to advocate needs relating to pain; however, they are often limited in their ability to relieve suffering, this being beyond the remit of their role (CH staff) or outside their capabilities (IFCs).
Theme 3: Autonomy vs. Dependence		

This theme explores the ability of PwD to act as decision makers regarding their treatment and endurance of suffering. It captures a group of subthemes that explore issues described by caregivers relating to autonomy, capacity and the individual preferences of the people with dementia.		
Deductive/ Inductive	Subtheme	Definition
Deductive	a. Supporting choice	Facilitating autonomous choice and supporting PwD with self-management of their own pain, even if this results in PwD resisting pain medications and choosing physical suffering.
Deductive	b. Assuming control	Diminishing capacity and potential risks of mis-medication precipitates caregivers becoming governors of pain medication and responsible to relieving suffering. Assuming this role placed increasing pressure on caregivers, they were negotiating the ethical issues arising from loss of autonomy, and their own illiteracy relating to medications.
Theme 4: The Pain of Caring		
Caring for those with dementia was described as challenging and an overwhelming task by caregivers. This theme explores the demands on caregivers through a cluster of subthemes that explore the wider difficulties and demands caregivers encounter within their roles and environments.		
Deductive/ Inductive	Subtheme	Definition
Deductive	a. Shifting relationships & identities	The changing nature of relationships IFCs share with their loved ones, and the resultant losses of familiar personhood and shifting identities experienced.
Deductive	b. Grief & Loss	Reflections on dementia and its all-encompassing impact to IFCs shared lives with loved ones. Grief and loss relating to changing lifestyles and loss of shared dreams.
Deductive	c. Practical, societal & systematic challenges	Practical challenges navigated in respect to caregivers' own understandings of dementia and ability to provide care. Issues confronted through societal interactions and interactions with healthcare systems and its providers.

The following will provide a detailed discussion of the results of ST-TA within each of the survey sections, drawing on select illustrative survey responses (further indicative survey responses can be found in Table H1 Appendix H). For the sake of parsimony and avoiding repetition in the text, main themes and subthemes prevalence are reported in Table H1 (Appendix H), only subthemes are reported in the text discussions. Subthemes discussed are those that were most prevalent, and thus indicative of shared experiences across survey responses, but additionally those that served to augment and add new dimensions to the findings of Study 1. As such, the presentation of subthemes does not follow the same order in which themes and subthemes have been presented in interview data (Theme 1, subtheme 1(a) and so on). Within each of the 5 survey sections, a brief description of the focus of each section is provided, before the most prevalent themes emerging from each section and its focus are narratively discussed.

7.3.1 Section 1: Demographic & contextual information

Section 1 included demographic questions about respondent’s personal characteristics and roles. It further included a series of open-ended questions exploring training received in the care of older people, and training received in the care of PwD. This section was not focused on capturing experiences, rather background contextualisation of the sample, however, unexpectedly caregivers’ brief descriptions did convey content that resonated with the following subtheme.

4c: Practical, societal & systematic challenges: In responding to this question, 26 (23%) caregivers highlighted challenges. Although many caregivers described receiving some dementia training (CH staff n=55; nursing students = 18; IFCs n=14), overall, 23% referenced the limited practical preparation they felt they had received in light of the demands of their roles and the complexity of dementia. Like interviewees, while they conveyed how training had offered them some insight into dementia, it was not exhaustive enough to support a sense of preparedness and they were keen to undertake more in-depth and regular training. For example:

> *"We only had a morning session on this, I think to really understand dementia we need more intense training, more in-depth". (Respondent 27. Activities co-ordinator)*

IFCs also described their role as challenging given a lack of support, something that was described at length in Study 1 by interviews. For example:

> *"I used to have 4 carers 5 times a week, but she got rid of them by her behaviour- wouldn't let them in the house or told them to leave. She refuses to go to day centre…So now it's just me". (Respondent 107. Carer for Wife)*

7.3.2 Section 2: Experiences of pain in people with dementia

This focus of this section of the survey was on exploring caregivers' encounters of pain in PwD, identifying from the perspective of caregivers, what events precipitated pain in PwD, and how it might be expressed or communicated. It also explored caregivers' consideration of pain within their caregiving roles. Themes 1 and 2 were most prevalent within this section.

Subtheme 1c Deteriorating Connections: 55% of caregivers (n=63) described how PwD may experience pain differently to those without dementia. Similarly, to Study 1, caregivers' thoughts on this fell into two polar extremes. Some described how dementia slowed responses or altered consciousness. This stripped away consciousness of pain and semantics, leaving PwD without pain expression. Others described that dementia gave rise to increased sensitivity to pain and led to excessively volatile responses. For both sides of these responses' caregivers reflected on the internal distress, confusion and fear which may arise from a lack of ability to communicate suffering or understand its meaning. Both sides of these responses are illustrated below:

> *“There has been a change. If for example she has a fall she will not complain of pain or say it doesn’t hurt...She broke her ankle and was walking on it with much complaint”. (Respondent 102. Carer for Wife)*
>
> *“They become increasingly anxious and may cry out louder in pain. They may also become extremely distressed and may need more assurance, care and attention around that time”. (Respondent 3. HCA)*

Subtheme 1a Speaking through the body: 45 (39%) caregivers, most often CH staff and nursing students, described the difference in how PwD many manifest or communicate their pain (given the changes to cognitive and communicate function in subtheme 1c). As in Study 1, caregivers were aware that verbal communication was limited, and this precipitated a change in the way those with dementia articulated their needs. Caregivers described how body language and behaviour were used as a means of reaching out by those with dementia and communicating their pain. For example:

> *"They cannot communicate effectively, so need to express it physically". (Respondent 78. Nursing student)*
>
> *"It depends on the level of dementia as to whether they can communicate this, if they can't communicate, they find other ways to make us aware of their pain". (Respondent 11. HCA)*

Subtheme 1d Person-centred approach: 11 (10%) CH respondents made poignant references to the importance of taking a person-centred approach to pain, irrelevant of their dementia status. They reflected on the human uniqueness of pain expression in considering how PwD may experience or express their pain. Caregivers drew on examples of particular residents in their care, referencing idiosyncratic behaviours to illustrate this. For example:

> *"It is the same for everyone, whether they have dementia or not. I think what is different for everyone, and not to do with dementia, is how each of us express it or what level of pain we can tolerate. The difference is in the person and body reaction". (Respondent 59. HCA)*
>
> *"The human element in dementia is still present, the response to pain is still human... If you crack a joke or another member of staff does, a resident can all of a sudden laugh just like that (clicks fingers). If the happy element is still there, then its mirror reflection of pain must be too." (Respondent 49. HCA)*

*Subtheme 2a Lack of prioritisation***:** In reflecting on pain and its relevance within their caregiver roles, 48 (42%) participants communicated that pain was not a priority. The underlying causes of this echoed those which emerged in Study 1, in which competing demands, managing dementia, and task orientated care was emphasised. CH staff described an anticipation and almost desensitisation to pain in their roles. They tended to reflect on pain being problematic when it interfered with personal care or gave rise to challenging behaviour, rather than for the distress, it could cause. For example:

> *"Obviously it's not nice to see someone in pain, and it used to panic me, now I'm used to it, it becomes part of the routine, you know when they'll have pain and when they need pain relief". (Respondent 16. HCA)*
>
> *"Not really, the pain is the least of our worries. The memory is the main worry- he leaves his door open and taps running. It depends on the pain as to how important I think it is. His pain doesn't keep him awake so I don't think it's anything to worry about". (Respondent 98. Carer for Husband)*

Subtheme 2c Existential suffering: 46 (40%) caregivers raised concerns regarding psychological suffering among PwD, primarily arising from loneliness and increasing dependence. This was discussed in contrast to physical suffering, existential suffering was seen to be more prevalent and more concerning. This resonated with the experiences of interviewees in Study 1. Interestingly, caregivers described that existential suffering (e.g., confusion, anxiety) could result from physical pain, yet the latter remained secondary. Caregivers also described the relationship between physical pain, suffering and loneliness. They indicated that often pain expression were manifestations of internal anguish, and a cry for comfort and human interaction. For example:

> *"I think her daily mental feelings is more of a priority than pain or her physical feelings". (Respondent 11. Carer for Mother).*
>
> *"Residents want companionship more, so that's a worry more than pain". (Respondent 12. HCA)*

*Subtheme 2d Acute vs. Chronic***:** 30% of caregivers (n=34) described encountering physical pain most often in the form of acute injury, visible injury, or infection, or at least pain was a descriptor associated primarily to such. Although, long-term and chronic conditions were highlighted (most often arthritis), physical pain was not directly associated these conditions and they did not concern respondents. These conditions were described as being known and recognised, and the pain they caused manageable, and to certain extent acceptable. The underlying cause of these complaints was viewed to be ageing, which normalised this pain. A focus on acute pain, arising from infection and injury (e.g., infection, falls) was dominant. Such indicated possible deterioration of the physical state of PwD, therefore respondents emphasised a need to be vigilant to and responsive to acute pain. For example:

> *"Residents with dementia are very prone to falls, due to UTIs...Working with residents closely we know when they are in acute pain and when it's uncomfortable pain, like from long-term conditions like back pain. Acute pain, like from falls, needs to*

> *treated immediately, but not for uncomfortable pain where we know the cause…" (Respondent 13. Senior Carer)*
>
> *"If they appear confused, we will do a urine test for UTI and if there is a problem we get the doctor to come to prescribed antibiotics. We will report acute pain, like a fall, to the ambulance, and uncomfortable pain we report to GP". (Respondent 46. Senior Carer).*

Subtheme 2e Adhering to roles & responsibilities: 31 (27%) caregivers described how being concerned with pain was a part of their wider caregiving duties and supporting the overall wellbeing of those with dementia. These responses were in contrast to those seen in Subtheme 2a *Lack of prioritisation*. Much like within Study 1, they described themselves as advocates, CH staff and nursing students often referring to their duty of care. Deteriorating communicative ability was described as increasing caregivers' sense of responsibility as interpreters and advocates of pain for PwD. Caregivers commented:

> *"It is absolutely, that is one area that compounds really, we are here to make sure they are comfortable. It is especially a concern when they can't voice it out, they can't articulate it". (Respondent 49. HCA)*

7.3.3 Section 3: Identifying pain in people with dementia

Section 3 of the survey explored how caregivers recognised the presence of pain among PwD. It aimed to elicit information from caregivers about the decision-making process underlying how pain was identified, exploring their interactions with those with dementia. Theme 1 was again most relevant to responses in Section 2, and to a lesser extent Theme 2 and Theme 3. The most salient subthemes of each of these are presented.

Subtheme 1a Speaking through the Body: 84% (n= 96) of caregivers described that pain was most evident in the behaviour and moods of those with dementia. A constant study and interpretation of body language, form and symbolism was the central means by which pain could be identified. They identified behavioural (such as limping, rubbing, guarding, resistive behaviour and aggression) signs of pain, in addition changes to usual behaviour (such as loss of appetite, mood changes, and uncharacteristic behaviour). These were similar to those identified in Study 1. One aspect that came through more strongly in surveys, however, was facial expressions. Caregivers identified how the face and eyes could be a window into what could not be conveyed verbally or by the body. Much like within Study 1, caregivers reflected on the challenges of translating the meaning of behaviour and deciphering what was dementia and what was a sign of unmet needs. Often this led to a process of elimination, in which caregivers attempt to identify causes of unusual behaviour and distress. CH staff were more confident in identifying pain than IFCs, with comments indicating "*We know", "Sometimes it is blindly obvious",* and "*We can usually figure it out".* There were less certain in respect to identify causes or severity of pain. Caregivers responded:

> *"I can tell by her expressions in her face and the way she acts. She will grimace her face and, in her movements, she doesn't want to move. She becomes agitated". (Respondent 101. Carer for Wife)*

> *“We have a resident who screams a lot and sometimes when it continues you think “Is that pain?”. Some of the signs are confusion, restlessness and agitation… Sometimes it is so difficult, like dealing with children or babies. You have to think “She’s crying today, and she wasn’t yesterday” and you have to investigate every possible avenue”. (Respondent 49. HCA)*

Subtheme 1e Informal vs. formal Assessment: 72% (*N*=83) of caregivers described using informal approaches to identifying pain. Caregivers had assimilated identifying pain into their day-to-day interactions with PwD, it was not described as a distinct process, rather as something that was incorporated into task-orientated care. They described how during personal care and interactions they would identify potential signs of pain automatically (e.g., through bruising or injury, restricted movement, crying). This would trigger caregivers to begin questioning those with dementia, attempting to discern the cause of pain, its location, and its severity. Dialogues about pain were described as arising through this route, or sometimes through everyday communications about general wellbeing. Caregivers also described using touch to identify pain. Pain could be identified in both a reaction to touch (e.g., flinching), or touch could be used to further explore potential causes of pain (e.g., applying pressure to an area of the body). Caregivers commented:

> *“We ask and we will touch them to see if they react to touch by moving away or if their face shows. Even if they can’t communicate there is generally a way for us to find out if it’s painful. If they won’t say we have to judge for ourselves by how they move or their faces”. (Respondent 40. HCA)*

> *"If I notice she's hobbling about I'll ask, "What are you hobbling abut for?". It's three main things I look out for: visual; sound and crying out; and telling me". (Respondent 107. Carer for wife)*

Subtheme 2e Adhering to roles & responsibilities: 14 (12%) CH staff respondents, all of whom were HCA, indicated that identifying pain was a team effort. They distinguished between their role and that of senior carers and nurses, indicating due to the intimate relationships they shared with residents, they were most able to identify when pain was present. However, they also reflected on the limitations of their expertise. HCA described that in the event of uncertainty, or when they exhausted their own strategies, they deferred to the expertise of more senior colleagues. A team approach was also important given that signs of pain may be missed, interactions with colleagues allowed HCA to learn from more senior staffs' experiences. For example:

> *"We are there to tell nurses if they're in pain, it's up to us as we spend the most time with residents to notice if there is pain. We would be most likely to notice, so it is a team effort". (Respondent 40. HCA)*

Subtheme 1b Deteriorating Connections: 49 (43%) caregivers described how identifying pain was complicated by deteriorating communicative and cognitive ability. They reflected on the ways in which they attempted to circumvent the challenges arising from this. Caregivers emphasised the centrality of maintaining communication via simple language and non-verbal responses. They described trying to find ways to connect and communicate non-verbally as a part of maintaining mutual relationships. Their responses also emphasised the importance of including those with dementia within their own care, to prevent them from becoming passive recipients. Caregivers described:

> *“Recently he’s been holding parts of his head and I ask, “What’s the matter? Is it sore?”’, but he’s not able to say why he’s holding his head, it’s probably because he doesn’t understand the question or can’t find the words…He doesn’t understand pain. He doesn’t understand body signals or discomfort…”. (Respondent 108. Carer for Husband)*
>
> *“The care remains communication focused even if they can’t communicate verbally. They might blink at you and that in itself is communication. We always try to engage them, interact with them. We take an empathetic approach, we hold their hand, we talk to them”. (Respondent 55. Nurse)*

Subtheme 1b Understanding through Connection: 39 (30%) caregivers described a relationship-centred approach to identifying pain to balance out challenges arising from dementia, much like that discussed by interviewees in Study 1. This was illustrated best when caregivers drew on examples of individuals with dementia and described the idiosyncratic ways, they could manifest their pain. In-depth knowledge was used to highlight a change from baseline or normal behaviours, or to piece together the underlying causes of uncharacteristic behaviour or distress. It was important that relationships were mutual, given trusting relationships could encourage PwD to reveal their pain. Caregivers indicated the relationships they shared with PwD, and the depth of their understanding of them, assured them they could identify pain even if the most challenging of circumstances. Caregivers responded:

> *"When you are with a client and something's going wrong you know it, you might not know exactly, but you know something's wrong. Even if they cannot tell you still try everything that you can and use all you know about them". (Respondent 45. HCA)*
>
> *"I would generally know. It's an intuitive thing, I know him well enough to know. This helps me to decide if its attention-seeking or more". (Respondent 88. Carer for Husband)*

Subtheme 3a Supporting choice: 14 (12%) caregivers described how strategies to identify pain, such as informal observation and engaging in dialogues about pain, could be undermined by resistance of those with dementia to communicate their suffering or their concealment of it. This was a tension that resonated with Study 1, in which caregivers were cognisant of upholding and respecting the preferences of those with dementia, as well insuring they received appropriate treatment. For example:

> *"They don't really talk about it [pain] unless you notice. We have some residents who will tell you in a general conversation or if you ask them about it. I will make a joke with them and say "Oh what have you done there?" but I don't press them". (Respondent 29. Activities Coordinator)*
>
> *"He will say "I'm fine", that's his stock answer, or "There's nothing wrong with me". (Respondent 105. Carer to husband)*

7.3.4 Section 4: Pain assessment tools

Section 4 of the survey explored the formalised approaches CH staff and nursing students used to identify pain, specifically their experiences using pain assessment tools (PATs). For IFCs, they were provided with an explanation of PATs and asked to recall visits to healthcare providers and reflect on the usefulness of these methods based on their caregiving experiences. Theme 1 was most prevalent within this section, and to a lesser extent Theme 2. The most salient subthemes relevant to Section 4 are presented.

Subtheme 1e Informal vs. Formalised Pain Assessment: 88 (77%) caregivers provided varied responses in relation to utilisation of PATs within their roles (or by healthcare providers for IFCs) and perceived usefulness of these methods. PATs were not used, nor were internal or external guidance documents for the assessment or management of pain. The follow demarks the common responses from caregivers:

Integrated into daily interactions: Caregivers described using informal approaches to pain assessment that incorporated elements of more formal approaches, such as observation and dialogues about pain. As Section 3 highlighted, because these approaches were already integrated into caregivers' daily interactions, caregivers described limited use (or limited consideration of value) of formalised pain assessment approaches. CH staff and nursing students referred to the requirements of care plans, indicating formal pain assessment was inclusive within this. For all caregiver groups, they described observation and dialogues as an automated response, thus not requiring more a formalised method to support this. CH staff further described having developed their own methods of assessing pain. These incorporated individualised strategies accommodating the limited communicative abilities of specific residents in their care. For example:

> *"'We generally tend to access them using questions and soft touching as if you gave them a chart, they'd just look at it. We have one resident who I will let squeeze my hand in response to pain questions". (Respondent 40. HCA)*

Experience & understanding: Caregivers described familiarity as their mechanism of pain assessment in preference to formalised approaches; this was underpinned by their in-depth and intuitive knowledge of those being supported. Such overlapped and fed into responses to *Theme 1a: Understanding through Connection*. This resonated with Study 1 and CH interviewees sense that pain assessment could be a gut response underpinned by acute understanding of an individual. However, by the same reason, caregivers did indicate that PATs might be useful for those who lacked caregiving experience or familiarity with individuals to underpin pain assessment. For example:

> *"PAINAD is in the care plans. It's there, and I know I can use it if I need to use it. I am familiar with the residents here and there is always a senior carer to ask, and often it's blindingly obvious they're in pain". (Respondent 28. HCA)*

Limitations of self-report in dementia: Caregivers questioned the appropriateness of using self-report PATs in dementia. They highlighted that those with dementia may lack comprehension of words and their meaning. As such, approaches requiring them to self-report a numerical representation of their pain may not yield accurate or informed responses. Further, these approaches were regarded as insensitive to individual tolerance of pain, scales and numbers being described as abstract measures of a varied experience. This seemed in conflict with caregivers own informal use of questions and dialogues to identify pain as expressed in Section 3. For example:

> *"The level of pain is only applicable to the individual, what is a high level for one does not apply to another". (Respondent 106. Carer for Husband)*

Limitations of observational PATs in dementia: The value of PATs with an observational focus were regarded as more appropriate than self-report, given that behaviour may be a clearer indication of pain than verbal communication. However, caregivers questioned the sensitivity of observational PATs (OPATs) to the individual nature of pain experience and expression. They commented that pain behaviour was not universal, and in dementia a further complicating factor may be behavioural manifestations of the condition which mask or mimic those of pain (e.g., agitation and restlessness). In light of such, caregivers returned to the centrality of experience and understanding of the individual being assessed in preference to OPATs. They indicated that use of OPATs would require this as a point of reference to be appropriately used in dementia. Caregivers commented:

> *"If you tried to observe them it would be hard to decide what is their illness and what is pain. One resident beats us up every time we do his personal care so if you were to observe him you might think he's in pain when really he doesn't like being touched.*

> *There is nothing universal, it’s all individual”. (Respondent 51. HCA).*

Gauging pain & need for intervention: Caregivers did reflect on the potential benefits of using PATs. While caregivers described with confidence their ability to identify pain, they commented on the challenges of quantifying the severity of pain and determining the need for intervention. Caregivers indicated PATs could be useful to illuminate such, in addition to determining if an intervention provided was effective. For example:

> *“I think they would be useful to find out how bad mum’s pain is, whether it is a niggle and she’s just expressing that, or if she’s in a lot of pain and needs to have paracetamol”. (Respondent 112. Carer for Mother)*

Subtheme 2e Adhering to roles & responsibilities: 14 (12%) respondents considered PATs within their roles, these responses primarily came from HCAs and were spilt into two viewpoints. Some HCA described the responsibility of formalised pain assessment as that of nurses or senior carers. They described themselves as identifiers of pain, and reporters of pain, however assessment to determine the severity of pain fell outside of their duties and level of knowledge. In contrast to this view, a cluster of HCAs expressed that although formalised pain assessment was outside their usual activities, they wanted to be included in this process. They described themselves as experts by experience on residents’ pain, sharing the closest and most consistent caregiving relationship with them. They expressed that a more inclusive approach to their role would enhance transparency and wider awareness about pain and enrich discussions about residents' care. Each viewpoint is exemplified below:

> *"We carers can recognise pain and we report it to a senior as we don't deal with medication, so it is the seniors who deal with assessing pain". (Respondent 33. HCA)*
>
> *"Everyone should be aware they [PATs] are there, it's the carers that see residents' everyday so we need to be aware dementia residents might express pain differently. If carers aren't aware, it might not be reported to a senior." (Respondent 28. HCA)*

7.3.5 Section 5: Treating pain in dementia

Section 5 of the survey explored caregivers' responses to pain and the ways in which they attempted to facilitate relief from suffering, including pain management strategies and seeking help from others (healthcare providers or fellow staff members). Responses to this section were broad and reflected aspects that resonated across all themes (Table H1 in Appendix H), however, Themes 2 and 3 were most prevalent. The most common subthemes from both are presented.

Subtheme 2e Adhering to roles & responsibilities: 89 respondents described pain treatment and its relevance within their specific caregiving roles and duties. Indicative responses to this subtheme are clustered below:

Hierarchy of responsibility: For CH staff and nursing students, there was a clear demarcation in their roles and responsibilities in relation to offering treatment for pain. The treatment of pain was team effort, in which all roles had a part to play and trusting relationships were important. For those in HCA roles, they described having an integral role in pain treatment by acting as more senior staffs' eyes, noticing changes in residents' behaviours, and advocating for the needs of residents. They were frontline members of the team who described their responsibilities as reporters of pain, initiators and prompters of pain treatment, and monitors (both in respect to the resident's status and the response of more senior staff). Once HCA had fulfilled this task, the onus fell on senior carers and nurses to respond and provide treatment for pain. For senior carers and nurses, they relied on HCAs and acknowledged their expertise in identifying pain. They conveyed themselves as being responsible for providing prescribed medications or escalating complaints up the hierarchy to doctors if pain treatment was not available. They were also responsible for determining the cause of pain, or underlying causes of unusual behaviour reported to them, such as initiating tests. For IFCs, their reflections on their role were similar to that of HCA. They described themselves as a middleman between loved ones and healthcare providers, serving as a voice for those they were supporting.

Going unheard: While acting as advocates for pain treatment, caregivers did reflect on positive experiences with colleagues and healthcare providers. HCAs described senior carers and nurses as receptive to their reports of pain, and some IFCs mirrored the same regarding their loved one's visits to healthcare providers. However, there were responses which described the opposite. For IFCs, they indicated that doctors did not listen or dedicate sufficient time for the voices of PwD or for them. Within the CH respondents, some HCA similarly reflected that more senior staff sometimes belittled their reports and expertise, leading to pain going untreated. Interestingly, more senior staff and IFCs felt a similar sense of dismissal among doctors. They described being dependent on doctors to provide stronger pain medications (than paracetamol) for residents, yet doctors could be reluctant to provided such, or acknowledge their clinical opinion. For example:

> *"They don't listen. They (doctor) don't listen to me; she can speak but won't speak to them. They've come to the point where they don't speak to her, they ask me and then I have to ask her. I have to assess what I think is wrong with her. I've got to guess what's wrong with her and I'm not a professional. I've ended up being her voice." (Respondent 102. Carer for Wife)*

Limits of roles, understanding & context: In reflecting on their roles in pain treatment, caregivers communicated some challenges. In particular, HCA and IFCs reflected on a lack of understanding of pain medication and medical knowledge. Their roles were ones in which they had become cogs in wheel, they played identifier and sometimes offered medications, yet they lacked an informed understanding of conditions and medications.

Subtheme 2a Lack of prioritisation: 13 CH respondents indicated that pain treatment may be prioritised based on pain and resident characteristics. This may impact upon their actions and those of other healthcare providers to whom pain was reported. Pain, which was indicative of physical decline, and occurring in patients without a history of reporting pain, would be responded to promptly. However, pain from long-term issues and among those who complained often, would be monitored before investigation and treatment was initiated. For example:

> *"Report it to the nurse on shift and nurse will go see the resident and if it's an ongoing pain we will monitor it. If it's a resident with ongoing pain the nurse on shift will give paracetamol but if it's a resident who doesn't usually complain of pain the nurse will react a lot quicker." (Respondent 20. HCA)*

Subtheme 2b Striking a balance: 92% (N=106) of caregivers reflected on using pharmacological and non-pharmacological interventions in dementia to treat physical pain. Responses reflected a diverse array of methods of treating pain, and caregivers described many considerations in light of dementia. The follow demarks the common responses from caregivers within this subtheme:

Pharmacological treatment-Paracetamol panacea: While stronger pharmacological treatments were referenced by caregivers (e.g., morphine patches, codeine), most often paracetamol was regarded as the safest option for PwD. Often paracetamol was used as a yardstick to inform if further intervention was necessary to relieve pain and determine pain severity. For IFCs, most described relying on paracetamol due to familiarity with its effects. For example:

> *"If he told me he was in pain I would give him paracetamol. I would only use paracetamol as he's on a lot of other medication. Paracetamol is not too strong but would be enough to help him". (Respondent 95. Carer for Husband)*

Pharmacological treatment-Reassuring those with dementia: Caregivers reflected on the benefits of offering pharmacological treatment for pain, the most obvious being to relieve suffering. This was understood to have ripple effect to mood and behaviour, settling agitated behaviour, and reassuring those with dementia their feelings were important. It could also be reassuring in the sense of precautionary treatment. Caregivers described that even in the event of uncertainty about pain or a lack of verbal confirmation from those with dementia, offering pain medication could be cautionary. For example:

> *"We know that the drugs have effect so even if patient can't communicate it should give at least some relief." (Respondent 65. Nursing student)*

Pharmacological treatment- Considering dementia: Caregivers were concerned that pain medication may exacerbate the symptoms of dementia (e.g., confusion, balance). They also indicated that because of communication and cognitive decline in dementia, they might be unable to ascertain pain location, severity and so on. Without this information, caregivers were concerned about under medicating and accidentally over medicating. For example:

> *"People with dementia feel the effect more of drugs. We have one lady who is on a lot of medications and has pain medication, she has been in bed and has had poor balance and falls". (Respondent 29. Activities Coordinator)*

Pharmacological treatment- Side effects: Treating pain in those with dementia was a considered approach and caregivers described navigating many challenges, including constipation, drowsiness, drug interaction, sedation, addiction, patient swallowing difficulties and overdose. They described taking preventative measures to reduce side-effects, such as offering laxatives to prevent constipation and offering liquid forms of medication to circumvent administrative issues. The risk of side effects and the potential for these to further complicate care needs, gave caregivers reservations about using pain medications. Caregivers were also concerned that pain medication may mask the underlying conditions giving rise to pain. For example:

> *"I tend to feel that all painkillers can be addictive and feel that in the view of the fact that most people with dementia are older (generally) and probably should be given a reduced dosage in view of any side-effects, lack of hydration etc." (Respondent 89. Carer for Mother-in-law)*

Non-pharmacological treatment- safer but short-lived: Caregivers described using a diverse array of non-pharmacological methods to relieve pain, including topical rubs (medicated and natural), repositioning, massage, and heat. They were used to relieve pain, promote circulation and movement in contracted hands, and prevent sores to the skin from immobility. These methods were described as having less side effects than pain medication. They also offered an alternative and individualised approach for those who may be unable or unwilling to take pain medication. Caregivers did, however, highlight the relief provided by these methods might be transient. For example:

> *“Massaged the area, also rub with a pain relief cream. My husband doesn’t like taking medication so rubbing pain relief gel is good for him”. (Respondent 80. Carer for Husband)*

Non-pharmacological treatment- reassurance of touch: Caregivers often referred to physical touch as method of relieving both physical and emotional pain, such as hugs, handholding, message, and stroking. They described touch as means of human connectivity and comfort, which offered distraction from pain and psychological reassurance. Pain was described as giving rise to, and being commingled with, distress, loneliness, and fear. In tandem with communication, touch was the method by which caregivers described conveying their empathy for those in pain. It was also used as means to reach out to those with dementia and acknowledge their presence, even though hazes of confusion and diminishing familiarity. The only challenge for caregivers in this sphere was the receptiveness of those with dementia to touch and interaction. For example:

> *“I use touch, I will hold their hand, so they know we are here and it’s a way of showing affection and that they aren’t alone. They respond to touch even if they don’t recognise you. They don’t choose not to recognise you, it’s the dementia not them. They might not be the dad or grandad you knew 5 years ago but they are still a person”. (Respondent 51. HCA)*

Subtheme 2b Assuming Control: 67% (N=77) of caregivers described tensions arising from PwD resistance to take pain medication, and caregivers' roles as governors of pain medication. PwD were described as reluctant to take pain medication, either due to their dislike of medication, or due to a lack of comprehension. CH staff tended to circumvent this tension and encourage PwD to conform by revisiting them later. For some IFCs, although they monitored their loved one's pain medications, they accepted their loved one's refusal to avoid conflict. Others however, exercised strict control of their loved one's pain medication. They described controlling how often it could be given and deciding when it was necessary. Some indicative responses to this subtheme follow:

> *“The doctor prescribed the paracetamol and the hospital prescribed the codeine. She is supposed to take them every day but I don’t give them every day. I ask her some days if she wants them and she’ll say “No”. I don’t think she needs them every day”. (Respondent 102. Carer for Wife)*
>
> *“He objects to my interference when I say I feel he is taking too much medication”. (Respondent 97. Carer for Husband)*

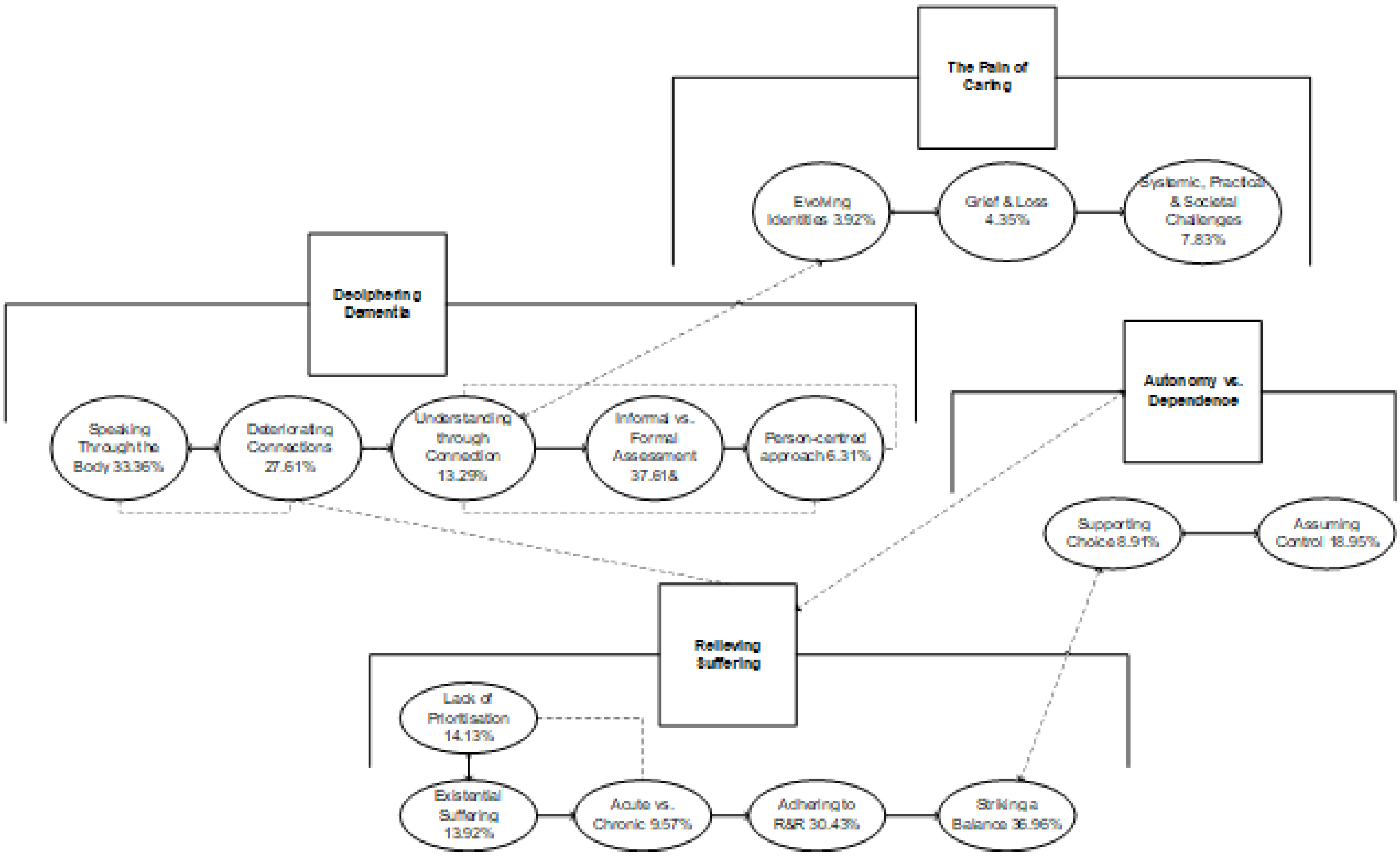
7.4 Summary: Qualitative Survey Findings

This chapter has presented the qualitative findings from the survey implemented in Study 2. The overall emergent themes and subthemes from the data, their interrelations and overall prevalence are presented visually in Figure 7.1.

As discussed throughout this chapter, and confirmed by the fit of themes deductively applied, the findings of Study 2 resonated well with the experiences of those in Study 1. This indicated that the findings from more in-depth interview could be corroborated and supported by the experiences of further caregivers. However, the presence of new themes, generated inductively from survey data, provide new dimensions which did not arise in Study 1. Particular themes seem to resonate less with Study 2's respondents, than they did in Study 1. *The Pain of Caring* and *Autonomy vs. Dependence* while featuring in survey responses (see Figure 7.1.), did not emerge as strongly in Study 2. One explanation for this is that a survey method was utilised for a more pain focused approach, and these themes while relating to pain, also relate to wider challenges and contextual issues associated with supporting PwD. The themes/subthemes which resonated most to survey respondents' experiences were: *Speaking through the Body, Deteriorating Connections, Informal vs. Formal Assessment, Adhering to Roles & Responsibilities,* and *Striking a Balance* (see Figure 7.1), featuring both themes from Study 1 and new themes developed for Study 2.

Mirroring the findings of Study 1, qualitative survey responses indicate that the process of recognising, assessing, and treating pain is a highly complex process, shaped by caregiver experiences and beliefs, context, and close, dyadic relationships. Study 2, adding further layers to our understanding, illuminated the role of interpersonal relationships and contextual role hierarchies, the mechanisms of informal (vs. formal) pain assessment, and the considerations of dementia to relation to pain treatment. The following chapter will revisit these findings alongside quantitative findings and Chapter 9 will present Study 2's findings in an integrated discussion drawing on existing literature.

Figure 7.1 Thematic map of themes from Study 2



Chapter 8- Study 2 Survey Results: Exploring & integrating quantitative findings

8.1 Introduction

Study 2 implemented a mixed-method survey, consisting of open-ended questions and The Pain Knowledge & Beliefs Questionnaire (PKBQ) (Zwakhalen et al., 2007). The results to the former qualitative element have been presented in the previous chapter, this chapter is dedicated to exploring the quantitative component and the PKBQ results. The first section of the chapter will present the results of the PKBQ. Caregivers' performance on the PKBQ will be explored descriptively and statistically, to examine caregiver scores and variations based on caregiver differences. Following this, a second section of the chapter will present an integrative analysis of qualitative survey responses and PKBQ scores. The process for facilitating the integration and quantification of qualitative survey data is described, followed by exploratory testing carried out for the purposes of examining potential relationships between these two data sets. The chapter then concludes with a brief discussion of the overall results of Study 2. The PKBQ will be briefly revisited, before moving to the first section to provide an understanding of the scale for forthcoming analysis and results. The research questions and hypotheses guiding exploration in this chapter will also be revisited.

The Pain Knowledge & Beliefs Questionnaire (PKBQ) (Zwakhalen et al., 2007 is a psychometric scale that measures knowledge and beliefs relating to pain in people with dementia (PwD), use of pain medication in older adults and PwD, and pain among older adults and those with dementia. Given that most PwD have the dual identity being both an older adults and a person with dementia, the items relating to pain in the context of ageing were equally of interest. The scale consists of 17 statements that are responded to a 5-point Likert scale of agreement. Respondents are asked to indicate their agreement from completely agree-completely disagree to statements such as: '*Dementia patients experience less pain than non-dementia residents'* and '*Pain medication should only be administered to residents suffering from severe pain'.* The first 3 items of the scale are dedicated to exploring caregivers pain practices, for example '*Where I work, pain is accessed correctly',* as such these items do not attract a score. The remaining items, however, can be scored based on respondents' agreement. Correct responses attract a score of 1, with scoring incremented for other responses. Lower scores therefore represent more optimal performance on the PKBQ. Performance on the PKBQ can be explored using both the overall score, and respondents' agreement to each item.

The PKBQ was incorporated into the survey to explore the level of understanding (as relevant to research question 4: *What are caregivers' understandings of pain, its assessment and its management pain treatment among PwD?)* among caregivers in relation to pain in PwD. In addition to responding to this research question, analysis of caregivers' performance on the PKBQ also served the purposes of hypotheses testing. Based on the literature and theoretical concepts reviewed in Chapter 2, it was hypothesised that caregivers' understanding or performance on the PKBQ may be influenced by their professional preparation, and years' experience. The first hypothesis (H1) predicted that caregiver roles indicative of training/professional preparation would perform more optimally on the PKBQ, scoring less and demonstrating more optimal understanding and appropriate beliefs. The second (H2) predicted those with increasingly years' experience as a caregiver would score more optimally on the PKBQ, again scoring less and demonstrating more a greater understanding and appropriate beliefs. Research question 4 and these hypotheses underpinned the forthcoming statistical analysis in Section 1 of the chapter. In addition, a further open-ended research question was proposed for the exploratory testing of integrated quant-qual survey data. This research question explored: *How does caregivers' performance on the PKBQ, relate to their qualitative responses within the survey?* and guided the purpose of Section 2 of the chapter.

8.2 Section 1: Descriptive & statistical analysis of PKBQ results

8.2.1 Reported frequency encountering pain

Caregivers were asked to report on the frequency with which they encountered pain in their day-to-day caregiving, from never to very frequently. This information provided an understanding of how often caregivers were negotiating it within their roles and how relevant it might therefore be to them. Across caregiver groups, care home (CH) staff described encountering pain most often, with over a third indicating they encountered pain in residents with dementia very frequently (35.48%) and similar indicating they occasionally encountered it (33.87%). For informal caregivers (IFCs) their encounters with pain were more spread, indicating variation in how relevant pain was within their roles. Around a quarter described encountering it from occasionally (25.71%) to very frequently (22.86%). Nursing students most often identified themselves as encountering it occasionally (31.58%). Across the board, overall caregivers described encountering pain most often occasionally (30.38%) within their respective roles.

8.2.2 Pain assessment tools & use of guidelines

CH staff and nursing students were asked if they were aware of pain assessment tools (PATs) prior to the survey. Half of CH staff were aware of pain assessment tools (31/62), and the majority of nursing students (16/19). Only 38%, primarily nursing students indicated that this awareness of PATs was related to training in the assessment of pain among PwD. The remainder either provided no response, and over a third qualitatively identified having seen them in care plans (34%). A minority of CH staff (20.97%) were aware of any guidelines used within their workplaces relating to the assessment and management of pain among PwD. In contrast, almost half (42%) of nursing students were aware of guidance. However, most respondents aware of guidelines provided no response as to which they had used or been advised to use.

8.2.2 Mean PKBQ scores across caregiver groups

Of the 3 survey respondent groups, CH respondents showed the lowest scores on the PKBQ (M=33.05, SD= 8.46), compared to nursing students (M=37.74, SD=6.87) and IFCs (M=40.69, SD= 8.58). Thus, CH staff demonstrating greater understanding and more appropriate beliefs relative to the other respondent groups. This was surprising given that nursing students had received greater professional preparation than the majority of CH respondents who were HCA or senior carers (n= 37).

CH respondents were diverse in their roles, as such they were categorised further to allow mean scores to be explored within these roles (Table 8.1). As Table 8.1 indicates, respondents in management positions scored lowest (M=30.55, SD=5.97), with nurses and nursing students scoring among the highest of all formal caregiver roles. IFCs performed the worst, scoring almost 3 more points than nursing students and nurses (M=40.69, SD= 8.58). Nurse respondents more often provided definitive responses, even if incorrect, rather than utilising the ‘no opinion’ responses, as other CH staff often did. Differences in mean scores indicated there was variation in

PKBQ scores based on roles, but perhaps not professional preparation. This was explored further using Analysis of variance (ANOVA), to determine if these group differences were statistically different (see ANOVA 1).

Table 8.1 Mean PKBQ scores across caregiver groups

	Caregiver role						
	HCA	Activities & Domestic	Management	Senior Carer	Nurse	Nursing students	IFCs
N	30	9	7	9	7	19	34
Mean PKBQ score	M= 33.70 SD= 8.96	M=31.00 SD= 6.87	M=30.55 SD=5.97	M=31.89 SD= 7.36	M=36.86 SD= 11.57	M= 37.74 SD= 6.87	M=40.69 SD= 8.58

The majority of caregivers had been supporting a person/people with dementia for between 2-5 years (n=29). However, a diverse spread of experience was present from under 6 months to over 10 years (Table 8.2). Exploring descriptives of PKBQ scores based on year's experiences indicated there were differences in mean PKBQ scores. There was some ascension in PKBQ scores, with those with 2 years or less experience scoring lowest (M= 33.98). Those with 7-10 years' experience scored highest (M= 40.81, SD= 7.71). This suggested the opposite of H2, that less years' experience may be related to lower PKBQ scores, and thus more understanding and less maladaptive beliefs. One explanation for this could be how recently training was received. For CH staff and nursing students within caregiver roles, training is offered at the commencement of their role. This may provide more optimal understanding for those with less experience within the role. CH respondents qualitatively reflected on this issue, expressing a need for continued dementia training throughout the course of caregiving roles. Further some IFCs who had recently taken on caregiving duties, were also those who had taken part in dementia training. These caregiver differences were explored further in a second ANOVA.

One possible alternative explanation for the difference observed descriptively between PKBQ scores and years' experience, is caregiver age. Literature indicates that older people have been described as endorsing stoicism, ageist beliefs regarding pain, and express concerns about medications (Vaismoradi et al., 2016). Those with increasing years, would have likely been within their roles for longer, as such may have been more likely to endorse beliefs or concerns underscored by such and measured with items in the PKBQ. Certainly, age descriptively appeared to have some impact on mean PKBQ scores with those over 65 years (M= 42.32, SD=7.79) scoring 10 points higher than those aged 18-24 years (M=32.29, SD= 7.12). The descriptive differences may be indicative of particular caregiver roles, which make up the age categories. For example, the average age of IFCs (M=65.85) would have placed them in the highest age category, and the highest scoring age category (as such scores relating to this role and the ages of those within these roles are consistent). IFCs might be anticipated to score higher, given a relative lack of training compared to formal caregivers. It is possible therefore, that age may be a factor in PKBQ scores, certainly for IFCs, however this cannot be disentangled within this sample, given that younger respondents' experience, roles, and training will be confounding variables.

Table 8. 2 Mean PKBQ scores, and caregivers' years' experience and age

	Years' experience						
	0-6 months	6 months- 1 year	1-2 years	2-5 years	5-7 years	7-10 years	10 or more years
N	16	16	19	29	7	5	15
PKBQ Score	M= 33.01 SD= 7.53	M=36.71 SD= 9.56	M=32.21 SD=9.45	M=37.55 SD= 10.08	M=39.02 SD= 7.69	M= 40.81 SD= 7.71	M=35.77 SD= 8.05

Caregiver ages						
Category	18-24 years	25-34 years	35-44 years	45-54 years	55-64 years	65 years or more
N	14	19	21	23	13	25
PKBQ Score	M= 32.29 SD= 7.12	M=31.25 SD= 7.67	M=36.67 SD= 9.52	M= 36.53 SD= 8.63	M=33.47 SD= 7.31	M= 42.32 SD= 7.79

At the level of percentage agreement to individual items, there were some notable differences across caregiver groups and potentially illuminating responses (see agreement to each item in Table IC 1, Appendix I). Most respondents appropriately disagreed that older people (Item 4) and those with dementia experience less pain (Item 8), or less intense pain. However less positively, over 30% of CH respondents and nursing students agreed that pain was a part of ageing process (Item 10). For IFCs, a large proportion (60.6%) endorsed this view. This normalisation of pain and ageing was indicative of caregivers' qualitative reflections to open-ended questions, and a lack of prioritisation given to physical suffering. Regarding pain assessment (item 9), the majority (74.5%) of CH staff disagreed that assessing pain among PwD was a guessing game. However, nursing students were less sure in their responses, with over a quarter endorsing this view, and a further quarter offering no opinion. Over half (54.7%) of IFCs endorsed the view that assessing pain in PwD is a guessing game. These responses were consistent with qualitative responses. While CH staff described the challenges of assessing pain, they too described their adaptive strategies and processes of elimination they deployed. IFCs by contrast overly used the term *'guess*' to refer to how they identified pain among their loved ones.

Responses to medication related items mirrored medication concerns and ambiguity expressed in qualitative responses to Section 5 of the survey, *Treating Pain*. There were a high proportion of no opinion responses observed among all respondent groups, more so for nursing students and CH staff, than IFCs. Over 40% of all respondents believed that there was an increased risk of side-effects from pain medication among the elderly (Item 7). Over a third of all respondents believed that pain medication in large quantities easily leads to addiction among the elderly (Item 12). Over a half further endorsed the belief that pain medication should be given as needed (Item 14), despite a fixed schedule being the most effective pain management approach. Across all aforementioned items, percentage agreement was consistently higher among IFCs, and they further endorsed views, which other groups only did, in a minority. More than half of IFCs agreed that older people are prescribed too much pain medication (item 14). Over a third also endorsed that PwD should report their pain before receiving their next dose (item 17), compared to over 75% of CH and nursing student respondents who disagreed with this item. Responses to medication items substantiated caregivers' qualitative reflections on the lack preparation they receive relevant to medication in their roles.

8.2.3.2 Validity & reliability of the PKBQ

As discussed in the previous section, items of the PKBQ scale and responses were often consistent with those reported qualitatively, suggesting items were appropriate, and meaningful to the sample. This supported the face and content validity of the items within the PKBQ. Moreover, internal consistency of the scale was acceptable (>0.70 acceptable-good), as indicated by a Cronbach's Alpha coefficient (total scale, 17 items α=0.74). The alpha coefficient is consistent with those reported by previous studies (Zwakhalen et al., 2007, α= 0.782; Ghandehari et al., 2013, α=0.72).

8.2.3 Exploring the role of training & professional preparation: ANOVA

Hypothesis 1 (H1) predicted that caregiver roles indicative of training/professional preparation would perform more optimally on the PKBQ, scoring less and demonstrating more understanding and appropriate beliefs. The null hypothesis (H0) predicted that there would be no significant variation in mean PKBQ scores between caregiver roles. To test H1, and determine if differences observed descriptively were significant, an ANOVA was carried out exploring PKBQ scores across the 7 caregiver groups (Table 8.1).

Prior to undertaking the ANOVA, assumptions were checked. A more in-depth discussion of assumption testing and ANOVA may be referred to in Appendix I, Section A. The Shapiro-Wilk Test confirmed that PKBQ scores across 6 of the caregiver groups were normally distributed (HCA W(30) = 0.98, p= 0.84; Activities & Domestic W(9) = 0.98, p=0.95; Management W(7) = 0.95, p= 0.75; Senior Carer W(9)= 0.89, p=0.19; Nurses W(7)= 0.92, p= 0.49; Informal Caregivers W(34)= 0.96, p= 0.23). PKBQ scores were not normally distributed for Nursing students (W(19)=0.89, p=0.03). However, visual inspection of histograms and Q-Q plots confirmed normal distribution of PKBQ scores within each level of the IV, including those for nursing students. Further, skewness (SK= -1.22, K=1.63) for nursing students were within acceptable ranges, suggesting normality was acceptable. A boxplot was used to determine if any outliers were present in the data, 6 scores fell outside the boxplots. On examination of raw data, these scores were genuine respondent scores. Given that these scores had not resulted in non-normality, they were kept. Levene's test for homogeneity of variance confirmed no significant variance across groups F(5,108) = 1.69, p= 0.33. This test further confirmed that although sample sizes across caregiver groups were not equal, this did not result in unequal variance. It further meant that follow-up testing could use Tukey’s test for post-hoc analysis.

Table 8.3 ANOVA results: PKBQ scores and caregiver roles

Source	***SS***	***Df***	***MS***	***F***	***Sig.***
Between	1551.60	6	258.60	3.76	.002
Within	7433.67	108	68.83		
Total	8985.26	114			

The results of the ANOVA are presented in Table 8.3. It was found that mean PKBQ scores between the different caregiver groups were significant F(6, 108)=3.76, p= 0.002. The Welch and Brown-Forsythe Robust Tests of Equality of Means confirmed this. To determine which levels of the IV, or which roles, scored significantly different on the PKBQ post hoc testing was carried out by way of Tukey's test. Based on multiple comparisons between caregiver groups and PKBQ scores, 2 comparisons were significant. HCAs (M=33.70, SD= 8.96) and informal caregivers (M= 40.69, SD= 8.58) scored significantly different, with HCA scoring a mean difference of -6.89 in PKBQ scores (p= 0.02). Activities and domestic staff (M= 31.00, SD= 6.87) and informal caregivers scored significantly different, with the former scoring a mean difference of -.9.69 on the PKBQ (p= 0.04).

The ANOVA results confirm that caregiver role, does impact upon PKBQ scores. However, both descriptive data and post-hoc testing indicated that professional preparation may not be the underlying cause of these group variations, as was predicted in H1. If appropriate caregiving professional preparation in higher education enhances knowledge and beliefs (and therefore performance on the PKBQ), it would be anticipated that nurses and nursing students would perform best. Therefore, these results do not support that professional preparation which entails higher education improves caregiver knowledge and beliefs in relation to pain in older people and those with dementia. Hypothesis 1 was therefore rejected, as was the null hypothesis, given that differences were indeed present, however not those predicted by H1. Considering these findings in light of nurses and nursing students' qualitative survey responses, there is congruence. Nursing students qualitatively described the limitations of the preparation they had received in dementia, and more specifically in pain. Further, some nursing students who were currently employed as HCAs indicated that they had not engaged with in-house provided dementia training, given their nursing degree enrolment. It is possible that nursing students (and possibly nurses) had not received the assumed level of preparation specific to dementia.

In reflecting on professional preparation, reconceptualising this offers some explanation of the findings observed. Preparation to care for those with dementia was reflected on by CH staff as something, which came from experiential learning, through exposure to the diversity and complexity of dementia. This came through their qualitative survey responses and in interviews in Study 1. Rather than professional training or education, it is possible that greater understanding will come from close interaction with many people with dementia. Certainly, this is supported by the subtheme *Understanding through Connection,* where relational closeness and intuition intersect to provide an in-depth understanding of dementia, and pain in those with dementia. This may further explain why HCA scored only marginally more than other CH roles, despite their relative lack of professional training or seniority. HCA are frontline staff, a role that leads to the development of close working relationships with diverse residents with dementia, as is discussed in the theme *Adhering to roles & responsibilities,* and in Study 1. As such, their role may be one, which provides the conditions for a comparable understanding of pain, ageing and dementia, to that of more senior CH roles.

The performance of IFCs offers some further weight to this rationale. IFCs scored highest of all caregiver roles (M=40.69, SD= 8.58). While some had attended dementia training through charitable organisations or through their prior employment as healthcare providers (n=14), most only had their experience supporting one individual with dementia to base their PKBQ responses on. Therefore, it was not surprising, and given the lack of preparation most had received, their scores reflected limited understanding and ageist and stoic beliefs about pain. The latter certainly resonated with qualitative survey responses from IFCs, and the subtheme *Lack of Prioritisation.*

8.2.3.1 Exploring the role of training & professional preparation: T-Test

To explore the role of training further (H1), a T-Test was undertaken to explore if training (independent variable) had a significant effect upon mean PKBQ scores (dependent variable). Given that few caregivers have received training related to pain, dementia training was used to explore the impact of overall dementia training upon understanding of pain in dementia.

Prior to undertaking the T-Test, relevant assumptions were satisfied. Normal distribution was present across both levels of the independent variable (training vs. no training) (training: W (88) = 0.98, p= 0.15 (p>0.01)) (no training) W(27)= 0.98, p= 0.92 (p>0.01). Independence of observations was satisfied given that the T-Test compared unrelated or unpaired groups (e.g., a participant was either allocated 1 to Group ‘training’ or allocated to 0 Group 'no training'). The dependent variable (PKBQ score) as a continuous variable was acceptable to be entered into a T-Test.

Homogeneity of variance was satisfied, and Levene’s Test of Equality of variances confirmed there was no significant variance between training and no training groups (F= 0.74, p= 0.79).

Mean PKBQ scores between those caregivers who had received dementia training (M= 35.77, SD= 8.89) and those who had not received training (M= 37.10, SD= 8.90), suggested there may be a descriptive difference between these two groups. However, the T-Test did not find any significant differences in mean PKBQ scores between groups t(112)=-.61, p=0.55. This finding likely reflects that dementia training may be too non-specific to particular care needs, such as pain, to have a meaningful impact upon caregivers’ understanding and beliefs relating to pain.

8.2.4 PKBQ scores & caregiver experience: ANOVA 2

A second ANOVA was carried out to determine the impact of caregiver experience and to test hypothesis 2. Hypothesis 2 (H2) predicted those with increasingly years’ experience as a caregiver would score more optimally on the PKBQ, again scoring less and demonstrating greater understanding and more appropriate beliefs. The null hypothesis (H0) predicted that there would be no significant variation in PKBQ scores based on caregivers’ years’ experience. PKBQ scores were explored on 7 levels (see Table 8.2), with years’ experience acting as the independent variable. For full discussion and statistical output from ANOVA 2, see Appendix I, Section B.

Prior to performing the ANOVA test, normality of PKBQ scores across each of the 7 levels of years’ experience was confirmed. The Shapiro-Wilk Test confirmed PKBQ scores were normally distributed across 6 levels of the independent variable (0-6 months W(16)= 0.91, p= 0.13); 6 months-1 year W(16)= 0.95, p= 0.55; 1-2 years W(19)= 0.93, p= 0.17); 2-5 years W(29)= 0.95, p=0.25; 5-7 years W(7)= 0.88, p=

0.24; 7-10 years W(5)= 0.92, p= 0.55; and 10 years or more W(15)= 0.96, p=0.64). Visual inspection of histograms and Q-Q plots confirmed no significant deviation from normal distribution. A boxplot identified outlier data points for those with 0-6 months experience. These, however, were not data entry errors, and ANOVA are robust to some deviation to normality, so these data points were kept. Levene's test confirmed homogeneity of variance was satisfied F(6,100) = 1.47, p= 0.20. While unequal groups were present within levels of years' experience, this did not give rise to heterogeneity of variance.

Table 8.4 ANOVA results: PKBQ scores and years of caregiver experience

Source	***SS***	***Df***	***MS***	***F***	***Sig.***
Between	669.58	6	111.60	1.37	0.24
Within	8174.27	100	81.73		
Total	8843.85	106			

The results of the ANOVA are presented in Table 8.4. The ANOVA indicated there was no significant difference in mean PKBQ scores based on caregivers' years' experience F(6, 100)= 1.37, p= 0.24. This indicates that the years caregivers had spent within their caregiver roles, did not significantly influence performance on the PKBQ. As such, H2 was not supported, and the null hypothesis (H0) was accepted.

8.3 Section 2: Integration of quantitative & qualitative results

Study 2, and the combined approach of Study 1 and 2, employed mixed methods designs in line with this thesis' pluralist approach to data collection methods and analytical strategies. A traditional mixed methods approach integrates qualitative and quantitative approaches at the level of study design and data collection, data sets are then drawn together in the discussion of findings. However, it is possible that integration can occur further at the analytical level (Fetters, Curry & Creswell, 2013). Integration in this way can add greater credibility to findings and provide new cohesive ways of understanding phenomenon (Creswell & Plano Clark; 2007; Fetters et al., 2013).

One method of facilitating analytical integration is the transformation of qualitative data into quantitative data to facilitate an analysis of how psychometric data relates with qualitative categories (Fetters et al., 2013). This approach was used to explore and integrate quantitative data derived from the Pain Knowledge and Beliefs Questionnaire (PKBQ) (Zwakhalen et al., 2007), with qualitative ST-TA results.

The aim of this integration was to openly explore whether the thematic distinctions made over the course of the qualitative analysis would meaningfully differentiate the pain knowledge and beliefs elicited by the PKBQ. Finding an association between themes and quantitative data would validate the two kinds of data as complementary lenses on the topic and throw up some potential illuminating findings and new avenues of study. ST-TA results were first transformed into nominal variables (1 = present, 0 = absent), then entered into the quantitative dataset. Inferential statistical testing was then carried out in an exploratory capacity to investigate the potential relationship between performance on the PKBQ, and qualitative survey responses. The outcome of this analytical integration is presented below.

Exploring PKBQ scores & the results of ST-TA

To explore the relationship between subthemes generated through ST-TA from qualitative survey data and the quantitative data in the survey provided by PKBQ scores; an exploratory set of inferential statistical tests was carried out using a set of T-Tests of differentiating qualitative themes as grouping variables. The objective of exploratory T-Tests was to provide a possible basis for understanding psychometric scores on the PKBQ, and to respond to the open-ended research question: *How does caregivers' performance on the PKBQ, relate to their qualitative responses within the survey?*

Two-tailed T-Tests were used to explore if there was a significant difference between PKBQ mean scores (acting as the dependent variable, DV), between those who showed the presence or absence of differentiating the themes (acting as independent variables in the test). Differentiating subthemes were selected on the basis of a frequency in the sample varying from 30% up to 60% (Creswell & Plano Clark, 2007). Using this cut-off, we could ensure that there would be a sufficient number of participants in both the presence and absence groups for a meaningful statistical comparison. A total of 6 subthemes occurred from 30-60% (see Table H1 Appendix H), with 1 subtheme (Deteriorating Connections) occurring twice within this cut-off in 2 different sections of the survey. As such, 6 differentiating themes were present, one occurring twice, leading to 7 T-Tests in which each theme acted as an independent variable (Table 8.5). So, they could act as independent variables, differentiating subthemes were quantified and transformed into nominal variables, their absence or presence being numerically demarked as absent- 0 or present- 1. It was then possible to compare PKBQ mean scores across these groups for the selected themes, thus fulfilling the aim to integrate the qualitative and quantitative data sets through analysis.

Table 8.5 Differentiating themes with mean PKBQ scores and T-Test results

		Mean PKBQ score		T-Test Results	
Prevalence	Differentiating subtheme	Theme present	Theme absent	Df, t value	p
S2 39%	Speaking through the Body	34.73	36.95	t(113) = 1.31	0.19
S3 30%	Understanding through Connection	36.08	36.08	t(113) = 0.00	1.0
S2 55% S3 40%	Deteriorating Connections	35.69 34.90	36.56 36.96	t(113)= 0.52 t(113)= 1.34	0.60 0.22
S2 42%	Lack of Prioritisation	35.74	36.51	t(113) = 0.37	0.73
S2 30%	Acute vs. Chronic	35.13	36.50	t(113) = 0.76	0.45
S2 41%	Existential Suffering	35.74	36.51	t(113) = 0.62	0.54

8.3.1 PKBQ scores & differentiating themes: Descriptive Exploration & T-Tests

Before T-Test were undertaken, mean scores across each differentiating theme were examined descriptively (Table 8.5). The presence of all subthemes, except one, resulted in lower mean scores on the PKBQ than those observed in the ‘theme absent’ group. This means that those respondents who expressed experiences or views related to the subthemes, scored more optimally in their understanding of pain in older people and dementia. These findings are worthy of some tentative interpretative consideration and further study. It is interesting that those who recognised deteriorating cognitive and communication function in dementia as a complicating factor for pain identification (Survey section 3- Subtheme-*Deteriorating Connections*), scored 2 points less (M= 34.90), than those respondents who did not express such in their qualitative survey respondents (M=36.96). Indicative of the subtheme *Deteriorating Connections* is the adaptive responses caregivers use to maintain communication, and an encompassing view of communication through verbal, non-verbal and other responses. This suggests that those who take a considered approach to pain communication in dementia endorsed more understanding in relation to their PKBQ responses. Reflecting on items in the PKBQ, such an approach, may relate to more appropriate responses to some items (e.g., A person with dementia should first report pain before receiving their next dose of pain medication).

Those who endorsed the subtheme *Speaking through the Body* also scored more optimally on the PKBQ. Respondents who described and recognised bodily narratives as communications of pain, scored over 2 points less (M= 34.73), than those respondents who did not (M=36.95). Those who endorsed this subtheme reflected on pain in dementia as something experienced, manifested, and communicated through bodily and behavioural narrative. This difference may potentially indicate that an approach to pain in dementia that emphasises embodiment is associated with more accurate knowledge of pain in dementia, and more appropriate beliefs about pain and ageing. This finding could be easily explored by further research on nonverbal communication skills and dementia pain care. If a robust finding were established, an intervention looking to boost nonverbal communication skills could be delivered and evaluated.

Those caregivers who endorsed the subtheme *Existential Suffering* further scored lower, than those who did not. This suggests those caregivers who expressed a concern and compassion for psychological and emotional trauma in their qualitative responses demonstrate more accurate knowledge of pain in dementia and ageing and express more appropriate beliefs regarding such. Therefore, it is possible that a more empathetic approach to mental pain could be mirrored by similar in relation to physical pain. Future research could explore this relationship quantitatively, comparing knowledge and beliefs (via the PKBQ) and caregivers' compassion (by way of a quantitative measure). It may further be worth exploring actual caregiver pain practices and responses, in light of the level of understanding and compassion they present. If a positive, relationship emerges between compassion and understanding, which can be mirrored by more appropriate pain practices, this provides a new lens from which caregiver up-skilling and training can be conceptualised.

Interestingly, for the subthemes *Lack of Prioritisation* and *Acute vs. Chronic*, it might have been anticipated that those who endorsed these subthemes would score higher on the PKBQ, than those who did not, given that these themes denote a lack of consideration of physical and chronic pain issues. Those who endorsed both themes did score marginally higher (Lack of Prioritisation: M= 35.74; Acute vs. Chronic: M= 35.13), than those who did not (Lack of Prioritisation: M= 36.51; Acute vs. Chronic: M= 36.50). Reflecting upon the items within the PKBQ, the items do not explicitly link to prioritisation or consideration of pain, which may explain why there was not a similar pattern in mean PKBQ scores as observed in relation to the other subthemes.

As descriptive analysis suggested there were observable differences between mean scores within each differentiating subtheme, T-Tests were carried out with each of the subthemes in Table 8.5.

8.3.2 T-Tests: PKBQ scores & differentiating subthemes

T-Test parametric assumptions were checked prior to analysis. The normality of the data distribution was acceptable based on a visual analysis of Q-Q plots and Shapiro-Wilks tests. Homogeneity of variance was also tested, and this assumption was satisfied. Levene's Test of Equality of Variances indicated no significant variance between the 'theme present' or 'theme absent' groups (Appendix I(C)).

The results of each T-Test are summarised in Table 8.5. All T-Test returned non-significant results, indicating that the presence of each subtheme had no significant relationship with PKBQ scores. While the T-Tests indicate mean differences observed were not statistically significant, the tentative suggestions made (Section 8.3.1) are worthy of further exploration. In culmination the endorsement of particular views or understandings of dementia (such as those demonstrated in subthemes) may be facilitators to supporting caregivers' understandings and beliefs about pain in dementia and may have implications for the content of training or other interventions which endeavour to improve such or caregivers' practices.

8.4 Summary: Quantitative survey findings

Study 2 aimed to collect further data and reach more caregivers to compliment and extend findings from Study 1. The previous chapter discussed the findings of the qualitative element of the survey implemented, and the current chapter has presented the results of quantitative element (The Pain Beliefs & Knowledge Questionnaire, Zwakhalen et al., 2007).

Quantitative findings indicated that all caregivers shared some knowledge deficits and endorsed maladaptive beliefs in relation to pain among older people and PwD, and its assessment and treatment. This was particularly so in relation to the scheduling, use and side-effects of pain medication among older adults and PwD. This mirrored qualitative survey responses (and those in Study 1) in which uncertainty (and reluctance) surrounded the use the pain medication. Informal caregivers had the least optimal knowledge. The majority endorsed ageist views of pain, again consistent with qualitative survey responses. Mean PKBQ scores indicated those caregivers with less years' experience providing care, and those in roles not requiring professional preparation, demonstrated more optimal understanding and less maladaptive beliefs. As such, neither hypotheses (Section 4.8.1) proposed were supported by the quantitative findings. ANOVA testing indicated differences between roles were statistically significant, with those in management roles, performing most optimally, with IFCs, and nursing students preforming least optimally. Analytical integration by way of exploratory T-tests revealed a descriptive relationship relationship between caregivers' understandings and beliefs (PKBQ scores), and caregivers' endorsement of particular subthemes. However, these relationships were not statistically significant.

The quantitative findings presented in this chapter are brought together, alongside qualitative survey findings and those from Study 1, in the following chapter. An integrated discussion of Study 1 and 2 is provided, with reflection on existing literature reviewed early in this thesis.

Chapter 9-Discussion: Integrated discussion of Study 1 & Study 2

9.1 Introduction

This chapter draws together the empirical findings from Study 1 and 2 with an integrated discussion. Both qualitative and quantitative findings are considered in conjunction with the literature reviewed in chapters 1 and 2, to identify similarities and differences in the data, and determine the contribution to knowledge that the findings from this thesis makes to the body of knowledge exploring pain in people with dementia. Following this, the methods used are reflected upon considering strengths and limitations, alongside a consideration of whether the research meets quality criteria relating to qualitative research. To conclude, this chapter discusses the implications of the key findings of the study and proposes ideas for further research to build upon the findings from this study to further expand the evidence base. To begin with and place this study within context of existing research, a brief recap of the aim and purpose of this thesis is provided.

This thesis aimed to explore the experiences of informal caregivers (IFCs) and care home (CH) staff supporting people with dementia (PwD), to identify how caregivers recognise, assess, and treat pain among this population. From a review of the literature four research questions were developed (Section 3.2) as a framework to guide the research. These questions focused on the challenges, processes and contexts underpinning caregivers' recognition, assessment, and management of pain among PwD (research question 1-2). They were further centred on establishing caregivers' understandings and consideration of pain among PwD (research question 3-4). To answer these research questions, a pluralist mixed method approach encompassing two empirical studies was adopted- Study 1 Interviews- and

Study 2 Mixed methods survey. The findings from both empirical studies presented earlier in Chapters 5-8 are revisited in the subsequent section in an integrated discussion with the literature. This integrative discussion is structured around key qualitative findings, followed by a section discussing the quantitative findings and how these build upon the qualitative findings.

9.1.1. Contribution to knowledge

This thesis is among the first mixed methods investigation into pain recognition, assessment, and management for people with dementia, living in CHs (alongside Corbett et al., 2016). As highlighted by the literature review (see Section 2.2.2), prior research exploring this topic has been limited and has tended to draw from small in-depth qualitative works. Although the literature base has developed in recent years to overcome some of these limitations and issues of methodological quality (see Section 2.2.1), the studies carried out in this thesis represent a larger scale and a shift towards obtaining a more diverse and arguably holistic viewpoint.

CHs are heterogenous environments (Luff et al., 2011; 2015), as are the levels of training received by staff within (see Section 1.2.2.1), as such collecting data from six different care homes offers more representative and applicable findings beyond the scope of previous studies conducted to date. The current studies illuminate the issues around pain as it occurs in the everyday of the CH environment, which may differ from those identified in hospice settings or relating to end-of-life care (Brorson et al., 2014; De Witt Jansen 2017a, 2017b, 2018; Midtbust et al., 2018) and those in acute care contexts (Lichtner et al., 2016; Dowding et al., 2016) (discussed further in Section 2.6). Moreover, as a study conducted in the UK, it represents an important contribution to the literature base dominated in the main by US, Canadian and Australian research.

The current studies took an all-encompassing approach to sampling within CHs. Prior work has focused primarily on registered or licensed nursing roles (e.g., Kaasalainen et al., 2007; Chang et al., 2011; Gilmore-Bykovksyi & Bowers, 2013; De Witt Jansen et al., 2017b), as discussed in Section 2.6. Responding to such, other papers have focused on unregistered roles, such as nursing assistants (e.g., Lui, 2013; De Witt Jansen et al., 2017a). The current studies, however, are a timely response to calls for studies that elucidate the range of different roles involved in the pain assessment and management process (De Witt Jansen et al. 2017b), and those most often confronting pain in their daily care provision (Andrews et al., 2019). The importance of this all-encompassing approach is amplified by the increasing dominance of HCAs roles in UK CHs and the recent introduction of the nursing associate role (and similar roles outside the UK) (see Section 1.2.2.1). It is recognised that any responses to address pain in CHs needs to be informed by all relevant stakeholders' input (Corbett et al., 2016), which the current studies contained in this thesis provide.

This study incorporated a quantitative aspect, in the form of the Pain, Knowledge and Beliefs Questionnaire (Zwakhalen et al., 2007), to explore current understandings of pain, its assessment and treatment among CH staff and IFCs. Previous UK studies exploring such (Barry et al., 2012; Burns & McIlfatrick, 2015), have focused primarily on either managerial or registered nurse roles and have not included the views of other formal roles or IFCs. As such, the current studies serve to break new ground as the first attempt to explore understanding among these groups from a quantitative perspective, outside the remit of studies that have attempted to explore this following educational interventions (e.g., Ghandehari, et al., 2013; Petyaeva et al., 2017). Given that inadequate understanding and misconceptions about pain and its treatment, are considered perpetuators of ineffective pain assessment and management (Geddis-Regan et al., 2019; May & Scammell, 2020; Jonsdottir & Gunnarsson, 2021), the relevance of the current findings are significant in contributing to the literature base and in the context of training and support for those providing care to people with dementia (see Section 9.4.1.).

As discussed in Section 2.6, the experiences of IFCs in supporting those with dementia in pain have rarely been considered. Studies that have considered this perspective have almost exclusively done so within the context of long-term environments (e.g., Mentes et al., 2005; Corbett et al., 2016), in which IFCs are not the primary caregivers responsible for pain assessment and treatment among those with dementia. The experiences of family, relatives and other IFCs in this context, are likely unrepresentative of those IFCs providing care for PwD living in the community. Until recently (Bullock et al., 2020), there had been no study to directly explore the experiences of IFCs supporting PwD living in the community with their pain, as done in the current studies. The literature on medication management (Section 1.6.2), alongside the limited literature available on IFCs regarding pain (Section 2.5.5), suggest that IFCs are likely to have a significant part in supporting those with dementia with their pain. This thesis provides insight into the experiences and perspectives of IFCs who act as the primary source of support for a person with dementia, in respect to how pain is recognised, assessed, and treated. With an increasing ‘professionalism’ of the role of IFCs and their role in advocacy for those they support (Wittenburg et al., 2019a; Glasby & Thomas, 2019), this is also an important contribution in the context of identifying the challenges they experience and support needs, in accordance with the drivers of national dementia policy (e.g., Department of Health, 2009; National Institute for Care & Excellence, 2018).

The literature base has developed since the commence of the two studies conducted (Section 2.2.1). As such, the current studies are an addition to this evolving literature base, particularly extending UK studies from Corbett et al. (2016) conducted in CHs, and a recent qualitative study from Bullock et al. (2020) with IFCs. Beyond those already discussed, is the potential contribution of the current findings to inform future pain practices and developments, training, and further research (Section 9.4), and the lessons learnt from critical reflection on the process of undertaking this research (Section 9.3). Such is discussed further below within the context of the wider literature reviewed in Chapter 1 and 2.

A final consideration is to the contribution of this thesis in respect to method. This thesis utilised a new form of analysis of brief text gathered from surveys; Structured-Tabular Thematic Analysis (Robinson, 2020). There is value in demonstrating how this method could be applied to qualitative data, the findings that this method can yield, and how it can be used to support a novel approach towards the integration of qualitative and quantitative datasets. With the increasing recognition of the benefits of using survey, online and other diversified approaches to collecting brief qualitative data (e.g., Terry & Braun, 2017), this thesis may serve as an exemplar of ST-TA as an analytical approach to qualitative and mixed-methods research designs.

9.2 Integrated discussion & reflection on the literature

9.2.1 Pain & existential suffering: Overlapping concerns

Pain and its treatment were not a main priority for concern. For caregivers, physical pain was secondary to competing care needs, including the management of symptoms related to dementia and personal care. This is in accordance with qualitative studies describing pain as low on the agenda in CHs, and dismissed by nurses and physicians (Kaasalainen et al., 2007; Corbett et al., 2016; Halifax et al., 2018). A comparative lack of engagement with pain and an emphasis on task-orientated aspects of care has been described by some HCAs in the literature (Liu, 2014; De Witt Jansen et al., 2017a). This may be underscored by a perception of pain as an addition to meeting basic needs, or an ’overshadowing’ of pain by dementia (Tolman & Denning, 2018). Previous studies have highlighted the emotional and physical demands of supporting those with dementia (Etters et al., 2008; Edvardsson et al., 2008). Caregivers may therefore need to prioritise particular care needs to manage, delineating between 'should do' and 'must do' tasks (Bowers et al., 2001). In contrast with the present findings, qualitative studies with nurses and HCAs providing end-of-life care to those with advanced dementia have described pain and facilitating its relief as a priority concern and essential aspect of their role (Brorson et al., 2014; De Witt Jansen et al., 2017b). This suggests issues of persistent pain that are 'lived with' need to be reconceptualised and put on a par with the way that pain during death and dying is assessed and treated.

In contrast to physical pain, existential suffering was a central preoccupation amongst all caregivers, with care focused on supporting those with dementia both emotionally and socially. Consistent with other studies (Karlsson et al., 2013; Karlsson et al., 2015; Vaismoradi et al., 2016), pain was related to human suffering encompassing mind, body, and soul, and gave rise to empathy among all caregivers. Existential pain arising from ageing, deteriorating health, dependence, and dementia, has been described as intensifying physical suffering (Karlsson et al., 2015; Vaismoradi et al., 2016). Physical pain has been reflected upon as easier to identity and treat compared to some of the more emotive aspects (Cohen-Mansfield & Creedon, 2002; Karlsson et al., 2013), however, it may be challenging for caregivers to distinguish between the two, given an overlap in how these may be expressed non-verbally. Within CHs, a focus on existential pain may reflect a care-foci, where the basis for interactions is relational, rather than treatment orientated (Gilmore-Bykovski & Bowers, 2013). As such, there may be an overall concern with wellbeing given the emotional impact upon shared relationships. In line with this, physical and psychological pain among those with dementia gives rise to 'secondary suffering' among IFCs, and distress among nursing assistants (Holloway & McConigley, 2009; Tarter et al., 2016). These findings illuminate an acute sensitivity to existential pain which, if honed within the context of physical pain, may lead to a more balanced consideration of both the physical and non-physical aspects of suffering.

9.2.2 Deciphering ementia: Complimentary strategies

Caregivers used multiple, often complimentary strategies to identify pain in the presence of dementia and declining cognitive capacity. These strategies were consistent with those observed within the literature; they included communication and dialogue (Karlsson et al., 2015; Corbett et al., 2016), observing non-verbal signs and behaviour change (Mentes et al., 2005; Liu et al., 2011; Bullock et al., 2020), touch/examination during personal care (Liu, 2014; De Witt Jansen et al., 2017a), intuitive and experiential perception (Parke, 1998; Lichtner et al., 2016) and relationship-centred assessment through familiarity (Karlsson et al., 2013; Corbett et al., 2016).

Through these strategies, caregivers were able to negotiate challenges arising in one domain (e.g., communication) by working through alternative approaches. Qualitative studies have emphasised the importance of using diverse non-verbal approaches to support caregivers to ‘build a picture’ of pain, particularly when verbal communication has diminished (Monroe et al., 2015; Geddis-Regan et al., 2018). These strategies appeared to support caregivers to view pain multidimensionally, an approach that integrates pain communication, behaviour, and assessment (Blomqvist & Hallberg, 2001; Snow et al., 2004). A more inclusive approach helps to overcome the challenges of relying primarily on verbal communication or external ratings when assessing pain in dementia (Snow et al., 2004); either potentially resulting in the underestimation (Apinis et al., 2014) or underreporting of pain (Snow et al., 2009). It is therefore important that caregivers have the knowledge and ability to reference multiple sources of information to improve their overall recognition of pain.

Caregivers had an in-depth understanding of verbal and non-verbal signs and changes (behavioural, physical and mood) indicative of pain that underpinned their observations of non-verbal/bodily narratives. These indicators were consistent with those identified in guidelines (Schofield et al., 2018), and support previous observations that staff informally incorporate strategies of pain assessment into their practices that are congruent with aspects of more formal approaches (Liu, 2014; De Witt Jansen, 2017a; De Witt Jansen et al., 2017b). Observation was incorporated into daily care interactions by CH staff and IFCs, particularly during personal care. Nursing assistants have previously reflected upon the usefulness of physical examination during daily care talks to identify changes indicative of pain (Karlsson et al., 2012; De Witt Jansen et al., 2017a), as have family caregivers to gather pain information (Bullock et al., 2020). By integrating observation opportunely as a synchronised aspect of daily care, this may have simplified pain assessment for caregivers and overcome barriers to pain identification raised in the literature, such as a lack of time (Fox et al., 2004; Barry et al., 2012), and resistance among those with dementia to physical examination (Chang et al., 2009; De Witt Jansen et al., 2017b). It may further allow pain to be observed at different times and during physical activity, where it may be most likely to emerge (Herr et al., 2019).

Importantly, these findings extend our understanding of the strategies used by IFCs to identify pain among those with dementia living in the community and previously explored in only one UK study (Bullock et al., 2020). IFCs drew upon a skill set consummate to formal caregivers, supporting findings that they develop a ‘common sense’ approach to identify pain and an awareness of behavioural changes (Bullock et al., 2020). This is an important contribution given the role of IFCs in respect to their potential roles as pain assessors, advocates, and pain managers (Section 1.6.2), and the lack of research engaging IFCs with regards to pain (Section 2.8).

In accordance with models of unmet needs in dementia (Algase et al., 1996; Cohen Mansfield, 2000; Kovach et al., 2005), behaviour and mood were recognised as having an interpretable communicative and symbolic meaning by caregivers, from which pain could be identified. Many caregivers, however, expressed uncertainty in their abilities to identify pain and distinguish pain from dementia-related behaviours and other needs. This was despite demonstrating skills and examples of good practice. Previous authors have observed this apparent disjunct, with CH staff and nurses clearly describing relevant approaches to identify pain, while reflecting with ambiguity on pain, and a lack of confidence and ownership (Kovach et al., 2000; Corbett et al., 2016). Family caregivers have similarly reflected upon the challenges of determining when ‘something else was going on’ with their loved ones (Bullock et al., 2020).

Dementia was perceived an intensifying the challenges of identifying pain, requiring ‘guess work’ and a process of elimination. This finding is reflected in previous qualitative studies in which nurses have described the identification of pain as ‘detective work’ (Monroe et al., 2015) and ‘trial and error’ (Lichtner et al., 2016) that may lead to pain being unidentified, misattributed, or delayed/no treatment provided (Kaasalainen et al., 2007; Gilmore-Bykovksyi & Bowers, 2013). Caregivers’ uncertainty may reflect the challenges of identifying pain when typical pain behaviours are often not present in dementia, and pain may manifest subtly or unexpectedly (Kaasalainen, 2007; Herr et al., 2019). Moreover, behaviour may not be specific to pain, and could be related to other issues, such as infection, or indeed dementia itself (Zwakhalen et al., 2018). Caregivers were preoccupied with dementia as the primary driver of behaviour (particularly that which was idiosyncratic), likely underpinned by a primary focus on dementia-related care needs. In accordance with this, the literature has described a tendency for nurses and long-term care staff to attribute behaviours among those with dementia to the behavioural and psychological symptoms of dementia, pain being considered latterly, after symptoms of dementia, or diagnosed conditions (Kovach et al. 2000; Kaasalainen et al., 2007; Peisah et al., 2014). The inability of nurses to see past diagnosis has previously been described as a ‘trained incapacity’ (Cohen-Mansfield & Creedon, 2002). Dementia may preclude further investigations of pain-related behaviours and mask the identification of pain. In potentially misappropriating pain-related behaviours to dementia, agitation, confusion, and behavioural symptoms of dementia may be exacerbated (Flo et al., 2014). Furthermore, mismanagement with psychotropic medication may occur (Kovach et al. 2000; Kaasalainen et al., 2007). This may lead to an overall escalation of care needs and suffering. In acknowledgement of the importance of this issue, guidance emphasises the need to consider pain as a driver of behavioural and psychological issues, especially prior to the administration of psychotropic medication (NICE, 2018). The current findings suggest that dementia and associated behavioural and psychological symptoms may be commingled and confused with pain.

9.2.3 The value of the person-centred approach

The current findings suggest an awareness of the importance of a person-centred approach to pain (Hicks, 2000; Brooker & Latham, 2016; Buron, 2008). Person-centred care is advocated as best practice in dementia (QCC[2]; NICE, 2018), as an approach to care that is needs driven, and aimed at understanding and meeting humanistic and individual needs (Kitwood, 1997; Brooker & Latham, 2016). Caregivers reiterated the importance of dyadic familiarity and relationship-centred pain assessment. This is described consistently in the literature as essential for creating trust, an intuitive sense of pain, and an in-depth understanding of unique pain-related behaviours (Parke, 1998; Karlsson et al., 2015; Lichtner et al., 2016; Corbett et al., 2016; Tarter et al., 2016). In adopting the view of the individual and the individuals' pain, caregivers were able to identify pain from the perspective of the person with dementia and from a contextualised understanding. This is consistent with findings that CH staff and relatives of those with dementia develop- that of an in-depth understanding of those they support, their pain conditions and their pain expressions (Mentes et al., 2005; Corbett et al., 2016). This is particularly salient given that caregivers often described behaviour change as a key indicator of pain, which may only be identified by those with an understanding of usual behaviours and the meaning of behaviours (Kovach et al., 2000; Mentes et al., 2005).

Familiarity with an individual's needs also supports nursing assistants and CH staff to tailor their care and pain treatment responses to the ‘likes and dislikes’ of those with dementia (Liu, 2014; Corbett et al., 2016). Relationship-centred assessment may therefore have concurrently facilitated caregivers to identify pain more readily and to respond with treatment in line with the preferences of an individual. This is in an accordance with the view that positive, reciprocal relationships allow caregivers to relate to, and understand pain among those with dementia, as an extension of their acknowledgement of their unique identities and personhood (Malloy and Hadjistavropoulos, 2004).

A relationship-centred approach is contingent on sufficient time with individual care home residents. The literature has reflected upon a lack of time and continuity of care as barriers to the development of familiar relationships and a relationship-centred approach to pain assessment (Martin et al., 2005; Karlsson et al., 2015; Dowding et al., 2016). Some CH staff did reflect upon a lack of time to sit and be with residents, due to increasing administrative tasks or a removal from direct patient care. They also reflected on potential challenges among those with dementia who had not been in the CH for a lengthy period of time. Concurrently, Monroe et al. (2015) found nurses were concerned that those with dementia not well known to them would have their pain inadequately identified, and consequently treated. Ensuring care contexts are conducive to familiar relationships and time may be feasibly challenging considering the wider context of CH environments and workload demand upon these workforces (Section 1.2.2.1) (McAuliffe et al., 2009).

9.2.4 Stoicism in the face of pain: A culture of concealing pain or a positive coping strategy?

Those with dementia were described as stoic in their responses to pain, refusing to communicate their pain, and accept help and intervention. Qualitative studies have similarly found older people and people with dementia are described as minimising, denying, and concealing their pain, impeding the ability of staff and family caregivers to assess and manage pain (Clark et al., 2004; Martin et al., 2005; Mentes et al., 2005). Vaismoradi et al. (2016) suggested that a culture of stoicism in NHs among both staff and older people alike ‘normalises suffering’, perpetuating older adults’ unwillingness to communicate their pain. They suggested conceptualisations of pain and ageing need to be altered, to encourage older people to report their pain and staff to take these reports seriously. The communications model of pain emphasises how the responses of caregivers may shape the pain communications provided by a sufferer of pain, and vice-versa (Hadjistavropoulos & Craig, 2002; Hadjistavropoulos et al., 2011). This reiterates that caregivers may be able to take a lead on encouraging more open pain dialogue through reflection on their own views towards pain and their responses to those they support.

While stoicism was framed as a negative attitude in the context of identifying pain, it was often framed as a positive coping strategy by IFCs who appeared to share consummate views regarding ‘going through’ pain described by older people (of which most IFCs were) (Clarke et al., 2012). Older adults have previously described stoicism as a coping mechanism to maintain a sense of control and independence over their pain and its treatment (Gammons & Caswell, 2014). It was unclear in the current studies as to how caregivers differentiated between stoicism and a declining ability to communicate pain. A lack of cognitive capacity is recognised as impeding both self-report and compliance to pain relief (Karlsson et al., 2016; Tarter et al., 2016). As such, it is possible that stoicism may have been assumed when cognitive capacity was in decline.

9.2.5 Communication vs. Cognitive Decline

All caregivers reflected upon the importance of communication and dialogue in identifying pain. Previously, self-report has been described as the 'most meaningful assessment route' where possible among those with dementia (Corbett et al., 2016) and as the foundation of pain assessment (Karlsson et al., 2014). However self-report is contingent on language. Caregivers highlighted the frequent inability of those with dementia to verbalise, recall pain, and use/understand language. This is an accordance with findings that neuropathological changes may result in a loss of semantic memory, detracting from the ability of those with dementia to describe pain (Benedetti et al., 2004; Oosterman et al., 2014). Reduced or altered communication has consistently been identified in the literature as a barrier to the assessment of pain (Geddis-Regan et al., 2018), with family caregivers and NH staff questioning whether those with dementia are able to provide accurate and reliable responses (Martin, et al., 2005). Caregivers also questioned, often IFCs, the authenticity of over-exaggerated pain reports and responses, that appeared dissonant and disproportionate to the cause of pain. Family caregivers have described the challenges of differentiating between real and imagined pain (Tarter et al., 2016), reflecting upon some responses as dramatic (Mentes et al., 2005). While evidence does suggest that those with dementia may experience an amplified pain experience (Stubbs et al., 2016), caregivers appraised over-reactivity as a behavioural or psychological issue. Prior research suggests that pain which is perceived as exaggerated is attributed to older adults' poor coping mechanisms, giving rise to a lack of empathy from nurses (Blomqvist, 2003). The impact of dementia upon pain communication, experience and expression have previously been explored physiologically (Section 1.3.4). These findings provide some experiential insight into how these changes may be responded to by caregivers.

As a result of communication challenges nurses and family caregivers have described a shift away from self-report and 'traditional methods' of pain assessment (Parke, 1998; Chang et al., 2009; Krupić et al., 2018). However, in the current studies, caregivers continued to communicate with those with dementia about pain and attempt self-reports. They (re)conceptualised language and communication to be more inclusive than that of the formal spoken word, facilitating communication. Comparably, acute care staff and family caregivers have described interpreting words into terms people with dementia can understand and making up shared languages (Lichtner et al., 2016; Tarter et al., 2016). An emphasis on maintaining communication is in accordance with current guidance (Herr et al., 2011; Schofield, 2018), and findings that even those with advanced symptoms may be able to self-report their pain (Pautex et al., 2006). Communication may serve to involve the care recipient in their care, despite their declining self-report capacity (Karlsson et al., 2014).

9.2.6 Formal pain assessment

Formal approaches to pain assessment by way of self-report and observational pain assessment tools (PATs) were perceived as having limited value to caregivers. In contrast with previous survey and qualitative findings (Barry et al., 2012; De Witt Jansen et al., 2017a), many nursing students and CH staff were aware of PATs, being a common feature in care plans in their workplaces. While this suggested an increasingly awareness of PATs, this did not appear to translate into practice, consistent with recent findings of a European survey identifying poor uptake and usage of PATs across care settings (Zwakhalen et al., 2018). Caregivers reiterated the strategies described earlier as a reflection of the skills they possessed and the relative usefulness of PATs in comparison. Nurses and physicians have indicated OPATs offer no ‘added value’ to the holistic evidence base they already used to identify pain (De Witt Jansen et al., 2018). Caregivers raised some concerns consistent to those in the literature, such as the specificity of OPATs to pain behaviours (Liu et al., 2014) and the ability of PwD to use self-report PATs (Karlsson et al., 2015). However, they did not reflect upon a lack of time or clinical relevance as identified by previous authors (Liu et al., 2014; Lichtner et al., 2015), suggesting more positivity towards these methods than is represented in the current literature. Some HCAs, comparably to the findings of De Witt Jansen et al. (2017a), expressed some interest (supported by senior staff) to be involved in formal pain assessment. HCAs may be well placed to be more involved in these processes (Fisher et al., 2002; Herr et al., 2011). Surprisingly, a few IFCs also suggested they might consider using a self-report scale with those they supported. Findings suggest that with guidance, lay people can effectively use OPATs (Ammaturo, Hadjistavropoulos, & Williams, 2017). This suggests there may an interest and consummate skill set that could support the integration of PATs as a tool available to IFCs. Such may support family caregivers who express there is *“no guide”* to support them in identifying pain (Bullock et al., 2020, p. 7).

The integration of PATs can enhance detection of pain (Apinis et al., 2014), as such formalised approaches remain necessary as a prerequisite for effective pain treatment (Achterberg et al., 2020). It is therefore important these tools are integrated into care settings, not only through a presence in care plans but in practical terms. Dowding et al. (2016) proposed that PATs have been developed with a view of pain assessment that does not account for more intuitive, subconscious approaches, characteristic of the preferred strategies highlighted by caregivers currently, and in the wider literature. It has been suggested that for PATs to be integrated into care successfully, it needs to be done in such a way that works with informal strategies (De Witt Jansen et al., 2018). Incorporating formal and informal strategies as complimentary approaches would not only optimise on apparent skills, it may also further improve negative perceptions and perceived utility (De Witt Jansen et al., 2015; Zwakhalen et al., 2018).

9.2.7 Views on drug treatments & non-drug treatments

The limited nature of pain treatment provided to those with dementia, and the wide-ranging concerns to be considered in using drugs among this group, was commonly reflected upon by participants. Caregivers were concerned about tolerance to medication, and risks of exacerbating dementia symptoms. These views are consistent with those identified in the literature, in which staff and family caregivers describe selecting appropriate analgesic relief as complex and restricted, (Martin et al., 2005; Lichtner et al., 2016), and with dementia considered an additional risk factor (Chang et al., 2009). The number of medications those with dementia were taking was also a concern, with caregivers and those with dementia reticence to introduce pain relief as an additional medication. Prior research supports this, finding physicians, family caregivers and those with dementia consider analgesia to be *"over and above"*" the large number of medications already taken (Bullock et al., 2020, p. 9). Studies suggest older people are reluctant to take multiple medications and prioritise medication for comorbid conditions viewed as more important (Crowe, Gillon, Jordan & McCall, 2017; Sale et al., 2006; Makris et al., 2015). These findings highlight the unique challenge of prioritising pain treatment in dementia in line with competing conditions requiring regular treatment. Certainly, side-effects, comorbidities, and polypharmacy need to be considered when managing pain (Aza et al., 2013; Achterburg et al., 2020), however, caregivers' concerns made them risk-adverse and reluctant to medicate. The concerns expressed likely contribute to the disparity of pain medication received by those with dementia compared to those without (Reynolds et al., 2008), and the wider challenges of the continued undertreatment of pain amongst the ever- increasing ageing population (Dunham et al., 2020).

Among CH staff and nursing students, concerns regarding drug treatment of pain among residents with dementia were consistently engrained across all roles, irrelevant of role or experience. In an ethnographic study, Harmon et al. (2019) found acute care nurses developed shared, culturally medicated pain practices that were informed by shared consensus, rather than evidence-based pain practices. It is possible that such concerns were shared views that fed into potentially suboptimal responses to pain. An apparent non-use of protocols or guidance to guide analgesic choice, dosage, and escalation likely compounded these concerns (e.g., WHO analgesic pain stepladder, Ventafridda & Stjernsward, 1996; Aza et al, 2013). The literature has consistently identified a need for training on pain and pharmacological pain interventions in dementia (Corbett et al., 2016; De Witt Jansen et al., 2017a; De Witt Jansen et al., 2017b). Furthermore, current available evidence-based guidelines only exist for the older adult population and not specifically for those with dementia (e.g., Aza et al., 2013; Schofield et al. 2018). With medication awareness training unregistered CH staff can support medication administration in CHs, alongside nurses. These findings are an important reflection on this training and its inclusivity of medication related to pain, and the expansion of unregistered roles in the management of pain.

Within the current studies, ‘as needed’ paracetamol was the mainstay response described by caregivers, suggesting limited routine usage or prescription of alternative options. This is consistent with qualitative findings in which paracetamol is described as a first-line approach to pain management in dementia by nurses (Kovach et al., 2000), CH staff (Corbett et al., 2016), and IFCs (Bullock et al., 2020), given its perceived safety. Audits of medication used among CH residents confirm that simple analgesia is the primary response to pain among residents with dementia, and they receive NSAIDs and opioids less commonly (Barry et al., 2014; Andrews et al., 2019). Caregivers' reliance on paracetamol also appeared to be underscored by physician resistance. Senior CH staff reflected on their unwillingness to escalate doses and diversify forms of pain relief prescribed. Nurses have previously reflected upon their dependency on physicians to obtain appropriate pain relief prescriptions for those with dementia and incidents of suboptimal and delayed prescriptions (Martin et al., 2005; Brorson et al., 2014; De Witt Jansen et al., 2017b). The findings suggest that stepwise escalation of pain treatment was not followed either by those prescribing pain relief or in its administration by caregivers, as recommended as the most optimal and safe response to managing pain (Aza et al., 2014; Dunham et al., 2020). In accordance with previous findings describing analgesic use in long-term care as ‘ad hoc’ and unsystematic (Peisah et al., 2014), there also appeared to be no follow-up to monitor side-effects or efficacy.

A recent review of the evidence suggests that the long-term use of paracetamol among older people may be associated with significant adverse events (Dunham et al., 2020). Moreover, it may not be effective for treating chronic pain (Dunham et al., 2020), which is a concern given the population of those with dementia living with painful comorbidities and pain conditions (Denard et al., 2010; Pablador-Plou et al., 2014). These findings suggest that while caregivers aired on the side of caution in using paracetamol, they may have inadvertently been undermanaging chronic pain issues and risking patient safety with long-term reliance.

Caregivers generally preferred to use non-drug options to relieve pain or provide comfort. Indeed, the literature has documented positive views towards non-drug methods and regular use among nursing home residents and people with dementia (Newton et al., 2014; Bullock et al., 2020), family caregivers of those with dementia (Martin et al., 2005; Bullock et al., 2020), and nursing home staff (Barry et al., 2012; McIlfatrick & Burns, 2015; Midtburst et al., 2018). Caregivers’ use of non-drugs appears to relate to many of the advantages reported in the literature, including being personalisable (Liu, 2013), the ability to use them in 'trial and error' to address pain and pain-related behaviours (Gilmore-Bykovsky & Bowers, 2013), and the avoidance of analgesic medications (Geddis-Regan et al., 2018). However, potentially new insight was caregivers’ reflections regarding resistance to touch, heat, and movement among some PwD. This suggests some consideration needs to be given to the potential practical limitations of using non-drug methods in advanced dementia.

Other studies have found that non-drug approaches are not usual in CHs (Corbett et al., 2016), with staff describing these methods as time consuming and ineffective (Petyaeva et al., 2017). However, in contrast to this, CH staff in the current studies had integrated non-drug approaches into their care interactions, with HCAs often leading on these approaches. Previous qualitative studies have observed that nursing assistants adapt their care and incorporate non-drug approaches, such as gentility and distraction, to prevent triggering pain (Karlsson et al., 2013; Liu, 2013). These findings suggest non-drug methods are amenable and adaptable for staff of different experiences or training. As discussed in section 2.7.2, this suggests HCAs may often be involved in managing pain as an aspect of daily care.

Interim Summary

The current findings are consistent with recommendations highlighting the need to take a person-centred approach to pain treatment through individual needs assessment and non-drug approaches, before responding with drug interventions (Abdulla et al., 2013). Moreover, adopting simple non-drug measures may reduce behavioural and psychological symptoms of dementia (Corbett et al., 2016) and play a role in reducing the analgesic burden and drug usage. However, the current findings suggest that non-drug approaches were used as a substitute for drugs, rather than as a complimentary approach to be used in tandem (Aza et al., 2013). In accordance with this, most interventions documented for NH residents with dementia are recorded as non-drug approaches only (Andrews et al., 2019), with combined approaches used in only 10% of audited incidents (Liu & Leung, 2017). This suggests a capacity to further explore non-drugs methods in practice, upskill caregivers (and perhaps PwD) in more creative or formal approaches, and emphasise these approaches as adjunctive (rather than replacements) to drug approaches.

9.2.8 Pain treatment in the context of care home hierarchies and roles

The findings indicate that within care homes, the process of recognising, assessing, and treating pain is contingent upon a hierarchy of roles and a collaborative team approach. Previous research has reflected upon the central role of communication and effective multi-disciplinary teamwork to 'build a picture of pain' to inform pain assessment and treatment (Fox et al., 2004; Corbett et al., 2016; Dowding et al., 2016). HCAs most often identified pain, reporting it to senior CH staff, initiating investigations, and informing treatment decisions. This is consistent with nurses' reflections on their dependence on the observations of HCAs to identify pain (Karlsson et al., 2015), and descriptions of this role as the eyes of nurses, gatekeepers, and perfectly positioned to identify pain (Holloway & McConigley, 2009; Karlsson et al., 2013; Liu, 2014). These findings are in contrast with other research, in which HCAs have expressed a reliance on nurses to assess pain, given a lack of confidence and skills to assess pain themselves (Corbett et al., 2016; De Witt Jansen et al., 2017a).

Some HCAs and non-direct care roles did reflect upon the challenges related to their role and pain communications with more senior staff. Similarly, to the experiences captured in the literature (Fox et al., 2004; Lloyd, Schneider, Scales, Bailey & Jones, 2011; De Witt Jansen et al., 2017a), HCAs described dismissal and depreciation of their role; their reports of pain received with varying receptivity. Previous qualitative studies suggest the experiences of HCA may be related to a lack of credibility and professionalism associated with the role and a negative work identity (Fox et al., 2004; De Witt Jansen et al., 2017b; Holloway & McConigley, 2009). Dysfunctional team dynamics may impact not only staff experience and patient care (Lloyd et al., 2011), but further upon HCAs engagement in pain identification its monitoring and subsequent reporting to senior staff (De Witt Jansen et al., 2017a). Previous research suggests HCAs are effective in recognising pain and that formal assessment of pain benefits from both the input of direct and nursing staff (Fisher et al., 2002; Ersek, Herr, Neradilek, Buck & Black, 2010). Moreover, the HCA role is expanding (Section 2.7.5), and inclusive working practices and effective collaboration are emphasised in dementia health and social care policy (NICE, 2018). The experiences of HCAs in the current studies suggest that senior staff were not optimising on or acknowledging the role and input of HCAs, which runs counter to effective working practices and the benefits of their inclusion within the pain communication channels.

Interestingly, senior CH staff did not express any tensions between themselves and HCAs or indirect care staff. They did, however, express dismissal of their input from physicians and other visiting healthcare providers. Certainly, challenging relationships between nurses and physicians have previously been reported as a barrier to effective pain treatment in dementia (Barry et al., 2012; Brorson et al., 2014; De Witt Jansen et al., 2017b). Although the views of physicians were not explored in the current work, other studies suggest this may occur due to different priorities and concerns, and physician distrust of nurses' assessments

(Kovach et al. 2000; Martin et al., 2005; Brorson et al., 2014; Peisah et al., 2014; De Witt Jansen et al., 2017a).

In culmination, the experiences of senior CH staff and HCAs indicate that negative working relationships consequently impact appropriate pain treatment in care homes (Peisah et al., 2014; Corbett et al., 2016). This study has made an important step and has reflected upon pain identification, assessment, and treatment as a holistic process in 'real life' (Corbett et al., 2016) from the perspectives of different staff roles. These findings extend current conceptualisations of pain communication and clinical decision making that have articulated the importance of organisational culture, and social and environmental determinants in shaping how pain is identified and assessed (Snow et al., 2004; Hadjistavropoulos et al., 2011; Dowding et al., 2016).

A significant omission in the hierarchy of roles described by CH staff was the role of family caregivers. In previous qualitative work, staff have described close working relationships with family caregivers, referring to them as key players within the pain communication channel (Corbett et al., 2016) and messengers on behalf of those with dementia (Lichtner et al., 2016). This is in accordance with recommendations that emphasise gathering individualised information and by-proxy input from family when assessing and treating pain among those with cognitive and communicative impairments (Fisher et al., 2002; Herr et al., 2019). In contrast with this, CH staff and nursing students (except for one interviewee) did not describe any liaison with family members regarding treating pain or acknowledge their contributions to pain communication channels. This is consistent with experiences of 'not being heard' expressed by relatives of CH residents in the literature (Barry et al., 2015; Corbett et al., 2016). These findings suggest CH staff and nursing students were failing to utilize information on previous experiences of pain, behaviours, and life history, that CH staff and nurses as recognise as important in helping them to identify pain and respond in accordance with individual preferences (Fox et al., 2004; Brorson et al., 2014; De Witt Jansen et al., 2017a). As such, there may have been missed opportunities to enrich their treatment responses from a person-centred perspective (Buron 2008; Hicks, 2000), and importantly approach relationship-centred care as actively involving family (Lichtner et al., 2016). Previous qualitative studies have described tensions between NH staff and with residents' family regarding pain and its treatment (Gropelli, & Sharer, 2013; Monroe et al., 2015), potentially explaining why CH staff did not refer to family in the communication of pain or collection of pain information.

9.2.9 Autonomy focus vs. Compliance focus

Caregivers identified a tension between emphasising choice and a person-centred focus on autonomy, and on the other hand having to ensure compliance with pain medication or other measures. Many caregivers described having a role in management and administration of pain medication, from supporting self-management (primarily IFCs), to assuming control (IFCs and CH staff). However, those with dementia were described as often non-compliant to pain medication regimes, refusing help and medications, and resistant to the involvement of caregivers. This gave rise to combative resistance to medication among those with advanced symptoms, and tension between those providing support and those receiving it. Previous studies have similarly identified non-compliance and aggressive rejection of care as a major barrier to the treatment of pain in dementia (Martin et al., 2005; Tarter et al., 2016; De Witt Jansen et al., 2017b). Non-compliance was sometimes an informed choice, based on the preferences of those with dementia (e.g., stoicism and medication fears as discussed previously). It may have also in part been based on a desire to maintain independence. Older adults have previously described their expressed wish to maintain independence over the management of their pain, giving rise to tension with family caregivers who try to intervene (Gammons & Caswell, 2014; McPherson et al., 2014).

Resistance to care and non-compliance was also related to medication administration challenges and diminishing cognitive capacity. Nurses have reflected on the challenges of using oral, intravenous, and subcutaneous routes of administration for those with dementia (De Witt Jansen et al., 2017). Both nurses and family caregivers have further described the challenges of encouraging compliance and allaying fears without the ability to engage those with advancing dementia in dialogue to explain the purpose of interventions (Brorson et al., 2014; Tarter et al., 2016; De Witt Jansen et al., 2017b). While alternative routes of administration were available to caregivers to support with compliance and reduce medication administration challenges, they described incidents in which liquid (including covert) and transdermal routes were still unsuccessful. These findings indicate that even when minimally invasive forms of administration are used, consistent with recommendations (Abdulla et al., 2013), adherence is still contingent upon the willingness or capacity of a person with dementia to accept treatment. Non-compliance, rejection of care and resultant pain, has been described as escalating confusion and pain (Rantala et al., 2014), and leading to feelings of helpless, failure and emotional distress among nurses and family caregivers (Givens et al., 2011; Tartar et al., 2016; De Witt Jansen et al., 2017b; Midtburst et al., 2018). This suggests caregivers were likely reciprocally impacted by non-compliance and resistance to their care, adding to the burden already experienced those supporting those with dementia (Feast et al., 2016).

The findings suggest that caregivers did not challenge medication refusal or non-compliance in relation to pain, yet they did regarding other medication regimes and the management of long-term conditions. As discussed previously, this may relate to perceptions of pain as ‘lower order’ compared toother comorbidities (Sale et al., 2006; Makris et al., 2015). In accordance with the current findings, a survey study of long-term care staff found non-compliance to analgesia through patient refusal was rarely prioritised (Peisah et al., 2014). However, non-compliance to psychotropic medications that was viewed as a significant concern. This reiterates earlier suggestions that the management of dementia related symptoms are more salient than the management of pain. It may also be the case that noncompliance was not prioritised because caregivers were limited in their ability to negotiate or respond to this. As discussed previously (Section 9.2.5), caregivers reflected upon communication challenges, and although caregivers had adapted to this, these skills were yet to be extended to dialogues to encourage treatment adherence. While the current study did not elucidate the use of pain medication using an audit, caregivers appeared to take no action or deferred to ‘wait and try again’. Pilot work suggests training can support healthcare workers in the development of communication methods that improve communication with persons with dementia (Weitzel et al., 2011). This may be equally as applicable and necessary for caregivers in the context of communicating about pain and its treatment with those they support. Previous research suggests that half of CH residents and half of PwD living in the community are not currently taking any analgesics (Napp Pharmaceuticals, 2014; Bullock et al., 2019). The experiences of caregivers indicate that this may not only result from the challenges in identifying pain and obtaining a self-report as impairment increases, but additional factors, such as the ability of a person with dementia to comprehend pain or comply with treatment, willingness to visit healthcare professionals, and willingness/capacity to accept relief offered. At present, issues around noncompliance in dementia have received limited attention (De Witt Jansen et al., 2017b). This study suggests however that it may be an important aspect of treating pain among those with dementia. It is an ethical quandary that crosses boundaries between choice and capacity. This is worthy of further exploration, as are the options to support caregivers to negotiate non-compliance more responsively.

For IFCs their roles as medication managers meant being primarily responsible for managing all conditions and medications. In accordance with these findings, family caregivers have described assuming responsibility for management of health conditions and medications among those with dementia to support with compliance and prevent medication errors (Maidment et al., 2017; Lim & Sharmeen, 2018). In the current studies, the involvement of IFCs varied on a continuum from supporting self-management to assuming total control, concomitant to symptom severity. A recent study found family caregivers described being responsible for analgesia, including prompting, monitoring compliance, and feeding back to physicians (Bullock et al., 2020). This was consistent with some of the roles described by IFCs presently, however for those who assumed more control their roles were more intensive (including scheduling, dosing, and withholding). IFCs involvement centred on minimising the risks, rather than other reasons discussed in the literature, such as monitoring compliance and gathering information for healthcare providers (Lim & Sharmeen, 2018; Bullock et al., 2020). This reiterates earlier discussions regarding caregivers’ preoccupation with the risks of pain medication use in dementia, rather than relief of pain (Section 9.2.7). This was a missed opportunity to monitor the effectiveness of pain medications and support those with dementia with regular scheduling of pain medications.

Many IFCs appeared to have incorporated strategies that supported choice and self-management of pain, such as prompting and making pain medication accessible. The importance of encouraging the self-management of pain among older people has been recognised, as has its role in supporting self-efficacy and improved pain outcomes (Hadjistavropoulos, 2012; Abdulla et al., 2013). Comparably, exerting control over pain and its treatment has been described as a coping mechanism among older adults, supporting a sense of independence (Gammons & Caswell, 2014). Supporting choice through input into self-management where safe and feasible may be as equally relevant for those with dementia. However, supporting self-management through self-medication, as did occur often among IFCs, relies on those with dementia having capacity to make informed choices. With advancing symptoms, those with dementia are at increased risk of poor health management and medication errors, as they become unable to manage their conditions and medications and strategies to support self-management cease to be effective (Arlt et al., 2008; Bunn et al., 2016). Identifying when self-management is no longer safe is therefore important, however it was unclear from IFCs at what point they would cease to support it. Self-management, however, does not need to only encompass medication, an active role in pain management can be supported through other methods, such as relaxation techniques, exercise, and adaptions to activities (Abdulla et al., 2013). This suggests they are additional and complementary approaches that IFCs could incorporate to support PwD to self-manage their pain, and thereby maintain a sense of control, even when self-medicating is no longer a safe option.

9.2.9.1The burden of managing medications

IFCs reflected upon the burden of managing medications, supporting self-management, and advocating on behalf of those they support about medical conditions. These experiences are indicative of those described by family caregivers regarding their role as medication managers and the complexities associated with becoming the decision maker amid poor medication literacy (Lim & Sharmeen, 2018; Barry et al., 2020). IFCs were concerned with their ability to gauge when medication was needed, the dose and manage side-effects or risks. These concerns are consummate with the experiences of family caregivers supporting older people and those with dementia, who reflect upon a lack of preparedness in being able to manage their loved ones' pain (McPherson et al., 2014; Tartar et al., 2016). While IFCs did not reflect on a lack of support from healthcare providers specifically regarding pain, some did reflect more widely on negative relationships with healthcare providers, issues in accessing healthcare and a lack of inclusion in dialogues about care. Such has been described by family caregivers of those with dementia as limiting opportunities to obtain information and advice about medicines (Smith et al., 2015; Barry et al., 2020). The challenges described by IFCs may have limited their opportunities to learn about the medications they were responsible for advocating and administering. A recent study on family caregiver's medication management emphasised the importance of engaging carers at the point of diagnosis to develop positive carer-healthcare provider relationships (Barry et al., 2020). These findings reiterate the importance of this as a potential strategy to allow for medication information to be relayed between both parties and enhance IFCs medication literacy. These findings while building on the literature exploring wider issues around medication management experiences of IFCs in dementia (Maidment et al., 2017; Barry et al., 2020), also highlight the distinct needs and problems associated with the management of pain medications which has rarely been explored (Bullock et al., 2020). These findings are increasingly important in revealing how IFCs navigate the management of medication and support of self-management, and associated challenges.

9.2.10 The systemic & personal challenges of caring

IFCs described many systemic and practical challenges, consistent with those in the literature, including inadequate access to healthcare providers, delayed diagnosis, and a lack of understanding of dementia among health care providers, negative relationships with healthcare providers, and poor access to respite and additional support (Knapp & Prince, 2007; Speechly et al., 2008; Carers Trust, 2013; Stokes et al., 2014; Werner et al., 2010). Inequalities in access to health and social care, particularly primary care, are a significant barrier for those with dementia (Cooper et al., 2016). However, as evident in these findings, also for their informal caregivers, forcing them to adopt ever more involved roles to compensate for systemic challenges. These experiences are consistent with descriptions of a growing reliance on family caregivers as an 'invisible workforce' and an increasing 'professionalisation' of their role (Glasby & Thomas, 2019). Systemic challenges not only exacerbated the burden of IFCs roles, but they also played a role more specifically in the context of pain. As discussed (Section 9.2.8), elements such as poor access to healthcare providers and advice, and a lack of understanding of medical conditions and medications, formed a backdrop from which specific aspects of care, like pain, were even more greatly challenging to address.

There were also personal challenges for IFCs. These have been previously identified in the literature and encompass feelings of inadequacy to provide care needed (Werner et al., 2010); grief around shifting relationships (Clare et al., 2012; Davies et al., 2010; Massimo, Evans & Benner, 2013); and adapting life changes and perceived changes in loved ones' identities (Pozzebon et al., 2016). The latter in particular gave rise to a diminished sense of familiarity with loved ones; caregivers struggling to reconcile uncharacteristic behaviour to the identities of their loved ones. Indeed, behavioural changes, such as aggression or inappropriate behaviour, are described as one of the most distressing symptoms for family caregivers (Feast et al., 2016). A context of deteriorating familiarity and relationship quality may have impacted how IFCs in the current studies related to loved ones and, as a result, their pain. Indeed, familiarity with behaviour is considered essential for identifying pain (Section 9.2.3). Moreover, the quality and authenticity of relationships between a carer-caree and acknowledging the caree's personhood will shape attention and understanding given to physical needs, including pain (Malloy & Hadjistavropoulos, 2004).

CH staff and nursing students reflected on some of the limitations of their preparation and training to support those with dementia. Most had received some form of training (as discussed in Section 9.2.10). However, they indicated the need for more thorough, regular, and expanded options for training. Reviews of dementia training provided in UK CHs have highlighted challenges relating to quality, availability, and standardisation (Fossey et al., 2014; Smith et al., 2019). The integration of dementia education across medical, health and social care higher education has also been highlighted as a challenge (Collier, Knifton & Surr, 2015). There has been an increased emphasis placed upon the health and social workforce to ensure they have the necessary knowledge, skills, and competence to provide quality, dignified care for those with dementia (Department of Health, 2015; NICE, 2018; The Dementia Training Standards Framework, 2015). The current findings suggest that dementia training was recognised by CH providers as an essential part of staff training and embedded at least within introductory training. Moreover, staff valued opportunities to understand dementia, providing the space for training to be included explicitly with more regularity and creativity. Previously e-learning forms of training have been described as lacking engagement, with HCAs and nurses suggesting alternative forms of continued professional development through mentoring would be more beneficial for their learning (De Witt Jansen et al., 2017a; 2017b). The current findings re-iterate the need for continued dementia training relevant to the needs of dementia care providers that form part of an ongoing conversation in which providers of dementia care can receive feedback, advice, and follow-on sessions (NICE, 2018). With appropriate education in dementia care, staff can more effectively manage their work's emotional and physical demands, alongside enhancing their adoption of person-centred approaches to care (Zimmer, et al., 2005).

There are contextual and workload challenges for those working in CHs (Section 1.2.2.1) that may impact upon the delivery of compassionate, quality dementia care. The delivery of dementia care itself has been described as emotionally and physically exhausting. This exhaustion can lead to depersonalisation of those being supported and a sense of poor accomplishment for staff (Evers et al., 2001; Brodaty et al., 2003; Edvardsson et al., 2008; Duffy et al., 2009). Although CH staff reflected on challenges within their roles and capabilities (Section 9.2.7), they reflected minimally on these contextual and dementia care challenges. They mainly focused on positive aspects of their roles in dementia care, related primarily to the relationships they share with residents. Previous research suggests that CH staff reflect on a sense of purpose and reward in their work (Coates & Fossey, 2016; Law et al., 2019). Further, close relationships with those with dementia allow staff to desensitise themselves from more negative aspects of their role and see the person past the disease (Tablot & Brewer, 2015; Schneider et al., 2010). This reinforces once more the importance of dyadic relationships and person-centred care as a reciprocally beneficial aspect of dementia care, highlighted in the context of pain (Section 9.2.3), and more broadly as a holistic concept of care (Fossey et al., 2014).

9.2.11 Quantitative findings & previous literature

The Pain Knowledge & Beliefs Questionnaire (Zwakhalen et al., 2007) was used to explore caregivers' understanding of pain, its assessment and management for PwD. There was cohesion between quantitative responses to the PKBQ and qualitative themes generated from interviews (Study 1) and open-ended survey (Study 2) responses. As such, findings gathered from the PKBQ support and expanded upon the qualitative findings of the current studies, alongside contributing to the broader literature base that has explored nursing home staffs' knowledge of pain, its assessment and management among those with dementia (Zwakhalen et al., 2007; Barry et al., 2012; Burns & McIlfatrick, 2015).

Findings from the PKBQ indicate caregivers have a good overall knowledge of the pain experience among older adults and those with dementia, as similarly stated in the literature (Zwakhalen et al., 2007; Chang et al., 2011; Barry et al., 2012; Burns

& McIlfatrick, 2015). Most caregivers endorsed the view that older people do not experience any less pain than younger people, nor those with dementia less than those without cognitive impairment. While research suggests that PwD may experience pain differently, current research suggests some forms of dementia may have an augmented vulnerability to pain (Achterburg et al., 2020). It is therefore important that caregivers recognise that any change that may occur does not arise in a reduced pain experience. A significant proportion also realised that older people might be affected by pain more frequently, consistent with the broader literature identifying an increasing vulnerability to pain among the ageing population, particularly in long term care settings (Abdulla et al., 2013; Dunham et al., 2020). The majority of nursing students and CHs did not believe that pain was a part of the ageing process, suggesting they did not ascribe to misconceptions regarding pain and ageing reported elsewhere as a barrier to effective pain assessment (Kaasalainen et al., 2007). Most CH staff and half of nursing students did not agree that assessing pain in dementia is a ‘guessing game’. While this positively suggests confidence in their assessment skills, this was not consistent with studies suggesting caregivers lack confidence in distinguishing between pain and other problems, such as delirium among those with dementia (Kovach et al., 2000; Martin et al., 2005; Lichtner et al., 2016). It was also in contrast with qualitative interview and survey responses describing the challenges experienced in determining pain, its cause and severity among those with dementia.

Responses to the PKBQ identified challenges concerning caregivers’ understandings of pain medication. Caregivers frequently utilised a ‘no opinion’ response in response to medication items. This is indicative of the significant ambiguity described qualitatively regarding pain treatment and multifactorial concerns about medication use in survey and interview responses (Chang et al., 2009; Newton et al., 2014; Geddis-Regan et al., 2018). Responses regarding the risk of addiction and side-effects and the efficacy of pain medication among older people, however, were ambiguous. These findings resonate with international and UK based surveys that have also identified that NH staff may over endorse the risk of addiction to pain medication (mainly related to opioids) in dementia, and express concerns regarding the side effects of analgesics and safe treatment of pain (Zwakhalen et al., 2007; Barry et al., 2012; Burns & McIlfatrick, 2015). While there are no equivalent quantitative studies of IFCs to which the current findings can be compared, qualitative literature affirms IFCs are apprehensive about the use of pain medication among older people and those with dementia (Tartar et al., 2016; McPherson et al., 2014; Bullock et al., 2020).

A significant proportion of all caregivers endorsed ‘as needed’ medicating as providing the most optimal treatment of pain. ‘As needed’ scheduling of medication is not considered appropriate among those with an impairment who may be unable to request additional relief (Schofield et al., 2018). Moreover, in practice, ‘as needed’ medication may be ad hoc (Peisah et al., 2014), further reducing its efficacy in relieving pain. More positively, however, most caregivers did not endorse that pain medication should be postponed in dementia to reduce the amount received or reserved for severe pain only. This suggests that caregivers’ deficits in understanding relate primarily to more practical aspects of medicating rather than the appropriate circumstances for the usage of pain medication.

The majority of CH staff and nursing students agreed that pain was assessed and treated correctly within their workplaces despite deficits in their understandings of optimal pain treatment. This anomaly was consistent with the findings of

Zwakhalen et al. (2007), who suggested that this may undermine attempts to improve pain management and assessment within care settings. In over overestimating their skills or understanding, staff may be less willing to engage with opportunities for training. Gropelli and Sharer (2013) found that nurses failed to recognise how their own perceptions may impede their ability to effectively manage pain. A lack of self-reflection may be a feasible explanation for this apparent disjunction in nursing students and CH staff reflections on their pain practices, and their understanding of optimal pain practices. Interestingly, most IFCs also agreed that pain was assessed and treated correctly when the person they supported visited healthcare providers. However, over a third of IFCs did not agree pain received much attention during these visits. An explanation for these conflicting responses may be that because other conditions are considered higher-order and dementia takes clinical dominance (Makis et al., 2015; Tolman & Dening, 2018), the purpose of visits to healthcare providers for pain may be uncommon or obscured by other needs. Overall, caregivers' responses to these items were inconsistent with the consensus in the pain literature that pain remains a challenge for persons with dementia, their loved ones, healthcare professionals, and society (Achterburg et al., 2020).

Previous studies have suggested that an increasing amount of clinical experience and length of time since nursing qualification may positively influence caregivers' understandings of pain, its assessment and treatment for older people and those with dementia (Sloman et al., 2001; Cohen-Mansfield and Creedon, 2002; Chang et al., 2011). The current findings did not report any significant differences in PKBQ responses based on experience, suggesting that more experience does not necessarily inform a greater understanding and more appropriate beliefs regarding pain, or at least it did not in the current sample. This was consistent with the findings from UK survey data among NH nurses and NH managers (Barry et al., 2007; Burns & McIlfatrick 2015). Of note however, descriptively mean PKBQ scores were more optimal for those with under 2 years' experience, with scores following a consistent increase with increasing years' experience. This suggests that those with less experience demonstrate a greater understanding of pain and endorse more appropriate beliefs. Initially, this finding does not align with the qualitative experiences described in survey or interview responses. Similarly, it does not fit with the literature in which caregivers' have described the importance of diverse clinical experience and repeated interactions to develop an understanding of pain in dementia (Parke, 1998; Falls et al., 2004; Chang et al., 2011). However, experience was measured in years in the current study, and it is possible that experience cannot be solely quantified in this way. Certainly, the literature has described pain assessment and treatment as informed by an intersection of intuition, familiarity, shared-sense making among teams, and personal judgment (Kenefick & Schulman-Green, 2004; Falls et al., 2004; Lichtner et al., 2016). As such, length of time may not reflect many aspects that may constitute or qualify experience. Alternatively, these results may be explained by those with less experience having received more recent training. Other studies have found that CH managers and hospital nurses who have recent training or are more recently qualified do have a more appropriate understanding of aspects of pain medication (Barry et al., 2012; Rantala et al., 2015). Staff new to their roles would be more likely to have received recent training. Similarly, for IFCs who had attended dementia training, this would have been provided following a diagnosis and thus early in their caregiving roles. The literature in this area has identified the importance of opportunities for ongoing continued professional development in the sphere of pain in dementia, yet there limited opportunities for such in the context of care homes (De Witt Jansen et al., 2017a; 2017b). Accordingly, CH survey respondents did communicate a need for regular, refresher training. In culmination, these findings suggest accessibility to recent training may be a realistic challenge for those who have been within their role for several years.

The findings observed regarding the role of experience may be accounted alternatively through caregiver burnout. As reviewed in Chapter 1, those supporting PwD experience high physical and emotional workloads, leading to symptoms of burnout (Edvardsson et al., 2009). Burnout may, in turn, negatively impact the quality of care provided towards a person with dementia and caregivers’ attitudes towards ageing and dementia (von Dras et al., 2009; Tadd et al., 2011). As such, increasing years of experience caring for PwD may cause symptoms of burnout, which may manifest in terms of greater apathy towards issues such as pain. Taking on board the qualitative findings regarding the emotional challenges of supporting persons with dementia, this could explicate why more experience may negatively impact upon caregivers’ understanding and beliefs regarding pain.

There were significant differences present between different caregiver roles and PKBQ scores. Perhaps unsurprisingly, HCAs, Management and Activities/Domestic roles all scored significantly lower (more optimally) than IFCs, who scored highest across all roles. More surprisingly given disparate professional preparation between roles, nursing students performed least optimally of all roles, and those in nursing and HCAs roles scored comparably. Zwakhalen et al. (2007) similarly compared knowledge among NH staff, RNs, and trainee pain specialists. Between these groups, only the latter group receiving specialist education provided different and improved responses. These findings suggest that training may need to be pain specific to impact understanding positively, irrelevant of the professional preparation different roles may have. It also suggests HCAs may experientially develop an understanding of pain through their direct-care roles, supporting that they have important contributions to make in informing pain-related care (Liu, 2013; Andrews et al., 2019). For nursing students, the findings suggest their education, alongside their recent placement in older adult care, had yet to prepare them concerning pain or pain in dementia sufficiently. A national survey exploring the content of curricula for pain education has identified that pain education within undergraduate curricula is limited and fragmentary in the UK (Carr, Briggs, Briggs, Allcock, Black & Jones, 2016). Although most of these nursing students had not yet reached their final year of studies, the findings are a cautionary warning that nursing education may need to place more emphasis on pain, and pain in dementia.

Previous studies have suggested that a lack of training and a lack of dissemination of current best practices and research contributes to inadequate knowledge of pain and its treatment and thus suboptimal pain practices in nursing home settings (Zwakhalen et al., 2007; Geddis-Regan et al., 2018). In the current study, most nursing students and CH staff reported having received training in dementia. For CH staff, the majority (76.52%) reported receiving dementia training. This is in line with estimates that around a third of CH staff do not receive any dementia training (Alzhiemer’s Society, 2016). The limitations of dementia training for CH staff in the UK has been raised as a matter for concern (Fossey et al., 2016; Smith et al., 2019). However, in the six CHs recruited training was provided to direct and non-direct care staff alike, with training rates higher than previous UK studies with CHs (Barry et al., 2012; Burns & McIlfatrick, 2015). While a quarter of CH staff had not received training, this may be a positive improvement consistent with targets to improve the delivery of dementia training and skill development of health and social care workforces in the UK (Department of Health, 2015; NICE, 2015, 2018). In terms of training related to pain, a minority of CH staff reported have received training in pain assessment and use of PATS. This was consistent with prior findings highlighting a lack of pain training provided to staff in UK CHs (Allcock, McGarry & Elkan, 2002; Corbett et al., 2016). The latter is consistent with the view that CH staff are poorly prepared in regard to training to support them in developing an understanding, or the necessary skills, to be able to identify, assess and treat pain among those with dementia (Corbett et al., 2016).

The knowledge deficits identified were likely further exacerbated by an apparent lack of awareness or use of protocols, guidance, or recommendations to inform decision-making. A minority of CH staff were aware of any guidelines advocated or used within their workplaces relating to the assessment and/or management of pain in dementia. This was in contrast to almost half of nursing students who were aware or had used guidelines. The apparent non-use of guidelines or policies is consistent with findings from an extensive European survey of dementia care and UK survey data that report over a third of care providers do not routinely use any guidelines to support pain treatment in dementia (Barry et al., 2012; Zwakhalen et al., 2018). A review of guidelines available in UK CHs previously identified a lack of context and dementia-specific guidance of pain assessment and treatment accessible to all (Corbett et al., 2016), suggesting this may also be a challenge encountered by CH staff and nursing students in the current studies. More recent guidance has been developed which aims to be applicable to all contexts where older people (and those with cognitive impairment) are supported and accessible to all caregivers (Schofield et al., 2018). However, it appears these guidelines or indeed any generic protocols (e.g., WHO analgesic pain stepladder), are poorly integrated into settings within which respondents were employed. Despite this (and a lack of pain training), half of CH respondents were aware of PATs, with a third indicating they had seen these within care plans. This awareness was greater than that reported in another recent UK study among HCAs (De Witt Jansen et al., 2017a). However, qualitative responses indicated this awareness did not translate into practice. As previously discussed, without the appropriate use of PATs, guidelines, or protocols, it is likely that pain assessment and its subsequent treatment will not be effective (Abdulla et al., 2013; Schofield et al., 2018). It also the case that CH staff and nursing students are not utilising resources to ill support them in the development and understanding of optimal pain assessment and treatment practices.

9.2.11.1 Implications of quantitative findings for training and upskilling needs

Overall, these findings are consistent with the view that limitations in knowledge, and training and preparedness, are a barrier to the effective pain assessment and treatment, as identified by nurses (Kovach et al., 2000; Chang et al., 2009; Kaasalainen et al., 2007), NH managers (Barry et al., 2021), and nursing assistants (Liu, 2014). These offer some explanation of suboptimal pain practices observed in the wider literature. Literature has consistently documented a disparity in pain medication provided to older adults with cognitive impairment, compared to older adults without impairment, despite similar pain complaints (e.g., Reynolds et al., 2008; Napp Pharmaceuticals, 2014). Further, pain treatment that is given often falls short of prescription recommendations or relies primarily on simple analgesia (Morrison & Sui, 2000; Haasum et al., 2011; Peisah et al., 2014; Andrews et al., 2019). Certainly, if consummate deficits in knowledge and ambiguities regarding the safety of medications identified here represent caregivers more widely, such will likely translate into the disparities observed. Further research should explore the broader applicability of these quantitative findings and challenges identified presently in terms of understanding and training within larger and more diverse samples, that encompass primary care, formal community care and acute contexts. Such will illuminate the multifactorial issues contributing to poor understanding (and thus practices) across care settings and provide some road map to improving the knowledge (and thus skills and abilities) of those supporting PwD with their pain.

The findings suggest that training and upskilling would be beneficial to develop caregivers' understandings regarding pain and its optimal treatment in dementia. Indeed, qualitative findings suggest these opportunities would be welcomed by all caregivers' groups sampled. Accessible, improved, evidence-based training is a consistent recommendation from the literature (Geddis-Regan et al., 2018; Jonsdottir & Gunnarsson, 2020; May & Scammell, 2020). Evidence suggests that training can positively improve knowledge and have a substantiate impact upon improving pain assessment and management practices (Ghandehari et al., 2013; Petyaeva et al., 2018). Within the CHs, training and leadership may further improve staff confidence and encourage staff to take greater responsibility for pain management (Corbett et al., 2016). Training, however, is not a single panacea to address the disparities present in caregivers' understandings of pain identified by PKBQ and improve pain practices. Critically in UK CHs, there remains a lack of available and quality dementia training packages and significant practical challenges for implementation (Fossey et al., 2014; Corbett et al., 2016). Furthermore, any training needs will require due consideration of the unique contextual challenges of different care environments and audiences, such as that provided to CH staff versus IFCs supporting those in the community. It is also important to consider, as highlighted in Study 1 and 2 and the literature, that improving what caregivers know about pain assessment and its treatment is one of many challenges to be overcome.

The current findings contribute to our understanding of training needs. In tandem with other studies (Barry et al., 2012; Corbett et al., 2016; De Witt Jansen et al., 2017a; 2017b), the findings identify areas training should focus on, who should receive training, and approaches of training that may be most amenable to different groups of caregivers. Further, the current findings provide the first quantitative insight into understanding pain and its assessment among diverse members of UK CH staff, including both unregistered and registered roles. As demonstrated qualitatively in Study 1 and 2 and noted within the literature (Liu, 2013; De Witt Jansen et al., 2017a), the expansion of unregistered roles within CHs makes the present findings increasingly relevant to current workforces within CHs and informing potential interventions to improve pain practices by identifying areas for support and upskilling among all staff roles.

9.3 Critical reflection on methods & limitations

9.3.1 An epistemological middle-ground- Critical Realism & pluralist approach to mixed methods

This thesis is one of the first to apply a mixed methods approach to explore pain recognition, assessment, and management. I am only aware of one other (Corbett et al., 2016). The epistemological perspective of critical realism (Bhaskar, 1978) underpinned the use of a mixed methods methodology. Critical realism provided an epistemological middle ground, bridging polarities between realist vs. constructionist epistemologies, and paradigm conflicts between qualitative and quantitative methods. From this middle ground, a pluralist, mixed method approach was taken, facilitating an all-encompassing lens to explore caregivers’ recognition, assessment, and treatment of pain among PwD. It captured both the measurable or explanatory elements (quantitative; caregivers’ understanding) and the more subjective or exploratory elements (qualitative; caregivers’ experiences, wider contextual issues).

In practice, committing to an epistemological middle ground and pluralist, mixed method approach brought strengths and limitations. Mixing of methods and triangulation of different data sets allows for a more complete understanding and overcomes the inherent weaknesses of adopting an either-or approach (Johnson & Onwuegbuzie, 2004). Study 1 provided in-depth context via interviews, while Study 2 provided brevity and wider applicability via a survey. In positioning the mixing of methods and data collection sequentially, the design of Study 2 and survey content could be built upon the findings and learning taken from Study 1. As such, the research could evolve from Study 1 to Study 2, becoming more relevant to the central issues identified by ‘real’ caregivers in interviews. Overall, the blend of two empirical studies facilitated the collection of multiple, inter-related data sets, and the triangulation and integration of this data to provide a contextualised, in-depth, yet broad understanding of caregivers’ experiences. In triangulating the different data sources, the overall findings of the thesis can be corroborated, validated, and made credible (Creswell & Plano Clarke, 2011).

There are some general criticisms which may be considered in relation to the mixed method approach adopted. The merging of different data sets into a meaningful whole that attends to the contradictions between data sets is both practically challenging and time-consuming (Creswell & Plano Clarke, 2011). In this thesis, the large body of qualitative data, alongside the quantitative element was an undertaking for a sole analyst. There are paradigm concerns also, some of which have been discussed in Chapter 3. It has been suggested mixed methods approaches privilege post-positivist thinking, while side-lining more interpretive discourses (Creswell, 2011). In the current works however, because of the adoption of an epistemological middle-way, no such preference for one or the other was taken. Moreover, the meaning and definition of mixed method research has been much debated, as to whether it can be considered a method *and/or* a methodology (Creswell, 2011). This thesis has explicated a position on this, adopting mixed methods as a method, underpinned by a critical realist methodology.

9.3.2 Data collection methods

The practical implementation of interviews in Study 1 and surveys in Study 2 have been reflected on in-depth in Chapter 4. In both studies, retrospective approaches were used, as such data collected only encompassed what could be recalled, or what participants were willing to diverge. No further data was collected to augment or corroborate what participants reported. A comparable limitation was also present in the single measure design used in Study 2. Only responses to the PKBQ were collected, as such it was not possible carry out any correlational analysis with other data.

9.3.3 Analytical strategies

In Study 1, reflective thematic analysis (RTA) provided the epistemology and approach for identifying patterns inductively across interview data (Braun & Clarke, 2006; Braun & Clarke, 2018). In Study 2, Structured Tabular Thematic Analysis (ST-TA) was used (Robinson, 2020). ST-TA supported the identification of thematic patterns across data the large body of textual data present in qualitative survey responses. Using an inductive-deductive hybrid approach, a thematic scheme developed from interviews in Study 1 was applied to a larger data set, and new themes developed as needed. This allowed Study 2 to build on Study 1 and demonstrated that Study 1's findings could be applied more widely. Practically, the use of spreadsheets to tabulate themes in ST-TA supported the generation of theme frequencies and inter-rater agreement, which are relevant to transparency and validity as discussed below. It further meant that themes and subthemes could be transformed into quantitative variables, and analytically integrated alongside quantitative responses on the PKBQ. This provided a new way to explore and explain quantitative findings in a way other analytical approaches would not have supported. ST-TA fitted well within an epidemiological middle ground. It fitted both with the interpretative qualitative element through its reflexive injunctions, and it supported the measurable quantitative element through the generation of theme frequencies and inter-analyst agreement. There was a tension between ST-TA and RTA, underscored by their conflicting approaches to the premise of generating theme frequencies. However, this was found to be a healthy, creative tension that represents the variety of ways that qualitative data can be rigorously analysed. In summary, these two analytical strategies supported the development of a set of themes from across two data sets and over 100 participants, providing depth, but also providing markers from which we are able to quantify the commonness of particular experiences.

As thematic approaches, both RTA and ST-TA share some general limitations. Thematic approaches do not analyse each case or participant experience, before developing across case analysis, as such they avoid an idiographic focus. Findings generated therefore represent overall, shared meaning and experiences, not individual cases, or experiences. Furthermore, thematic approaches do not tend to explicitly explore relationships between generated themes. As such, how data themes relate together is not explicitly addressed in thematic approaches.

9.3.4 Samples & wider application

Sample biases and limitations were inherent due to the nature of recruitment, the necessity of gatekeeper approval and participant self-selection. As the first limitation, the findings must be acknowledged as contextually situated and localised to the Southeast of England. This is a limitation but is also a strength. Contextual embeddedness may be a caveat to generalisability; however, the context also provides a meaningful locale from which the findings originate. This is discussed further below in relation to the criteria for evaluating qualitative research.

The resonance of findings with the wider literature supports the relevance of sample and representativeness of experiences presented. Overall demographics and composition of samples did reflect broader characteristics of IFCs, and those working in CH contexts here in the UK (Chapter 1). IFCs represented spouses, children, and other close relatives. However, all IFCs were White British. For CH staff, while some diversity in ethnicity was present, the majority of staff were also White British. The homogenous nature of these samples in terms of ethnicity and diversity suggests that cultural and ethnic variations in conceptualisations of pain may not be represented in the current studies. Evidence suggests that race, culture, and ethnicity can shape illness perceptions, attitudes towards pain, coping strategies, and treatment choices (Orhan et al., 2018). Race, ethnicity, and culture may therefore be important influencing factors that relate to how a caregiver may interpret, identify, or respond to the pain of others. Similarly, the intersection of culture in the provision of dementia care and perceptions of illness, disease, and dementia among caregivers (Brooke, Cronin, Stiell & Ojo, 2018) may not be represented sufficiently in the current samples. The applicability of the present findings need to be considered mindfully in terms their representativeness of diversity in culture and ethnicity.

The CHs recruited did represent the heterogeneous landscape of UK CH; with diverse CQC ratings, capacity, ownership, and care provision modalities (nursing and residential) present (Appendix H). Rather than a case-study approach and a focus on specific roles (as is common in the literature), multiple CH sites were recruited and diverse CH staff roles.

A further limitation is that the sampling was based on a voluntary process, and thus there will be a self-selection bias (Robinson, 2013). This means that those who volunteer for qualitative research are not necessarily a random sample of those within the potential sampling universe; they are more likely to find the possibility of participating to be a rewarding experience, thus those who have distressing experiences or negative attitudes to convey may not come forward. This is particularly relevant given that pain is a challenging topic to discuss, particularly for IFCs for whom pain was not an immediately resonating issue.

Furthermore, the recruitment of IFGs was contingent on caregivers identifying themselves as a ‘carer’ or ‘caregiver’, and their attendance at dementia support groups. While other attempts to recruit IFGs were made (Section 4.3.1), support groups were the primary mechanism by which recruitment occurred. This may be a limitation in sampling and applicability of findings, given that some providing support for spouses and relatives may not self-identify as a ‘carer’ and as a result do not access support (Carers UK, 2016). As such, the sample recruited reflected those who had acclimated to this carer-status, and by this had been able (or willing) to access support groups (and training for some).

The exclusion of PwD may have been a limitation in terms of sampling, and the findings of this thesis. PwD were not invited to take part, which was an active choice reflecting the focus on caregivers’ perspectives as central to the research questions. However, during data collection often PwD were present. There were instances in which they offered their responses to questions directed at caregivers, or rebuttals. While these were incorporated into the researchers overall understanding, these insightful dialogical exchanges could not be incorporated into the final analysis. There was no means of determining the intersubjective validity of events described by caregivers, nor unearthing potentially important reflections on these events from perspective of PwD.

9.3.5 Quality evaluation- qualitative findings

Chapter 4 (Section 4.6; Section 4.9) explicates the criteria for assessing the quality of qualitative research. It combines guidance provided by Braun & Clarke (2006; Clarke & Braun, 2019; Braun & Clarke, 2020a) and Yardley’s appraisal criteria (2000; 2008), including: sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance. The following section reflects on whether the criteria outlined were met within the empirical part of this thesis.

Quality in any form of TA is contingent on a researcher's transparent identification of the particulars and parameters of their specific thematic approach, and the relationship of such to their underpinning methodology and method (Braun & Clarke, 2006; Clarke & Braun, 2019; Braun & Clarke, 2020a). An informed and justified discussion of specifics of RTA and ST-TA is present in Chapter 4, alongside a justification of these methods considering a CR methodology. Quality checks and considerations made in the undertaking of RTA and ST-TA encompassed (a) checks to ensure a close correspondence between transcribed and original data, (b) thorough and inclusive coding of all original data (not anecdotal or individual examples), and (c) the provision of audit trails documenting the analytical process (Appendix G-H) (Braun & Clarke, 2006; Clarke & Braun, 2019; Braun & Clarke, 2020a). The latter supports the transparency of these research findings and emergent themes. As demonstrated by illustrative extracts in results chapters for both RTA and ST-TA (5-7), themes generated and analytic claims are grounded in, and consistent with, the data. Themes generated were distinctive (see theme definitions Table 7.1), and drawn together to present a consistent, coherent, and justified analysis (Interviews: Chapter 5 & 6; survey: Chapter 7). Both ST-TA and RTA position the researcher as active in the development of themes, as such quality and transparency require reflexivity. Reflexive considerations have been made (Appendix G), drawing attention to the researchers own position in the research process.

To explore internal coherency and consistency of the thematic scheme developed for surveys in Study 2 using ST-TA, inter-analyst agreement was explored (Section 4.8.5.3). Agreement between the second analyst and myself was 92.22%, implying that the thematic scheme developed was trustworthy and conceptually solid. The process of checking inter-analyst agreement also supports the qualitative quality criteria of rigour and coherence (Yardley, 2000; 2008), as does the tabulation of theme frequencies. For each theme and subtheme (Figure 7.1), prevalence has been presented and statements about themes are supported by concrete and transparent affirmations about their commonness across survey data.

Sensitivity to context is one of the validation criteria provided by Yardley (2000; 2008). It encompasses the entire research process, including a sensitivity to existing understanding and the socio-cultural contexts in which research (and the participants and the researcher), interaction, and data collection occurs (Yardley, 2000; 2008). Sensitivity has been demonstrated by situating qualitative findings alongside the current literature in the area (current chapter) and contextualising them through descriptions of the settings and demographics of participants (Appendix F: *Case Studies).* Sensitivity to context was present in the adaptive approaches used to support data collection (Section 4.4.1.4; 4.7.3). Further, qualitative approaches were open-ended supporting sensitivity to the words and interpretations of participants. While analysis of participant responses inevitably reflects my own lens of the world, I was cognisant not to impose my own meaning upon the experiences of participants. Reflexivity formed a part of this cognisance (Appendix G: Reflective Account), as did the provision of exemplars of participant responses to make central their words.

Coherence and transparency are further criteria that Yardley (2002) proposes as key to high quality qualitative research. *Transparency* refers to the extent to which the research process (and that which may have influenced such) has been clearly explicated (Yardley, 2000). The steps relating to transparency in the analytical process previously described relate to this (Section 4.6.1*),* as does inter-analyst agreement and the provision of theme frequencies (Section 4.8.5.3*).* Transparency also involves the disclosure of the researchers own experience, which has been reflected upon (Appendix G: Reflexive Account). A with-in method plurality combining different forms of qualitative data from Study 1 and Study 2 also enhances the transparency of this qualitative research (Frost, et al., 2010).

Creating *coherence* in qualitative research is principally centred on the alignment of aims, research questions, theoretical basis, data collection, and findings, to create a whole (Yardley, 2000; 2008). Throughout this thesis, these different elements have been interwoven, and the relationship and cohesion of these both explicated (Chapter 4: Methods) and reflected upon in the current chapter. Mastering coherence in the context of a pluralist approach where tensions are present and where the research has evolved to meet contextual challenges could be a limitation to coherence.

Commitment and rigour are further criteria that have been woven into the process of conducting the thesis. Commitment involves the prolonged engagement with the research topic, and rigour refers to completeness of data collection and analysis (Yardley, 2000). Commitment involved extensive engagement with the subject matter, a figurative finger of the pulse, collating and synthesising existing and new publications into my understanding of the subject matter (Chapter 1 & 2). It encompassed a commitment to understand the lived experiences of caregivers and contexts of research through volunteer work in CHs. It further encompassed a commitment to pluralism, encompassing within-method and across method pluralism, analytical pluralism, and analytical integration of qualitative and quantitative survey findings. Rigour was supported by the triangulation and integration of findings from across both studies. Inter-analyst agreement in ST-TA and the audit trial provided of analysis (Appendix G-H), further support that a thorough, rigorous approach to data analysis was present.

The final criterion proposed by Yardley (2000) is *impact and importance*. Such can be appraised by weighing the contributions to knowledge, and the actual or potential implications of findings. Until tangible change can be traced back to these findings, at this time such can only be appraised against the contributions described early in this chapter, and with the explication of potential implications of findings below. Thinking differently about impact and importance, qualitative findings of this thesis do offer resonance. The stories of caregivers were both inspiring and shocking. Many IFCs appeared to use data collection cathartically and as outlet, often discussing their own existential pain and voicing perceived injustices. Some caregivers reflected on their approach to pain during the course of data collection, seemingly re-evaluating the construct of pain and its meaning.

9.4 Implications

9.4.1 Pain training

The findings indicate that CH and IFCs were responsible for recognising, assessing advocating, and treating pain among PwD, but that there was a clear lack of preparation for this, with knowledge deficits and misconceptions relating to pain, its assessment, and its treatment present. The findings therefore highlight, in line with previous recommendations (Napp Pharmaceuticals, 2014; Schofield et al., 2018), the importance of providing *all* caregivers with the necessary skills and knowledge to support them in identifying and relieving pain. Dementia care policy has previously called for the provision of relevant skills and support for the dementia workforce and IFCs (Department of Health, 2016; NICE, 2018; Health and Social Care Committee, 2020), the findings from this thesis are supportive in relation to the specific issue of pain.

The deficits in knowledge about pain in PwD identified in this research may be used to inform the expansion of existing training, or the development and implementation of new, standardised training programmes. These programmes need to be targeted at, and accessible to those on ‘front line’ of dementia care. Providing caregivers with the essential skills and understanding will inform more optimal pain practices and will raise awareness of pain and its negative implications, reducing a culture of normalisation and stoicism.

In the CH context, participant feedback indicates dementia training requires improvement, which needs to be responded to at the level of CH providers and care policy. As discussed in Chapter 1, in the UK there is currently no mandated requirement for accredited dementia training nor a standardised approach to essential content (Smith et al., 2019). It is therefore recommended that dementia care policy standardise the requirements of accredited dementia training and mandate the inclusion of pain as a compulsory element. For IFCs it should be mandated that relevant training and information sources, for both dementia and pain, is signposted by healthcare professionals (at the point of dementia diagnosis and more regularly, for example following an injury and prescription of pain medication), and that it is readily available to IFCs through support services, for voluntary engagement. This could include the upscaling and expansion of existing training programmes and information sources provided through diagnostic centres (e.g., memory clinics) or through charitable organisations.

9.4.2 Existential suffering & behavioural & psychological symptoms of dementia

A central theme in the findings was the existential suffering found among PwD, and the cyclical relationship with dementia, physical illness, and pain. Identifying how psychological distress is linked to pain is particularly important considering the inappropriate use of antipsychotic among PwD who have pain (Barry et al., 2014). Meeting the challenge of fostering greater understanding of how psychological symptoms and physical pain interact entails upskilling in the use of non-drug approaches and psychosocial interventions for both mental health and pain in PwD. There is evidence that supports the use of non-drug methods in the management of mental health, and to some extent, physical pain in PwD (McDermott et al., 2019; Atcherberg et al., 2020). The use of non-drug approaches may be particularly amenable to CH staff and IFCs, given that some already incorporate simple non-drug approaches to provide comfort from physical and psychological pain into their care provision.

9.4.3. Guidelines & pain assessment tools

This research found that guidelines for the assessment and management of pain (e.g., Abdulla et al., 2013; Schofield et al., 2018) were not used in CHs. Practices reported were incongruent with recommended assessment and treatment practices, and pain was not formally assessed regularly. These findings indicate a disconnect between recommended, evidence-based best practice, and non-standard informal processes that may lead to sub-optimal assessment and treatment (Bullock et al., 2019). CH staff expressed challenges, such as determining the extent of pain and use of pain medication, which support tools such as guidelines and PATs may help with. This implies a need for guidelines and PATs to be embedded into daily CH practices. However, they need to be embedded and incorporated in such a way which compliments caregivers existing informal and relationship-centred approaches already developed and implemented by CH staff. The latter will be particularly important in conceptualising pain assessment as a wider multi-modal process (Snow et al., 2004), that combines standardised and measured approaches with those more informal and person-centred approaches. The latter is salient, given that CH staff did demonstrate existing expertise and skills based on years of experience, which should be celebrated and built upon.

9.4.4. Care homes

CH staff highlighted the importance of familiarity to support relationship-centred pain assessment, and individualised pain treatment. CH organisations should provide the opportunity for familiar relationships by matching key workers to specific residents (which does occur across some CHs at current), and by allowing staff ‘free time’ to engage in different modalities of interaction with residents. The more effective integration of patient histories into care plans, may further support a sense of familiarity with PwD. Promoting positive care in this way will require investment in resources, workforce employment, and infrastructure at policy level, to change culture and practices in CHs.

CH staff described pain assessment and management as contingent on a collaborative team approach. HCAs were central within the team, underpinning the initial identification of pain and initiating a response from colleagues. These findings highlight the potential for HCAs to contribute meaningfully to a critical area of dementia care. This was consistent with the growing recognition of the expanding roles of unregistered staff in the context of pain, in both research in the area (De Witt

Jansen et al., 2017a; Andrews et al., 2019) and recommendations for pain assessment (Herr et al., 2019). HCA need to be empowered to act on their observations and clinical insights and should be invited to contribute to relevant multidisciplinary meetings or care planning meetings, alongside more senior care staff and clinical healthcare providers. An optimisation of the HCA role in pain may further require, as suggested by others (Liu, 2013; De Witt Jansen et al., 2017a), a reconceptualisation of the role of HCAs that emphasises the skills of this workforce.

9.4.5 Healthcare providers

IFCs described a lack of understanding of dementia and their needs as a dementia caregiver, poor cohesion of services and inaccessibility/unavailability of support. Such seemed in conflict with UK dementia care policy centred on improving the lives of PwD and their caregivers (Department of Health, 2009; NICE, 2018). These findings suggest a need to review current services and support available to PwD and their caregivers. They further suggest healthcare professionals may require their own support, such as dementia training, to prepare them to positively engage with PwD and their caregivers. These findings demonstrate that IFCs play a critical role in the identification and management of pain among community dwelling PwD. Alongside appropriate training, healthcare professionals have a key role in supporting IFCs within this capacity. Healthcare professionals should provide timely, accessible, and appropriate information regarding pain, including the outcomes of appointments, the diagnosis of conditions, and the appropriate use of prescribed medications. This can be in part achieved by including IFCs within care decisions relating to their loved one’s pain. Certainly, the multimodal assessment of pain and the development-individualised approaches to pain management necessitates the input of IFCs or close proxies (Schofield et al., 2018; Herr et al., 2019; Dunham et al., 2020). As such, including IFCs within pain-related care decisions and supporting an informed view, is not only desirable to support healthcare professionals obtaining integral sources of pain information, but also the confidence and preparedness of IFCs. This awareness may be in part supported through a reframing of the role of IFCs and the support they receive. Given that IFCs engage with diverse healthcare professionals this suggests a ‘whole system’, or integrated approach is needed, including community services such as pharmacists and district/admiral nurses- all of whom have a role to play in supporting IFCs and PwD in the context of pain.

9.5. Future Research & work

9.5.1 Building the literature on informal care in the community

Further work is needed to explore the experiences and support needs of IFCs in relation to the assessment, identification & treatment of pain among those with dementia living in the community. A nationwide prospective mixed-method survey could be implemented for this purpose. Dyads of IFCs and PwD could be recruited at the point of dementia diagnosis, and followed up at 6-month time intervals, until CH admission, death, or end of the study period. The inclusion of PwD will be an important addition to the literature as noted by Bullock et al. (2020). A qualitative survey component could document aspects of lived experiences of pain among these dyads, such as perceived challenges, barriers, and support needs. A quantitative component meanwhile could explore conditions/diagnoses associated with pain, use of drug and non-drug methods, pain frequency and ratings, and psychological issues (e.g., caregiver burden and presence of symptoms of poor mental health). This approach would allow for the first prospective investigation of the pain among community dwelling PwD, helping to identify pivotal points of support for IFCs and PwD alike, and exploring the outcomes of pain on PwD (such as hospital admission, behavioural and psychological symptoms of dementia, and CH admission).

9.5.2 Collection real-time data in care homes

The current studies collected retrospective qualitative data, relying on CH staff to recall pain events, their responses, and the responses of others involved. As such, it was not possible to directly corroborate experiences with actual pain practices. This may be salient considering the dissonance between healthcare professionals' recognition of pain, and their reporting of pain to colleagues, their documentation of pain, their assessment using evidence-based PAT, their use of pharmacological intervention and their follow-up (Achterberg, et al., 2007; Lichtner et al., 2016; Andrews et al., 2019). Future research is warranted to explore CH staff experiences as they occur through the collection of real-time data, using approaches such phone applications and real-time audio diaries, augmented with audits of care plans, pain documentation, and use of drug-based treatment. This would allow for the whole process from the occurrence of an episode pain to resolution, to be captured, revealing CH staffs' 'in the moment' decisions and practices. Such a study could be used to inform processual changes within CHs to support more effective assessment and management approaches.

9.5.3 Training & evaluation

An audit of currently available training and information resources on pain, its assessment and management among PwD, should be carried out. From such, and in tandem with existing guidance (Schofield et al., 2013; Herr et al., 2019; Dunham et al., 2020), and the key support areas identified by this research, a training programme for IFCs and one for CHs *(*for *all* staff) could be developed. Thiswould prepare caregivers for pain and support optimal pain practices, by increasing knowledge, skills, and capabilities. The findings of this research could be used in a feedback exercise to build increasingly relevant themes for training, including IFCs, PwD and CH staff in the development of participatory and innovative ways of supporting and promoting learning about pain. Previous programmes have demonstrated short term success in raising the profile of pain (e.g., *See Change: Think Pain*; Napp, 2014), and improving pain management practices (PAIN-Dem; Petyaeva et al., 2018), suggesting more formalised, regular, and integrated training can have a positive impact.

A mixed methods research evaluation could serve as a follow up such a training programme, over the course of 24 months to determine improvements in knowledge, skills, and practices. Qualitative data could be used to obtain feedback on the training, in terms of relevance and implementation into daily care. Quantitative data could compare reported practices with audits of pain medication, pain documentation, care plans, patient records, and use of medication. Pre and (multiple) post measures could implement the PKBQ (Zwakalen et al., 2007), this research having established applicability among these caregiver groups. This would allow for improvements in knowledge and beliefs to be captured and explored in relation to other variables. The impact of training upon empathy (via The Empathetic

Care Scale, Lamberton, Leana & Williams, 2015) and principles of person-centred care (Personhood in Dementia Questionnaire, Hunter, Hadjistavropoulos, Smythe, Malloy, Kaasalainen & Williams, 2013) could also be explored, given that this research suggests empathetic approaches are linked to greater understanding of pain, and principles of PCC were described as underscoring individuals pain assessment and treatment.

9.6 Conclusion

This thesis provides an in-depth understanding of pain recognition, assessment, and treatment among community dwelling PwD, and those living in care homes in the UK. Through the integration of qualitative and quantitative data, the experiences of CH staff and IFCs have been captured and presented. This current chapter has provided an interpretative and contextual overview of the key findings of this thesis, while also discussing the limitations and implications of the research. The findings from the thesis reflect the changing landscape of care and present a more inclusive picture of pain in dementia that encompasses the experiences of those increasingly responsible for meeting the care needs of this population. The critical role of IFCs and CH staff in the identification, advocation, assessment and treatment of pain among PwD is evident from these findings, as are the substantive challenges faced and requirements for additional support or training. Future capacity-building initiatives, such as use of guidelines and the development of training that seek to improve pain assessment and treatment among PwD, must engage these caregiver groups, while optimising upon their existing informally acquired expertise. To overcome the limitations of the research undertaken in this thesis, more empirical worked is needed-longitudinal studies that include both carers and PwD in the data collection process.

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Appendices

Appendix A: Information sheet for Study 1 & 2

Research Title: Identifying & Treating Pain in Dementia: The Experiences of Caregivers

What is the purpose of the study?
The purpose of this independent research project is to explore caregivers, both paid and informal, experiences of caring for people with dementia who have pain.

Do I have to take part?
Your participation is completely voluntary and will not impact upon your employment, academic record, your relatives or friends care, or your attendance to support groups.

What will happen to me if I take part?
Interviews: If you choose to take part in an interview you will participate in a one-to-one interview with the student researcher. Interviews will last around an hour, and be audio recorded. Interviews may take place at (*insert care home name as appropriate*), your own home or a place of your choosing.
Survey: If you choose to take part in a paper or email survey you will be asked to answer a number of questions, it will take around 30 minutes depending on your responses.

During interviews and throughout the surveys you may decline to answer any questions, withdraw yourself at any time, and your data up to two weeks following your participation without giving any reason. To facilitate withdrawal, you will be required to select a personal code which will be known to you, this will preserve your anonymity should you wish to withdraw your data at a later date. Your interview audio file and responses to surveys will be securely kept in a password protected computer file and any paper copies locked secure place.

Are there any risks in taking part?
The project has been approved by the University of Greenwich Ethics Committee. This research is not anticipated to involve physical or mental harm, however those who have recently experienced a traumatic life event, such as bereavement within the last 6 months, or are experiencing depression or any other active mental illness, may be distressed, so are asked not to participate.

What are the benefits of taking part?
Your experiences supporting a person/people with dementia, particularly in relation to how you might be supporting them in relation to pain and advocating for their needs is of interest. It will contribute to our understandings of the roles of caregivers in relation to pain, and highlight challenges or support needs.

Will my taking part be confidential and anonymous?
Your anonymity will be protected in all information and data obtained. Your real name will not be used in connection with your interview or survey data. Pseudonyms

will be used instead, and any other names mentioned. Any other identifying features will be omitted from the report and resulting publications. Confidentiality will further be protected by the researcher and further academic parties who may be involved.

What will happen to the results?
The results of this research may be published or reported; however, your name will not be used or identifiable in the published data. The researcher, as a PhD student, will be using results in a thesis for partial fulfilment of a PhD.

How do I contact the student researcher to either take part, or find out additional information?
If you would like to take part, please contact the researcher at the provided email, or telephone number. You will be asked to sign a consent form to indicate your agreement to participate. If you would like further information before agreeing to participate the researcher is happy to provide additional details.

I thank you in advance for your participation in this study, I anticipate this study will produce findings of significance and further our understanding of the experiences of those who provide care for people living with dementia.

Appendix B: Participant Consent Form for Study 1 & 2

Research Title: Identifying & Treating Pain in Dementia: The Experiences of Caregivers

To be completed by the participant. If the participant is under 18, to be completed by the parent / guardian / person acting *in loco parentis*.

- I have read the information sheet about this study
- I have had an opportunity to ask questions and discuss this study
- I have received satisfactory answers to all my questions
- I have received enough information about this study
- I understand that I am / the participant is free to withdraw from this study:
    - At any time (until such date as this will no longer be possible, which I have been told)
    - Without giving a reason for withdrawing
    - (If I am / the participant is, or intends to become, a student at the University of Greenwich) without affecting my / the participant's future with the University
    - Without affecting any medical or nursing care I / the participant may be receiving.
- I understand that my research data may be used for a further project in anonymous form, but I am able to opt out of this if I so wish, by ticking here. ☐
- I agree to take part in this study

Signed (participant)	Date
Name in block letters	
Signed (parent / guardian / other) (if under 18)	Date
Name in block letters	
Signature of researcher	Date

Key:
- **Questions**
  - ○ **Sub-questions**
  - \- **Probes**

Appendix C: Study 1 Interview Schedules

Interview Topic Guide- Informal Caregivers

Demographics & Personal Information

- What is your age?
- Have you ever been in the caring profession? (*Role and years' experience)*
- What is your relationship to the adult with dementia you provide care for?
  - ○ What is their age?
  - ○ How long have they experienced symptoms of dementia?
  - ○ How long have they been diagnosed with dementia?
  - ○ What form of dementia are they diagnosed with?
- How long have you been their caregiver?
  - ○ Are you their sole caregiver?
- Have you attended any dementia training?

Pain in Dementia

- Does the person you care for have any conditions which causes them pain?
  - \- Have they experienced any injuries or falls?
- How frequently would you say they have pain?
- Since having dementia, has there been any change is their response to pain?
  - \- Are there any examples you can draw on?
- Do you think about pain in your day-to-day support of the person you care for?
  - \- Is pain a concern in your day-to-day caregiving?

Pain assessment in Dementia

- How do know if the person you care for is in pain?
  - \- What behaviours, noises, or signs do you look out for?
  - ○ What kind of questions do you ask them, if any, to find out about their pain?
- What are some of the challenges, if any, you have experienced in trying find out if the person you care for is in pain?
  - \- Could you describe any examples of occasions you have found it hard to find out if the person you care for in is pain?
- Are you familiar with pain assessment tools? *(Explain pain assessment tools)*
  - ○ Have you observed or been aware of healthcare providers using any such tools with the person you care for?
  - ○ What are your thoughts about using pain assessment tools to identify pain in people with dementia?
  - \- Based on your experience as a caregiver, do you think they might be useful?

Pain Management in Dementia

- ○ When you have noticed or believed the person you support is in pain, how have you responded?
- Have you used any pain medications, if so what kind?
- ○ Do you assist the person you care for in managing any of their pain medications?
- ○ What do you think are the benefits of pain medications?
- ○ Do you have any concerns about giving the person you care for pain medication?

- Have you used any non-drug methods to relieve pain in the person you care for, such as massage or alternative therapies?
    - What do you think are the benefits of using these methods?
    - Would you have any concerns about using these methods with person you care for?
- Have the person you support visited a healthcare professional for pain or condition which causes them pain?
    - What action did the healthcare professional take to help with relieving pain in the person you care for?

Perceived Barriers

- (*Those with pain conditions)* Do you feel equipped to care for a person with dementia who has pain and pain related conditions?

\- What might make you feel better equipped?

- There is some suggestion that pain might go unnoticed and untreated in people with dementia. What do you think about this?
    - What do you think could be done to improve how pain is noticed and treated in people with dementia?

Thank you for taking the time to share your experiences and answer my questions.
Are there any additional comments you would like to make?

Key:
- **Questions**
  - **Sub-questions**
    - **Probes**

Interview Topic Guide- Care Home Staff

Demographics & Personal Information

- What is your age?
- What is your nationality?
- What is your job title?
  - How many years' experience have you had within this role?
  - Prior to this job role had you worked in the caring profession? *(Previous role and years' experience)*
- Have you received any training in relation to the care of older adults?
  - Did this training cover dementia and/or pain?
- In your current role how often do you provide care for older adults who have dementia or are cognitively impaired?

Pain in Dementia

- In your day-to-day work, do you encounter residents with dementia who have pain or conditions that might cause them pain?
  -What kind conditions or injuries do you encounter that cause residents with dementia pain? You can draw on specific residents or examples.
- If you know or are involved in medication, what kinds of pain medication or relief is used with residents with dementia?
- Would you say that pain is a concern in your day-to-day caregiving role?
- In your experience, do residents with dementia respond differently to pain than other residents?
  - Are there any examples you can draw on?

Pain Assessment in Dementia

- How do know if a resident with dementia has pain?
  - What behaviours, noises, or signs do you look out for?
  - What kind of questions do you ask them, if any, to find out about their pain?
- What are some of the challenges, if any, you have experienced when trying to find out it a resident with dementia has pain?
  - Could you describe any examples of occasions you have found it hard to find out if a resident with dementia is in pain?
- Are you familiar with pain assessment tools? *(Explain pain assessment tools)*
  - Please describe any pain assessment tools you have used or those used with the care home.
  - Have you observed or been aware of healthcare providers using any such tools with residents with dementia?
  - What are your thoughts about using pain assessment tools to identify pain in people with dementia?
- Are there any guidelines relating to the recognition and treatment of pain in people with dementia that you are aware of within the care home?

Pain Management in Dementia

- When you have noticed or believed the person you support is in pain, how have you responded?
- Have you or another healthcare professional used any pain medications, if so what kind?

- What do you think are the benefits of pain medications?
- What concerns might you have about giving a resident with dementia pain medication?
- Have you or another healthcare professional used any non-drug methods to relieve pain in the person you care for, such as massage or alternative therapies?
  - What do you think are the benefits of using these methods?
  - What concerns might you have about using these methods with residents with dementia?
- Have you reported pain in a resident with dementia to another healthcare professional or nurses?
  - What action did the healthcare professional take to help with relieving pain in the resident?
  - Was your reported acted upon?

Perceived Barriers

- Do you feel equipped to care for residents with dementia who have pain and pain related conditions?
- What might make you feel better equipped?
- There is some suggestion that pain might go unnoticed and untreated in people with dementia. What do you think about this?
  - What do you think could be done to improve how pain is noticed and treated in people with dementia?

Thank you for taking the time to share your experiences and answer my questions.
Are there any additional comments you would like to make?

Appendix D: Study 2 Survey

Care Home Staff Survey

Instructions

The focus of this survey is on pain, and how you deal with pain in the residents you care for. Pain can refer to chronic or long-term conditions, such as arthritis, or acute or short-lived pain, such as a headache.

If you believe the residents/clients you care for do not have any pain (a question about this is included) I would still invite you to answer this survey, as your thoughts as a caregiver are still of interest and value to this research.

The survey consists of open-ended questions which invite you to write a response on the lines provided, or closed questions which require you to tick off/mark/ the most appropriate answer. If you feel a particular question does not apply to you or the residents/clients you care for, you may indicate so by writing this, or for example indicating N/A, or skipping the question. If there are questions which you do not wish to respond too, then you may leave these questions blank.

Please write as little or as much as you like, if you require extra writing space feel free to write on the back of the questionnaire, or a separate piece of paper. If you do require additional writing space, please indicate which question you are continuing (e.g., 7a) continued).

I thank you in advance for your time and for sharing your experiences.

Demographics

1) Age: **2)** Gender: M [ ] F [ ] **3)** Nationality:__________

4) What is your job title? ____

5) How many years of experience do you have in this job role?

6 months or less	**6 months to 1 year**
1-2 years	**2-5 years**
5-7 years	**7-10 years**
7-10 years	

6) What are your main responsibilities in this job role?_______________________

____

____

7) Prior to this job role, have you ever worked in the caring professions? Yes [ ] No [ ] **(i)** If yes, please provide brief details of previous job_____________________

____

____

8) In your current job role, have you received any training relating to the care of older adults? [ ] No [ ]

(i) If yes, please provide a brief overview of what training you have received: ___

____

____

9) Have you received any training in relation to dementia? Yes [ ] No [ ]

(i) If yes, please specify what training you have received:________________________

____

____

Pain in residents with dementia

10)a) At the care home what kind of conditions do you frequently encounter which might cause residents/clients with dementia pain? For example: Bed sores or arthritis____

____

____

i) For those residents/clients who have painful conditions, are they prescribed any pain relief? Yes [ ] No [ ] Not sure [ ]

If yes, please specify what they are prescribed if you know: ___________________

____

____

____

11)a) i) How frequently would you say that you encounter residents/clients who have dementia in the care home? (Please circle)

Very frequently	Frequently	Occasionally
Rarely	Very rarely	Never

ii) How frequently would you say that you provide direct care for residents/clients who have dementia? (Please circle)

Very frequently	Frequently	Occasionally
Rarely	Very rarely	Never

b) i) How frequently would you say that you encounter residents/clients with dementia who have pain? (Please circle)

Very frequently	Frequently	Occasionally
Rarely	Very rarely	Never

ii) How do you know if residents/clients with dementia are pain-free?____________

____

____

12) Would you say that pain is a concern in your day-to-day caregiving? Yes [ ] No [ ]

Please specify why it might, or might not be a concern: ______________________
____
____

13) In your experience, do residents/clients with dementia react differently to painful circumstances compared to those residents/clients who do not have dementia? For example, they might react more or less than residents/clients without dementia.____
____
____
____

14) How do you decide if a resident/client with dementia is in pain? For example, what kind of changes, behaviours, or words or sounds do you look out for?______________
____
____

a)Do you ask them about their pain? Yes [ ] No [ ]
i) If yes, what kind of questions do you ask: __________________________________
____
____
ii) If you do not ask them about their pain, why is this? _________________________
____
____
____

15) Have you experienced any challenges in deciding if a resident/client with dementia is in pain? Yes [ ] No [ ]
i) If yes, what kind of challenges have you encountered? _____________________
____
____

16) Pain assessment tools have been developed to help identify when people with dementia have pain. Some self-report pain assessment tools require a person with dementia to answer questions about their pain, for example to rate their pain on a scale from 1 to 10, or to pick a face which most represents the degree of their pain. Other observational pain assessment tools require a caregiver to watch a person with dementia and rate the presence of potential signs of pain, such as crying, calling out, aggression, changes to usual habits, or body language. Observational pain assessment tools have been developed specifically for those who have reduced ability to communicate their pain verbally.

a) Prior to this survey, were you aware of pain assessment tools?
Yes [ ] No [ ]
(i) If yes, had you received any training about them?
(ii) Yes [ ] No [ ]

Please explain further:____

b) i) Have you ever used self-report pain assessment tool in the residents/clients you care for? Yes [ ] No [ ] If yes, please specify which you have used if possible: _

ii) Have you ever used an observational pain assessment tool in the residents/clients you care for? Yes [ ] No [ ] If yes, please specify which you have used if possible:

iii) Have you ever seen another healthcare provider use a self-report or observational pain assessment tool with a resident/client with dementia? Yes [ ] No [ ] Don't know [ ] If yes, please specify which you have seen a healthcare provider use if possible: ____

c) i) Do you think pain assessment tools are/might be useful to help workout when people with dementia are in pain? Yes [ ] No [ ] Don't know [ ]

ii) Why do you think this?____

(iii) Do you think pain assessment tools should be made available for all caregivers supporting people with dementia? ____

17) Have you ever used or been advised to use guidelines relating to the recognition, assessment or management of pain in older adults or those with dementia? Yes [ ] No [ ]

i) If yes, which guidelines have you used? ____

Treating pain in residents with dementia

18) i) When you have believed a resident/client with dementia is in pain did you report this to another member of staff (e.g., manager, GP, registered nurse)? Yes [ ] No [ ] If yes, who did you report it to and what action did they take?

ii) When you have believed a resident/client with dementia is in pain have you used any drug/s to relieve their pain? For example, paracetamol or prescribed medication.

Yes [ ] If yes, which drug/s have you used and why did you feel this/they were the most suitable? ____

____

____

____

No [ ] If no, why do you not use drugs to relieve their pain? (If your job role does not involve the administration of drugs, please indicate so) ________________________

____

____

ii) What do you think are the advantages and disadvantages of using drugs to relieve pain in people with dementia? ____

____

____

____

19) When you have believed a resident/client with dementia has pain have you used any non-drug methods to relieve their pain? For example, massage, aromatherapy or heat.
Yes [ ] No [ ] **(i)** If yes, which non-drug methods have you used? ____________

____

____

____

ii) What do you think are the advantages and disadvantages of using non-drug methods to relieve pain in people with dementia? ____________________________

____

____

____

20) Do you feel that recognising pain and making sure it is treated is a part of your role as a caregiver? Yes [ ] No [ ] **) (i)** Please explain: __________________________

____

____

____

____

21)i) Research suggests that pain in people with dementia can go unnoticed and untreated. What do you think about this?____________________________________

____

____

21)ii) How do you think we might improve how pain is recognised and treated in people with dementia?____

____

____

22)i) Do you feel equipped to care for residents/clients with dementia who have pain?
Yes [ ]

No [ ] **ii)** What do you feel would make you feel better equipped?

____

Pain Knowledge and Beliefs Questionnaire (PKBQ)

Pain statements

To respond to the following statements about pain please encircle the number for the answer concerned. The idea is to express to what extent you agree or disagree with the statement, i.e., give you opinion.
For example, if you disagree completely with a statement, you should encircle the number 1, see the example below:

	Completely disagree	Fairly disagree	No opinion	Fairly agree	Completely agree
A person who is sleeping does not experience pain	1	2	3	4	5

Please only encircle one response for each statement.

Questions about Pain

	Completely disagree	**Fairly disagree**	**No opinion**	**Fairly agree**	**Completely agree**
Pain management at the care home					
1. Where I work, pain is assessed correctly	**1**	**2**	**3**	**4**	**5**
2. Where I work, pain is treated correctly	**1**	**2**	**3**	**4**	**5**
3. Where I work, much attention is given to pain in dementia patients	**1**	**2**	**3**	**4**	**5**
Pain experience of older compared to younger people					
4. Older people experience pain less intensely than younger people	**1**	**2**	**3**	**4**	**5**
5. Pain medication works better young people than in the elderly	**1**	**2**	**3**	**4**	**5**
6. Pain medication works longer in the elderly than in younger people	**1**	**2**	**3**	**4**	**5**

7. Pain medication has more side-effects in the elderly than in younger people	**1**	**2**	**3**	**4**	**5**
8. People with dementia experience less pain than those without dementia	**1**	**2**	**3**	**4**	**5**
9. Assessing pain in people with dementia is a matter of guessing	**1**	**2**	**3**	**4**	**5**
Pain treatment in older adults					
10. Pain is part of the ageing process	**1**	**2**	**3**	**4**	**5**
11. Older people are affected by pain more often than younger people	**1**	**2**	**3**	**4**	**5**
12. Pain medication, if administered in large quantities, easily leads to addiction among the elderly	**1**	**2**	**3**	**4**	**5**
Pain medication					
13. Pain medication should only be administered to patients suffering from serious pain	**1**	**2**	**3**	**4**	**5**
14. Older people are often prescribed too much pain medication	**1**	**2**	**3**	**4**	**5**
15. It is better to administered pain mediation 'when necessary', rather than according to a fixed schedule	**1**	**2**	**3**	**4**	**5**
16. Administering pain medication should be postponed as long as possible, because a person with dementia should receive as little pain medication as possible	**1**	**2**	**3**	**4**	**5**
17. A person with dementia should first report pain before receiving the next dosage of pain medication	**1**	**2**	**3**	**4**	**5**
Please check if all questions are answered					

Informal Caregiver Survey

Instructions

SEE CARE HOME SURVEY

Demographics

1) Age:___________**2)** Gender: M [ ] F [ ] **3)** Nationality: ________________

4) Have you ever been in the caring profession? Yes [] No [ ] Please specify, including years' experience within the role: ___________________________

____

5) a) What is your relationship to the person with dementia that you care for?

____

b) How long have you been their caregiver?

6 months or less	**6 months to 1 year**
1-2 years	**2-5 years**
5-7 years	**7-10 years**
7-10 years	

c) Are you their sole caregiver? Yes [ ] No [ ] If no, please specify any additional support: ____

____

6) What age is the person you provide care for? ______________________________

7) a) How long has the person you care for had symptoms of dementia? (Please circle)

6 months or less	6 months to 1 year	1 year-2 years
2 or more	Not sure	

b) How long have they been diagnosed with dementia? (Please circle)

6 months or less	6 months to 1 year	1 year-2 years
2- 5 years	5-7 years	7-10 years
10 years or more	Not sure	

c) What type of dementia have they been diagnosed with? (Please circle)

Not sure	They have not received a clinical diagnosis yet	Alzheimer's Disease
Vascular	Fronto-temporal	Lewy bodies
10 years or more	Mixed: (Please specify) ____________________________	

8)i) Have you received any training in relation to dementia? Yes [ ] No [ ] If yes, please specify what training you have received:__________________________

____

8)i) Did this training include anything relating to pain?_________________

____

____

Pain in the person you care for

10)a) Does the person you care for have any conditions that you are aware of that might case them pain? Yes [ ] No [ ]

b) i) If yes, please specify what conditions they have:_________________________

____

____

ii) If yes, have they been prescribed any pain relief for the above conditions? Yes [ ] No [ ] If yes, please specify: ____

____

____

c)i) If yes, how frequently would you say they have pain? (Please circle)

Very frequently	Frequently	Occasionally
Rarely	Very rarely	Never

ii) How do you know when the person you care for is pain-free? _______________

____

____

11) Would you say that pain is a concern in your day-to-day caregiving? Yes [ ] No [ ] Please explain: ____

____

12) Since having dementia, has the person you care for reaction to pain changed? For example, since having dementia they might react more or less_________________

____

____

13) a) How do you decide if the person you care for is in pain? For example, what kind of changes, behaviour, words, or sounds do you notice_______________________

____

____

b) Do you ask them about their pain? Yes [ ] No [ ]
i) If yes, what kind of questions do you ask? ____________________________________

____

____

ii) If you do not ask them about their pain, why is this? ___________________________

____

____

14) Have you experienced any challenges in deciding if the person you care for is in pain?

Yes [ ] No [ ] **i)** If yes, what kind of challenges have you encountered? __________

____

____

15) Pain assessment tools have been developed to help identify when people with dementia have pain. Some self-report pain assessment tools require a person with dementia to answer questions about their pain, for example to rate their pain on a scale from 1 to 10, or to pick a face which most represents the degree of their pain. Other observational pain assessment tools require a caregiver to watch a person with dementia and rate the presence of potential signs of pain, such as crying, calling out, aggression, changes to usual habits, or body language. Observational pain assessment tools have been developed specifically for those who have reduced ability to communicate their pain verbally.

a) Prior to this questionnaire, were you aware of pain assessment tools? Yes [ ] No [ ]
(i) If yes, please elaborate ____

____

ii) Have you ever seen a healthcare provider use a self-report or observational pain assessment tool with the person you care for? Yes [ ] No [ ] Don't know [ ] If yes, please explain further ____

____

c**) i)** Do you think pain assessment tools are/might be useful to help workout when people with dementia are in pain? Yes [ ] No [ ] Don't know [ ]

ii) Please explain your response:____

____

iii) Do you think pain assessment tools should be made available for all caregivers supporting people with dementia? ____

____

Treating pain in the person you care for

16)i) When you have believed the person you care for is in pain have you (or they) used any drug/s to relieve their pain? For example, paracetamol or prescribed medications. Yes [ ] No [ ]

(i) If yes, which drug/s have you (or they) used and why did you feel this/they were the most suitable?____

____

____

ii) What do you think are the advantages and disadvantages of using drugs to relieve pain in people with dementia?

____

____

____

17) When you have believed the person you care for is in pain have you (or they) used any non-drug methods to relieve their pain? For example, massage, aromatherapy or heat.

Yes [ ] No [ ]

(i) If yes, which non-drug methods have you used? __________________________

____

____

ii) What do you think are the advantages and disadvantages of using non-drug methods to relieve pain in people with dementia?

____

____

____

18) i) Has the person you care for visited a healthcare provider for pain or a condition causing pain? For example, doctor, dentist, osteopath, physiotherapist, or a consultant in pain management. Yes [ ] No [ ]

ii) If yes, which healthcare provider/s did they see and what action did the healthcare provider/s take?____

____

____

19) What barriers or challenges, if any, have you and the person you care for encountered when trying to get pain recognised and treated? ____________________

____

____

20) i) Research suggests that pain in people with dementia can go unnoticed and untreated. What do you think about this?

____

____

____

____

21)i) Do you feel equipped to care for a person with dementia who has pain? Yes [ ] No [ ] **ii)** What do you feel would make you feel better equipped?______________

____

Pain Knowledge and Beliefs Questionnaire (PKBQ)

Pain statements

To respond to the following statements about pain please encircle or highlight the number for the answer concerned. The idea is to express to what extent you agree or disagree with the statement, i.e., give you opinion.

For example, if you disagree completely with a statement, you should encircle the number 1, see the example below:

	Completely disagree	Fairly disagree	No opinion	Fairly agree	Completely agree
A person who is sleeping does not experience pain	[✓ 1]	2	3	4	5

Please only encircle one response for each statement.

Questions about Pain

	Completely disagree	**Fairly disagree**	**No opinion**	**Fairly agree**	**Completely agree**
Pain management					

1. During visits to healthcare providers, pain is assessed correctly in the person I care for	**1**	**2**	**3**	**4**	**5**
2. During visits to healthcare providers, pain is treated correctly in the person I care for	**1**	**2**	**3**	**4**	**5**
3. During visits to healthcare providers, much attention is given to pain in the person I care for	**1**	**2**	**3**	**4**	**5**
Pain experience of older compared to younger people					
4. Older people experience pain less intensely than younger people	**1**	**2**	**3**	**4**	**5**
5. Pain medication works better young people than in the elderly	**1**	**2**	**3**	**4**	**5**
6. Pain medication works longer in the elderly than in younger people	**1**	**2**	**3**	**4**	**5**
7. Pain medication has more side-effects in the elderly than in younger people	**1**	**2**	**3**	**4**	**5**
8. People with dementia experience less pain than those without dementia	**1**	**2**	**3**	**4**	**5**
9. Assessing pain in people with dementia is a matter of guessing	**1**	**2**	**3**	**4**	**5**
Pain treatment in older adults					
10. Pain is part of the ageing process	**1**	**2**	**3**	**4**	**5**
11. Older people are affected by pain more often than younger people	**1**	**2**	**3**	**4**	**5**
12. Pain medication, if administered in large quantities, easily leads to addiction among the elderly.	**1**	**2**	**3**	**4**	**5**
13. Pain medication should only be administered to patients suffering from serious pain	**1**	**2**	**3**	**4**	**5**
14. Older people are often prescribed too much pain medication	**1**	**2**	**3**	**4**	**5**
15. It is better to administered pain mediation ‘when necessary’, rather than according to a fixed schedule	**1**	**2**	**3**	**4**	**5**
16. Administering pain medication should be postponed as long as	**1**	**2**	**3**	**4**	**5**

possible, because a person with dementia should receive as little pain medication as possible					
17. A person with dementia should first report pain before receiving the next dosage of pain medication	**1**	**2**	**3**	**4**	**5**
Please check if all questions are answered					

Appendix E: Study 1 Reflexive Thematic Analysis Memos

RTA Version 1 – Initial themes

Main Themes	
Frequency Encountering Pain	Pain Assessment Tools
Pain Response (PwD)	Response to Pain (Caregivers)
Detecting Pain	Treatment Challenges
Drug Pain Management	Improving Detection
Non-drug Pain Management	The Pain of Caring

Theme & analysis notations

Initial clustering of common patterns using interview schedule topics.

Unanticipated theme- The pain of caring- The challenges caregivers' experience. Physical pain and existential pain are both present for PwD and those supporting them. It is becoming clear that larger issues eclipsing physical suffering, and what was being communicated was pain and challenges of another kind, but they could not be segregated, unteased.

Caregivers are in tune with need- *"And I've noticed if she's cold or hot or hungry or thirsty or something that triggers her mood as well".* Responding to needs in other ways, pain is not subsumed within 'needs'.

Caregivers contradict themselves- e.g., Interviewees' wife has arthritis but no longer does, or is it because she can no longer communicate this? (which he acknowledges). Another interviewee describes her husband as having irregular pain "*yet it occurs happens several times throughout the day, possibly as often as half a dozen times, yeah."*

Pain and weakness- e.g., *"never succumb to pain*

Pain has many lenses, its existential, physical, historical.

Temporality of pain- Pain is priority and is ‘seen’ when its injury, it’s in the here and now, the present moment, long-term conditions/pain are not seen as pain in the same way. There is an acuteness, a physical means, a prelude to pain.

RTA Version 2- 6 Themes

Theme	Subtheme
Encountering Pain	Pain Conditions Expectations of Ageing Stoicism & Belittlement
Communication & Connection	Loss of Semantics & Memory Making Contact
Independence and Autonomy	Capacity for Choice Negotiating
Deciphering Dementia	Speaking Through the Body Understanding through Connection Misappropriation & Unpredictability
Treatment Advantages	Managing Behaviour Death & Dying Alternative Therapies
Treatment Issues	Administrative Challenges Paracetamol Panacea Uncertainty & Reluctance Striking a Balance

Theme & analysis notations

More in-depth clustering of themes and generation of initial subthemes.

Communication & connection- they lose the meaning of words, the memory of pain and what it means. Caregiver’s bridge these loses with meaningful and familiar connection, and an intuitive or experiential ability. Caregivers negotiate with capacity.

Independence vs. Autonomy - reflect the power struggles and conflicts caregivers experience when attempting to support PwD who remain agents of their own choices but have diminishing cognitive capacity. Walking a line between being an advocate and being in control. As dementia progresses, caregivers shift from advocates to responsible.

Encountering pain- pain is a reality, a normality of ageing. Informal caregivers in particular treat the expression of pain with belittlement, stoicism is rewarded (e.g., copes with pain well, doesn't succumb to pain). Informal caregivers contradict themselves, often indicating the person they support does not have pain, and then describing conditions which cause pain. Is pain in the everyday context not pain to them? Is pain only pain when it's in the here and now? There is a temporality to what is seen as pain.

Deciphering dementia- what is pain, and what is dementia? Dementia as a puzzle of many representations and versions, it causes unpredictable behaviour which clouds all things in mystery, like pain. Caregivers would rather believe a behaviour is indicative of dementia, rather than indicative of pain.

Treatment advantages- all caregivers did not prioritise pain, but care home staff did discuss it in the context of death and dying. Pain is considering less acceptable in death, and yet acceptable in life.

Treatment issues- what is pain, what is dementia? How do we treat when there is uncertainty? Informal caregivers and those they support are anti-medication, paracetamol is used- and seen as the only safe option. To strike a balance between side-effects, but a balance is rare, suffering is seen as more acceptable than risk. Risk aversion. Informal caregivers talked relatively little about how they treated pain.

Speaking through the Body- reciprocal relationship with below. The stories told by the physical body. Speaking through the body represents the alternative voice which PwD use to convey their pain and emotions.

Understanding through Connection- When there is not connection, or it is not enough they use a process of elimination. They will report that they would know- despite the fact they report the person is different and their behaviour can be odd or unpredictable. They indicate they will self-report, despite saying the disease has progressed to the point where either communication, understanding or cognition has become problematic.

Uncertainty & Reluctance- unwilling to medicate because of uncertainty of what is pain. What is pain and what are the idiosyncrasies of individuals brought on by dementia. Caregivers fear misappropriating behaviour to pain, when it is dementia. Dementia is seen as unpredictable.

Bridging the Gap- Most indicate there is change in reaction to pain in dementia, either a physical change- they feel more pain, a change in ability to cope- a personality change, or a communication change- in which they express it physically or behaviourally rather than verbally .

Communication and connection- adapting their language and behaviour to make contact or bridge the gap where semantic meaning and memory are failing.

RTA Version 3- 5 Themes

Meta-Theme	Subthemes
1. Relieving Suffering	A. Striking a Balance B. Paracetamol Panacea
2. Deciphering Dementia	A. Speaking Through the Body B. Understanding Through Connection C. Uncertainty & Reluctance D. Bridging the Gap E. Care Vs. Dementia
3. Social Expectations & Norms	A. Putting ‘Pain’ in a Box B. Ageism C. Stoicism
4. The Pain of Caring	A. Evolving Identity B. Grief & Loss C. Systemic Challenges
5. Autonomy vs. Dependence	A. Power Conflicts B. Capacity & Choice

Theme & analysis notations

Power Conflicts- the transition from ‘mother’ to caree, results in conflict over control. Misuse or control over medications, often unconscious but neither the less is there. Power conflicts also relating to care home staff, and their experiences with getting pain relief from doctors.

Capacity & Choice- they have a right to medication and a right to choose not to take it. Free will as a barrier. Cognitive capacity vs. choice. At which point do we empower or endanger. They negotiate. Carers evolving identity make it difficult for them to allow choice, as they are in control. Often PwD want to exercise control and choice, which can make the caregivers role more difficult.

They are a subset of carers who described the person they support as being resistive to going to the doctors or taking medication, and for them they could not get this person to engage in reporting their pain or engaging in the management of it.

The dialectic between allowing them agency and independence in decision-making and them no longer being able to do so with accuracy- She has pain, I will ask if she wants pain relief, and she will say no.

There are some people with dementia who carers seem to allow to self-manage their pain and be actively engaged in this independently. This had varying results with overdose of medication being reported, and use of alcohol as a coping mechanism.

Pain of Caring-The challenges caregivers’ experience. Physical pain and existential pain. Larger issue eclipsing pain, and what was being communicated was pain and challenges of another kind, but they could not be segregated, unteased.

Grief & Loss- dementia is like cancer, and it hides, it is not a physical illness which can be treated, bandaged etc. There is a loss of identity but also a loss of a particular lifestyle. They value social support, and use it to give themselves perspective, there are others which have it worse. Yet PwD seek to distance themselves from others ‘like them’. Grief, guilt and stigma are intertwined,

Evolving Identity- Caregivers become the protector, particularly for adult children it is a shift to this. They bare the pain/resentment it so that their charge does not have to. They have competing health problems but place the needs of the other at the centre of their world. They experience their own loss of personhood, be that as a husband or wife, and must adjust to a new being as a carer. Some carers do not accept the growing dependency of their loved ones or the diagnosis. They go from a ‘normal’ life into a full-time carer often with no preparation for it physically, emotionally or practically.

The people with dementia also experience a transition in self-perception and abilities, as they are aware of the changes to themselves from the disease. They are aware of the shift from independent or ‘wife’ to dependent. They do not want to be around other people with dementia, distance themselves, links to stigma.

Many informal caregivers expressed something relating to stigma or shame in relation to dementia. It appears like many illnesses with a history of institutionalisation and connotations of mental illness and undesirability, the roots of dementia and origins of its namesake still permeate the minds of the older generation. There were those who found accepting their relative or spouse has dementia was hard enough a task, and thus opening up to a researcher about their experiences was not something many easily did or were willing to. Duty to care.

Pain of Caring- for care home staff they were removed from the PwD, they were more distant from changing roles (as they are caregivers, before familiar or connected person). They did speak of residents with affection and consideration.

Systemic Challenges- informal caregivers experience challenges in getting a diagnosis, and abandonment by memory clinics.

Care vs. dementia- dementia is all consuming. Dementia is in opposition because of its dominance to everything other.

Systemic Challenges- diagnosis challenges, abandonment. Informal caregivers and those they support fear institutionalisation.

Social norms- pain can be seen (or not) depending on the expectations of society, and the expectations of caregivers. Stoicism-pain should be endured and accepted, when it's not belittlement results and reports of pain are interpreted as over dramatised. Social norms to 'live with' pain, get on with it.

When you look at the phrasing of informal caregivers around how stoic their charge is it seems that such is positively appraised, i.e., IFC interviewee 5 states *'I think you suffer the pain quite well really'.* The expectation is that these people should be able to tolerate a certain level of pain and maintain a stiff upper lip.

Ageism- old people have pain, it is the norm.

Putting 'Pain' in the box- 2 meanings- for pain to be acknowledged it must take on a certain form, it must fit within the predetermined ideas of the caregiver. Generally, caregivers anticipated it to manifest from physical injury, poor mobility or poor health, and the reports of pain would have been consistent e.g., "*regular basis" Interviewee 2.* Yet it may not be possible for a PwD to consistently report pain verbally, and similarly they may more in spite of pain (e.g., if they wander with purpose). Pain must tick the correct criteria (and the behaviours, verbalisations must all line up) for it to be treated. The second meaning is that it is very much put in a box aside from anything else. The overwhelming and all-consuming nature or dementia and caring for ‘dementia’ takes priority (we see the challenges and likely underscoring reasons for that in the ‘pain of caring’)

RTA Version 4-4 Themes

Meta-Theme	Subthemes
1. Relieving Suffering	A. Striking a Balance B. Paracetamol Panacea C. Putting ‘Pain’ in a Box D. Ageism & Stoicism
2. Deciphering Dementia	A. Speaking Through the Body B. Understanding Through Connection C. Uncertainty & Reluctance D. Bridging the Gap
3. The Pain of Caring	A. Evolving Identity B. Grief & Loss C. Systemic Challenges
4. Autonomy vs. Dependence	A. Power Conflicts B. Capacity & Choice

Theme & analysis notations

Amalgamating themes.

Theme 3 Social norms- collapsed into Relieving Suffering and all its contents.

Care vs dementia- subtheme shift into in Deciphering dementia.

Putting pain in a box- moved to main theme Relieving Suffering.

RTA Version 5- 4 Themes

Theme	Subtheme
1. Deciphering Dementia	A. Speaking Through the Body B. Understanding Through Connection C. Bridging the Gap
2. Relieving Suffering	A. Lack of Prioritisation B. Striking a Balance

	C. Paracetamol Panacea
3. The Pain of Caring	A. Evolving Identity B. Grief & Loss C. Systemic Challenges
4. Autonomy vs. Dependence	A. Power Conflicts B. Capacity & Choice

Theme & analysis notations

New subtheme and subthemes collapsed. Ageism and stoicism- now lack of prioritisation in theme 1, Putting pain in a box move into lack of prioritisation.

Lack of prioritisation- This refers to what they think causes pain- how clear it is to them and also to how they prioritise it. How they describe it and what they count as pain says a lot about how they are prioritising it. They have certain expectations about pain too which seem to relate to a lack of priority given to it. They expect pain in older people, so it's not a big deal. They also expect pain to manifest as something physical, or as causing significant impairment. Lack of priority comes from PwD themselves who are described as responding with stoicism as a coping mechanism.

Pain is not prioritised because it is so challenging. Task-orientated care and other needs are easier to meet so become priority "*But, actually it's very difficult, I would say half of my residents can tell me they're in pain and the other half I have to guess, you know by the way their verbalising."* (CH Duty Manager)

When asked about pain they draw on illustrative examples, vague, reactive to known conditions: "*Erm, I'm trying to think now what causes them pain. Erm, I know we have one gentleman who it's his knees and legs that cause him more pain than anything. Erm, trying to think. We've got a lady, like her left arm she gets a lot of rheumatism in, so she'll say, 'Oh my arm, my arm is aching"* (CH HCA). It was quite challenging to get caregivers, even care home staff, to think about what causes pain. This implies it is not a priority, conditions causing pain or pain was not at the forefront of caregivers’ minds.

Physical pain is not as well recognised as existential pain, this suffering was more concerning to informal caregivers and tended to elicit a more empathetic approach.

Bridging the Gap- has many meanings. Caregivers believe that PwD can bridge the gap in declining cognitive and communicative ability. Informal caregivers tend to cling to the idea that the person will still be able to find a means to communicate their pain to them, yet they will contradict this when discussing how cognitive ability and communication is declining. Perhaps their closeness does not allow them to recognise potential increasing needs.

It also refers to how care home staff, and informal caregivers (e.g., going to training and learning about dementia), bridge the gap between lack of training and their skills. They bridge it with experience and knowledge of the person. E.g., *“the rest of it is just hard worn experience”* (CH Duty Manager)

Recruitment- Informal caregivers felt they were not able to contribute much to conversations about pain.

“No, not really. No, I don’t think there was anything at all about pain, which is why when I read your sheet I thought ‘I don’t know whether I am going to be helpful about this’, you know whether it’s what you really want because Ralph has pain but it’s not particularly related to his Alzheimer’s.”

"No, I feel as though, when I read your thing and I thought 'I'm not sure I'm going to be very good for this'. I'm learning about more, not about the pain thing, but more and more about the dementia..."

RTA Version 6 Final- 4 Themes

Theme	Subtheme
1. Deciphering Dementia	A. Speaking Through the Body B. Understanding Through Connection C. Bridging the Gap
2. Relieving Suffering	A. Lack of Prioritisation B. Striking a Balance C. Existential Suffering
3. Autonomy vs. Dependence	A. Capacity & Choice B. Negotiating Comfort
4. The Pain of Caring	A. Evolving Identity B. Grief & Loss C. Systemic Challenges

Theme & analysis notations

Paracetamol Panacea- focused on the perceived efficacy/safety of the drug, as safe bet. Also focused on the resistance of PwD and informal caregivers with regards to pill taking. The contents would work better within Striking a Balance.

Paracetamol Panacea moved into Striking a Balance.

Autonomy and dependence- subthemes revisited. Power conflicts collapsed into Capacity & Choice.

Capacity & Choice refers to the power conflicts and tension between autonomy and dependence which arise during relieving pain. PwD remain able to choose and caregivers must negotiate their agency, alongside holding some control over medications.

Contents from across themes relating to how caregivers negotiate increasing dependency alongside supported autonomy moved into new subtheme Negotiating Control.

Negotiating Comfort- the means by which caregivers negotiate control vs. independence. How they negotiate with PwD to try to offer them comfort. Control vs. pain.

Bridging the Gap- renamed to Deteriorating Connections

Appendix F: Study 1 & 2 Case Study Notes & Survey

Care homes & Care home Interviewees

The care homes recruited were primarily independently privately owned (3), privately owned by national chains (2), and one was charitable/not for profit (1). Two provided nursing care, while 4 provided residential and personal care only. All were registered to provide dementia care, and all indicated on their online webpages their staff received regular training in relation to care and dementia more specifically. The Quality Care Commission (QCC) ratings varied across care homes, with those requiring improvement overall present, and those rated an outstanding in relation to care.

Care homes A-D were case studies for interviews in Study 1, however were also included in Study 2 alongside care home E and F.

Care homes Study 1 & 2

Care home A was one of larger homes recruited, with a 60-resident capacity. The care home offered specialist dementia and nursing care and was divided over two floors to house those with dementia on the upper floor.

Interviewee 1, Jane, represented care home A, she had only been in post 6 months as a healthcare assistant. Jane had no previous experience in a caring role, and had only completed taster training at the time of interview. Jane, due to the rotation of weekly shifts, spent one day each week working with the residents with dementia. She indicated that she would usually encounter pain in one of these residents during her weekly shifts, identifying falls as the most common cause of pain. Jane was not aware of medications residents were taking, given she was not involved in medicines.

Care home B was home to 32 residents with and without dementia, advertising itself as ‘Dementia friendly’. It provides only residential and personal care, not nursing care..

Interviewee 2, Ceri, was recruited to represent care home B. Ceri was a recently appointed duty manager. Prior to this role Ceri had spent almost 30 years working as a healthcare assistant and more senior caring roles in care homes. She reported having training in older adult care but qualified her knowledge and skills were developed primarily from experience. Ceri indicated she had received relatively little dementia training, which was in part related to her previous experience in care homes which did not specifically offer dementia care. Ceri worked daily with residents who had dementia and could single out residents she knew to have pain complaints. She was aware of different pain and anti-inflammatory medications used in topical, tablet and oral form used in the care home.

Care home C was split over 3 floors and consists of units to house 41 residents with and without dementia. Again, this care home offered only residential and personal care, not nursing care.

Interviewee 3, Elaine represented care home C. Elaine is a senior carer with 10 years’ experience in her current role. Prior to this, Elaine was a nursing auxiliary for 10 years. Elaine reported training in older adult care and dementia, but she too made a qualification on her training. She indicated *“‘I haven’t had exceptional training”,* and highlighted the increasing need given the rising numbers of residents with dementia under her care. Elaine’s descriptions of pain she observed in the care home and how it was treated were vague. Elaine did not elaborate on the types of medication used to treat pain in the home, using the term ‘pain killer’ as all-encompassing of treatments used. Elaine’s vagueness seemed to reflect her reservations about revealing resident information. She made several comments during her interview, such as *“you’re recording so I can’t say too much”,* which seemed to suggest she was conscious of what she was revealing.

Care home D is a nursing home offering care for up to 113 older people with dementia and enduring mental health issues. It was purpose built with separate units for different conditions. In addition to offering residential care, this home also offers nursing care.

Interviewee 4, Clare, represented care home D. Clare is a healthcare assistant with 30 years’ experience. Clare reported having done dementia, other mandatory training, and medication training. She drew on specific residents to illustrate the kinds of pain complaints residents had at the home. Clare indicated the frequency with which she encountered pain varied on her shift rotation, reporting in the morning and mid-afternoon when prescribed pain medications have worn off, she would hear residents complain of pain. She was able to identify a number of pain and anti-inflammatory medications prescribed to residents in the home.

Care homes Study 2

Care home E offers residential care to up to 60 older people with dementia.

Care home F is a care home offering residential care to up to 43 older people with dementia.

Informal Caregiver Interviewees

Interviewee 5, Mary, has been supporting her mother for last 18 months. Her mother was diagnosed with Alzheimer’s Disease around 3 years ago, she is able to communicate still, however Mary describes a recent decline in her mother's condition. Mary receives respite care by visits from a carer, and her mother attends a day centre a few days a week. Prior to taking on supporting her mother, Mary had no experience caring for someone and had not been to the training sessions on dementia provided by a carers charity she was in contact with.

Mary was interviewed in her home, while her mother was at a day centre. She was keen to take part in an interview and had written herself some prompts about her caring experiences, but she did question her ability to contribute to discussions about pain. Mary described conflict arising from daily situations, and her mother's growing obsessive tendencies. Mary highlighted several conditions, including spondylitis and rheumatism, which cause her mother pain frequently, but particularly during movement. Paracetamol has been prescribed to manage pain; however, Mary describes her mother as unwilling to take this regularly. In describing her mother's pain, Mary indicates her mother is intolerant of pain, which is met with some scepticism by Mary and an attitude of that some pain is necessary (e.g., pain when getting in and out the bath).

Interviewee 6, John, has been caring for his wife for 5 years since she was diagnosed with Alzheimer's Disease. He receives some respite care each week, carers to assist shower his wife, and his wife attends a day centre.

John was interviewed at his home; his wife was present intermittently. John spoke often to his wife during the interview, to reassure her or to include her in what he was describing. John spoke of the changes in lifestyle he was adjusting to, , and the changes in his wife's character.

John believed his wife at current was not experiencing any pain, or underlying conditions which could cause pain. However, he did describe his wife had previously had arthritis in her wrist. He described her wandering and constant physical movement as a sign of her health.

Interviewee 7, Emma, assists her father, *Interviewee 8* Derek, in caring for her mother Jan. Jan was diagnosed with dementia 7 years ago, she is still able to communicate with some lucidity, however, no longer consistently recognises Emma or Derek. Derek provides the most care (supported by some domiciliary care), while managing his own health issues. The interview with both Emma and Derek occurred within Derek’s home. Emma and Derek both emotively described the impact dementia had on their relationships with Jan.

Emma explained that her mother did not suffer from any painful conditions; however, Derek did provide examples of incidents in which his wife had described pain, including headaches and tooth ache. Emma described her mother’s prior lifestyle as one of active engagement and attributed her good physical health and mobility to this.

Interviewee 9, Caroline, assists her father-in-law in supporting her mother-in-law. Caroline has been supporting her mother-in-law for around 6 months, since she was diagnosed with vascular dementia. At current Caroline is the only support her father-in-law has. Caroline’s mother-in-law is in the early stages, and as such can still communicate quite well, however does confuse everyday items.

This interview occurred at a café. Caroline described having learnt and read about dementia, to try to understand what her mother-in-law was experiencing. Caroline indicated her mother-in-law had constant pain, but that she tolerates this pain, and its only sign is in her movement. Caroline was not aware if anything has been prescribed to her mother-in-law.

Interviewee 10, Rose, carers for her husband who had been diagnosed in the last year with dementia. Rose has been attending a course on dementia provided by a charitable organisation to learn more about her husband's condition.

The interview occurred within the home, Rose and her husband were present together and Rose would often include her husband in her comments or direct her responses at him. Rose explained that her husband had been showing symptoms dementia for several years but had only been diagnosed within the last year. Rose and her husband share a reciprocal caring relationship, as she too has her own conditions and she describes herself as "*struggling sometimes*".

Rose described her husband as having depression and having frequent pain from a historic injury in his ankle and foot. Rather than take tablets Rose explained her husband distracts himself from the pain by doing "little jobs".

Interviewee 11, Donna, supports her husband. Donna's husband was diagnosed with Alzheimer's Disease 4 years ago, however he had experienced symptoms for around 5 years before receiving any diagnosis. To assist with her husband, Donna has support from a carer in the mornings. She has also been attending the same course as other interviewees, however indicated this did not include any material on pain.

The interview took place in the home, where Donna was joined by her husband Ralph. Donna described the changes to their life and her frustrations about Ralph's symptoms, including some behaviours she described as obsessive.

Donna indicated her husband has pain currently and frequently, caused by underlying conditions and surgeries. Donna described her husband as stoic and having a high pain tolerance. This made him reluctant to take prescribed or over the counter medication. Donna described her husband's tag line to be *"I'm fine".*

Interviewee 12, Tom, and supports his wife. His wife has been diagnosed with Alzheimer's Disease for 1 year, however had experienced symptoms for a year before a diagnosis was received. Tom indicated his wife was reluctant to visit a GP on the onset of her memory problems and was resistant to any help within the home and visits to healthcare providers. He is the sole caregiver for his wife.

Tom describes his wife as having relatively good physical health, however, has hip pain from hip replacement. Paracetamol is prescribed for this, but it was unclear if Tom's wife regularly receives this now she has recovered from her hip replacement surgery. The major concern Tom voiced was related to his wife's weight loss.

Interviewee 13, Anne, was supporting her husband with vascular dementia up until his death 5 years ago. Anne was her husband's sole caregiver for the duration of his illness. The interview took place at a carer support group. Anne described dementia as an *"insidious thing"*. She suggested that perhaps her interview would stimulate others to be willing to speak to the researcher. Anne talked about the loss of identity that happens to spouses and family members.

Anne explained she could recall several incidents when she had witnessed her husband with pain, however described that her husband was reluctant to seek medical help and *"wasn't one to complain."*

Interviewee 14, Joyce, has been supporting her husband with the assistance of their son for 6 months. Joyce's husband was diagnosed with Alzheimer's disease 6 months ago but began showing symptoms over a year.

Joyce was interviewed a carer support group, which her husband does not attend. Joyce describes her husband as having other health concerns, including diabetes and a heart condition which need to be routinely managed. The diagnosis of dementia has allowed Joyce to take on responsibility for managing these medications, as she indicates her husband was not compliant in self-managing.

Joyce indicates her husband does not suffer pain; however, Joyce did contradict this later indicating she used herbal oil typically used on rheumatism.

Interviewee 15, Eric, supports his wife was diagnosed with vascular dementia around 1 year ago, supported by a relative and some domiciliary care. Eric has attended the same course that other interviewees had.

Eric's interview occurred at a café. Eric described social isolation and dementia as *"life changing".* Eric describes his wife as having several health issues that cause pain, identifying her crumbling spine as most distressing and causing consistent pain. He describes using Ibuprofen and co-codamol at night and morphine patches. Eric identified his wife's swallowing a problem for taking medication.

Interviewee 16, Irene, supports her mother who was diagnosed with Alzheimer's Disease around 5 years ago. Irene's mother is also supported by Irene's sister and a live-in carer. Irene was interviewed at her home.

Irene talked about preparing herself for her role and her mother's dementia by research and using online resources. While Irene indicated her mother could still communicate, she did confuse words and she had noticed the declining conversational ability of her mother.

Irene's mother has osteoarthritis in her joints and has been prescribed paracetamol and codeine phosphate. Irene expresses a dislike of medication, or *"pill popping"* and prefers alternative therapies, such as tiger balm and deep heat rub. In describing her mother's pain, Irene describes her mother's tolerance as low and suggests the response is dramatised.

Interview 17, Lyn, supports her husband, with the assistance of her children. Her husband was diagnosed with Alzheimer's Disease 3 years ago, having shown symptoms of the disease a few years prior to this.

Lyn's interview took place at the carer support group, as was her preference. She was present with her husband, whom she checked her responses with throughout the interview. Lyn husband suffers with scoliosis and osteoporosis, which she describes as causing consistent and progressive pain. Despite this Lyn indicates that he has not been prescribed any pain relief. She reflects that over-the-counter medications are available at home, however she does not offer these to her husband, nor does he request pain relief or discuss his pain with her.

Interviewee 18, Betty, supports her husband who has memory problems. Betty has been trying to get her husband diagnosed with dementia for some time, suspecting dementia is the underlying cause of his memory and behavioural problems. She described not being heard by the doctor when trying to highlight her suspicions.

Betty was interviewed at a support group. Betty described the existential pain her husband has been experiencing, highlighting his memory loss, and age-related declining health as contributing to this. Betty also talked about her husband's physical pain. Although she initially talked about his pain as irregular, she qualified this as being numerous times throughout the day. Betty is aware her husband's hip surgery causes reduced mobility and likely pain; she also suspects he has regular headaches. However, her husband in described as *"concealing*" his pain and as having *"never succumb to pain".* Betty's husband is also described as resistant to medication, indicating that due to his comorbidities he is "*loathed"* to take anything further.

Table F1: Study 2 Survey structure & content

Section	Key Topics
Instructions	Instructions for completion and: "The focus of this survey is on pain, and how you deal with pain in the residents/PwD you care for. Pain can refer to chronic or long-term conditions, such as arthritis, or acute or short-lived pain, such as a headache. If you believe the residents/clients you care for do not have any pain (a question about this is included) I would still invite you to answer this survey, as your thoughts as a caregiver are still of interest and value to this research."
Section 1 Demographic & Contextual information (Q1-9)	Demographics (Q1-3) Work/Caring history & characteristics of PwD supported (Q4-7) Relevant Training (Q8-9)

Section 2 Experience of pain in PwD (Q10-13)	Pain conditions & frequency of pain in people/person with dementia supported (Q10-11) Reaction to pain among people/person with dementia supported (Q12-13
Section 3 Identifying pain in PwD **(**Q14-15)	Signs of pain among people/person with dementia supported and/or challenges to identifying pain (Q14-15)
Section 4 Pain Assessment Tools (Q 16-17)	Description of pain assessment tools (PATs) Awareness, use of PATs and thoughts on utility (Q16) Use of any guidelines (Q17)
Section 5 Treating Pain in PwD	Report of pain to other healthcare providers or visits to healthcare providers (Q18) Use of drug treatments, and suitability/concerns (Q18)

(Q 18-22)	Use of non-drug treatments, and suitability/concerns (Q19) Preparedness to assess and treat pain among PwD (Q20-22)
Section 7 Pain Knowledge & Beliefs Questionnaire (PKBQ, Zwakhalen et al., 2007)	
Item	**Domain**
Item 1-3	Pain assessment & treatment in context
Item 4-9	Pain experience of older compared to younger people
Item 10-12	Pain treatment in older adults
Item 13-17	Pain medication

Table F2: Overview of the Pain Knowledge & Beliefs Questionnaire (PKBQ, Zwakhalen et al., 2007)

PKBQ (Zwakhalen et al., 2007)	
Summary of questionnaire	Developed to identify knowledge gaps and inaccurate beliefs in relation to pain in dementia.
Number of items	17, 4 factors
Content areas and % variance explained (where reported)	Factors are: 'Knowledge about the pain experience of older adults compared to younger' 24.9%, 'Pain management at the ward' 12.4%, 'Pain medication'10.1%, and 'Pain and pain treatment in older adults' 7.9%
Content Validity	Face validity established by pain experts and nursing home nurses
Internal consistency	Good (Cronbach's alpha= 0.78)
Scoring methods	Each item rated on a five-point Likert scale (1= completely disagree to 5= completely agree) Lower scores indicate higher knowledge
Country of development	The Netherlands
Respondent and administrative burden	Not reported- 17 items

Appendix G: Reflective Account

I began this PhD journey 8 years ago, having been awarded a PhD scholarship to explore a pre-decided focus on ‘Dementia & Pain’. I approached this thesis with a background in psychology, and ageing research. As such, I had an understanding of ageing, and of dementia. I well understood pain in the sense of psychological suffering, while I was less familiar with physical pain. I wonder, with reflection, if my limited understanding of physical suffering at the beginning of this journey mirrored that expressed by caregivers. That being said, from my background I was able to recognise the salience of physical suffering by its the cyclical relationship to emotional and mental states.

Prior to undertaking this thesis, and for two years in, I volunteered in care homes. From this, I was familiar with care home environments as workplaces, homes to its residents, and places of care. I also familiar, and empathetic to those working in these environments. As such, it is likely I arrived at data collection with my own perspective of the workforce, and a certain affinity to the challenges that CH staff described. I was less familiar with forms of community care, and the role of IFCs by juxtaposition, however I easily resonated with many of the IFCs recruited, given that many were older people and had previously undertaken research with this demographic. Dementia was a thorny issue to talk about, and highly emotive for IFCs. They used data collection as an opportunity to describe their fears, their perceived injustices and to ask me questions about dementia and services. This was a difficult position to be in, I empathised with their stories, however there was a constant need to re-centre dialogues on the key interest, without degrading their experiences. This was challenging, dementia was domineering, as was the existential suffering that clung to it. It is likely such is reflected in the findings, in which pain is conceptualisation as not solely that derived from the body, but existential and enveloping both PwD, and their caregivers.

During data collection I was perceived by IFCs as having some vital information to depart about dementia, in a position of *knowing*. This blurred the role of an objective researcher, and it could only be resolved by signposting onto support services. For CH staff on the other hand, I am sure at times I was perceived as an auditor, which will have inevitably shaped how they responded to me and my questions. In both cases I was viewed an expert in pain, yet I viewed caregivers as the experts. For some I could affirm them this was the case, that they *were* the experts. For others they would qualify their statements, indicative of some sense of judgement from me about the accuracy of what they were describing. I wondered for the latter, if they were scared to reveal things, and for CH staff to what extent fear of reprisal form their employer or colleagues filtered some of what was described. Analysis of the findings spanned a number of years. I had completed analysis, and re-entered analysis following an interruption to my studies. I re-arrived at my data with an entirely new lens, as such I understand it is possible that another may have analysed the offerings of caregivers entirely differently to what I have presented. Alongside a culmination of my background, and the insights shared above, this research endeavour has been shaped by time. This has been an undertaking which has carried across my early adult life and early career development. As such this thesis has evolved with me, and as a result it has been an apprenticeship, often resulting in hindsight reflections on my choices and some discordance.

Appendix H: Chapter 7 Study 2: Qualitative Survey Data: Structured-Tabular Thematic Analysis

Table H1 ST-TA: Prevalence of subthemes across 5 sections of the survey

T	ST	Section 1	Section 2	Section 3	Section 4	Section 5
1	a. Speaking	0	45/115 39.13%	96/115 83.48%	1/115 0.87%	11/115 9.57%
	b.Understanding	0	9/115 7.83%	34/115 29.57%%	6/115 5.22%	12/115 10.43%
	c.Deteriorating	0	63/115 54.78%	46/115 40%	6/115 5.22%	12/115 10.43%
	d.Person-centred	0	9/115 7.83%	7/115 6.09%	7/115 6.09%	6/115 5.22%
	e.Informal	0	0	83/115 72.17%	88/11576.52%	2/115 1.74%
2	a.Lack	0	48/115 41.74%	2/115 1.74%	2/115 1.74%	13/116 11.30%
	b.Striking	0	11/115 9.57%	5/115 4.35%	0	106/115 92.17%
	c.Existential	0	46/115 40%	10/115 8.70%	2/115 1.74%	6/115 5.22%
	d.Acute	0	34/115 29.57%	4/115 3.48%	2/115 1.74%	4/115 3.48%
	e.adhering	0	23/115 20%	14/115 1 12.17%	14/11512.17%	89/115 77.39%
3	a.Supporting	0	12/115 10.43%	14/115 12.17%	1/115 0.87%	14/115 12.17%
	b.Assuming	0	5/115 4.35%	4/115 3.28%	0	77/115 66.96%
4	a.Grief	0	9/115 7.83%	2/115 1.74%	1/115 0.87%	8/115 6.96%
	b.Shifting	0	7/115 6.09%	3/115 2.61 %	1/115 0.87%	7/115 6.09%
	c.Practical	26/115 22.61%	1/115 0.87%	0	0	9/115 7.83%

Table H2. Example indicative survey responses from caregivers

Theme 1: Deciphering Dementia	
Subtheme	Indicative survey responses
a. Speaking through the body	“Changes in behaviour or reduced mobility. It’s a process of elimination, if they flinch when you touch them you know they are in pain, or they hold their head, or if they’ve got bruising from a fall.” (Respondent 13. Senior carer). “They can’t all tell you, so you have to study your client and changes in their life is telling you something is wrong, it’s giving you the information.” (Respondent 45. HCA) “If I try to dress/undress him and try to lift his foot he will resist as it causes knee pain. It can lead to aggressive and abusive behaviour, which is both defensive and attacking, he will lash out with his fists or even head butt.” (Respondent 108. Carer for husband) “You can see something is wrong quite easily by touch or looking at them, it can be quite hard to pinpoint exactly what that something is, whether it’s pain or illness. You have to use a process of elimination, ‘Is it pain?’ ‘Are they wet?’. Because of the lack of communication, it can a bit of detective work.”(Respondent 51. HCA)

	“Aggression, abusiveness. The trouble is at this stage he cannot tell me, and I have to figure it out. For example, when he had thrush he resisted having his teeth brushed and would baulk at toothpaste… I learned he had thrush.” (Respondent 108. Carer for husband)
b. Understanding through connection	“Some people might not see the signs, like a small flinch, so it wouldn’t be noticed. If you know the residents, you see small signs. If you don’t know the residents then unless their screaming and shouting, they might not know. We have one resident who screams and shouts all day and night and swears. If she is in pain, then tone of her voice changes but someone who didn’t know her might just think she’s shouting for the sake of it.” (Respondent 40. HCA) “It can be hard to know if it’s pain if the person with dementia don’t want to tell me or a senior, so we will find someone on shift who the resident likes or feels connected to and they’ll usually tell them what’s wrong. One day you can be their best friend, the next day their enemy, it doesn’t work the same.” (Respondent 27. Activities coordinator) “This probably depends on how well the carer knows the person with dementia. Having been married for all these years it is not too much of an issue.” (Respondent 84. Carer for husband) “It’s a constant awareness and because they all act differently in communicating it, you have to be quite intuitive.” (Respondent 17. HCA)

c. Deteriorating Connections	“Dementia changes the entire person. I think some can overreact to pain, like one lady screams the place down if you touch her arm and hand. Other don’t react to pain, they might have a bruise and it’s not until you touch it, they realise they are in pain.” (Respondent 51. HCA) “It must be very distressing for them not being able to hold on to the fact that they’re in pain, so they forget and relive it every time they go to get up or move.” (Respondent 28. HCA). “He will rub and swing his knees and he moan ‘Oh’. The problem is, you’re not sure whether he’s doing it because it’s something he recalls, its habit, or whether it’s because he is in pain….When he moans, I will ask ‘What’s the problem?’ and he will say ‘I don’t know’. He does not know himself if he’s in pain. He will moan or whimper and when you ask, he cannot say what’s wrong. He’s either forgotten, or can’t articulate, or remember the words for it. The more you ask about it he gets more confused.” (Respondent 99. Carer for father) “I always talk to them; they are still a person and might not be able to communicate and they might not be able to make sense, but you still let them know what you are doing and what’s happening, so they aren’t frightened. If I ask them if they want tea, they might not give you the right answer, or the one you want, but it’s still communication.” (Respondent 51. HCA)
d. Person-centred approach	“People have different thresholds of pain you have to consider. You’ve got to treat them all as individuals.” (Respondent 13. Senior carer)

	“It depends on the individual person, what works for someone doesn’t work for another.” (Respondent 33. HCA) “We have others who become aggressive. We have some who are very tearful…It’s weird how they can all react differently.” (Respondent 16. HCA).
e. Informal vs. formal assessment	“He makes various noises which I don’t think are pain, they are to do with the dementia so if someone was observing for pain and hear these noises, but didn’t know my husband, they might think it was pain when it’s not.” (Respondent 109. Carer for husband) “All staff should be aware of it, but I think one person should be delegated to make sure the pain assessments are looked at and not left to the side. We should then all meet to discuss it.” (Respondent 29. Activities coordinator) “Everybody should know what’s happening and what forms nurses are filling out. If all carers know what pain assessment tools are and what they say about a resident, they won’t misinterpret pain and will know what is happening with a specific resident.” (Respondent 43. Activities coordinator) “If you’ve just come into a home and don’t know the residents or haven’t cared before it’s (PAT) useful until you learn what residents’ triggers and responses are. If there is a case where staff are unsure it could be useful.” (Respondent 48. HCA)

	“I think it should be available for any carer if it allows you to gauge their pain, particularly if they’ve lost their communication ability then you lose the subjective input from them so an observational or objective would be good.” (Respondent 17. HCA) “My mum is unable to communicate so I understand it would be good to be able to observe someone to find out if there’s pain. If I thought my mum was in pain, I would want to know how I find out, as she cannot say herself.” (Respondent 83. Carer for mother)

Theme 2: Relieving Suffering

Subtheme	Indicative survey responses
a. Lack of prioritisation	“It is a concern, but it’s not top of the list. Making sure he’s safe is my top priority…he’s lived with the pain for such a long time it no longer bothers him.” (Respondent 105. Carer for Husband) “We have one resident who is in constant pain and when you try to do personal care you have to determine whether it’s his continuous pain or a new different pain that he is suffering. He worries new staff because they only have to touch him, and he cries out and they say ‘What have I done!?’ and you have to say ‘It’s nothing you’ve done that’s how he is.” (Respondent 40. HCA) “Nurse- if it sounds serious, they will be checked by the nurse straight away. If it’s less serious use healthcare assistants will be asked to monitor it and report back to them.” (Respondent 10. HCA)

	“The seniors reaction depends on the level of pain, the perceived cause of the pain and the resident. If the resident never is any trouble and never complains, they know something is wrong. If the cause of pain is a fall or symptomatic of a heart attack they will react quickly.” (Respondent 28. HCA) “If I ask him, he might tell me how bad it is. I sympathise and say, ‘Oh never mind’ and I try to distract him, like ‘Have another cup of tea’.” (Respondent 110. Carer for husband)
b. Striking a balance	“Constipation is caused by co-codamol and in dementia it’s yet another thing, and they cannot express the constipation pain.” (Respondent 52. Nurse) “Some of them are on tablets to calm them down, if they have pain medication on top of this it makes them zonked and unresponsive.” (Respondent 28. HCA) “Some medications can enhance the symptoms of dementia and make them slide quicker. Possibly, because they don’t understand there is pain there, they could injure themselves more. It could be too, I don’t know if this is true, that those in the late stages don’t recognise they’re in pain or whether it’s just they because they can’t recall.” (Respondent 112. Carer for husband) “Perhaps occasionally paracetamol but she is already taking a number of other medications and there is always a concern about interaction. At times it must be necessary but with caution and only on recommendation. … I feel it is sometimes difficult to identify which pills can be addictive- I appreciate a GP would know this but an ordinary person on the street might not. I tend to feel that all painkillers can be

	addictive and feel that in the view of the fact that most people with dementia are older (generally) and probably should be given a reduced dosage in view of any side-effects, lack of hydration etc.” (Respondent 89. Carer for mother-in-law) “I talk to my mum to calm her when she is in pain. Massage mum’s hands and arms, stroke her hair and face seems to work. I feel that mum is more relaxed than just giving her drugs.” (Respondent 103. Carer for mother) “We use hand and finger massage, and we hold their hands. We use an empathetic approach; we empathise with them. It’s a way of interacting with them and getting them to interact with us.” (Respondent 55. Nurse)
c. Existential suffering	“One resident is always complaining about stomach ache, but I think it’s more anxiety based.” (Respondent 19. HCA). ‘I will touch them, like rest my hand on them, I will stroke their hands or their hair. This helps them to feel they aren’t alone; I will sit with them while they’re in bed in pain. I have got no issue with sitting with someone in pain and supporting them/spending time with them, so they don’t feel alone. It is very important because it effects everything, including emotional, physical, mood.’ (Respondent 29. Activities co-ordinator)

	“Sometimes he gets pain in his head but it’s not a headache, they think it’s part of his awareness that this is happening to him and its stress. It appears to be escalating now…” (Respondent 110. Carer for husband) “Not very often do they have pain, if they are kept busy, they are not complaining, it’s when they left idle that’s when they start thinking or saying their hands hurt or they’ve got a headache. If you leave them too long, they remember the pain. If I’m with them they don’t complain, the minute I walk aware their aches and pains start.” (Respondent 27. Activities co-coordinator)
d. Acute vs. chronic	“If they are in pain its managed well with medication and we do regular observations. Pain is occasional unless there is an injury. We have one lady in constant pain in her hand and we know to handle her with care.” (Respondent 51. HCA) “Regularly injures herself, cuts herself, falls out of bed and bruises herself. Her boots rubbed her leg, and she now has a large sore on her leg.” (Respondent 107. Carer for wife) “It's not a concern, you know the reasons why they are in pain, i.e., arthritis, or any other obvious condition.” (Respondent 2. Activities co-ordinator.) “If we notice a resident has a high temperature we will give paracetamol, as they might have a UTI or headache but most of the time if you give them paracetamol, they tend to be okay.” (Respondent 41. Nurse)

e. Adhering to roles & responsibilities	“How nurses react depends on the nurse, some will tell you ‘You haven’t been here long enough’ ‘You don’t know the resident’ ‘Don’t be silly he’s fine’. For that reason, I carry a notebook and record everything I report, so a nurse can’t say I didn’t report something to them.” (Respondent 51. HCA) “I once noticed a gentleman had swollen genitals, I did not think it was painful, it didn’t occur to me it was out of the ordinary. It was only when another carer noticed I realised something was wrong. So, it’s all about team work so others can pick up on oversights.” (Respondent 49. HCA) “We are responsible for ensuring that our residents are given the highest level of care whilst ensuring their wellbeing safety and attending to their needs. To not treat residents’ pain recognised pain would be abuse and neglect.” (Respondent 3. HCA) “I take even the little things serious even if my colleagues don’t. Even if it was reported 2 weeks ago, I’ll report it again, so it gets acted on this time. I think this shows I’m concerned about a resident.” (Respondent 57. HCA) “My senior in charge of shift. Their response is always good, in that they take all reports of pain seriously. Where necessary, depending on the situation, they have either called a doctor or ambulance out, administered pain medication, and always documented it and monitored the residents’ pain thereafter.” (Respondent 3. HCA)

	“The GP is the next step if paracetamol is not working, but the GP can be reluctant to prescribe anything stronger than paracetamol. If a resident has regular falls the GP will prescribe something stronger but if the resident has no history of falls or is well in themselves otherwise the GP will request a blood test and further investigations before giving anything stronger.” (Respondent 41. Nurse)
Theme 3: Autonomy vs. Dependence	
Subtheme	Indicative survey responses
a. Supporting choice	“It depends on the resident and their character; some would be less willing to talk about it and others want to tell you the world. It’s hard to tell, it depends on dementia as to if they can tell you where and what’s hurting. You have to try and work it out, sometimes if you just chat and reassure them, they will tell you. Those who don’t want to talk about it I will report their pain to a carer or a senior.” (Respondent 31.Domestic) “Rarely will he moan or say he has pain. He would just say he was fine if I asked.” (Respondent 81. Carer to husband) “It also depends on the person with dementia, some suffer in silence, some don’t. I think women suffer in silence and men complain more.” (Respondent 101. Carer for husband)

	“Every human being has the individual right to accept/refuse/request pain relief.” (Respondent 8. Senior carer)
b. Assuming control	“For some residents they don’t like taking tablets, so they refuse them - you have to try again later which usually works.” (Respondent 52. Nurse) “If the pain is bad then they should be given pain relief, but they don’t always want to take it.” (Respondent 35. HCA) “My mum was prescribed paracetamol, but it kept piling up, so I cancelled it off her prescription. She rarely takes it, but she has it available if I think she needs it.” (Respondent 111. Carer for mother) “I encourage mum to take paracetamol for hip pain, but she usually declines. It depends on the level of pain. Mum was in agony with neck pain so regular medication is of great help, but she can tolerate her hip pain, so prefers not to use medication for this.” (Respondent 93. Carer to mother)
Theme 4: The Pain of Caring	
Subtheme	Indicative survey responses
a. Shifting relationships & identities	“I am unwell myself and a carer for my husband and daughter, so there is no one to care for me. I am a carer for my husband with dementia and my daughter, so if it’s not him, it’s her, and if it’s not her, it’s him. I struggle because there is no one to care for me. I don’t exist, I have lost my identity.” (Respondent 110. Carer for husband)

	“I feel equipped now to deal with her pain. I do get scared about what to do in the future when her episodes become worse. She has started to get physical with carers and tried to break down doors. It scares me that she is becoming someone else and how I will deal with it as she progresses more.” (Respondent 111. Carer for mother)
b. Grief & Loss	“I just don’t like my life at the moment, and what it’s done to my husband. I’m floundering, finding my way through it.” (Respondent 105. Carer for husband) “As she is my wife, I can tolerate it. If it was someone else, I’d get too frustrated and impatient. It would be like looking after someone else’s kid.” (Respondent 107. Carer for wife)
c. Practical, societal & systematic challenges	“Both online and with a trainer. It was really interesting; I didn’t know there was so many forms. I thought you got it because you didn’t use your brain, not just that anyone can get it.” (Respondent 54. Domestic) “I try to attend as much [training] as possible; every little bit helps to understand dementia.” (Respondent 49. HCA) “Training from Dementia Diagnostic Centre: All types of dementia and how to deal with/cope with it.” (Respondent 96. Carer for husband) “He used to go the day centre but no longer goes. I have a carer who comes, she takes him out for respite for me.” (Respondent 108. Carer for husband)

	“We recently moved in with daughter so she is there for physical and moral support should we need her, and to prevent I or my husband going into a home.” (Respondent 110. Carer to husband). “I go to carers support groups and people share their issues or give each other tips or help. You listen to other people’s stories.” (Respondent 91. Carer for wife). “Seeing the doctor for mum’s pain was a positive experience, as helpful as possible. However, in relation to dementia we haven’t really discussed in depth mum’s dementia which I believe is because she was referred to the memory clinic to deal with her dementia. We found the memory clinic totally unhelpful, and they have now discharged mum. They did not have the time to address our real concerns.” (Respondent 111. Carer for mother) “When he kept complaining about his finger we saw a doctor, she said she could see nothing wrong with it. He kept complaining about it, so I took it more seriously and when he had an x-ray he had a healing fracture which I did not know about. I believed the doctor when she said there was nothing wrong with his finger, it was only when went to A and E we found out he has a healing fracture.” (Respondent 109. Carer for husband)

Appendix I: Chapter 8 Study 2: Exploring Pain Knowledge & Belief (PKBQ) Scores

The following provides a detailed account of the statistical analysis performed relevant to the Chapter 7. All reported figures are to 2 decimal places.

To respond to research question 4 and for the purposes of testing H1 and H2, the PKBQ scores were explored descriptively and using Analysis of Variance (ANOVA). ANOVA was selected as the most appropriate inferential statistical test for the purposes of testing the hypotheses proposed prior to Study 2. ANOVA enables the exploration of mean scores on a dependent variable (DV) across different independent variables (IV), allowing significant differences on mean scores across IV groups to be identified. In this context, ANOVA was used to explore differences in PKBQ scores, across caregiver groups. The following provides detailed discussion of the results of both descriptive exploration and ANOVA testing.

PKBQ Scoring & Changes

More optimal scores on the PKBQ, or lower scores, demonstrate more appropriate knowledge and beliefs regarding pain, its assessment and its treatment among PwD. Items 1-3 relate to reported pain practices, as such as not scored. For items 4-17 the appropriate response to each of these items is disagreement. As such, where a respondent agrees with the statement, they will receive a score of 1. For more information on how the PKBQ was scored please see Appendix I. For CH staff the PKBQ scale was used without any changes, however items (1-3) were slightly reworded to be applicable for the IFCs. The following change was made:

Original wording (item 1-3): “Where I work….”

IFC wording (item 1-3): “During visits to a healthcare provider….”

Data Entry

PKBQ scores: scores were generated by assigning participant responses a score of 1-5. Lower scores indicate better performance on the PKBQ, given that incorrect responses are scored higher. Correct responses (on items 4-17) were scored at 1 (strongly disagree), ascending to 5 for strongly disagree.

Missing values: Missing PKBQ scores (n= 5) and those for years’ experience (n= 8) were replaced using the series mean.

I(A): ANOVA 1 & H1: Caregiver Roles & PKBQ Scores

H1 was tested first. PKBQ scores were used as the DV, and there were 7 levels on the IV, (HCA, Activities & Domestic, Management, Senior Carer, Nurses, Nursing Students, and Informal Caregivers).

Descriptives

Initially, descriptive output was used to explore PKBQ scores based on different roles (Table I(A) 1.1). This output indicated that caregivers in management positions scored lowest (M= 30.55, SD= 7.36), and therefore demonstrated increasing understanding and more appropriate beliefs about pain in PwD. Nursing Students were one of the lowest performing groups (M= 37.74, SD=6.87). Informal caregivers performed the worst, scoring highest (M= 40.69, SD= 5.58). These differences were then explored for significance using ANOVA.

Descriptive data was already used to generate percentage agreement among each respondent group (care home staff; nursing students; informal caregivers) (Table IA 1)

Table 1A 1: Caregiver Agreement to 17 items of the PKBQ

	Care home responses					**Nursing student responses**					**Informal caregiver responses**				
Statement	**Completely Agree**	**Fairly Agree**	**No opinion**	**Fairly Disagree**	**Disagree completely**	**Completely Agree**	**Fairly Agree**	**No opinion**	**Fairly Disagree**	**Disagree completely**	**Completely Agree**	**Fairly Agree**	**No opinion**	**Fairly Disagree**	**Disagree completely**
1. Where I work/*During visits to healthcare providers,* pain is assessed correctly	61%	35.6%	3.4%	-	-	15.8%	42.1%	15.8%	21.2%	5.3%	21.2%	44.7%	9.1%	9%	15.2%
2. Where I work/ *During visits to healthcare providers,* pain is treated correctly	64.4%	28.8%	6.8%	-	-	10.5%	52.6%	15.8%	15.8%	5.3%	27.3%	36.4%	12.1%	9.1%	15.2%
3. Where I work/ *During visits to healthcare providers,* much attention is given to pain in dementia patients/*person I support*	62.7%	30.5%	6.8%	-	-	10.5%	26.3%	42.1%	22.2%	-	21.2%	24.2%	15.2%	18.2%	21.2%
4. Older people experience pain less intensely than younger people	3.4%	1.7%	20.3%	25.4%	49.2%	-	10.5%	21%	31.6%	36.8%	6.1%	3.0%	12.1%	27.3%	51.5%
5. Pain medication works better in young people than in the elderly	-	5.1%	30.5%	27.1%	37.3%	5.3%	10.5%	42.1%	21.2%	21.2%	6.1%	9.1%	39.4%	9.1%	36.4%
6. Pain medication works longer in the elderly than in young people	1.7%	8.5%	32.2%	18.6%	37.3%	5.3%	15.8%	36.8%	26.3%	15.8%	6.1%	12.1%	42.4%	18.2%	21.2%
7. Pain medication has more side effects in the elderly than in younger people	11.9%	30.5%	28.8%	11.9%	19.6%	11.1%	38.9%	22.2%	22.2%	5.6%	30.3%	21.2%	36.4%	3%	9.1%

8. Dementia patients experience less pain than non-dementia residents	-	6.8%	13.6%	20.3%	59.3%	-	5.6%	16.7%	33.3%	44.4%	3%	3%	15.2%	27.3%	51.5%
9. Assessing pain in a dementia patient is a matter of guessing	3.4%	13.6%	6.8%	16.9%	57.6%	11.1%	16.7%	22.2%	33.3%	16.7%	24.4%	30.3%	3%	15.2%	24.4%
10. Pain is part of the aging process	8.5%	20.3%	25.4%	16.9%	28.8%	5.6%	33.3%	16.7%	27.8%	16.7%	36.4%	24.2%	6.1%	24.2%	6.1%
11. Older people are affected by pain more often than younger people	13.6%	39%	10.2%	16.9%	20.3%	16.7%	55.6%	11.1%	5.6%	11.1%	36.4%	30.3%	6.1%	18.2%	9.1%
12. Pain medication, if administered in large quantities, easily leads to addiction among the elderly	10.2%	25.4%	39%	6.8%	18.6%	16.7%	22.2%	33.3%	22.2%	5.6%	15.6%	31.3%	30.4%	18.8%	3.1%
13. Pain medication should only be administered to residents suffering from severe pain	8.6%	11.9%	11.9%	18.6%	50.8%	11.1%	33.3%	11.1%	16.7%	27.6%	18.2%	12.1%	3%	33.3%	33.3%
14. Residents/older people are often prescribed too much pain medication	1.7%	23.7%	28.8%	16.9%	28.8%	5.6%	33.3%	22.2%	22.2%	16.7%	33.4%	23.5%	21.2%	14.7%	6.1%
15. It is better to administer pain medication ‘when necessary’, rather than according to a fixed schedule	23.7%	32.2%	28.8%	10.2%	5.1%	27.8%	33.3%	16.7%	11.1%	11.1%	45.5%	30.3%	6.1%	15.2%	3%
16. Administering pain medication should be postponed as long as possible, because dementia patients should receive as little pain medication as possible	3.4%	1.7%	20.3%	16.9%	57.6%	5.6%	-	11.1%	38.9%	44.4%	9.1%	9.1%	12.1%	27.3%	42.4%

17. A dementia patient should first report pain before receiving the next dose of pain medication	6.8%	10.2%	13.6%	23.7%	45.8%	-	10.5%	16.7%	44.4%	27.8%	20.6%	15.2%	12.1%	18.2%	33.3%

Table I(A)1.1 Descriptive output for PKBQ scores & caregiver roles

Descriptives

	CaregivingRole			Statistic	Std. Error
PKBQScore	Healthcare Assistant	Mean		33.7033	1.63516
		95% Confidence Interval for Mean	Lower Bound	30.3591	
			Upper Bound	37.0476	
		5% Trimmed Mean		33.6333	
		Median		33.0250	
		Variance		80.213	
		Std. Deviation		8.95615	
		Minimum		16.00	
		Maximum		53.00	
		Range		37.00	
		Interquartile Range		10.25	
		Skewness		.044	.427
		Kurtosis		-.183	.833
	Senior Carer	Mean		31.8944	2.45233
		95% Confidence Interval for Mean	Lower Bound	26.2394	
			Upper Bound	37.5495	
		5% Trimmed Mean		31.5494	
		Median		29.0000	
		Variance		54.125	
		Std. Deviation		7.35699	
		Minimum		24.00	
		Maximum		46.00	
		Range		22.00	
		Interquartile Range		10.52	
		Skewness		1.050	.717
		Kurtosis		.287	1.400
	Management	Mean		30.5486	2.25810
		95% Confidence Interval for Mean	Lower Bound	25.0232	
			Upper Bound	36.0739	
		5% Trimmed Mean		30.3962	
		Median		29.0000	
		Variance		35.693	
		Std. Deviation		5.97438	
		Minimum		22.84	
		Maximum		41.00	
		Range		18.16	
		Interquartile Range		7.00	

		Skewness		.707	.794
		Kurtosis		.447	1.587
	Domestic/Activities	Mean		31.0000	2.29129
		95% Confidence Interval for Mean	Lower Bound	25.7163	
			Upper Bound	36.2837	
		5% Trimmed Mean		31.0000	
		Median		33.0000	
		Variance		47.250	
		Std. Deviation		6.87386	
		Minimum		20.00	
		Maximum		42.00	
		Range		22.00	
		Interquartile Range		10.50	
		Skewness		.009	.717
		Kurtosis		-.516	1.400
	Nurse	Mean		36.8571	4.37214
		95% Confidence Interval for Mean	Lower Bound	26.1589	
			Upper Bound	47.5554	
		5% Trimmed Mean		36.9524	
		Median		40.0000	
		Variance		133.810	
		Std. Deviation		11.56761	
		Minimum		21.00	
		Maximum		51.00	
		Range		30.00	
		Interquartile Range		23.00	
		Skewness		-.410	.794
		Kurtosis		-1.490	1.587
	Nursing Student	Mean		37.7368	1.57622
		95% Confidence Interval for Mean	Lower Bound	34.4253	
			Upper Bound	41.0483	
		5% Trimmed Mean		38.1520	
		Median		40.0000	
		Variance		47.205	
		Std. Deviation		6.87057	
		Minimum		20.00	
		Maximum		48.00	
		Range		28.00	
		Interquartile Range		5.00	
		Skewness		-1.218	.524

	Kurtosis		1.634	1.014
Informal Caregiver	Mean		40.6871	1.47160
	95% Confidence Interval for Mean	Lower Bound	37.6931	
		Upper Bound	43.6810	
	5% Trimmed Mean		40.7167	
	Median		40.6600	
	Variance		73.630	
	Std. Deviation		8.58081	
	Minimum		25.00	
	Maximum		55.84	
	Range		30.84	
	Interquartile Range		13.37	
	Skewness		-.226	.403
	Kurtosis		-.834	.788

ANOVA 1: Assumption Testing

Normality

Before commencing ANOVA testing, necessary assumptions were explored. Firstly, normality was checked using Shapiro-Wilk test. The Shapiro-Wilk Test confirmed the dependent variable (PKBQ scores) was normally distributed within 6 levels of the IV (caregiver roles) (Table I(A) 1.2) (HCA W(30) = 0.98, p= 0.84; Activities & Domestic W(9) = 0.98, p=0.95; Management W(7) = 0.95, p= 0.75; Senior Carer W(9)= 0.89, p=0.19; Nurses W(7)= 0.92, p= 0.49; Informal Caregivers W(34)= 0.96, p= 0.23). PKBQ scores, however, were not normally distributed for Nursing students (W(19)=0.89, p=0.03).Visual inspection of histograms and Q-Q plots confirmed normal distribution of PKBQ scores within each level of the IV, including those for nursing students Further, skewness (SK= -1.22, K=1.63)for nursing students were within acceptable ranges, suggesting normality was acceptable.

Table I(A)1.2 ANOVA 1: Normality Testing for PKBQ scores and caregiver roles

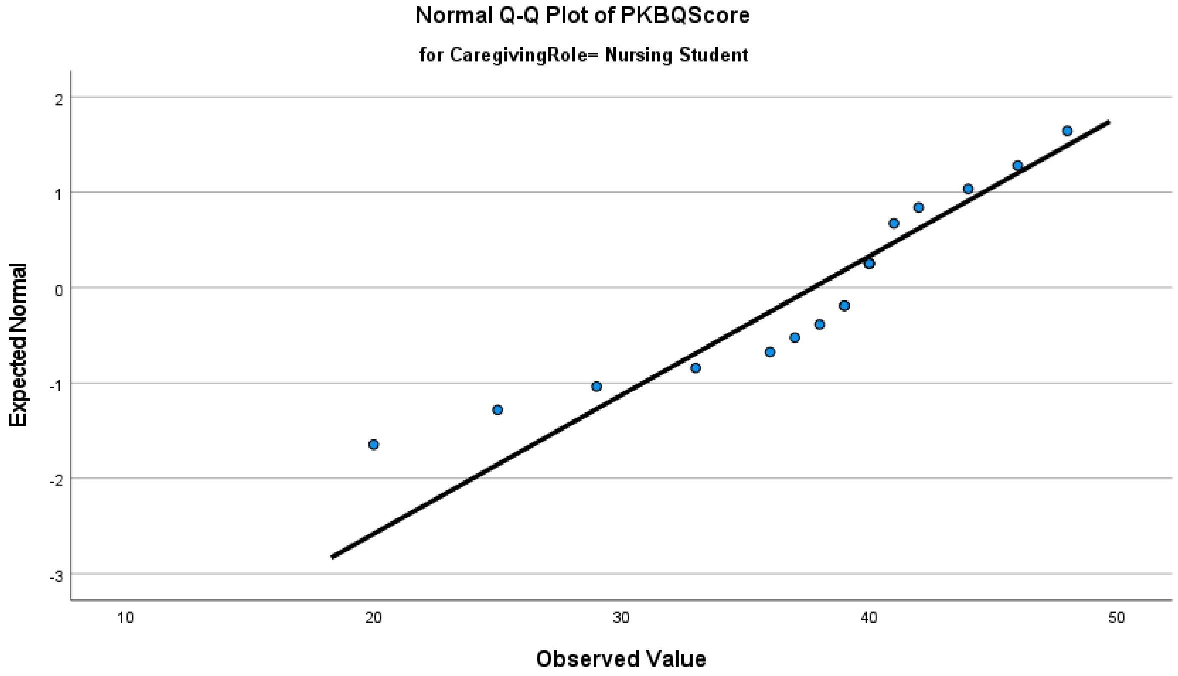
Tests of Normality

		Kolmogorov-Smirnov^a			Shapiro-Wilk		
	CaregivingRole	Statistic	df	Sig.	Statistic	df	Sig.
PKBQScore	Healthcare Assistant	.106	30	.200*	.981	30	.843
	Senior Carer	.215	9	.200*	.889	9	.193
	Management	.174	7	.200*	.953	7	.754
	Domestic/Activities	.170	9	.200*	.978	9	.953
	Nurse	.179	7	.200*	.923	7	.489
	Nursing Student	.205	19	.035	.885	19	.026
	Informal Caregiver	.122	34	.200*	.959	34	.229

*. This is a lower bound of the true significance.

a. Lilliefors Significance Correction

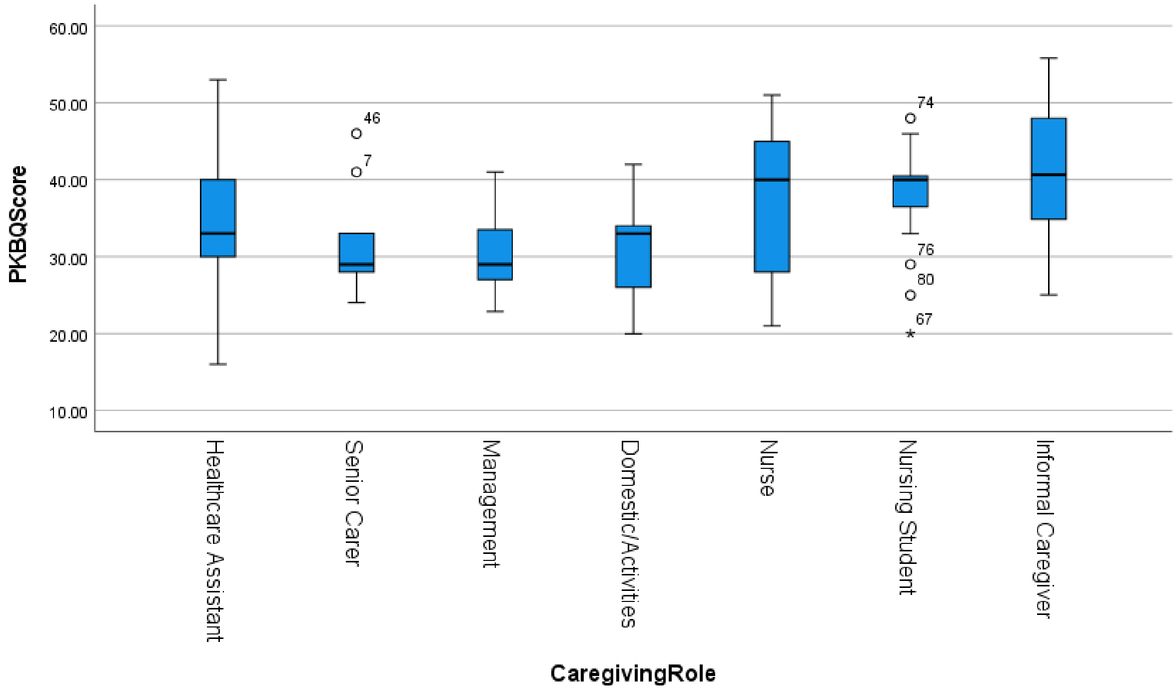
Figure I(A). 1.1 ANOVA 1: Q-Q plot for PKBQ scores and nursing students



Outliers

A box plot (Figure I(A. 1.2) was used to explore if there were any outliers identified. 6 scores were flagged as potential outliers, however on referring back to the raw data these were confirmed as genuine PKBQ scores, not measurement or data entry error. In light of this, and that these outliers had not resulted in significantly non-normally distributed data, the flagged PKBQ scores were kept.

Figure I(A). 1.2 ANOVA 1: Box Plot for PKBQ scores and caregiver roles



Equal Sample Sizes

ANOVA requires that samples sizes across IV levels or groups (caregivers) are equal and above 20. This assumption was violated as sample sizes vary across groups and some groups did have less than 20 participants in (Table I(A) 1.1). Unequal sample sizes are problematic when they cause heterogeneity and when using factorial ANOVA, however homogeneity was satisfied in this data set. In addition, this is only a one-way ANOVA with a one independent variable (with 7 levels). Therefore, an ANOVA was proceeded with.

Homogeneity of variance

Homogeneity of variance assumes that variance across the data should be equal, or at least similar. This was tested using Levene's test (Table I(A) 1.3). Levene's test indicated there was no significant variance present, demonstrating the assumption of variance has been satisfied, F (5,108) = 1.69, p= 0.33. This also confirms that group sizes across the IV, although not equal, did not result in unequal variance. Where equal variance or homogeneity is present, post-hoc testing (if there is a significant ANOVA result) using Tukey's test can be carried out.

Table I(A) 1.3 ANOVA 1: Homogeneity of Variance testing for PKBQ scores and caregiver roles

Tests of Homogeneity of Variances

		Levene Statistic	df1	df2	Sig.
PKBQScore	Based on Mean	1.169	6	108	.328
	Based on Median	1.068	6	108	.386
	Based on Median and with adjusted df	1.068	6	100.913	.387
	Based on trimmed mean	1.209	6	108	.307

ANOVA 1: Results & Post Hoc Testing

ANOVA results (Table I(A) 1.4) indicate there is a significant difference between mean PKBQ scores between different caregiver roles F(6, 108)=3.76, p= 0.002. Welch and Brown-Forsythe Robust Tests of Equality of Means confirmed this.

To determine which levels of the IV, or which roles, scored significantly different on the PKBQ post hoc testing was carried out. Turkey's HSD (Table IA 1.5) identified 2 comparisons that were significant. HCAs (M=33.70, SD= 8.96) and informal caregivers (M= 40.69, SD= 8.58) scored significantly different, with HCA scoring a mean difference of -6.89 in PKBQ scores (p= 0.02). Activities and domestic staff (M= 31.00, SD= 6.87) and informal caregivers scored significantly different, with the former scoring a mean difference of -.9.69 on the PKBQ (p= 0.04).

Table I(A) 1.4 ANOVA 1: ANOVA results for PKBQ scores and caregiver roles

ANOVA

PKBQScore

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	1551.595	6	258.599	3.757	.002
Within Groups	7433.667	108	68.830		
Total	8985.263	114			

Robust Tests of Equality of Means

PKBQScore

	Statistic[a]	df1	df2	Sig.
Welch	3.954	6	28.205	.005
Brown-Forsythe	3.848	6	44.458	.004

a. Asymptotically F distributed.

Table I(A) 1.5 ANOVA 1: Tukey's Post Hoc Test for PKBQ scores and caregiver roles

Multiple Comparisons

Dependent Variable: PKBQScore

Tukey HSD

(I) CaregivingRole	(J) CaregivingRole	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval Lower Bound	95% Confidence Interval Upper Bound
Healthcare Assistant	Senior Carer	1.80889	3.15312	.997	-7.6651	11.2829
	Management	3.15476	3.48242	.971	-7.3087	13.6182
	Domestic/Activities	2.70333	3.15312	.978	-6.7707	12.1774
	Nurse	-3.15381	3.48242	.971	-13.6173	7.3097
	Nursing Student	-4.03351	2.43249	.645	-11.3423	3.2753
	Informal Caregiver	-6.98373*	2.07816	.018	-13.2279	-.7396

Senior Carer	Healthcare Assistant	-1.80889	3.15312	.997	-11.2829	7.6651
	Management	1.34587	4.18099	1.000	-11.2166	13.9083
	Domestic/Activities	.89444	3.91096	1.000	-10.8566	12.6455
	Nurse	-4.96270	4.18099	.898	-17.5251	7.5997
	Nursing Student	-5.84240	3.35715	.591	-15.9295	4.2447
	Informal Caregiver	-8.79261	3.11002	.079	-18.1371	.5519
Management	Healthcare Assistant	-3.15476	3.48242	.971	-13.6182	7.3087
	Senior Carer	-1.34587	4.18099	1.000	-13.9083	11.2166
	Domestic/Activities	-.45143	4.18099	1.000	-13.0139	12.1110
	Nurse	-6.30857	4.43461	.789	-19.6330	7.0159
	Nursing Student	-7.18827	3.66818	.446	-18.2099	3.8333
	Informal Caregiver	-10.13849	3.44344	.059	-20.4848	.2079
Domestic/Activities	Healthcare Assistant	-2.70333	3.15312	.978	-12.1774	6.7707
	Senior Carer	-.89444	3.91096	1.000	-12.6455	10.8566
	Management	.45143	4.18099	1.000	-12.1110	13.0139
	Nurse	-5.85714	4.18099	.800	-18.4196	6.7053
	Nursing Student	-6.73684	3.35715	.417	-16.8239	3.3502
	Informal Caregiver	-9.68706*	3.11002	.037	-19.0316	-.3425
Nurse	Healthcare Assistant	3.15381	3.48242	.971	-7.3097	13.6173
	Senior Carer	4.96270	4.18099	.898	-7.5997	17.5251
	Management	6.30857	4.43461	.789	-7.0159	19.6330
	Domestic/Activities	5.85714	4.18099	.800	-6.7053	18.4196
	Nursing Student	-.87970	3.66818	1.000	-11.9013	10.1419
	Informal Caregiver	-3.82992	3.44344	.923	-14.1763	6.5164
Nursing Student	Healthcare Assistant	4.03351	2.43249	.645	-3.2753	11.3423
	Senior Carer	5.84240	3.35715	.591	-4.2447	15.9295
	Management	7.18827	3.66818	.446	-3.8333	18.2099
	Domestic/Activities	6.73684	3.35715	.417	-3.3502	16.8239
	Nurse	.87970	3.66818	1.000	-10.1419	11.9013
	Informal Caregiver	-2.95022	2.37636	.876	-10.0903	4.1899
Informal Caregiver	Healthcare Assistant	6.98373*	2.07816	.018	.7396	13.2279
	Senior Carer	8.79261	3.11002	.079	-.5519	18.1371
	Management	10.13849	3.44344	.059	-.2079	20.4848
	Domestic/Activities	9.68706*	3.11002	.037	.3425	19.0316
	Nurse	3.82992	3.44344	.923	-6.5164	14.1763
	Nursing Student	2.95022	2.37636	.876	-4.1899	10.0903

*. The mean difference is significant at the 0.05 level.

T-Test: Exploring Training & PKBQ scores

To explore the role of training further (H1), a T-Test was undertaken to explore if training (IV) had a significant effect upon mean PKBQ scores (DV). Given that few caregivers have received training related to pain, dementia training was used at the IV. Prior to undertaking the T-Test, all relevant assumptions were satisfied.

T-Test: Assumption Testing

Normal distribution in the DV across the IV

T-Test require the dependent variable to be normally distributed across the levels of the DV. this was checked using the Kolmogorov-Smirnov Test and the Shapiro-Wilk Test (Table I(A).1.6). The latter is more appropriate for small sample sizes (n=< 50) but can be used for larger samples (n= <2000). The Shapiro-Wilk Test indicated the ‘training’ was normally distributed; PKBQ scores did not significantly deviate from a normal distribution, W (88) = 0.98, p= 0.15 (p>0.01). It further indicated for ‘no training’ was not normally distributed W(27)= 0.98, p= 0.92 (p>0.01).

Table I(A) 1.6 T-Test: Normality for PKBQ scores and training in dementia

Tests of Normality

		Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	TrainingDem	Statistic	df	Sig.	Statistic	df	Sig.
PKBQScore	Yes	.081	88	.200*	.978	88	.146
	No	.075	27	.200*	.983	27	.923

*. This is a lower bound of the true significance.

a. Lilliefors Significance Correction

Independent groups & Outcome variable

Independence of observations was satisfied given that the T-Test compared unrelated or unpaired groups (e.g., a participant was either allocated 1 to Group ‘training’ or allocated to 0 Group 'no training'). The third assumption for conducting T-

Tests is that the outcome variable, or dependent variable, is not nominal or ordinal. The PKBQ score is a continuous variable, so this outcome variable was acceptable to be entered into a T-Test.

Homogeneity of variance

T-Test require that variance between the two groups being compared (Group ‘training’ vs. Group 'no training') to be equal in population. Homogeneity of variance was tested using Levene’s Test of Equality of Variances. Table 1(A) 1.7 presents the results of this. The assumption was satisfied, and no significant variance was found between the two groups (F= 0.74, p= 0.79).

T-Test: Results

Table 1(A) 1.7 presents the results of the T-Test to explore if training had a significant impact upon PKBQ scores This indicates mean scores in PKBQ scores were not significantly different for the Group 1 ‘training’ and Group 2 ‘no training’ t(112)=-.61, p=0. 27.

Table 1(A) 1.8 presents the descriptives, which indicates although not statistically significant, those with training did score more optimally on the PKBQ (M= 35.77, SD= 8.89), compared to those who had not received training (M= 37.10, SD= 8.90).

Table I(A) 1.7 T-Test: Equality of Variance for PKBQ scores and training in dementia

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means							
						Significance				95% Confidence Interval of the Difference	
		F	Sig.	t	df	One-Sided p	Two-Sided p	Mean Difference	Std. Error Difference	Lower	Upper
PKBQScore	Equal variances assumed	.074	.786	-.606	112	.273	.546	-1.20890	1.99403	-5.15981	2.74201
	Equal variances not assumed			-.601	40.365	.276	.551	-1.20890	2.01294	-5.27607	2.85827

T-Test results

Table I(A) 1.8 T-Test:Descriptives PKBQ scores and training in dementia

Descriptives

	TrainingDem			Statistic	Std. Error
PKBQScore	Yes	Mean		35.7684	.94858
		95% Confidence Interval for Mean	Lower Bound	33.8830	
			Upper Bound	37.6538	
		5% Trimmed Mean		35.7245	
		Median		35.5000	
		Variance		79.183	
		Std. Deviation		8.89848	
		Minimum		19.00	
		Maximum		55.84	
		Range		36.84	
		Interquartile Range		12.75	
		Skewness		.012	.257
		Kurtosis		-.783	.508
	No	Mean		37.1011	1.71289
		95% Confidence Interval for Mean	Lower Bound	33.5802	
			Upper Bound	40.6220	
		5% Trimmed Mean		37.2136	
		Median		37.0000	
		Variance		79.217	
		Std. Deviation		8.90041	
		Minimum		16.00	
		Maximum		54.84	
		Range		38.84	
		Interquartile Range		12.00	
		Skewness		-.100	.448
		Kurtosis		-.002	.872

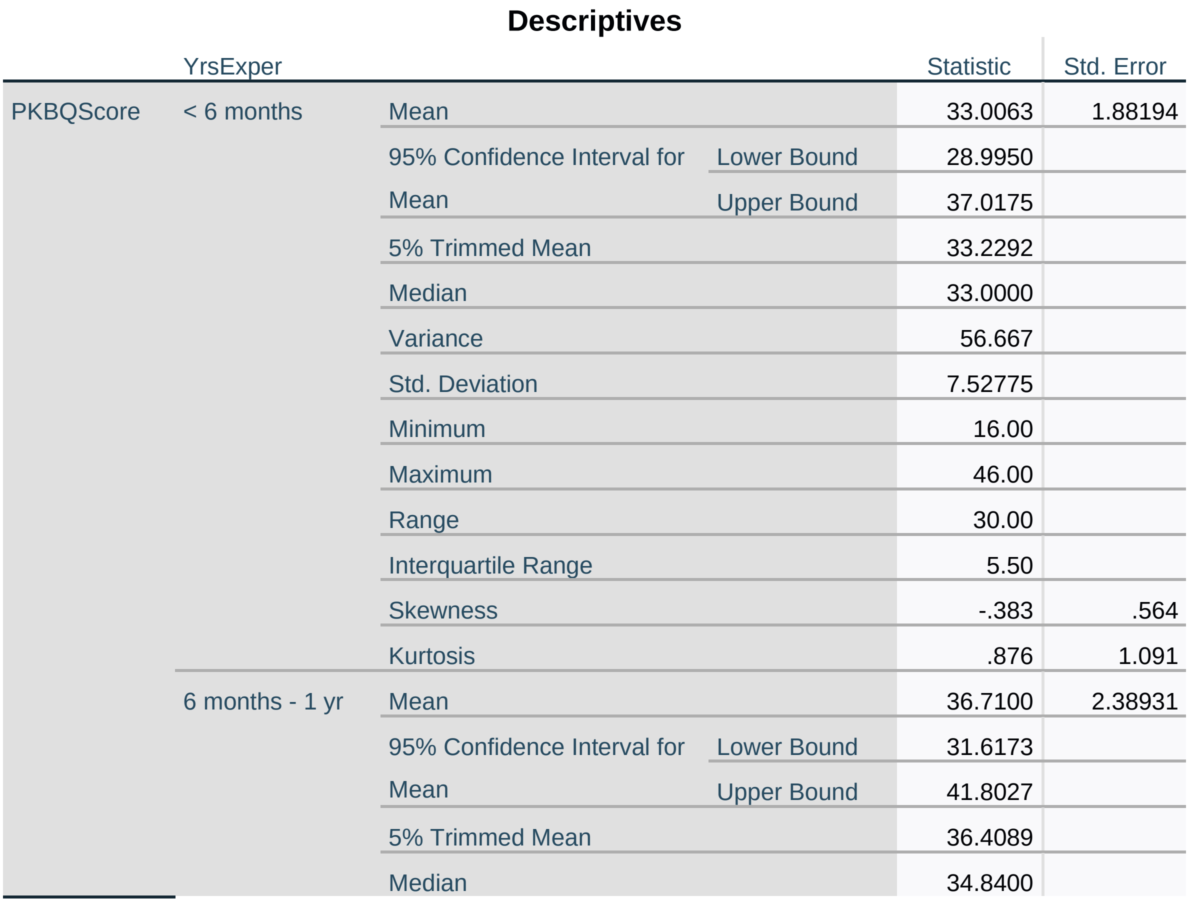
I(B): ANOVA 2 & H2: Years’ Experience & PKBQ Scores

H2 was tested in ANOVA 2. PKBQ scores were used as the DV, and there were 7 levels on the IV (0-6 months; 6 months- 1 year; 1-2 years; 2-5 years; 5-7 years; 7-10 years; and 10 years and more)

Descriptives

An initial exploration of descriptives for PKBQ scores across different years of experience (Table I(B) 1.9) indicated some ascension in scores, with those with1-2 years scoring lowest (M= 32.21, SD= 9.45), and those with 7-10 years experienced scored highest (M= 40.81, SD= 7.71). This suggested the opposite to the prediction of H2.

Table I(B). 1.9 Descriptive output for PKBQ scores & years’ experience



Descriptives

	YrsExper			Statistic	Std. Error
PKBQScore	< 6 months	Mean		33.0063	1.88194
		95% Confidence Interval for Mean	Lower Bound	28.9950	
			Upper Bound	37.0175	
		5% Trimmed Mean		33.2292	
		Median		33.0000	
		Variance		56.667	
		Std. Deviation		7.52775	
		Minimum		16.00	
		Maximum		46.00	
		Range		30.00	
		Interquartile Range		5.50	
		Skewness		-.383	.564
		Kurtosis		.876	1.091
	6 months - 1 yr	Mean		36.7100	2.38931
		95% Confidence Interval for Mean	Lower Bound	31.6173	
			Upper Bound	41.8027	
		5% Trimmed Mean		36.4089	
		Median		34.8400	

		Variance		91.341	
		Std. Deviation		9.55725	
		Minimum		23.00	
		Maximum		55.84	
		Range		32.84	
		Interquartile Range		16.75	
		Skewness		.391	.564
		Kurtosis		-.518	1.091
	1-2 yrs	Mean		32.2105	2.16779
		95% Confidence Interval for Mean	Lower Bound	27.6562	
			Upper Bound	36.7649	
		5% Trimmed Mean		31.9006	
		Median		32.0000	
		Variance		89.287	
		Std. Deviation		9.44916	
		Minimum		20.00	
		Maximum		50.00	
		Range		30.00	
		Interquartile Range		16.00	
		Skewness		.235	.524
		Kurtosis		-1.221	1.014
	2-5 yrs	Mean		37.5462	1.87268
		95% Confidence Interval for Mean	Lower Bound	33.7102	
			Upper Bound	41.3822	
		5% Trimmed Mean		37.6303	
		Median		37.0000	
		Variance		101.700	
		Std. Deviation		10.08467	
		Minimum		19.00	
		Maximum		54.84	
		Range		35.84	
		Interquartile Range		18.50	
		Skewness		.025	.434
		Kurtosis		-1.049	.845
	5-7 yrs	Mean		39.0229	2.90535
		95% Confidence Interval for Mean	Lower Bound	31.9137	
			Upper Bound	46.1320	
		5% Trimmed Mean		39.2476	
		Median		40.3200	
		Variance		59.087	

		Std. Deviation		7.68683	
		Minimum		27.00	
		Maximum		47.00	
		Range		20.00	
		Interquartile Range		15.84	
		Skewness		-.813	.794
		Kurtosis		-.857	1.587
	7-10 yrs	Mean		40.8100	3.44980
		95% Confidence Interval for Mean	Lower Bound	31.2318	
			Upper Bound	50.3882	
		5% Trimmed Mean		40.6750	
		Median		40.0000	
		Variance		59.506	
		Std. Deviation		7.71398	
		Minimum		33.05	
		Maximum		51.00	
		Range		17.95	
		Interquartile Range		14.98	
		Skewness		.376	.913
		Kurtosis		-1.898	2.000
	>10 yrs	Mean		35.7680	2.07804
		95% Confidence Interval for Mean	Lower Bound	31.3111	
			Upper Bound	40.2249	
		5% Trimmed Mean		35.7511	
		Median		37.0000	
		Variance		64.774	
		Std. Deviation		8.04820	
		Minimum		22.84	
		Maximum		49.00	
		Range		26.16	
		Interquartile Range		13.00	
		Skewness		-.030	.580
		Kurtosis		-.978	1.121

ANOVA 2: Assumption testing

Normality

The Shapiro-Wilk Test confirmed the dependent variable (PKBQ scores) was normally distributed across 7 levels of the IV (years' experience) (Table I(B) 1.10) (W(16)= 0.91, p= 0.13); 6 months-1 year W(16)= 0.95, p= 0.55; 1-2 years W(19)= 0.93, p= 0.17); 2-5 years W(29)= 0.95, p=0.25; 5-7 years W(7)= 0.88, p= 0.24; 7-10 years W(5)= 0.92, p= 0.55; and 10 years or more W(15)= 0.96, p=0.64).

Table I(B) 1.10 ANOVA 2: Normality Testing for PKBQ scores and years' experience

Tests of Normality

		Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	YrsExper	Statistic	df	Sig.	Statistic	df	Sig.
PKBQScore	< 6 months	.250	16	.009	.914	16	.134
	6 months - 1 yr	.140	16	.200*	.954	16	.555
	1-2 yrs	.146	19	.200*	.929	19	.168
	2-5 yrs	.157	29	.067	.955	29	.253
	5-7 yrs	.265	7	.147	.882	7	.237
	7-10 yrs	.211	5	.200*	.924	5	.553
	>10 yrs	.133	15	.200*	.957	15	.636

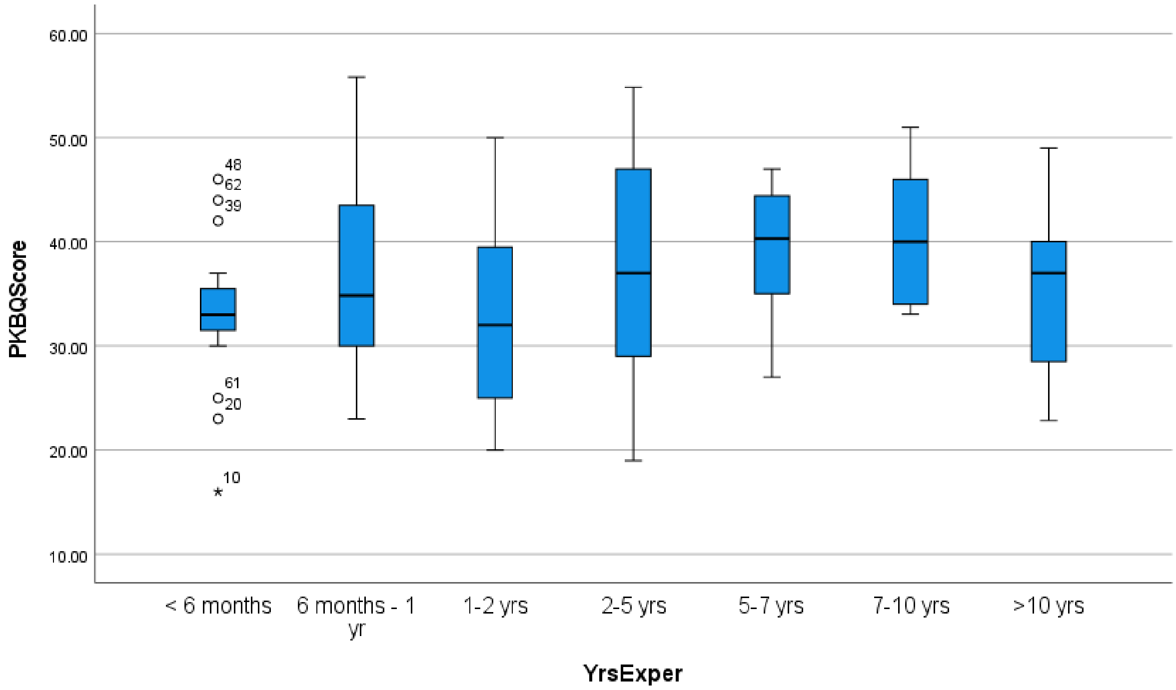
*. This is a lower bound of the true significance.

a. Lilliefors Significance Correction

Outliers

A box plot (Figure I(B) 1.3) was used to confirm if there were any outliers present. Outliers were present with 6 data points. The raw data however, indicated these were genuine PKBQ scores, not data entry errors. Given that no issues were present with normality, these data points were kept.

Figure I(B) 1.3 ANOVA 2: Box Plot for PKBQ scores and years' experience



Equal sample sizes

There were not equal groups across all levels of the IV. However, unequal sample sizes did not cause heterogeneity, therefore an ANOVA was proceeded with.

Homogeneity of variance

Levene's test (Table I(B) 1.11) indicated there was no significant variance present, demonstrating the assumption of variance has been satisfied, F (6,100) = 1.47, p= 0.20. This also confirms that group sizes across the IV, although not equal, did not result in unequal variance.

Table I(B) 1.11 ANOVA 2: Homogeneity of Variance testing for PKBQ scores and years' experience

Tests of Homogeneity of Variances

		Levene Statistic	df1	df2	Sig.
PKBQScore	Based on Mean	1.468	6	100	.197
	Based on Median	1.394	6	100	.225
	Based on Median and with adjusted df	1.394	6	93.774	.225
	Based on trimmed mean	1.431	6	100	.210

ANOVA 2: Results

Table I(B)1.12 presents the results of the ANOVA. There was no significant difference present between levels of the IV F (6, 100)= 1.37, p= 0.24. Welch and Brown-Forsythe Robust Tests of Equality of Means confirmed this also. This indicates that the years caregivers had spent within their caregiver roles, did not significantly influence upon their understanding of pain in PwD, nor their beliefs, as measured by the PKBQ. H2 was therefore not supported, and the null hypothesis (H0) was accepted.

Table I(B) 1.12 ANOVA 2: ANOVA results for PKBQ scores and years' experience

ANOVA

PKBQScore

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	669.581	6	111.597	1.365	.236
Within Groups	8174.269	100	81.743		
Total	8843.849	106			

Robust Tests of Equality of Means

PKBQScore

	Statistic[a]	df1	df2	Sig.
Welch	1.386	6	28.299	.255
Brown-Forsythe	1.518	6	75.198	.184

a. Asymptotically F distributed.

I(C): T-Tests Differentiating themes & PKBQ Scores

T-Tests were carried out to compared mean PKBQ scores (dependent variable DV), based on differentiating themes (independent variable IV, 2 levels: Group ‘subtheme absent’ and Group ‘subtheme present’).

Differentiating themes

Using the 30-60% cut-off ST-TA identified 6 subthemes (one occurring twice) from across the 5 survey sections which were prevalent These included: *Speaking through the Body*, S2 39%; *Understanding through Connection*, S2 30%; *Deteriorating Connections*, S2 55%, S3 40%; *Informal vs. Formal Pain Assessment* S3 55%; *Lack of Prioritisation,* S2 42%; and Acute vs. Chronic, S2 30%.

These 6 subthemes were quantified to act as a nominal variable, in which the presence and absence of a theme across all 115 survey respondents was denoted by code 1 (Group ‘subtheme ‘present’) and code 0 (Group ‘subtheme absent’).

T-Test 1 (DV: PKBQ scale, IV: Speaking through the Body)

The first T-Test carried out explored if there was a significant relationship between mean PKBQ scores (the DV) for those who did not (Group ‘subtheme absent’) allocate, and those who did allocate (Group 'subtheme present') to the subtheme *Speaking through the Body*. Before the T-Test was undertaken, all assumptions were checked.

T-Test 1: Assumption testing

Normality of the dependent variable across groups

For the presence (Group 'subtheme present') of the subtheme *Speaking through the Body*, the Shapiro-Wilk Test indicated the dependent variable (PKBQ scores) was normally distributed across both the absence of the subtheme (Group 'subtheme absent') W(45) = 0.98, p= 0.43, and for subtheme present (Group 'subtheme absent'), W (70) = 0.99, p= 0.80. Normality was therefore satisfied (Table I(C)1.13).

Table I(C) 1.13 T-Test 1: Normality

Tests of Normality

	SpeakingthroughthebodySec two	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
		Statistic	df	Sig.	Statistic	df	Sig.
PKBQ	no subtheme	.061	70	.200*	.989	70	.795
	Subtheme	.089	45	.200*	.975	45	.430

*. This is a lower bound of the true significance.

a. Lilliefors Significance Correction

Independent groups & Outcome variable

Independence of observations was satisfied given that the T-Test compared unrelated or unpaired groups (e.g., a participant was either allocated 1 to Group 'subtheme present' or allocated to 0 Group 'subtheme present'). The third assumption for conducting T-Tests is that the outcome variable, or dependent variable, is not nominal or ordinal. The PKBQ score is a continuous variable, so this outcome variable was acceptable to be entered into a T-Test.

Homogeneity of variance

T-Test require that variance between the two groups being compared (Group 'subtheme present' vs. Group 'subtheme absent') to be equal in population.

Homogeneity of variance was tested using Levene’s Test of Equality of Variances. Table I(C)1.14 presents the results of this. The assumption was satisfied, and no significant variance was found between the two groups (F= 15, p= 0.70).

T-Test 1: Results

Table I(C)1.14 presents the results of T-Test 1. It was found that mean scores in PKBQ scores in Group 'subtheme present', were not significantly different to those in Group 'subtheme absent' t(113) = 1.31, p= 0.09.

Table I 1.14(C) T-Test 1: Homogeneity of variance and T-Test result

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means							
						Significance		Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
		F	Sig.	t	df	One-Sided p	Two-Sided p			Lower	Upper
PKBQ	Equal variances assumed	.145	.704	1.306	113	.097	.194	2.20905	1.69108	-1.14130	5.55939
	Equal variances not assumed			1.327	98.788	.094	.188	2.20905	1.66495	-1.09465	5.51275

Table I 1.16(C) T-Test 1: Homogeneity of variance and T-Test result

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means							
						Significance		Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
		F	Sig.	t	df	One-Sided p	Two-Sided p			Lower	Upper
PKBQ	Equal variances assumed	.168	.683	.520	113	.302	.604	.86749	1.66872	-2.43855	4.17353
	Equal variances not assumed			.525	111.972	.300	.601	.86749	1.65308	-2.40788	4.14286

T-Test 2 (DV: PKBQ scale, IV: Deteriorating Connections)

The second T-Test carried out explored if there was a significant relationship between mean PKBQ scores (the DV) for those who did not (Group 'subtheme absent') allocate, and those who did allocate (Group 'subtheme present') to the subtheme *Deteriorating Connections*. The same assumptions as in T-Test 1 were explored.

T-Test 2: Assumption testing

For the Group 'subtheme absent' of the subtheme *Deteriorating Connections*, the Shapiro-Wilk Test indicated the dependent variable (PKBQ scores) was normally distributed; PKBQ scores did not significantly deviate from a normal distribution, W (52) = 0.97, p= 0.18 (p> 0.05) (Table I(C)1.15). This was also the case for the Group ‘subtheme present’ W(63)=0.99, p= 0.62 (p>0.05). The assumption of normality within both groups of the DV were therefore satisfied.

Table I (C) 1.15 T-Test 2 normality

Tests of Normality

	DeterioratingConnectionsSectwo	Kolmogorov-Smirnov^a			Shapiro-Wilk		
		Statistic	df	Sig.	Statistic	df	Sig.
PKBQ	no subtheme	.120	52	.058	.968	52	.175
	subtheme	.084	63	.200*	.985	63	.632

*. This is a lower bound of the true significance.

a. Lilliefors Significance Correction

Independent groups & Outcome variable

See explanation for T-Test 1.

Homogeneity of variance

Homogeneity of variance between the two groups being compared (Group 'subtheme present' vs. Group 'subtheme absent') was tested using Levene’s Test of

Equality of Variances. Table I(C) 1.16 presents the results of this. The assumption was satisfied, and no significant variance was found between the two groups (F = 0.17, p = 0.0.68).

Test 2: Results

Table I(C) 1.16 presents the results of T-Test 2. It was found that mean scores in PKBQ scores in Group 'subtheme present', were not significantly different to those in Group 'subtheme absent' t(113) = 0.52, p= 0.30. Descriptive exploration of mean scores across groups did not indicate any indication of difference (Group 'subtheme present' M= 35.69; Group 'subtheme absent' M =36.56). As such, whether respondents described and recognised dementia related deterioration of communicative and cognitive function (as captured by the subtheme Deteriorating Connections) or not, this did not have a significant impact upon mean scores on the PKBQ.

T-Test 3 (DV: PKBQ scale, IV: Lack of Prioritisation)

The third T-Test carried out explored if there was a significant relationship between mean PKBQ scores (the DV) for those who did not (Group 'subtheme absent') allocate, and those who did allocate (Group 'subtheme present') to the subtheme *Lack of Prioritisation*. Relevant assumptions were checked before undertaking the T-Test.

T-Test 3: Assumption testing

Normality

For the Group 'subtheme present' of the subtheme *Lack of Prioritisation,* the Shapiro-Wilk Test indicated the dependent variable (PKBQ scores) was normally distributed; PKBQ scores did not significantly deviate from a normal distribution, W (48) = 0.99, p= 0.97 (p> 0.05) (Table I(C) 1.17).This was the same for the Group 'subtheme absent' W (67) = 0.98, p = 0.97 (p>0.05).

Table I(C) 1.17 T-Test 3: Normality

Tests of Normality

		Kolmogorov-Smirnov^a			Shapiro-Wilk		
	LackofPrioritisationSectwo	Statistic	df	Sig.	Statistic	df	Sig.
PKBQ	no subtheme	.091	67	.200*	.978	67	.287
	subtheme	.065	48	.200*	.991	48	.970

*. This is a lower bound of the true significance.

a. Lilliefors Significance Correction

Independent groups & Outcome variable- Satisfied

See explanation for T-Test 1.

Homogeneity of variance

Homogeneity of variance between the two groups being compared (Group 'subtheme present' vs. Group 'subtheme absent') was tested using Levene’s Test of

Equality of Variances. Table I(C)1.18 presents the results of this. The assumption was satisfied, and no significant variance was found between the two groups (F=0.25, p=0.62).

Test 3: Results

Table I(C) 1.18 presents the results of T-Test 3. It was found that mean scores in PKBQ scores in Group 'subtheme present', were not significantly different to those in Group 'subtheme absent' t(113) = 0.35, p= 0.36. Descriptive exploration of mean scores across groups did not indicate any indication of difference (Group 'subtheme present' M= 35.74; Group 'subtheme absent' M =36.33). As such, whether respondents described a lack of prioritisation for physical pain (as captured by this subtheme) or not, this did not have a significant impact upon mean scores on the PKBQ.

Table I(C) 1.18: T-Test 3: Equality of variance and T-Test result

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means							
						Significance		Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
		F	Sig.	t	df	One-Sided p	Two-Sided p			Lower	Upper
PKBQ	Equal variances assumed	.254	.615	.348	113	.364	.729	.58582	1.68533	-2.75312	3.92476
	Equal variances not assumed			.349	103.299	.364	.727	.58582	1.67637	-2.73875	3.91039

Table I(C) 1.20 T-Test 4: Homogeneity of variance and T-Test result

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means							
						Significance		Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
		F	Sig.	t	df	One-Sided p	Two-Sided p			Lower	Upper
PKBQ	Equal variances assumed	.000	1.000	.618	113	.269	.538	1.04318	1.68865	-2.30234	4.38870
	Equal variances not assumed			.621	100.973	.268	.536	1.04318	1.67929	-2.28808	4.37444

T-Test 4 (DV: PKBQ scale, IV: Existential Suffering)

The fourth T-Test carried out explored if there was a significant relationship between mean PKBQ scores (the DV) for those who did not (Group 'subtheme absent') allocate, and those who did allocate (Group 'subtheme present') to the subtheme *Existential Suffering*. Relevant assumptions were checked before undertaking the T-Test.

T-Test 4: Assumption testing

Normality

For the Group 'subtheme present' of the subtheme *Existential Suffering,* the Shapiro-Wilk Test (Table I(C)1.24) indicated the dependent variable (PKBQ scores) was normally distributed; PKBQ scores did not significantly deviate from a normal distribution, W (47) = 0.98, p= 0.0.61 (p> 0.05). This was also the case for the Group ‘subtheme absent’ W(68)= 0.98, p= 0.29.

Table 1(C) 1.19 T-Test 4: Normality

Tests of Normality

		Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	ExistentialSufferingSectwo	Statistic	df	Sig.	Statistic	df	Sig.
PKBQ	no subtheme	.084	68	.200*	.979	68	.294
	subtheme	.141	47	.021	.980	47	.608

*. This is a lower bound of the true significance.

a. Lilliefors Significance Correction

Independent groups & Outcome variable

See explanation for T-Test 1.

Homogeneity of variance

Homogeneity of variance between the two groups being compared (Group 'subtheme present' vs. Group 'subtheme absent') was tested using Levene’s Test of

Equality of Variances. Table I(C)1.20 presents the results of this. The assumption was satisfied Levene’s Test indicated equal variance (F= 0, p= 1.00).

Test 4: Results

Table I(C) 1.20 presents the results of T-Test 4. It was found that mean scores in PKBQ scores in Group 'subtheme present' (M= 13.45, SD= 6.76) were not significantly different to those in Group 'subtheme absent' (M= 10.61, SD=5.90) t(113) = 0.627, p= 0.27.

T-Test 5 (DV: PKBQ scale, IV: Acute vs. Chronic)

The fifth T-Test carried out explored if there was a significant relationship between mean PKBQ scores (the DV) for those who did not (Group 'subtheme absent') allocate, and those who did allocate (Group 'subtheme present') to the subtheme *Acute vs. Chronic.* Relevant assumptions were checked before undertaking the T-Test.

T-Test 5: Assumption testing

Normality

For the Group 'subtheme present' of the subtheme *Acute vs. Chronic,* the Shapiro-Wilk Test (Table I(C) 1.21) indicated the dependent variable (PKBQ scores) was normally distributed; PKBQ scores did not significantly deviate from a normal distribution, W (35) = 0.95, p= 0.16 (p> 0.05). This was also the case for the Group ‘subtheme absent’ W(80)= 098, p= 12.

Table I(C) 1.21 T-Test 5 Normality

Tests of Normality

		Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	AcuteChronicSectwo	Statistic	df	Sig.	Statistic	df	Sig.
PKBQ	no subtheme	.102	80	.040	.975	80	.119
	subtheme	.116	35	.200[*]	.955	35	.162

*. This is a lower bound of the true significance.

a. Lilliefors Significance Correction

Test 5: Normality

Independent groups & Outcome variable

See explanation for T-Test 1.

Homogeneity of variance

Homogeneity of variance between the two groups being compared (Group 'subtheme present' vs. Group 'subtheme absent') was tested using Levene’s Test of Equality of Variances. Table I(C) 1.22 presents the results of this. The assumption was satisfied (F= 0.38, p= 0.54).

Test 5: Results

Table I1.29 presents the results of T-Test 5. It was found that mean scores on the PKBQ for Group 'subtheme present' (M= 11.93, SD= 5.94) were not significantly different to those in Group 'subtheme absent' (M= 12.45, SD=6.94) t(78.98) = -0.42, p= 0.66.

Table I(C) 1.22 T-Test 5: Homogeneity of variance and T-Test Results

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means							
						Significance				95% Confidence Interval of the Difference	
		F	Sig.	t	df	One-Sided p	Two-Sided p	Mean Difference	Std. Error Difference	Lower	Upper
PKBQ	Equal variances assumed	.377	.540	.762	113	.224	.448	1.37325	1.80253	-2.19790	4.94440
	Equal variances not assumed			.772	66.972	.221	.443	1.37325	1.77858	-2.17684	4.92334

T-Test 6 (DV: PKBQ scale, IV: Understanding through Connection)

The sixth T-Test carried out explored if there was a significant relationship between mean PKBQ scores (the DV) for those who did not (Group 'subtheme absent') allocate, and those who did allocate (Group 'subtheme present') to the subtheme *Understanding through Connection*. Relevant assumptions were checked before undertaking the T-Test.

Assumption testing

Normality

For the Group 'subtheme present' of the subtheme *Understanding through Connection, the* Shapiro-Wilk Test (Table I1.23) indicated the dependent variable (PKBQ scores) was normally distributed; PKBQ scores did not significantly deviate from a normal distribution, W (39) = 0.97, p= 0.35 (p> 0.05). This was consistent for Group ‘subtheme absent’ W(76)=0.99, p= 0.49.

Table I(C) 1.23 T-Test 6: Normality

Tests of Normality

	UnderstandingthroughConnectionSecthree	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
		Statistic	df	Sig.	Statistic	df	Sig.
PKBQ	no subtheme	.059	76	.200[*]	.985	76	.487
	subtheme	.096	39	.200[*]	.969	39	.353

*. This is a lower bound of the true significance.

a. Lilliefors Significance Correction

Independent groups & Outcome variable

See explanation for T-Test 1.

Homogeneity of variance

Homogeneity of variance between the two groups being compared (Group 'subtheme present' vs. Group 'subtheme absent') was tested using Levene’s Test of Equality of Variances. Table I(C)1.24 presents the results of this. The assumption was satisfied. (F= 0.88, p= 0.35).

Test 6 Results

Table I(C) 1.24 presents the results of T-Test 6. It was found that mean scores on the PKBQ for Group 'subtheme present' (M= 36.08, SD= 8.08) were not significantly different to those in Group 'subtheme absent' (M= 36.08, SD=9.31) t(113) = -0.0, p= 0.50.

Table I(C) 1.24 T-Test 6: Homogeneity of variance and T-test result

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means							
						Significance				95% Confidence Interval of the Difference	
		F	Sig.	t	df	One-Sided p	Two-Sided p	Mean Difference	Std. Error Difference	Lower	Upper
PKBQ	Equal variances assumed	.878	.351	-.001	113	.500	.999	-.00152	1.75645	-3.48136	3.47833
	Equal variances not assumed			-.001	86.932	.500	.999	-.00152	1.67822	-3.33719	3.33415

Table I(C) 1.26 Homogeneity of variance and T-Test 7 result

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means							
						Significance				95% Confidence Interval of the Difference	
		F	Sig.	t	df	One-Sided p	Two-Sided p	Mean Difference	Std. Error Difference	Lower	Upper
PKBQ	Equal variances assumed	.089	.766	1.236	113	.110	.219	2.06402	1.67028	-1.24511	5.37316
	Equal variances not assumed			1.226	100.307	.112	.223	2.06402	1.68405	-1.27697	5.40501

T-Test 7 (DV: PKBQ scale, IV: Deteriorating Connections)

The final T-Test carried out explored if there was a significant relationship between mean PKBQ scores (the DV) for those who did not (Group 'subtheme absent') allocate, and those who did allocate (Group 'subtheme present') to the subtheme *Deteriorating Connections*. Relevant assumptions were checked before undertaking the T-Test.

T-Test 7: Assumption testing

Normality

For the Group 'subtheme absent' of the subtheme *Deteriorating Connections, the* Shapiro-Wilk Test (Table I(C) 1.25) indicated the dependent variable (PKBQ scores) was normally distributed; PKBQ scores did not significantly deviate from a normal distribution, W (66) = 0.87, p= 0.55 (p> 0.05). This was also the case for the Group ‘subtheme present’ W(49)= 0.98, p= 0.50 (p>0.05). The assumption of normality was satisfied.

Table I(C) 1.25 T-Test 7: Normality

Tests of Normality

	DeterioratingConnectionsSecthree	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
		Statistic	df	Sig.	Statistic	df	Sig.
PKBQ	no subtheme	.077	66	.200*	.984	66	.547
	subtheme	.090	49	.200*	.978	49	.502

*. This is a lower bound of the true significance.

a. Lilliefors Significance Correction

Independent groups & Outcome variable

See explanation for T-Test 1.

Homogeneity of variance

Homogeneity of variance between the two groups being compared (Group 'subtheme present' vs. Group 'subtheme absent') was tested using Levene's Test of Equality of Variances (Table I (C) 1.26). The assumption was satisfied. (F=0.09, p= 0.77).

Test 7: Results

The T-Test (Table I(C)1.26 indicated mean scores on the PKBQ for Group 'subtheme present' (M= 34.90, SD= 9.13) were not significantly different to those in Group 'subtheme absent' (M= 36.96, SD=8.64) t(113) = 1.24, p= 0.22.