

Knowing The Patient Well: Learning Disability Nurses'  
Experiences of Caring for Terminally Ill People with  
Profound Learning Disabilities in Residential Care Settings

Julie Siew Wan Ng (nee Tey)

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Philosophy

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## **DECLARATION**

“I certify that this work has not been accepted in substance for any degree, and is not concurrently being submitted for any degree other than that of Doctor of Philosophy being studied at the University of Greenwich. I also declare that this work is the result of my own investigations except where otherwise identified by references and that I have not plagiarised the work of other’s”.

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## THESIS ABSTRACT

This thesis reports on a research project guided by the principles of grounded theory. It examines how learning disability nurses care for terminally ill people with profound learning disabilities in two National Health Service residential homes. The aim of the study is to explore the perceived knowledge and skills of this group of nurses. It concerns how they assess, recognise and discover patients' illnesses and how they provide end of life care needs. A total of 36 learning disability nurses participated in in-depth interviews.

Thematic analysis is achieved through analysis of interview transcripts and reflexive journaling (field notes). The analysis of data suggests that the main theme "longitudinal knowing" leads to the production of "knowing the patient well". "Longitudinal knowing" is the principal process through which the "normal" and the "pathological" continuum is constructed. The observed changes help learning disability nurses to establish a clear demarcation between learning disability-related behaviour and disease-related behaviour. The strategy of "longitudinal knowing" the patient well helps learning disability nurses to understand what their patients are like before the illness, and after the onset of illness. In addition, this thesis reveals that learning disability nurses draw on different types of knowledge. This knowledge includes "intuition", "commonsense" knowledge and "formal" knowledge. The analysis of data shows that the four types of knowledge derive from "longitudinal knowing". They help learning disability nurses to understand and assess patient's changing health conditions. These types of knowledge serve as tools to help learning disability nurses make appropriate nursing decisions about a patient's health status. In this study, participants sometimes used a mixture of lay and technical language to describe their observed signs and symptoms.

The analysis of data shows an area of “uncertainty of knowing”. It concerns an ambiguity about whether the specific signs and symptoms are attributed to the learning disability or to an illness. “Uncertainty of knowing” may be a potential barrier to the delivery of appropriate comfort care.

The thesis also reveals an area of “certainty of not knowing”. This refers to moments when participants know for sure where the gaps in knowledge are. The analysis of data shows that participants seek to address this gap by searching for relevant internet resources. They also know that they need educational input in pathophysiology of advance diseases. This helps to reduce the tension created by “uncertainty of knowing” and comfort care. The thesis shows that for all participants, “longitudinal knowing” is fundamental for learning disability nurses in the delivery of appropriate and timely “comfort” end-of-life care.

## CONTENTS

DECLARATION		ii
ACKNOWLEDGEMENTS		iii
THESIS ABSTRACT		iv
CONTENTS		vi
TABLES		x
FIGURES		xii
CHAPTER 1	AN OUTLINE OF THE THESIS AND BRIEF CHAPTER OUTLINE	1
1.0	Introduction	2
1.1	Background - an account of my choice of topic for my thesis	2
1.2	Defining and distinguishing the term people with profound learning disabilities (PPLD) and other levels of learning disabilities	4
1.2.1	The concept of “normal” and “abnormal”	6
1.3	Defining the terms terminal illness, terminal care and palliative care	10
1.4	Defining residential homes	11
1.5	Outline of the chapters	11
CHAPTER 2	THE NATURE, PAST AND PRESENT HISTORY OF PPLD AND PHILOSOPHY OF CARE - A LITERATURE REVIEW	15
2.0	Introduction	16
2.1	Search strategy	16
2.2	Historical perspectives	17
2.3	Contemporary care philosophy and the health of people with profound learning disabilities	30
2.3.1	Present living services	32
2.3.2	Care staff - skill mix	32
2.3.3	A place for dying - where do terminally ill PPLD die?	34
2.3.4	Care of the dying or terminally ill PPLD - previous studies	36
2.4	Conclusion	44
CHAPTER 3	THE PHILOSOPHY OF HOSPICE AND PALLIATIVE CARE AND SOCIAL POLICY - A LITERATURE REVIEW	45
3.0	Introduction	46
3.1	The modern hospice movement	46
3.2	Palliative care	50
3.3	Social policy	59
3.4	Conclusion	65

CHAPTER 4	LEARNING DISABILITY NURSING, EDUCATION AND TRAINING - A LITERATURE REVIEW	67
4.0	Introduction	68
4.1	What is learning disability nursing?	68
4.1.1	Learning disability nursing - a “profession” or “occupation”?	70
4.1.2	What do learning disability nurses do?	73
4.2	Defining a competent and knowledgeable nurse	76
4.3	Educational influences - learning disability nursing registration and NVQ in health and social care	80
4.3.1	The 1970s syllabus	81
4.3.2	Practical experience	83
4.3.3	Reflecting on the 1970s syllabus	85
4.3.4	The 1982 syllabus	86
4.3.5	Practical experience	88
4.3.6	Reflecting on the 1980s syllabus	89
4.4	Fit for purpose and practice?	93
4.5	Conclusion	96
CHAPTER 5	SOURCES OF NURSING KNOWLEDGE - A LITERATURE REVIEW	98
5.0	Introduction	99
5.1	The concept of “knowing the patient”	99
5.2	“Intuition”	107
5.3	“Commonsense knowledge”	116
5.4	Conclusion and research questions	119
CHAPTER 6	RESEARCH DESIGN AND METHODOLOGICAL CHOICES	121
6.0	Introduction	122
6.1	The value of qualitative research	122
6.1.1	Types and differences in qualitative approaches	125
6.1.2	Methodological tools - value and limitations	130
6.2	Selecting my research design	133
6.2.1	Rationale for qualitative approach-the grounded theory method	134
6.2.2	Rationale for using semi-structured interviews	139
6.2.3	Choosing my research settings	140
6.2.4	The setting profiles	140
6.2.5	Ethical considerations: entry, consent and confidentiality	143
6.2.6	The participants	145
6.2.6 i	Recruitment of participants	146
6.2.6ii	Inclusion and exclusion criteria	147
6.3	Data collection (a) Interviews	147
	(b) The reflective journal	148
6.4	Methods of data analysis	149
6.4.1	Content analysis	149
6.5	Methodological rigour of the research study - reliability and validity	153
6.6	On being an “insider” and an “outsider” researcher	156
6.7	Methodological contributions	158
6.8	Conclusion	160

CHAPTER 7	PRESENTATION OF RESULTS	161
7.0	Introduction	162
7.1	Constructing “longitudinal knowing”-“knowing the patient” and “intuition”	166
7.1.1	Sensing and noticing disease-related physical changes	175
7.2	“Commonsense” knowledge	183
7.3	“Formal” knowledge and “commonsense” knowledge	188
7.4	“Uncertainty of knowing”	194
7.5	“Comfort” care	201
7.5.1	“Longitudinal presence of the nurse”	202
7.5.2	“Positioning and personal cleanliness of the patient”	205
7.5.3	“Certainty of not knowing”- gaps in knowledge about pathophysiology of illness/disease and pain relief	212
7.6	Conclusion	218
CHAPTER 8	DISCUSSION AND CONCLUSION	220
8.0	Introduction	221
8.1	Research question: how do learning disability nurses recognise a patient’s changing health condition?	222
8.1.2	Contextualising “longitudinal knowing the patient well” in the recognition of patients’ changing health condition	224
8.1.3	Contextualising “intuition”	230
8.1.4	Contextualising “commonsense” knowledge and “formal” knowledge	234
8.1.5	Contextualising (a) “uncertainty” of knowing and (b) “certainty of not knowing” (gaps in knowledge)	235
	(a) “Uncertainty of knowing”	235
	(b) “Certainty of not knowing” (gaps in knowledge)	237
8.2	Research question: how do learning disability nurses care for terminally ill PPLD - “Comfort” care	241
8.3	Research question: what services and resources were used by learning disability nurses to care for terminally ill PPLD - “ <i>knowledge gaps filled by others</i> ”	244
8.4	Limitations of my study	247
8.5	Contributions to new knowledge	248
8.6	Implications for nursing practice	252
8.7	Recommendations for future research	253
8.8	Conclusion	254
CHAPTER 9	REFLECTIONS	255
9.0	Introduction	256
9.1	Preparation- my role as a researcher - interviewer	256
9.2	Experience concerning entry to research sites	257
9.3	Supervision and support	259
9.4	Participation by practitioners	260
9.5	Seminar presentation – how participants responded to my finding	262
9.6	Using a Computer Assisted Qualitative Data Analysis (CAQDAS) software package	264
9.7	Why this research matters and achievements of the study	264
9.8	Conclusion	265
REFERENCES		266



APPENDICES 1-8

Appendix 1	Interview guide for participants	287
Appendix 2	Research Protocol	288
Appendix 3	Participant Information Sheet (PIS)	295
Appendix 4	Consent form	298
Appendix 5	Honorary Contract	299
Appendix 6	Transcription symbols	303
Appendix 7	Letter of approval from research ethics committee -University of Greenwich(04/5.4.3)	304
Appendix 8	Letter of approval from local research ethics committee (LREC) (07/Q0806/15)	305

## LIST OF TABLES

1	Timeline on the provision of care and services for people with learning disabilities between year 1904 and 2001	30
2	Areas of concern: themes and findings derived from the literature review on patients with a mild, moderate, severe and profound learning disability needing palliative care.	43
3	Level Descriptors adapted from the work of Benner (1984) from Kingston University Nursing Curriculum [permission to use granted by the Dean, FHSCS, 2010]	76
4	Three streams taught in the student nurse's GNC 1970 training syllabus	82
5	A summary of practical experience associated with the student nurses' 1970 training syllabus	83
6	A summary of practical experience associated with the pupil nurses' 1970 training syllabus	84
7	The 1982 RNMH training syllabus (ENB, 1982)	87
8	An interpretation of the 1982 training syllabus for the Registered Nurse for the Mentally Handicapped in one school of nursing	88
9	A summary of practical experience associated with the 1982 mental handicap training syllabus	89
10	Selective literature review on "knowing the patient"	100
11	Selective literature review on "intuition"	108
12	Similarities and differences concerning the goal, methodology and analytic methods of the three qualitative methods	133
13	Demographic variables of nursing staff interviewed	145
14	Data collection: timeline	147
15	'Markers' and frequency distribution - learning disability nurses' talk in constructing the "normal and the pathological" continuum	151
16	Themes and sub-themes emerging from data analysis	162
17	Operational definitions of the analytic categories	166
18	Indicators of marked behavioural changes observed by participants	167
19	Indicators of marked physical changes observed by participants	175
20	Examples of what learning disability nurses did in response to experiences of intuition	182
21	Descriptors and frequency for using intuitive knowledge	182

22	Some examples of lay language and technical language used to describe signs and symptoms by unqualified LD nurses	187
23	Some examples of lay language and technical language used to describe signs and symptoms by qualified LD nurses	188
24	Some properties of “comfort” care	202
25	A checklist for identifying disease-related changes in patients with profound learning disabilities	239

## **LIST OF FIGURES**

1	Analytical sequence for generation of data and formulation of a theory	153
2	The Pathway of Assessment - the “normal and the pathological continuum”	165

## **Chapter 1**

**An outline of the thesis and brief chapter outline**

## **1.0 Introduction**

The chapter provides an account of how I came to undertake this topic for my thesis. The term people with profound learning disability (PPLD) will be defined, together with the different levels of learning disabilities. The terms and definitions used in this thesis are then clarified. This chapter also provides an outline for the structure of the thesis.

### **1.1 Background - an account of my choice of topic for my thesis**

I have chosen the topic of learning disability nurses' experience of caring for terminally ill people with profound learning disabilities in residential homes. My choice of the topic stems from two reasons. Firstly, anecdotal accounts of two learning disability nurses, identified as nurse 'A' and nurse 'B', revealed gaps in their knowledge of care for terminally ill patients with profound learning disabilities. Nurse 'A' worked in a care home owned by a National Health Service trust (NHS) while the latter worked in a home owned by an independent charitable organisation. Both services provide residential care to a group of elderly male and female adults with a mixed range of disabilities, from mild to profound learning disabilities with complex health and social care needs. The philosophy and principle of care for these homes is to provide and promote independent living for this group of patients, the right to live an ordinary life in the community with dignity and esteem (Wolfensberger, 1972; O'Brien and Lyle, 1987). These nurses worked in different organisations, yet told me strikingly similar stories about their concerns relating to caring for their terminally ill patients who remained in the homes until death. Their expressions of concern were made during one of my many visits to the homes in my working capacity as the clinical liaison lecturer. For example, nurse 'A' remarked: "we are not sufficiently trained to provide care to those diagnosed with a terminal illness". I pursued the matter further by asking her to clarify her comment that 'nurses are insufficiently trained'. She added, "Well, we are not general trained nurses. We lack the skills that require one to look

after a person who is dying from a terminal illness”. Her experience was related to an elderly male with profound learning disability diagnosed with cancer of the colon. The patient was admitted to a hospital but was discharged to be looked after by nurses in the home. Apparently, it transpired that nurses in the local hospital could do no more for the patient. Nurse ‘B’ was uncertain about the patient’s illness. She remarked that she had to rely on her common sense and intuition to guide her practice.

Secondly, a survey study on the educational needs of care practitioners in learning disability settings in relation to death, dying and PLD carried out in 2001 (Ng and Li, 2003) revealed areas of concern. This study involved distributing eighty questionnaires to two NHS Trusts providers for people with learning disability, ranging from mild to profound learning disability in the South of England. The survey findings revealed a lack of consistent policy in the recording of death in residential care homes for dying persons with learning disability, and a lack of knowledge amongst learning disability nurses, particularly in psychosocial aspects and skills in the care of dying persons.

Such anecdotal accounts and findings from the survey study stirred me to investigate why this was happening in this branch of nursing. I wondered how terminally ill people with profound learning disabilities are being cared for in the community or residential care settings. Thus, in this thesis, the underlying interest for me is how learning disability nurses care for the terminally ill or dying patients with profound learning disabilities in residential care homes.

In this study, nurses with learning disability nursing experience in caring for terminally ill PPLD are my primary focus. Nurses in this study comprise qualified and unqualified nurses. A qualified learning disability nurse is someone who holds the registration - ‘Registered Nurse for the Mentally Subnormal’ or ‘Registered Nurse for the Mentally

Handicapped' [RNMS/RNMH], but may hold more than one nursing qualification. A health care support worker [or care assistant – some participants still hold this title] will usually have a level 2 national vocational qualification in care. For the purpose of this study, all participants are referred to as 'learning disability nurses', but a distinction is made in the data analysis, for example, the letter 'Q', represent a qualified nurse, while the letter 'U' represent an unqualified nurse (healthcare support worker) (see also Appendix 6, transcription symbols).

## **1.2 Defining and distinguishing the term people with profound learning disabilities (PPLD) and other levels of learning disabilities**

For the purpose of this study, the language and terminology appropriate to the periods discussed within the literature review section will be used. Previous terms of 'subnormality' or 'handicap' were subsequently replaced by the term 'learning disabilities' (LD). The abbreviation PPLD, referring to patients with profound learning disabilities will be used generally throughout. In this study therefore, terminally ill PPLD will be referred to as 'patient(s)' because of their physiological changes or health condition.

Under the International Classification of Functioning and Disability (WHO, 1999), the concept of learning disability is described as a lifelong condition characterized by cognitive impairment and adaptive skills. The term learning disability is generally used in the United Kingdom to describe an individual with significant impairment of intellectual functioning, including significant impairment of adaptive and social functioning with the onset before the person reaches adulthood (that is, less than 18 years of age). The terminology originated in a speech made to Mencap by the then Minister for Health, Stephen Dorrell (Emerson et al, 2001). The definition of learning disability uses dual criteria, low intelligence quotient (IQ) and a reduction in ability to cope independently, which suggests a deficit in adaptive functioning (Whitaker, 2004). The definition 'learning



disability' is therefore an umbrella term that covers different levels or degree of learning disabilities.

Presently, in the United Kingdom, there are four categories of learning disabilities. For the purpose of this study, I will start with the definition of people with profound learning disability, followed by severe, moderate and mild learning disability. These are described as follows (DOH, 2001a):

A person with a profound learning disability has an IQ score of below 20. The person has substantial cognitive and sensory motor impairments and requires total care throughout their lives. Most of them have additional severe physical or mobility deformities restricting their capacity to cope with the demands of the environment. The individual will require help in all aspects of physical care, such as feeding, continence and other daily activities of living including dressing, washing and bathing. The person often has communication difficulty, difficulty in articulation, may not have spoken words or language, and many have hearing loss and poor vision. Thus, the individual is totally dependent on the nurse or carer.

A person with a severe learning disability has an IQ score of around 20 to 34. The individual may have some very basic care skills and may have difficulty learning new skills. They may require help in everyday activities such as practical skills like tying shoe laces, buttoning up clothes, making a cup of tea; lacking in social skills such as holding a conversation, with many having difficulty in understanding new or complicated information. Some may have minimum speech or may not speak.

A person with a moderate learning disability has an IQ score of 35 to 49. He /she is able to self care and live as well as function successfully in the community in a supervised environment; normally with the support of a carer, or a family member.

A person with a mild learning disability has an IQ score that ranges from 50-70. The individual is often able to acquire basic academic skills such as basic reading and writing and elementary arithmetic. Many are fairly self-sufficient in meeting their daily activities of living such as in personal self-help skills. In some cases, the person can live independently with support from a carer or a family member.

Based on the definitions, the phrase ‘a person with a learning disability’ means that the child or adult has difficulty in learning new skills, both intellectually and socially. In 40-80 per cent of individuals with a profound learning disability, the cause may not be clear (Wynbrandt and Ludman, 2000). In some cases, genetics, chromosomal abnormalities or environmental factors may be cited as the cause (Wynbrandt and Ludman, 2000). However, assumptions were made regarding a profoundly disabled person as abnormal (Gates, 2007; Atkinson, Jackson and Walmsley, 1997; Wright and Digby, 1996; Sinason, 1992) (see also chapter 2, historical perspectives). A useful way of contextualising a person with profound learning disability is to examine the concept of “normal” and “abnormal”. It is in this context that I will next discuss the concept of “normal” and “abnormal” based on Canguilhem (1989) and Goffman’s (1963) work.

### **1.2.1 The concept of ‘normal’ and ‘abnormal’**

Canguilhem (1989) a historian and a philosopher, in his book entitled, ‘The normal and the pathological’, relates the concepts “normal” and “abnormal” to health and disease. He defines “normal” as “symptomless” or “free from a disorder or disease”. He conceptualises “abnormal” as “pathological”. The term “pathological” refers to the disease itself and the

physiological responses to it. It is recognised by a set of signs and symptoms, a result of altered normal bodily functions. His view about the concept of “the normal and the pathological” comes from a medical-biological background. So, in this case, does the theory of the “normal” and the “abnormal” or “normal and the pathological” fit in with how people with profound learning disabilities are viewed? On what grounds should an individual be labelled as “normal” or “abnormal”? Are PPLD considered “abnormal” or “pathological”?

PPLD have a lifelong condition which includes genetic disorders. Some examples include Williams syndrome, Down’s syndrome or Prader-Willi syndrome. Williams syndrome is caused by a deletion of a small amount of genetic material on the 7<sup>th</sup> chromosome. The most common symptoms of Williams syndrome include profound physiological, physical and cognitive disabilities (Martens et al, 2008).

Down’s syndrome also known as trisomy 21 is a condition where a person inherits an extra copy of one chromosome. The condition means the person has a total of 47 chromosomes instead of the normal 46 (Heaton-Ward, 1973). The extra genetic material causes delay in the way an individual develops, both mentally and physically.

Prader-Willi syndrome is caused by an abnormality on chromosome 15. The majority of cases are caused by a deletion on the chromosome 15 inherited from the father, while about 25% are caused by inheriting two chromosome 15s from the mother, instead of one from the mother and one from the father. A small minority of people have a translocation or imprinting irregularity involving chromosome 15 (Whittington et al, 2004).

For PPLD, their conditions often result in a variety of disabilities. Here, “disability” denotes the presence of physical or cognitive impairments, located in the person. In this

instance, the individual is considered “abnormal”. These individuals’ conditions are not curable. However, this does not necessarily mean they are unhealthy or diseased. They may have a permanent debilitating condition, yet, on the other hand, enjoy a “normal” healthy lifestyle. Mostly, their physical deformities and abnormalities are “symptomless”.

The questions raised here then are: should these individuals be categorised as being ill or “diseased” or “abnormal”? For surely nature does not come with a label. Should they be “stigmatised”, “ostracised” or pathologised for their imperfections simply because of their genetic make-up?

Goffman (1963), a well-known sociologist, offers provocative insights for understanding the concept of “normality”. He shows us that society constructed a rather prejudiced view about people whom they considered to be “negatively different” because of their “abnormalities”. He shows us that stigma can result in discrimination and vice versa. Goffman portrayed these people – “the abnormal” - as having to constantly struggle to adjust to the “normal” identity to fit in with society’s perception of a “normal” person. Along this line, others often determine what is normal. His work helps to shed light on socialisation processes. The stigmatised individual is often misunderstood, labeled as a deviant, and at the best of times discriminated against. The term “deviant” refers to someone who departs from the expectations of a group. They include the physically disabled, the mentally ill, those who took to drug addiction or alcoholism and those with a criminal background. As such, a “deviant” is identified as a “social reject”, linked with negative stereotypes and most certainly is at risk from lack of social acceptance. In this sense, a person who is profoundly disabled is likened to a “deviant”.

Theoretically, Goffman’s theory of social stigma provides a useful framework for a better understanding of the social dimension of PPLD. But, in situating the concept of ‘normal’

and ‘abnormal’ in the context of PPLD, the question raised here is: is stigmatisation or “stigma” a problem of ignorance? If people are given the facts about PPLD, stigma or ignorance about them can be removed. It is important to see the person and not the disability.

Reflecting on the two theories (Canguilhem’s and Goffman’s), the concepts of the “normal” and “abnormal” can be shown to have two meanings. Firstly, the concepts “normal” and “abnormal” are created by individuals who, for the most part, generate a negative perception as a response to their own misunderstanding and fears of not knowing. This is presented in Goffman’s work - “Notes on the Management of Spoiled Identity” (1963). He focuses on society’s attitude towards an individual who possesses an attribute that falls short of societal expectations. In this scenario, a person who is profoundly disabled who has physical deformities, is cognitively impaired, is thus viewed as “abnormal”. Historically, commonly used images of disabilities were portrayed, categorised and stereotyped which likened them to freaks, monsters, or as people who are deviant or maladjusted (Brulle and Mihall, 1991; Longmore, 1985). PPLD fits the profile of Goffman’s impression of the “normal” versus the “abnormal”. My argument is that discrimination and devaluation of PPLD does not simply occur naturally. Rather, it is about how society behaves towards another whose appearance may be “different”. “Abnormality” or “pathological” in this instance is created by society. In other words, society seems to determine what is normal and what is not. Society stigmatises and “pathologises” people with congenital defects. In this sense, the concept of the “normal” and the “abnormal” is socially constructed.

Secondly, the “normal” and the “abnormal” is health related. Here, the concept implies a biologically based or biologically altered state of health - the “normal and the pathological

continuum” (Canguilhem, 1989). One could argue that the distinction between the “normal” and the “abnormal” (or “pathological”) may not be so clear-cut in terms of somebody having a profound learning disability. For PPLD, their physical disabilities or cognitive impairments are attributes of their learning disability condition. Along this line, a person with a profound disability is not the same as “abnormal” or “pathological”. Rather, a profoundly disabled individual becomes ‘abnormal’ or ‘pathological’ because of harmful processes that threaten the individual’s health. This is normally indicated by a set of signs and symptoms and their physiological responses to a disease or an illness.

Thus, in this study, within the context of learning disability, the concept of “normal” or “normality” for a person with profound learning disabilities is defined as (a) having a learning disability condition, and (b) the condition is free from other pathological conditions. My thesis therefore draws on Canguilhem’s concept of the “normal and the pathological continuum” to understand how learning disability nurses recognise or define the markers of disease-related or learning disabilities-related illnesses.

### **1.3 Defining the terms - terminal illness, terminal care and palliative care**

In this research study, the term ‘terminal illness’ refers to an illness or disease, regardless of the causation or nature, which results in a person with profound learning disability needing terminal care from the learning disability nurse. The definition of the duration of terminal illness in this research for PPLD is an individual who has not more than one year to live. In this research study, the term ‘terminally ill’ is also used synonymously with dying. In this research study, the definition of a terminally ill patient with profound learning disabilities is described as:

‘a person whose death is certain and for whom treatment is no longer appropriate and the patient is in a state of decline’.

Terminal care is an important part of palliative care and usually refers to the management of patients during the last few days or weeks or months of life from a point at which it becomes clear that the patient is in a state of decline (Watson et al, 2005; NCHSPC, 2003). For the purpose of this study, the intent of care concerns comfort and alleviation of symptoms, not prolongation of life. Palliative care is defined as the active total care of patients whose diseases are not responsive to curative treatment (NCHSPC, 2003; Watson et al, 2005). The objectives are to control pain and other symptoms; to alleviate isolation, anxiety and fear, and to make possible a comfortable and dignified end; and to provide support for the patient's family, before and after death.

#### **1.4 Defining residential homes**

In this study, residential homes are a cluster of ordinary houses owned by the National Health Service (NHS) Trust. Most of the homes are purpose built bungalows, located in the suburban area. They are a place of residence where a group of people with profound learning disabilities live together, supported by care staff - learning disability nurses. Each bungalow is normally 'home' to not more than 12 residents. The design and layout of the physical environment is structurally similar in each one. The 'homes' operate and meet the legal requirements, such as those relating to the structure of the building, health and safety matters and fire safety procedures. In this setting, learning disability nurses and healthcare support workers are patients' primary carers (see chapter 2, care staff - skill mix). In this study, the term residential care homes and residential homes are synonymous.

#### **1.5 Outline of the chapters**

Chapter two provides a review of the nature, past and present philosophy of care for PPLD. The reason for this inclusion is to provide readers with a brief historical background about the nature of PPLD. A review of literature on issues and concerns in palliative care provision received by PPLD is also included in this chapter. Within this chapter, I also

present the image of PPLD and why this group of people should not be pathologised, applying Canguilhem's (1989) concept of 'the normal and the pathological continuum'. This chapter shows two tables. Table 1 shows some of the significant landmarks that relate to the provision of care services for people with learning disability between 1904 and 2001. The reason for including year 2001 was to show the start of a new era in learning disability services, the focus of my next section (section 2.3), 'contemporary care philosophy and the health of people with profound learning disabilities'. 2001 was also the year that saw one of the major documents published - "Valuing People": a new strategy for learning disability since the last White Paper 'Better Services for the Mentally Handicapped' in the early 1970s (DHSS, 1971). Table 2 present a summary of areas of concern about this group of patients needing palliative care, derived from the literature review.

Chapter three provides a literature review of the modern hospice movement and how policies might affect terminally ill PPLD. Three areas of concern pertaining to terminally ill PPLD are also presented. Firstly, terminally ill PPLD may be discriminated against within 'normal' arenas of care. Secondly, this discrimination is even more apparent within the arena of providing specialist care and support. Third, there is less care or expertise offered when the need for care is more extreme among terminally ill PPLD.

Chapter four provides a review of learning disability nursing, nurse education and training. I discuss what preparation learning disability nurses received to help them to care for terminally ill PPLD. Participants in this study were trained prior to Project 2000, therefore, the focus of the review will be on the 1970s and 1980s nurses' training syllabi.



Chapter five provides a literature review on the concept of “knowing the patient” and related concepts, namely “intuition” and “commonsense” knowledge in nursing. I discuss how these concepts are applied in other branches of nursing, specifically in acute nursing. The reason for reviewing literature relating to acute nursing is a lack of evidence and research about these concepts in learning disability nursing and practice. From the research evidence that I have reviewed, I suggest that similar strategies may be used in learning disability nursing and practice. Finally, this chapter sets out the aim and objectives of the thesis and my three research questions.

In chapter six, the methodological choices are critically discussed. It also includes a description of my choice of research settings, inclusion and exclusion criteria, sample population, data collection methods and issues of data analysis and methodological rigour. This chapter also considers some of the relevant ethical issues, ‘self-presentation’, ‘insider’ and ‘outsider’ research.

Chapter seven presents my results, guided by the principles of grounded theory (Glaser and Strauss, 1967). The findings are presented thematically and an illustration is provided (“the pathway of assessment - the normal and the pathological”). The theory of “longitudinal knowing” is presented as the main theme. The theory of “knowing the patient well” is presented as a process that learning disability nurses use to establish a baseline with which they assess patients’ changing condition. This means “knowing the patient well” allows participants (learning disability nurses) to recognise patients’ ill health. In this study, participants also drew on “intuition”, “commonsense” knowledge as well as “formal knowledge” to assist them in the assessment of a patient’s changing health status.

“Knowing the patient well” also facilitated nurses in giving “comfort” care. In this study “comfort” care is considered a significant and a primary component of learning disability

nursing practice. Three types of “comfort” care were identified by participants, namely, “longitudinal presence of the nurse”, “physical comfort” and “relief from pain”. I also showed that learning disability nurses sought the support of experts in relieving patients’ pain associated with the illness/ disease.

Chapter eight draws together and discusses the main findings of the thesis, namely, “knowing the patient well”, “intuition”, “commonsense” knowledge and “formal” knowledge. As shown in figure 2, the four forms of knowledge function as a pathway of assessment - “the normal and the pathological continuum”, to achieve “comfort” care. I also provide an outline of the possible contributions of my thesis to learning disability nursing curricular development and discuss implications of my thesis in an unbiased way. A conclusion is then offered with suggestions for future research in the area.

Chapter nine concludes the thesis with a reflection on the research journey taken during this study. Included in my reflections are preparation and role as a researcher-interviewer, using a computer software package, participants’ participation, and how attendees responded to my seminar presentation of the research findings. I also briefly described the problems I encountered prior to entry to research sites. Finally, I explain why this research matters and achievements of the study.

**Chapter 2**  
**Literature review**  
**The nature, past and present history of PPLD and philosophy of care**

## **2.0 Introduction**

An outline of the search strategy is provided at the start of this chapter. This is followed by a brief exploration of the nature, past and present philosophy of care for PPLD. A review of literature relating to the care of terminally ill PPLD in residential care settings will be provided. Issues concerning where PPLD live and die and the experiences of care of terminally ill PPLD will be included. This leads to a discussion and analysis of 'the concept of the normal and the pathological continuum' that provides an overall view of how PPLD are perceived, generally. In concluding this chapter, two tables are presented. Table 1 shows the timeline that depicts significant events and developments in learning disability nursing, and the provision of care and services in the history of learning disability. Table 2 presents a summary of areas of concern from the literature review about patients with a mild, moderate, severe or profound learning disability needing palliative care.

## **2.1 Search strategy**

The focus of the search was on terminal care and PPLD. My initial literature search came from primary and secondary sources; databases included CINAHL, MEDLINE, CANCERLIT, British Nursing Index and ASSIA from 1995 to 2009. Searches were carried out both electronically and manually. There was little literature found on this subject matter. The search was carried out using a combination of key words. These were 'people with profound learning disabilities', 'with profound intellectual disabilities', 'with profound mental retardation'. These words were then combined with 'terminal illness', 'terminal care', 'end-of- life care', 'palliative care' 'terminally ill', 'terminal illness', 'cancer', 'cancer care', 'terminal disease'. Similar keywords were used to locate studies undertaken in other parts of the world, for example, Australian studies, American studies and European studies.

A manual search of books and journals was also conducted to enhance the search. This included searches conducted over a ten year span using references listed in articles such as the European Journal of Cancer Care, Journal of Advanced Nursing, Journal of Intellectual Disability Research, Journal of Palliative Care, Journal of Palliative Nursing, Disability and Health, British Medical Journal, Journal of Urology, Mental Handicap, British Institute of Learning Disabilities (BILD) and American Journal Mental of Retardation. The Department of Health (DOH) and the National Institute for Health and Clinical Excellence websites were also searched. The search revealed a dearth of studies on PPLD. The search was then enlarged to include people with learning disabilities. A total of 43 articles and research studies were retrieved of which 20 were selected and scanned for appropriateness for literature review. Of the 20 articles relating to this subject matter, these studies were on mild, moderate and severe learning disabilities.

## **2.2 Historical perspectives**

The focus of this section is on the history of care for people with profound learning disabilities. The attitudes and beliefs that society held towards them, the impact of social policy and legislation will also be examined. In my search on the history of people with profound learning disabilities, I became aware that there was nothing much written about them. The history of people with profound learning disabilities and learning disability nursing is indeed underdeveloped (Mitchell, 2003, 2001, 1998). There were two possible reasons for the lack of information or literature about people with profound learning disabilities. Firstly, statistically, people with profound learning disabilities born with neurological defects, together with their degree of severity and no known effective treatment meant that in most cases few would survive beyond the first few years of their lives. Many affected children died in early infancy (Heaton-Ward, 1973). Those who survived were those with mild, moderate or severe learning disability. Secondly, history

tells us there is no clear distinction between the different levels of learning disabilities. They were ‘lumped together’ as a group and perceived as subhuman, a menace, objects of pity, diseased organisms, objects of ridicule, holy innocents or eternal children (Gates, 2007, 2003). As such as there is only a handful of historical literature that has its focus on people with learning disabilities (Mitchell, 2003, 2001, 1998). Because of the absence of written records on the social history of people with profound learning disabilities, I shall draw on what little literature there is on the wider learning disability population.

Historically there is no clear distinction in the way care was provided for this population. They were simply seen as ‘abnormal’, and known by various names, often derogatory (Gates, 2007, 2003). Some of the most commonly recorded terms were: ‘idiots’, ‘feeble-minded’, ‘incurables’, ‘defectives’, ‘retarded’, or ‘imbeciles’ (Atkinson, Jackson and Walmsley, 1997; Wright and Digby, 1996; Sinason, 1992). The perception held by society at large was that this group of people were not considered to be intelligent, were lacking in skills, therefore were not seen to be ‘valued’ members of society, but considered to be a burden, both socially and economically (Mitchell, 2003, 2001, 1998; Gates, 2007, 2003). Some writers go as far as to point out that this group has been described as being made ‘socially dead’, hence removed from communities, kept in institutions, hidden away to ‘die symbolically within institutions’ (Todd, 2006: 18). Mostly, they were seen as a ‘sad and alien class, incompetent to manage their lives, unsuited for normal life, normal education, and normal jobs’ (Bourguignon, 1994: 180). In some cases, there were those who viewed this group of people as ‘evil’ with no place in the so-called rich and normal world (Bourguignon, 1994). They were generally housed and cared for in unsuitable asylums, segregated from the rest of society. However, some were cared for and lived in the community where care was provided by their families in villages within rural societies where close-knit ties were the norm (Malin, 1995). They were often referred to as the ‘village idiot’ or the retarded then; and most of them were able to contribute to life in the

rural communities where labour and illiteracy was the accepted norm. Those who could not be cared for in their own home were placed in institutions.

Interestingly, in the United States and throughout Europe, treatment and conditions meted out to this population group were no better. A statement written by Dorothea Lynde Dix<sup>1</sup> recorded some of the cruelties shown towards this group of people. Dorothea Dix recounted in her moving Memorial to the Legislature of Massachusetts a catalogue of general neglect and abuse, which included leg locks, handcuffs, and chains. In her statement as an eyewitness, she itemised the state of dreadful abuse witnessed town by town for the insane and retarded as confined in cages, closets, cellars, stalls, pens, chained, naked, beaten with rods and lashed into obedience, one man chained, one woman caged, one man stall-caged, three idiots never removed from one room, four females in pens and stalls, two chained certainly and one jailed (Dix, 1976). Because of Dix's indictment and her concern about the unkindness meted out, efforts to provide a place of security began.

In England, institutions for this population soon mushroomed - a place of security for people with learning disabilities. The first institutions were introduced in the early part of the nineteenth century. Such institutions accommodated people with learning disabilities as well as those with mental illness (Borsay, 2005). However, the general public continued to hold the views that people with learning disabilities were a threat to society as a whole (Scheerenberger, 1983). The place of safety or institution which was built to provide 'care' soon became a place of isolation and segregation (Jones and Fowles, 1984). In other words, institutions became 'dumping grounds' to protect society from people with learning disabilities (Todd, 2006; Scheerenberger, 1983).

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<sup>1</sup> Dorothea Dix, an American activist (1840-1841) and a lobbyist worked tirelessly on behalf of the insane, and was the creator of the first generation of American mental asylums.

In England, many authority figures held negative views about people with learning disabilities. They believed that this group of people would dilute the normal, healthy population, spread diseases and lower the general vigour of the nation (Tredgold, 1909). These beliefs coincided with the eugenics movement, the then current theory based on Darwin's ideas of the survival of the fittest, and developed by Galton, a pioneer of statistics and a cousin of Darwin. During the late nineteenth and early twentieth centuries, the eugenics movement sought to "improve" the human species and preserve racial "purity" through planned human breeding. Galton claimed the way to prevent the degeneration of society was by inhibiting procreation, a strategy for controlling the defectives and the feeble-minded by means of segregation, locked away in asylums and institutions (Wright and Digby, 1996; Stainton, 1992).

The work of Gregor Mendel on heredity published in 1865 and 1866, was "re-discovered" in 1900 (Bowler, 1989). Goddard (1931) argued that the long line of defective offspring in the Kallikak Family was a hereditary trait; thus supporting Mendel's law of heredity. The impact of Goddard's theory reinforced the idea of segregation of the insane or the mentally retarded from society. In fact, Goddard's work (in the United States) opened the opportunity for non-consensual sterilisation. Thus, the response from society was no longer simply segregation, rather it had moved to elimination.

Interestingly, similar interventions were also seen to be carried out across Europe. In Scandinavia, compulsory sterilisation was the favoured method. In Germany, the mentally retarded were victims of Hitler's efforts to create a master race. Hitler's quest for a pure, strong, Aryan race (Disability Rights Advocates, 2001; Tannsjo, 1998) meant mass genocide of people with mental and physical disabilities. A person with learning disabilities was considered as a 'life not worthy of life' (Disability Rights Advocates, 2001: 3). It was also during this period when western countries were competing to be the



most powerful nations. Therefore, 'survival of the fittest state' was the key to domination or imperialism (Alaszewski, 1988). The term 'fittest' implied mental and physical vigour, which was theorised as 'Social Darwinism' (Bowler, 1989). In England, a few prominent figures such as William Beveridge, George Bernard Shaw, H.G. Wells and Arthur Balfour, led by the then Home Secretary, Winston Churchill, introduced a bill in 1910 that included forced sterilisation programme (Gilbert, 2009). The emphasis here was to control the mentally retarded population and to protect the public by means of state intervention. The writer G.K Chesterton led a successful effort in defeating the bill, thus the programme was rejected.

In 1904, a Royal Commission was set up to examine how best to contain the 'problem' of people with learning disabilities (Gates, 2007: 51). The solution to this was the establishment of large institutions or colonies. An institution was defined as 'a place of residence and work where a large number of like-situated individuals, cut-off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life' (Goffman, 1963: xiii). Life in an institution was characterised by lack of privacy, isolation and rigid routines (Alaszewski, 1988). The first institutions accommodated both those with a mental retardation and mental illness. The physical wellbeing of individuals was neglected (Alaszewski, 1988). At this time, there was the belief that the mentally retarded if given sufficient attention and with education and training could become useful and could return to live in their own communities (Gates, 2007). Therefore, along this new direction there was an increased recognition for education and literacy skills for the mentally retarded. Thus, institutions soon became a place that offered custodial care, therapeutic care, as well education (Perrow et al, 1966). The Royal Commission also sought to address the identity of the mentally retarded. The reason being that prior to the Royal Commission, there was no clear distinction, identification or classification for the mentally retarded and the mentally ill. Society held the views that

people with learning disabilities were deviants - lacking in socially acceptable behaviours (Gelb, 1995; Kurtz, 1981). Because of the lack of official identification and classification of the mentally retarded and the mentally ill, the Mental Deficiency Act was enacted in 1913.

Under the Mental Deficiency Act of 1913, a legal category of mental deficiency was established. Any person deemed to be mentally defective was to be detained, certified and placed in an institution (Alaszewski, 1988). Under the 1913 Act, four categories of mental defectives were identified (i) 'idiot' - this was in reference to a person who was unable to care for or guard himself or herself against dangers, (ii) 'imbecile' - this was in reference to a person who was not as imperfect as the 'idiots', but still unable to manage their own lives, (iii) 'feeble-minded' - this referred to a person who whilst not considered as an 'imbecile', still required protection, care and supervision for his or her needs, (iv) 'moral defective' - this was in reference to a person who from an early age displayed some permanent defect with added vicious or criminal inclination (Gates, 2007: 53). Soon after, the 1914 Elementary Education Act endorsed the establishment of separate schools for the educable mental defectives.

In 1920, the Wood Committee reinforced and advocated for the establishment of self-sufficient colonies that were to cater for all groups of mental defectives (Gates, 2007), thus the colony system was to replace institutions, although 'colonies' were no different from institutions. The care and provision for this group of people continued to be one of containment, where they lived, worked and undertook leisure activities on the same site. Segregation of males and females was the normal practice. This type of practice and care provision continued into the early 1970s. Recalling my own experience of working with people with learning disabilities, the provision of care and services for this group of people was contained within one site. The colonies were built and designed to be self-sufficient. It

was normal to find a farm, workshops, school, laundry facilities, hairdressers, and clothing store, catering services, church, cinema, entertainment hall and even a small hospital within one site (Gates, 2007).

Living conditions in the colonies were exposed as being poor and they were characterised as 'places of profound humiliation' (Alaszewski, 1988:27). The care and provision for this group of people were less than humane, which stripped individuals of their civil liberty. It seems that people living in this type of establishment were stripped of human dignity (Felce, 1996). Added to this observation was the fact that the eugenicists' views were no longer scientifically sound. Furthermore, the post war and subsequent disclosures of atrocities in Europe changed society's attitude towards people with learning disability. These conditions informed the need for de-colonisation; hence, colonies became an integral part of an organized health service with the inception of the National Health Service.

Another contributing factor that influenced the de-colonisation of the mentally retarded<sup>2</sup> was the rise of the civil rights movement which emphasised that all human beings were worthy of dignity and respect (Felce, 1996). The pressure group, the National Council for Civil Liberties (NCCL) (now known as Liberty) began campaigning in 1947, and published a report which drew attention to the lack of resources and poor care practices in large institutions (Alaszewski, 1983). Because of the growing sensitivity and concerns about the treatment meted out, and the poor living situation in the colonies, the Royal Commission on the Law Relating to Mental Illness and Mental Deficiency was set up in October 1953. Representatives to Royal Commission included the medical and law professions under the chairmanship of Baron Percy of Newcastle. Its terms of reference

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<sup>2</sup> Mentally retarded and mental defective(s) - the terms were used interchangeably until the abolition under the Royal Commission in 1957.

were to inquire into the care of persons who were suffering from mental illness or a mental defect. By 1957, the Royal Commission had practically ended compulsory certification and detention of individuals with learning disabilities. In effect, the Royal Commission ended custodial care methods. The Royal Commission recommended the breakdown of segregation and placed new emphasis on community care (DHSS, 1971). It also recommended the development of local authority services to run in parallel to institutions. However, long term nursing care and medical support continued to be provided in institutions, whilst parallel services were developed for those who could be cared for in the community (Alaszewski, 1988).

Additionally, the Royal Commission replaced the term 'mental defective' with the term 'mental subnormality' and 'severe mental subnormality' (Gates, 2007). It also re-classified the terminology - 'moral defective' was replaced by the terms 'mental subnormality' and 'severe mental subnormality'. (The terminologies - 'mental subnormality' and 'severe mental subnormality' were later replaced by the common phrase "mental handicap" in England and Wales in early 1970s). The Royal Commission also recommended the re-training of hospital staff (refer to the section on the role and preparation of learning disability nurses). One other significant recommendation of the Royal Commission on the Law Relating to Mental Illness and Mental Deficiency was that it paved the way for a new Mental Health Act in 1959 and introduced Mental Health Review Tribunals.

Towards the late 1950s and 1960s, a number of notable changes were introduced. The pressure for change was multi-factorial. Firstly, there was a proliferation of early educational research work undertaken in the early 1950s by educational psychologists on the effects of institutionalisation. Several studies were reported suggesting that some people with learning disabilities were capable of learning and improvement (Bowlby, 1951; Tizard and O'Connor, 1952). These studies showed that many individuals living in

institutions had the intellectual and social capabilities to live in the community. In addition, the studies revealed that institutional life did little to support personal development. The work of Bowlby (1951) demonstrated that children in large institutions were denied the opportunities of social interaction and stimulation which was to have a detrimental effect on a person's development. Such findings have support in the work of Clarke and Clarke (1954) who confirmed the relationship between a stimulating environment and a person's performance.

Following on from this period, between the 1960s and 1970s a series of scandals concerning the appalling, impoverished conditions in the hospitals, poor practice and degrading and inhumane mistreatment of people with learning disabilities came to light. This led to public outcry and several high profile public enquiries such as the inquiry into Ely Hospital (Howe Report, 1969). The Howe Report identified squalid living conditions, lack of privacy and the emphasis on custodial care among the nursing staff. One notable movement was the founding of the 'Campaign for People with Mental Handicap' in 1971. The goal of the movement was to move individuals from large institutions to small group homes with community-based services. Thus, the 1971 White Paper - 'Better Services for the Mentally Handicapped' became an important document for reducing the number of long stay hospital places for adults with mental handicap.

Such reports and findings about the negative effect of institutionalisation were later to lead to the introduction of care in the community. Thus, from 1970s onwards, the resettlement programme was set in motion (DOH, 1971; DOH, 1990) and the route to de-institutionalisation was thus assured. Funding was difficult and the plan took several years to implement, but many people were moved to smaller, on-site facilities with a more conducive home-like environment. Subsequently, other reports were to follow. They were the "*King's Fund*" report (King's Fund, 1980), with its publication on 'ordinary living',

the “*All Wales Strategy*” (AWS) (Welsh Office, 1983), the “*Griffiths Report*” (1988) and the NHS “*Community Care*” (DOH, 1990) policy. The first long stay 1,000 plus bed institution to be closed was Darent Park in Kent<sup>3</sup>, swiftly followed by many more across the United Kingdom. The last long stay hospital to finally shut its door was Orchard Hill in 2009, formerly known as Queen Mary's Hospital<sup>4</sup>, located on a 136 acre site at Carshalton, Surrey.

Importantly, these reports showed the beginning of the application of the social care model and the beginning of de-medicalisation of learning disability nursing. From the late 1970s onwards, the life and conditions for people with learning disabilities were transformed. The concept of normalisation was recognized, and the need for collaborative working based on the multi-disciplinary approach was adopted (All Wales Strategy, Welsh Office, 1983; King's Fund, 1980).

The concept of normalisation was developed in Scandinavia and the North American continent (Bank-Mikkelsen, 1969; Nirje, 1969). ‘Normalisation’ was defined as an existence for the mentally retarded as close to normal living conditions as possible (Bank-Mikkelsen, 1969). This definition suggested ‘securing normal housing, education and work and leisure conditions for people with learning disabilities’ (Gates, 2007: 58). During this period, throughout the 1970s and 1980s, the implementation of the philosophy of normalisation was not without criticisms. This approach arose because of misunderstanding over the use of the word ‘normalisation’. It was thought that the underpinning principle of normalisation was on promoting normal living conditions and equal rights for people with learning disabilities; however, what was normal may be difficult to define. Somehow, it was viewed as another form of imposing certain lifestyles

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<sup>3</sup> Opened in 1890, it housed over 1,000 children and adults with LD, and finally closed in August 1988.

<sup>4</sup> Opened in 1914 as a long-stay hospital, housed over 100 adults with learning and physical disabilities.

on those who used the service (Brown, 1994). Because of the criticisms, Wolfensberger re-defined normalisation as 'Social Role Valorisation' (Wolfensberger, 1983; Wolfensberger and Thomas, 1983).

Within this theory, the underlying principle of normalisation (Wolfensberger, 1972; O'Brien and Tyne, 1981) was about embracing an individual as a valued citizen, who lives a normal lifestyle in an ordinary home in the community. The concept of normalisation implies that a person with a learning disability (or the mentally retarded) would live in a normal house, have education, secure employment and have leisure time. Reflecting on this definition, it is worth remembering that this concept was first thought of and developed in Denmark, then Sweden. This definition seems to suggest that everyone no matter how severe or profound their disabilities might be will have equal rights. Central to this concept was the provision of a service tailored to the needs of individuals. However, what this definition has not made clear was how to integrate those who are profoundly disabled into society or the community. Nonetheless, the idea of promoting equal rights for people with learning disability including those with complex or profound disabilities has support in the United Kingdom (UK). This means the principles of 'normalisation', later renamed 'social role valorisation' were operational in UK, but re- modified or re-adapted to fit in with local practices (O'Brien and Tyne, 1981). The new concept, 'social role valorisation', was underpinned by a set of service principles including the need for social inclusion, integration and participation (O'Brien and Tyne, 1981) within community settings. This was also the principle of the Jay Committee that 'mentally handicapped people have a right to enjoy a normal pattern of living within the community' (DHSS, 1979).

Coincidentally, during this period, Advocacy Alliance and Citizen Advocacy were established with their core principle of upholding human rights and statutory entitlements.

This provided the most vulnerable people in society the right to have a say, the right to make decisions and choices, the right to be recognized as citizens first and most importantly, removing outdated and negative language of the stereotypical and stigmatising terms. The application of the principles of 'social role valorisation' has support in legislative documents such as The White Paper- Caring for People (DOH, 1991).

Following on from the introduction of the NHS and Community Care Act (DOH, 1990), people with a learning disability including PPLD were enabled to remain in their own homes where possible. In fact, even though the development of community care began in the early 1990s in England, the concept of community care was first thought of in the late 19<sup>th</sup> century, but was never implemented due to lack of community services (Scull, 1977). Nonetheless, the introduction of care in the community meant that the principal aim of 'social role valorisation' was to be realised for many people with learning disability and PPLD.

From my observation, despite the implementation of community care, and the promotion of the principles of rights, inclusion, choice and independence, the extent to which the needs of PPLD are being met is debatable. According to Peckham and Meerabeau (2007), the definition of community care was never properly clarified. Community care suggests a number of people being cared for, residing in homes within the community settings. The majority of people with learning disabilities, excluding those with profound learning disabilities, normally live in this type of set-up. Those with profound learning disabilities may be living in supported living accommodation, or purpose-built houses located in the old hospital ground, often in secluded residential care areas. The providers of care comprise mainly care workers and nurses. In 2000, it was documented that residential care homes were largely owned by the independent sector as well as NHS providers. The



number of residential care places in the community had increased to 53,400, from 4,900 since the White Paper in 1971 (DOH, 2001). A downward trend of occupied beds in the NHS facilities (DOH, 2001; Hollins et al 1998; Blisard et al 1988) was documented. For example, in 1969, there were 58,850 patients with learning disabilities (adults and children) in NHS hospitals. In year 2000, approximately 10,000 patients remained in NHS facilities. This figure is taken to cover a range of disabilities, from profound to mild (DOH, 2001).

In concluding this section, I present table 1 (page 30) to show the timeline that depicts significant events and developments in LD nursing; the provision of care and services in the history of PPLD between 1904 and 2001.

**Table 1 - Timeline on the provision of care and services for people with learning disabilities between year 1904 and 2001.**

YEAR	EVENTS AND DEVELOPMENTS
1904	The Royal Commission – led to the Mental Deficiency Act of 1913
1913	Mental Deficiency Act – the term ‘Mental Defectives’ was established. Anyone admitted to an institution* was certified as a ‘mental defective’. Institutions were known as colonies.
1914	Elementary Education Act – separate schools for ‘educable mental defectives’
1919	The first mental deficiency certificate was issued by the Medico-Psychological Association (MPA)
1920	The Wood Report- the mentally defectives were seen as ‘threat’ to society.
1930	Lobbying for sterilisation by the Eugenicists Movements
1948	The inception of the National Health Service (NHS) – large institutions (‘colonies’) became an integral part of an organized health service. The institutions or colonies became hospitals. The NHS hospitals were designed to secure improvement for people with learning disabilities in England and Wales; to provide and secure the effective provision of services for people with learning disabilities.
1954-1959	The Royal Commission on the Law relating to Mental Illness and Mental Deficiency (The Royal Commission in 1957), ended custodial care, and emphasised community care, provision of local authority –based residential care, recommended re-training of staff. Terminologies – the term ‘moral defective’ was removed, replaced by the terms mental subnormality and severe mental subnormality.
1960 – 1970	Various hospital scandals related to ill treatment and poor practice. The nature of ill treatment included physical and psychological abuse.
1970	Terminologies – the terms mental subnormality and severe subnormality were abolished. The term ‘mentally handicapped’ was legalised.
1971	The publication of the report – ‘Better Services for the Mentally Handicapped’. The White Paper advocated closure of large institutions and a move to community-based care.
1979	Jay Report – reinforced the principles of community based-care.
1980	The publication of the King’s Fund report – ‘An Ordinary Life’ - leading a normal life.
1982	Terminologies – the registration of nurses in the nursing register as ‘Registered Nurse for Mental Handicap’ (RNMH). This was to reflect and replace the previous title – ‘Registered Nurse for Mental Subnormality’.
1983	The report of ‘All Wales Strategy’ recommended for further developments and expansion of services to mentally handicapped people
1989	The publication of the White Paper – ‘Caring for People’, set out the principles for shift to community based care.
1990	Terminologies – the term mentally handicapped was replaced by the term ‘people with learning disabilities’ (PLD).The NHS and Community Care Act – to provide support to enable those who are able to live and remain in their homes. This Act included the introduction of a range of services such as domiciliary care, respite care, and day services and the promotion of independent care options and a greater emphasis on supporting informal carers.
1996	The change of title and registration of nurses – Registered Nurse for Mental Handicap (RNMH) was replaced by the new registration – ‘Registered Nurse for Learning Disability’ (RNLD).
2001	Valuing People - a new strategy for learning disability nursing in the twenty-first century (DOH) – reinforced the principles of ‘rights’, ‘independence’, ‘inclusion’ and ‘choice’ for people with learning disabilities.

### **2.3 Contemporary care philosophy and the health of people with profound learning disabilities**

It is clear that the nature, care and service provision for PPLD has changed since the early 1900s. This group of patients is living longer and into old age (DOH, 2001a, Mencap, 2001; DOH, 1995a). For example, nowadays children and young people with profound, complex and multiple disabilities survive into adulthood (DOH, 2001a). Furthermore, diseases increase with greater level of disabilities (DOH, 2001a) particularly where some

conditions or diseases may be related to the aetiology of a person's learning disability (Stanley and Ng, 1998). People with profound learning disabilities are not capable of self-care, for example cleaning their own teeth; poor oral hygiene may then lead to chronic dental disease. They have poor feeding skills, which may result in a lack of nutritional intake. Some have poor or no washing, bathing and continence skills which may expose them more to the possibility of infection (DOH, 2001a).

In the United Kingdom, statistically, it is estimated that there are about 350,000 persons with a profound learning disability (Foundation for People with Learning Disabilities, 2008). Some authors state that by year 2021, the number over the age of 50 is expected to increase by 53% (Emerson and Hatton, 2008). This figure is taken to cover a range of disabilities, from profound to mild learning disabilities. The possible reasons for longer lifespan could be technological advances in healthcare and healthier lifestyles. Moreover, there is better control of epilepsy and an increase in the use of percutaneous endoscopy tube feeding (PEG) (DOH, 2001).

Because of longevity, their health problems may also be similar to those of the non-disabled population (DOH, 2001a). For example, the chances of developing Alzheimer's or other dementia (Mann et al, 2008; Stuart-Hamilton, 2006) are also greater (Emerson and Baines, 2010; Kerr and Wilkinson, 2005). This is especially true for PPLD with Down's syndrome. This group of people is more prone to early onset of dementia due to the extra x chromosome (Emerson and Baines, 2010; Kerr and Wilkinson, 2005).

While there are no firm statistics to show whether deaths associated with particular terminal illnesses or diseases are on the increase, cancer seems to be on the rise for PPLD (Hogg et al, 2001). Some of the cancers included leukaemia, testicular cancer (Dieckmann,

et al, 1997) and cancer of the gastro-intestinal tract (Cooke, 1997). Moreover, deaths linked to long-term conditions such as cardiovascular disease and certain cancers are also considerably higher among this group of patients (DOH, 2005b, DOH, 2001a). Thus, if PPLD are dying with long-term conditions, the issue about care of the dying then becomes pertinent. I will examine where PPLD live and die and how care is given to those who enter the dying process within the community settings in the following sections.

### **2.3.1 Present living services**

There are now a wide range of living arrangements for PPLD. Some of them are living in service-based accommodation in the community such as residential or nursing care homes. These types of service-based accommodation may be provided either by the NHS Trust, private or charitable organisations. However, some continue to live with their families. About 160,000 PPLD are known to live in residential care settings (DOH, 2002). This figure only takes into consideration those in touch with learning disability services (DOH, 2002; DOH, 2001). According to the Department of Health, at least 25% are not accounted for (DOH, 2002; DOH, 2001). This may possibly be because they are not on the local electoral register. Some might not even be registered with the local GP services or community team for learning disability (CTLTD).

### **2.3.2 Care staff - skill mix**

In England, the closure of large mental handicap hospitals and the emphasis on care in the community (DOH, 1990) for PPLD meant new ways of working. According to Gates (2009: 283), 'there are a wide range of possible team structure and memberships, however, it is important that decisions about team structures should be selected to match the individual needs'. For example, the 'skill mix' of health personnel working within the team was crucial. The term 'skill mix' is used to describe the mix of nursing personnel in

an organisation (DOH, 2003b; Buchan and Dal Poz, 2002). It also refers to the combination of activities or skills needed for each job within the organisation (DOH, 2003b; Buchan and Dal Poz, 2002). Within residential care homes, most of the homes employ learning disability nurses and health care support workers to provide immediate care to PPLD. However, a profoundly disabled person may also require the support of a physiotherapist or an occupational therapist. In general, learning disability nurses and the health care support workers are the main carers for PPLD.

Learning disability nurses work with other health care professionals, such as social workers, psychologists, occupational therapists, physiotherapists and speech and language therapists (SALT ) to provide a comprehensive coordinated service for PPLD in residential care services (DOH, 2001a). Each professional group of staff is managed within their own professional line management structure. For example, a nurse would report to a nurse manager and a social worker to a social worker manager (Sines et al, 2001). In the case of nursing people who are profoundly disabled, it is necessary to ensure that the ‘right’ mix of staff work together and collaboratively to achieve a common, that is, to provide quality care for PPLD (Gates, 2009). In England, the nurse in learning disability practice is the key figure; involved in giving direct care as the patient’s main carer or key worker in a residential home (Lacey and Ouvry, 2001). Some of their work may also include organising coordinated support for individuals in residential homes. This means they have management responsibility such as the day-to-day running of the homes as well as responsibility for their patients. There are approximately 17,000 first level nurses registered on the Part One Mental Handicap Nursing register, and approximately 4,000 on the Part 14 (post 2000) Learning Disabilities nursing register (NMC, 2003). The figures do not indicate how many of them are actually working with PPLD in residential homes.

There is no accurate data to suggest how many health care support workers are employed at present across residential care homes. The role of health care support workers is to assist registered (qualified) learning disability nurses in the delivery of care to PPLD in residential homes. The majority employed in residential homes have undertaken or are undergoing vocational training. Their training enables them to carry out nursing tasks under the supervision of a nurse such as bathing and feeding.

So far, 'skill mix' in learning disability practice means an increasing number of health care support workers are being employed to assist learning disability nurses in the delivery of care to PPLD. According to the Department of Health (DOH, 2001a), 75 per cent of the staff employed in learning disability practice (including residential care homes) are thought to be without a nursing qualification. To date, the effectiveness of skill mixes within learning disability nursing remains relatively unexplored. From my observations during my fieldwork in the two NHS trusts, I noted that there was no agreed formula or ratio to determine the number of nurses required in relation to the number of PPLD within each of the homes.

### **2.3.3 A place for dying - where do terminally ill PPLD die?**

The Office for National Statistics (2007) classified six types of places of death. They are: (i) at home, (ii) psychiatric hospitals, (iii) hospices, (iv) NHS hospitals and non-NHS establishments such as nursing homes, (v) other communal establishments (vi) other private homes or elsewhere. The classification of place of death seems to relate to the general population, excluding those with PPLD. In fact, there are no statistics to show where PPLD die. Additionally, most of the reports on the place of death relate to the non-disabled population. Reports have shown that about 17% of the non-disabled population

die in hospices (O'Neill and Rodway, 2004), while hospital deaths stand between 21% and 24% (Gomes and Higginson, 2008; Froggatt, 2004).

The White Paper - Valuing People (DOH, 2001) clearly showed an increase of residential care places in the community. As yet, there are no figures or reports to show how many PPLD remained in residential care settings until death. Furthermore, there are no firm figures to show how many PPLD die in hospices or in their own home (personal correspondence with Addington-Hall, 1999<sup>5</sup>). There is also no clear statistical evidence to show the rate at which PPLD have died following hospital admission. However, what is certain is that this group of people has little access to hospice facilities. They are rarely referred to a hospice (McEnhill, 2006; NICE, 2004). This begs the question why this is so. From my observation, it seems that PPLD are marginalised when living and in dying.

From my observation, not knowing the data on where PPLD die shows the low priority given to this group of people. It reinforces the view that PPLD are still an undervalued group of people in today's society. Interestingly, some writers claim that a lack of interest about the status of dying and PPLD may be seen to be a concrete expression of society's view and treatment imposed on PPLD. Historically, PPLD have been described as 'socially dead' (Todd, 2006, p18), thus, they are viewed as already dead. On the other hand, is care of the dying PPLD a challenge for nurses in residential care settings?

Some writers are in agreement that PPLD should be helped to die in their own home unless their needs are too complex or their dying too protracted for this to be managed at home (Brown, Burns & Flynn, 2002). The findings of a survey study by Ng and Li (2003) indicated that the majority of learning disability nurses were more likely to state that the

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<sup>5</sup> personal correspondence with Addington-Hall (1999): my original request was to the National Council of Hospices and Specialist Palliative Care Services for information on PPLD. This request was re-directed to Professor Addington-Hall, the then Deputy Head of Department of Palliative Care and Policy at King's College / St Christopher's Hospice.

place of death was in the 'home'. The term 'home' in this study represented a place of residence where the patient would have been looked after for most of his or her life. Here, the notion of dying in the 'home' implied dying in a familiar environment, surrounded by familiar people.

In order to throw light on how terminally ill PPLD are being cared for in residential care homes, a literature review was conducted on issues about the care of dying or terminally ill PPLD.

#### **2.3.4 Care of the dying or terminally ill PPLD - previous studies**

A review of literature shows that the focus of most of these studies is mainly on people with mild or severe learning disabilities (Tuffrey-Wijne et al, 2010; Li and Ng, 2008; Black and Hyde, 2004; Ng and Li, 2003; Tuffrey-Wijne, 2003; Lindop and Read, 2000; Read, 1998; Bycroft, 1994; Hendren et al, 1990). Some are either a case study or qualitative study, with small sample size. Table 2 presents a summary of the themes and findings.

So far, there are a handful of small studies on people with mild or moderate learning disabilities and palliative care needs (Tuffrey-Wijne et al, 2010; Li and Ng, 2008; Black and Hyde, 2004; Ng and Li, 2003; Tuffrey-Wijne, 2003; Lindop and Read, 2000; Read, 1998; Bycroft, 1994; Hendren, et al, 1990). Knowledge of the nature of terminal illness for people with profound learning disabilities has important implications for providers of health and social care. There is evidence to suggest that characteristics associated with PPLD may mask or be confused with disease-related signs and symptoms (Hendren et al, 1990). This phenomenon is sometimes referred to as "diagnostic overshadowing" (NPA, 2004; Hogg et al, 2001; Hendren et al, 1990). This means that healthcare professionals



sometimes confuse the signs that show someone is unwell with characteristics of their learning disabilities.

A study by Hendren et al (1990) on a 12-year-old patient with autism who died of Ewing's sarcoma is an example of this issue. The patient's complaints were largely ignored because healthcare professionals thought they were linked to his autistic characteristics. One of the characteristics of autism is that they have difficulty relating to others. They are withdrawn and socially isolated, dislike changes, and have difficulty in self-expression. As such, they may not co-operate with physical examinations (DOH, 2001).

Other studies observed that delay in diagnosis and recognition of symptoms was the result of poor communication and communication difficulties between healthcare professionals and patients with profound learning disabilities (McEnhill, 2004; Brown et al, 2002; Mencap, 2001a). A report - 'Death by Indifference' (Mencap, 2007) claimed that it was harder for this group of people to make themselves heard when they were feeling unwell. The implication is that there is a need for healthcare professionals to learn how to communicate with people with profound learning disability.

Moreover, learning disability nurses may lack knowledge of the pathophysiology of illness and disease. Recognition of the state of health of PPLD without spoken words depends on nurses' ability to recognise the onset and the processes of illness and disease. Knowing the processes of diseases enables nurses to manage pain and other distressing symptoms better. Delayed diagnosis may deny proper treatment. Bycroft (1994) who described the case of a handicapped woman with metastatic breast cancer found that there was a lack of basic knowledge among nurses about the nature of the disease itself.

In 2003, Ng and Li carried out a descriptive study of learning disability nurses working in residential care homes. This study was conducted in two NHS Trusts. The aim of the study was to explore the educational needs of learning disability nurses caring for dying PLD in residential care settings. The findings showed areas of concern that included a lack of experience of care for dying patients and a lack of knowledge about the causation of deaths. This study highlighted the issue of nurses' knowledge about the causation of certain diseases and illnesses leading to death. It also raises concern about the inability of nurses to accurately describe and recognise the signs and symptoms of impending death. This study also highlighted that learning disability nurses are aware of the importance of communication; they may need to communicate effectively and sensitively when breaking bad news. It suggested that communication and how to break bad news should form a core component of the nursing education curriculum in learning disability nursing.

Following on from this, a second study was carried out in 2007 by the same researchers (Li and Ng, 2008). This second study was carried with the aim of examining five learning disability nurses working in one residential care home. In this study, Li and Ng (2008) reported a lack of advanced knowledge and practical skills among learning disability nurses caring for dying PPLD. This finding reinforced the first study (Ng and Li, 2003), demonstrating a lack of pathophysiological knowledge of both malignant and non-malignant diseases among LD nurses leading to delayed diagnosis.

The discovery about the lack of knowledge and understanding among nursing staff concerning terminal illness or cause of death was also found in another study (Tuffrey et al, 2010). Tuffrey et al (2010) using the observation technique reported that staff had little knowledge of the physical and emotional processes of cancer. The study also highlighted a

lack of knowledge among staff in recognising the signs of advanced illness or impending death. This study used participant observation with 13 people who had mild to severe learning disabilities, diagnosed with cancer.

Lindop and Read (2000) examined the educational needs of district nurses who provided palliative care to patients with learning disabilities. The study did not indicate the degree of disabilities among this group of patients. However, the authors concluded that district nurses lacked knowledge of the nature of learning disabilities. They reported that nurses in this study did not know how to communicate with their patients. The implication of their findings is that these nurses may not have the appropriate skills to carry out accurate assessment and management of pain. They also reported that it is also likely that learning disability nurses may not have palliative care training.

Other studies observed that delay in diagnosis and recognition of symptoms was the result of poor communication and communication difficulties between healthcare professionals and patients with profound learning disabilities (Tuffrey-Wijne et al, 2005). Tuffrey-Wijne et al (2005) undertook a qualitative study, which involved interviewing five people with a mild learning disability. The study concluded that this group of people was shielded from cancer information. It was thought they did not need as much information as the able-bodied population. It appears therefore that the subject of how to give information about dying remains one of the most difficult tasks encountered by learning disabilities nurses.

Other studies found that healthcare professionals are hesitant in providing the treatment options for people with learning disability. The reason was the perception that generally, this group of people will not understand the meaning of risks and possible treatment

outcomes (Northfield and Turnbull, 2001; Cumella and Martin, 2000; Keywood et al, 1999; Howells, 1997). As such, decision-making regarding consent issues and treatment for PPLD is difficult, but cannot be ignored.

Under English law (DOH, 2003a) and The Mental Capacity Act 2005 (DOH, 2005a), all adults are deemed capable of giving consent unless there is evidence to the contrary. One of the five key principles stated in Section 1 of the Mental Capacity Act 2005 states that every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise. The Mental Capacity Act 2005 provides a statutory framework to empower and protect vulnerable people. Under this Act, the term 'capacity' is used in relation to treatments and /or interventions relating to each decision for each individual. If it can be proved that an individual lacks the capacity to make a decision, then the decision must be made in their best interests. It is possible that many people with mild, moderate or severe learning disabilities are able to make decisions with support. Gates (2007: 74) points out: 'adults with learning disabilities are assumed to be able to make their own decisions'. Nevertheless, the ability of PPLD to make decisions may be beyond their current level of capacity because of their substantial cognitive impairment. From this perspective, learning disability nurses and other healthcare professionals need to recognise that there is a difference between patients with a mild form of learning disability and those with PPLD in their ability to make decisions. Thus, if the individual is incapable of giving consent or making decisions due to his or her incapacity that is profound and permanent, it is lawful to carry out a procedure or treatment which is deemed as in the 'best interests' of the person concerned (The Mental Capacity Act, DOH, 2005a; DOH, 2003a). This means for PPLD, there is always somebody else such as an Independent Mental Capacity Advocate (IMCA) consenting on their behalf in relation to medical and nursing treatment or interventions. The Mental Capacity Act, 2005 - regulation section 6 (1) states that an Independent Mental Capacity Advocate is appointed

by an NHS body or a local authority which instructs a person to act and represent vulnerable people.

Only one major study was found that looked at bereavement counselling for people with mild and moderate learning disability. The study was undertaken by Read (2004) as part of her PhD thesis, and was a qualitative study, with its focus on two distinct groups, that is, 30 people with learning disability who had been referred to the counselling agency for bereavement counselling, and relevant bereavement counsellors involved in the work. Read claims that people with learning disabilities are seldom given the appropriate support when they experience bereavement. Her study was aimed at increasing practitioners' understanding of bereavement counselling and the use of a manual to support future counselling practice with people with learning disability experiencing a major loss in their lives; she argued that communication techniques must match the cognitive and developmental level of the individual concerned. Similarly, Todd (2005: 81) revealed that there is little evidence to suggest that 'people with learning disability are involved in or had opportunities to talk about their dying'. This view is also shared by others such as Dodd (1999) and Bihm and Elliot (1982) that this group of people has difficulty in conceptualising serious physical illnesses because of the lack of understanding about such issues. What this study has shown is that PPLD are not likely to be involved in the grief process.

The studies reviewed so far revealed that there is a lack of skills and knowledge among learning disability nurses in caring for terminally ill people with learning disability, generally. Recognition of the state of health of PPLD is dependent on nurses' ability to recognise the onset and the processes of illness and disease. Knowledge of the processes of diseases could only mean better control and management of pain and other distressing symptoms. A delay in diagnosis of an illness or disease may deny individuals proper

treatment. These studies also implied that because of communication difficulties, there will be under-reporting of symptoms and signs of physical illness and diseases within the learning disability population. The studies showed that communication difficulties pose a challenge for nurses caring for this group of patients.

Based on the literature reviewed, it is clear that there is therefore a gap in knowledge concerning the experiences of learning disability nurses and their care for terminally ill PPLD. Knowledge of the nature of terminal illnesses and diseases for PPLD has important implications for providers of health and social care. In addition, it is clear that some PPLD will not be able to articulate or describe their physical symptoms (Mencap, 2007b). Some PPLD such as a person with Prader-Willi syndrome when ill may not show signs of illness (Cassidy, 1997). What's more, the NHS-End of Life Care Report (2006) states that as life expectancy has increased, so has the incidence of dementia, even though it is not clear how many of them are PPLD. The issue here then is about a nurse's knowledge of his or her patient, and signs and symptoms of diseases / illnesses. I surmise that unless a nurse knows his or her patient well, there is the possibility of overlooking the vulnerability of the patient at risk. The noticing of signs and symptoms of disease-related physiological changes and disease-related behavioural changes is made easier if the nurse knows the patient well. This means that recognition of illnesses and symptoms are embedded in "knowing" what is "normal" and what is "not normal" about the person.

In concluding this section, I present table 2 (page 43) showing a summary of areas of concern derived from the literature review on patients with a mild, moderate, severe and profound learning disability needing palliative care.

**Table 2 - Areas of concern: themes and findings derived from the literature review on patients with a mild, moderate, severe and profound learning disability needing palliative care.**

Themes	Areas of concern
<p><b>Lack of knowledge about the nature of pathophysiology of diseases or illnesses</b></p> <p><b>Lack of specialist skills and palliative care</b></p>	<p>Some learning disability nurses may have difficulty in recognising symptoms of ill health because of insufficient knowledge about the pathophysiology of illnesses and diseases or impending death (Tuffrey et al, 2010; Li and Ng, 2008; Bycroft, 1994).</p> <p>Many professionals working in the generic services such as district nurses have a lack of experience, understanding and knowledge about the nature and condition of learning disability and the needs of people with learning disabilities (Lindop and Read, 2000).</p> <p>Learning disability nurses lack confidence in caring for dying patients due to a lack of knowledge and skills about (i) causation of illness leading to death and (ii) care for dying persons leading to death (Ng and Li, 2003).</p> <p>Learning disability nurses may underestimate patients' complaints, often due to lack of specialist skills to support a person who may be faced with a life threatening illness (Black and Hyde, 2004). LD nurses require up-to-date information about appropriate nursing interventions, such as pain control, the nature of cancer and cancer nursing care (Bycroft, 1994).</p> <p>Learning disability nurses may lack the skills required for the delivery of psychosocial care (Ng and Li, 2003). They are not trained or qualified to deal with pain relief (Todd, 2005).</p>
<p><b>Under identification and difficulties of recognising ill health / Diagnostic Overshadowing and late detection of illness in PPLD</b></p>	<p>Life threatening illness in PLD may be overlooked and may not be detected early due to a lack of routine screening, health promotion activities and campaigns. Such activities occur less frequently and are seldom aimed at PLD (Howells, 1997; Ng and Li, 2008).</p> <p>The condition of PPLD often overrides and obscures their physical illness (Hendren et al, 1990). Late diagnosis, poor decision-making, lack of honesty and failure to offer patients a choice are some of the problems identified (Brown, Flynn, Burns, 2005).</p>
<p><b>Inexperienced carers in coping with physical and emotional processes of cancer; pain and symptom management</b></p>	<p>Staff had little knowledge of the physical and emotional processes of cancer (Tuffrey et al, 2010). Some nurses may not be skilful in dealing with pain and other distressing symptoms (Todd, 2005).</p> <p>Some nurses are not well equipped to deal with challenging behavior, therefore pain sensitivity may need to be considered for this group of patients (Read, 1998), or else they may be prevented in seeking initial health care (Dodd, 1999; Cumella and Martin, 2000). Generally, these patients have little understanding of pain, it is harder for them to ask for help or describe symptoms when they are feeling ill, or are in pain (National Patient Safety Agency 2004).</p>
<p><b>Accessing / availability of support services / collaborative relationship services</b></p> <p><b>Consent issues and information</b></p>	<p>There is a need for improved support services for staff who deal with care for the dying clients (Todd, 2005). Healthcare professionals need to work together and share information and expertise (Bycroft, 1994).</p> <p>There is concern that few people with learning disabilities access specialist care (Brown et al 2002; McEnhill, 2004) and mainstream care services.</p> <p>There is a lack of equity and parity of palliative care services for people with learning disability. There is a lack of understanding about where, when and who to refer. There is resistance from some professionals to involve palliative care specialists. There is the perception that palliative care services are for cancer patients only, and missed opportunities associated with cultural background (Ahmed et al, 2004).</p> <p>There is concern for this group of patients' understanding and their awareness about consent issues and lack of literature to inform and help with their illness (Black and Hyde, 2004).</p> <p>Patients were not given the information they need - it has been suggested that they are protected from cancer information, even though some (people with mild and moderate LD) wanted this information and are capable of understanding it (Tuffrey-Wijne, et al, 2005).</p>
<p><b>Guidelines and Protocols</b></p>	<p>There are no clear guidelines or protocols for dealing with the terminal phase of a person's life (Todd, 2005). There is a need for clear written information and knowledge about people with learning disabilities diagnosed with cancer in order to bring cancer services for these patients to the level of those for the general population (Black and Hyde, 2004).</p>
<p><b>Communication difficulties</b></p>	<p>Communication problems between healthcare professionals and patients (Read, 2000), particularly for those with a profound learning disability as many do not speak nor articulate (Brown et al, 2002; McEnhill, 2004; Mencap, 2001).</p> <p>The need for appropriate disclosure and information sharing between agencies and professionals about care for the dying (Tuffrey-Wijne et al, 2005; GOLD, 2008). Some</p>

	nurses may lack the skills in communicating about illness (Tuffrey-Wijne et al, 2005; Foundation for People with Learning Disabilities (GOLD) 2002) and dying process. Care practitioners (LD nurses) must develop verbal and non-verbal communication skills to break bad news (Ng and Li, 2003).
<b>Death and Bereavement</b>	Care staff in residential homes may need to develop awareness about death and grief responses (Read, 2006; 2003).

## 2.4 Conclusion

What I have shown so far is the social history of care given to PPLD. It seems that little is known about the PPLD in supported living, and less so about supported dying. My literature review shows that care for dying or terminally ill PPLD has not been given the attention it deserves. It seems that this group runs the risk of being ‘invisible’ within services when they enter the dying phase. How care is provided for terminally ill PPLD remains largely unknown and areas of concern were highlighted as shown in table 2. It is therefore necessary to address how care is provided to dying or terminally ill PPLD in residential care settings. Along this line, the questions raised then are: (i) are learning disability nurses able to recognise signs and symptoms of illnesses and diseases? (ii) how much knowledge and understanding do they have about the pathophysiology of illnesses and diseases and the signs and symptoms? I believe this is a productive area for my research.

In the next chapter (chapter 3), I will examine the philosophy of hospice and palliative care. This will throw some light on how palliative care is provided in the hospice setting other than in learning disability residential care homes. I will also examine some significant social care policies for cancer care, and their effectiveness for transferring guidelines into practice in the way care is provided for terminally ill PPLD.



**Chapter 3**  
**Literature review**  
**The philosophy of hospice and palliative care and social policy**

### **3.0 Introduction**

This chapter provides a brief overview of the modern hospice movement. I also examine the significance of palliative care. In addition, a general impression of the work of specialist palliative nurses in the hospice setting will be considered as there is little information about palliative care and PPLD. I will also examine the National Service Framework (NSF) for cancer care, and its effectiveness for transferring guidelines into practice in the way care is provided for terminally ill PPLD.

### **3.1 The modern hospice movement**

The origin of the word 'hospice' derives from the Latin - 'hospitalis'. It means 'friendly - the welcome to the stranger' (Kendall, 2004, p54). Historically, a hospice has no connection with dying. It was a place that offered and welcomed travellers or pilgrims a place of rest, a place of safety and sustenance (McNamara, 2001; Manning, 1984).

The modern hospice movement developed out of dissatisfaction with the care of dying people in UK after the Second World War (Field and James, 1993). The name that is equated with the hospice movement is that of Dame Cicely Saunders who in 1967 established the first hospice in England at St Christopher's Hospice in South London (Froggatt, 1995). Dame Cicely was trained as a nurse, social worker and doctor. Her personal experience of observing patients dying in pain and patients not knowing they were dying motivated her to seek an alternative place for the terminally ill or dying. The establishment had an emphasis on patient care, as well as teaching and research.

With the changing nature and pattern of diseases and patients' needs, St Christopher's Hospice, like many other hospices, has now evolved. Hospices now also function as places of care for patients with neurological conditions such as motor neurone disease, multiple

sclerosis and AIDS/HIV (Payne et al, 2008; Field and Addington-Hall, 1999). Cancer patients continue to make up more than 95% of hospice and specialist palliative care services (DOH, 2007). In the main, hospices continue to uphold and provide palliative inpatient care units, particularly when the patient's pain and symptoms become too great (Payne et al, 2008).

Hospice services continued to develop well after St Christopher's had opened in London. Instead of providing exclusively in-patient units, the principles of hospice care could be practiced in many settings, for example, home care, day care and bereavement services. Growth and diversification in the later twentieth century saw 1,000 specialist Macmillan nurses working in palliative care in the United Kingdom and about 5,000 Marie Curie nurses providing care in the home (Payne et al, 2008). Modern hospices represent a warm and informal institutional unit (Lawton, 1998; Froggatt, 1995; Hunt, 1989; Li, 2002; Arber, 2004) for those in need of care at the end stage of life. They continue to function as a place where community specialist palliative care teams operate as well as educational and resource centres.

A literature review shows that hospices have particular expertise and resources to offer to patients and their families (Lawton, 1998; Froggatt, 1995; Hunt, 1989; Li, 2002; Arber, 2004). Lawton (1998) conducted a 10-month participant observation study in an in-patient hospice in Southern England. In her study, Lawton demonstrates the function and role of the hospice as a place where disease symptoms might be managed appropriately. This was illustrated in her case study of a patient whose cancer was in its late stages, where the symptoms could not be controlled at home. The reason for the patient's request for admission to the hospice was because the patient felt she could not get enough privacy at home to attend to her personal hygiene. Other findings included how patients and nurses work together to develop an informal caring environment. This was symbolised by nurses

not wearing uniform and the use of props such as plants and aromatic oils. However, the use of aromatic oils on the wards was for masking the 'very offensive smell' or stink, rather than for its aesthetic purposes.

Critiquing Lawton's work, Lawton shows us that a hospice is not merely a place for dying. Rather, it caters for patients when their diseases and symptoms cannot be controlled in their own homes. Lawton also shows us that an environment such as the hospice may well allow patients to maintain some sort of self-identity. I believe that Lawton's work also showed the legitimising of patients feelings of personal integrity. Thus, recognition and preservation of self -identity is an important aspect of hospice-palliative care nursing.

Froggatt (1995) in her ethnographic study within hospice settings states that hospice care embraces open awareness of death and dying. She describes nurses as "ritual specialists". This means that their work is to facilitate the dying passage for people and their families through the transition between life and death (Froggatt, 1995). Her findings also demonstrated that these nurses as "ritual specialists" have to keep a balance in order to meet the emotional demands of hospice work.

Hunt (1989) carried out a study on a group of symptom control team (SCT) nurses in the community. Hunt's study showed that nurses not wearing uniform, and being known to their patients on first name terms represented their friendliness and informality.

Li (2002) demonstrates the co-performance between nurses and patients. In her ethnographic study within three hospice settings, she found that hospice nurses performed acts of "niceness" and that patients reciprocated this performance. Li (2002) argued that this type of co-performance contributed to psychosocial care. She termed this as "symbiotic niceness".

Arber (2004), using a grounded theory approach, showed that specialist palliative care nurses have expertise in pain management. In her thesis on “pain talk”, she demonstrated how palliative care nurses construct their competence and credibility as specialist nurses in and through their talk. Her findings revealed that nurses’ expertise was achieved through inter-professional work with doctors.

These studies have shown that the hospice model of palliative care provided an alternative for dying patients. Often, an admission to a hospice is a clear sign that death is imminent, and for some, death and dying can be painful issues to talk about. What these studies have shown is that in the hospice death and dying issues are managed in an open and participatory manner, between nurses, patients and families. The studies showed that it is important to embrace good psychosocial care and relationships between patients, patients’ relatives, nurses and doctors. The studies also demonstrated that hospices can be flexible, informal and friendly, and at the same time expertise and resources are provided with their team of specialists. It is possible for dying patients to maintain their ‘dignity’ and ‘identity’ until death. Importantly, the studies showed that much of the hospice model of palliative care whether provided in a hospice or elsewhere, when appropriate, aims to achieve the best quality of end-of-life care for the patient and family. In the cancer context, the principal aim of hospice care is on caring, not curing (Kendall, 2004; McNamara, 2001; Dickenson et al 2000). This means the philosophy of the hospice movement was, and still is, concerned with normalising life, so death and dying is seen as a natural event. This is also reflected in the underpinning principles and philosophy of palliative care (NCHSPCS, 2002) which are:

- To affirm life and regard dying as a normal process
- To neither hasten or postpone death

- To provide relief from pain and other distressing symptoms
- To integrate the psychological and spiritual aspects of care
- To offer a support system to help patients live as actively as possible until death
- To offer a support system to help patients' families cope during the patient's illness and in their own bereavement

In the next section, I will examine critically the definition of palliative care.

### **3.2 Palliative care**

The National Council for Hospice and Specialist Palliative Care Services (NCHSPCS, 2002) defines palliative care as:

*“the active total care of patients whose disease is not responsive to curative treatment. The prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other other problems, physical, psychosocial and spiritual, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families”.*

There are three key issues within this definition; I will unpack and deal with each issue separately. Firstly, the issue of comfort is implicit within the definition. It implies that when a cure is not possible, the focus is to prevent and alleviate suffering. I consider this definition to mirror the specific aim of the NICE framework (2004) and the NHS end-of-life care programme (2006), contained in the Gold Standard Framework, to ensure high quality end-of-life care for all patients. So, within the context of end-of-life care, when medicine has nothing more to offer, I suggest that “comfort” for the patient becomes a priority; an essential part of the nursing goal of end-of-life care. By definition, the term “comfort” suggests an absence of conditions or elements such as pain or suffering; relief from discomfort (Kolcaba, 2003; 1991; Kolcaba and Kolcaba, 1991). Reflecting on the

definition, I regard comfort care as enabling the patient to live as comfortably as possibly, free from pain until death; a desired outcome of end-of-life care.

Kolcaba (1991) defines the concept “comfort” in four ways. Firstly, comfort as a cause of relief from discomfort. For example, when referring to nursing practice, comfort measures are initiated in response to a specific comfort need; if the measure is successful, the need is met and the outcome is comfort. Secondly, comfort is a state of ease and peaceful contentment. In this instance, nurses are agents who prevent, identify and eliminate the source of discomfort before the patient experiences discomfort. Third, comfort is relief from discomfort. This refers to a state of comfort, which may be partial or temporary. Fourth, comfort is whatever makes life easy or comfortable. Based on the four meanings, the consequences of comfort is to ultimately relieve suffering. Thus, the term comfort is defined in terms of relief and relieving.

A review of the literature shows that many factors can be associated with the term “comfort” (Katz et al, 1999; Degner et al, 1991; Hamilton, 1989; Aikens, 1908) in nursing practice. Katz et al (1999) investigated the care of dying residents in residential, nursing and dual-registered homes for older people in England. Information about caring for dying residents was collected from a number of people. They included care assistants, home managers, residents, relatives, GPs, community nurses and specialist palliative care nurses. Findings presented from the qualitative data showed that the home managers described comfort to mean pain relief and symptom control. For example, they spoke about preventing pressure sores: ‘making sure that they (the residents) are looked after properly and they are comfortable and not in pain’ (Katz et al 1999: 62). Views from other participants were not clearly identified or explained. The study revealed that the home managers from nursing and dual registered homes were dissatisfied with the medical management of pain and symptoms in dying residents. In this study, the findings showed

that the home managers were dependent on GPs to provide pain control. It is not clear if the home managers were all qualified nurses or whether they had knowledge and skills about pain and symptom control. However, what this study has shown was that comfort is associated with relief from physical discomfort, that is, pain and symptom control.

Degner et al (1991), in their qualitative study identified comfort care to denote pain control. This was a Canadian study conducted with a group of palliative care nurses and nurse educators using a semi-structured interview guide. The study found two circumstances in which the patient's physical comfort could be compromised. Firstly, when a nurse avoided the patient and as a result neglected the physical needs of the patient. Secondly, comfort is compromised when a nurse provided inadequate symptom management due to a poor knowledge base. Another interesting outcome in this study was the fact that the need to provide adequate physical comfort for the patient was taken for granted by practicing palliative care nurses. What this study shows was that a lack of knowledge would contribute to poor management of patients' physical symptoms. It also shows that knowledge must be maintained and upheld by all those caring for dying patients regardless of nursing status. This means palliative care nurses, supposedly seen as experts in care for the dying, must keep themselves updated in their approach to caring for their patients.

A study by Hamilton (1989) using interviews revealed several factors are considered necessary to achieve "comfort" care. Her findings showed patients identified three areas of 'comfort' (i) physical comfort, (ii) psycho-spiritual comfort and (iii) socio-cultural comfort. (i) Physical comfort means relief from pain. Here, the concept comfort encompassed all the physiological effects of medical conditions; the disease process. To relief discomfort, any abnormalities must be treated to ease and maintain physical comfort. Some examples are ensuring fluid balance, stable and normal blood chemistry and



adequate oxygen saturation. Physical comfort also included good positioning in well-fitting furniture, sitting correctly and a feeling of being independent. (ii) Psycho-spiritual comfort refers to a combination of mental, emotional and spiritual components of self. They included having faith in God, being independent, being relaxed, being informed and feeling useful. (iii) Socio-cultural comfort refers to nurses' ability to make patients comfortable. Providing friendliness, caring, approachable staff and continuity of care are some of the examples that were shown to contribute to achieving social comfort.

A much earlier study by Aikens (1908) described "comfort" care to include the presence of a nurse, in particular the nurse who has had close contact with the patient. These nurses were perceived to have time to attend to the "little things" or patient's details. What this means is that a nurse who knows the patient would be able to make the patient comfortable. Other elements that helped to create "comfort" (some of which would not be used today) included the use of bed cradles, sand bags for positioning limbs, alcohol rubs, adjusting bedcovers, and positioning pillows.

So far, studies of "comfort" have demonstrated that the defining criteria for the meaning are about relief and ease of discomfort such as physical discomfort; an exception is Hamilton's study. In Hamilton's study, comfort was identified as including other care aspects such as psycho-spiritual comfort and socio-cultural comfort. Other theorists that highlighted "comfort" as an important aspect of nursing care included Maslow (1970), Florence Nightingale (1970) and Saunders (1963).

In Maslow's (1970) hierarchy of needs, "comfort" care is an essential nursing component; Maslow's hierarchy of needs is a humanistic-psychological model, developed in 1943. The model looks at what affects the person as a whole, for example, their environment, and

social setting, thus an essential nursing component for PPLD. This means each individual is a unique being with his or her unique circumstances and needs. An interpretation of Maslow's hierarchy of needs is represented as a pyramid with its five stages arranged in hierarchical order. The five stages are: (i) biological and physiological needs, (ii) safety needs (iii) belongingness and love needs (iv) esteem needs and (v) self-actualisation needs. The model shows that needs at the bottom of the pyramid are the most basic and urgent. Maslow perceived some of the basic and fundamental needs to include physical or physiological needs, such as nutrition, elimination, rest, oxygen or air, relief from pain, and prevention of infections. Psychological or emotional needs such as safety needs are considered equally relevant. I regard the first three stages to form the basis of “comfort” care for PPLD. Thus, Maslow’s theory remains valid and relevant for nursing care of the terminally ill PPLD.

Florence Nightingale (1970) had a similar nursing viewpoint about comfort care for the dying patient. She wrote in her book “Notes on Nursing: what it is, and what it is not” that comforting the sick was a primary component of nursing. She defines comfort activity to include proper use of fresh air, light, warmth, cleanliness and care in the administration of diet.

Dame Cicely Saunders was known for her humanistic approach to care for dying patients. Her main goal was to prevent and to ease the suffering of terminally ill patients with intractable pain due to cancer (Clark and Seymour, 1999). In Saunders’ early writings (1963; 1978; 1983), she defined the concept of “total pain” as the suffering that encompasses all of a person's physical, psychological, social and spiritual elements. Saunders (1963) says if the patient’s physical symptoms are alleviated, then mental pain is often lifted also. In my view, “total pain” covers a range of signs and symptoms. For example, most patients nearing the end of life suffer from fatigue, breathing difficulties or

skin irritations, develop digestive problems and are more prone to temperature sensitivity (Payne et al, 2008).

Overall, on reflection, the term “comfort” is highly significant in the theories of Maslow, Nightingale and Saunders. Here the term could be understood to mean care that is ‘person-centred’ or ‘individualised’ (Sheldon, 1997). A patient diagnosed with a terminal illness will no doubt suffer from physical discomfort, but suffering as it relates to the cancer experience goes beyond the “physical”. Stanley (2000) describes suffering as the perception of impending destruction that extends beyond the physical. Reflecting on this statement, I argue that “comfort” care should include not just a comforting environment or comfortable measures to meet the physical needs of the patients, but psycho-spiritual, and social needs of the patients as advocated in the end-of-life care programme. Importantly, Aikens (1908) points out that the presence of the nurse relates to someone who has close contact with the patient and is able to attend to the “little things” or patient’s details. Base on Aiken’s definition, I argue that the notion of the “presence of a nurse” embraces patients’ feelings. This means the presence of the nurse in some way provides comfort and peacefulness; diminishes anxiety, loneliness and vulnerability especially among patients who have no spoken words such as PPLD. The presence of a nurse is therefore reassuring for dying patients. Patients with cancer recognise and value nursing presence across the illness continuum (Stanley, 2000). Comfort is therefore multidimensional. This leads me to surmise that the terms palliative care and ‘comfort’ care are synonymous. ‘Comfort’ is an inherent part of palliative care practice.

As yet, there are no known research studies on “comfort” care of terminally ill PPLD. But what has been established is that several reports have shown that palliative care services have not met the needs of people with learning disabilities (Jones et al, 2007; Cardy, 2005; Read, 2005; Todd 2005; Tuffrey-Wijne, 2002). The focus of these reports was on people

with learning disability, generally. PPLD were not the focus of these studies. If this is the case, does this mean “comfort” nursing care for terminally ill PPLD has been over-looked. It seems that the art of “comfort” nursing care does not appear to receive the attention it deserves in learning disability practice, specifically PPLD. Could it be because some of it is intangible and undemonstratable in clinical practice? Or is “comfort” nursing care for PPLD in residential care settings not worth mentioning? Or does the lack of research work in this population group suggest that perhaps uncertainties exist about the types of care given? Surely, there is a need to explain and to account for how care is given to terminally ill PPLD in residential care homes. For example, what strategies or methods do learning disability nurses use to ease or relieve discomfort experienced by terminally ill PPLD in residential care homes? Until recently, residential homes were places where the nursing care activity was normally directed towards the promotion of ordinary living - a principle of social role valorisation (Wolfensberger, 1983; Bank-Mikkelsen, 1969; Nirje, 1969). Now these places are an increasingly important place of death for the majority of PPLD (Gates, 2007). I put forward my view that dying within a caring community such as in a residential home has become a crucial aspect for organising care. I believe “comfort” nursing care is an area worthy of research, and that my study involving how learning disability nurses care for terminally ill PPLD will be a positive contribution to the research and literature discussed so far.

The second issue that relates to the definition is about early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. This is evident in the work of doctors or specialist nurses who use their specialist skills (Arber, 2004; Li, 2002; Lawton, 1998; Froggatt, 1995; Hunt, 1989). Many learning disability nurses working in learning disability residential care homes have not had the experience of caring for a dying person. In residential care homes, the promotion of ordinary living is the norm. The work of learning disability nurses is largely concentrated

on promoting and providing comfortable nursing care and interventions (Gates, 2007; Sines et al, 2002). In other words, the focus and role of learning disability nurses is supporting PPLD to live well as opposed to supporting patients to die well. Early identification and impeccable assessment of the terminally ill may be an anomaly for some learning disability nurses.

Some studies have shown that the detection and management of pain in people with learning disabilities is lacking (Todd, 2005; National Patient Safety Agency 2004; Read, 1998). Saunders' work on the "total pain" concept relates to the non-disabled population. I wonder how applicable the "total pain" concept is to PPLD. Often, a person who is profoundly disabled has no spoken words to express or describe physical pain or mental distress (National Patient Safety Agency 2004). They have little understanding about the concept of pain (National Patient Safety Agency 2004). Recognition of signs and symptoms of pain or discomfort are important issues for those caring for dying or terminally ill PPLD. Yet, understanding pain and suffering in terminally ill PPLD is still an unexplored area in residential care homes. One could speculate that the "total pain" concept is perhaps considered more relevant to the non-disabled population. I believe this is an area worthy of research in the field of PPLD.

Thirdly, palliative care is essentially multidisciplinary. Much of the philosophy and knowledge of palliative care is about prevention and management of pain and other distressing symptoms. A multidisciplinary team-working approach is therefore necessary. It would be unrealistic to expect one profession or individual to have the skills or ability to carry out the necessary assessment or interventions. Learning disability nurses working in residential homes often care for several other patients at the same time in one unit. Specialist resources and support are highly significant particularly if learning disability nurses are not well equipped to care for terminally ill or dying individuals in residential

care homes. Collaborative teamwork, reflected in the Gold Standards Framework ([www.goldstandardsframework.nhs.uk](http://www.goldstandardsframework.nhs.uk); 2009), the National Preferred Priorities for Care Review (2007) and the Liverpool Care Pathway (Ellershaw and Wilkinson, 2003) all show that support is a necessity for those caring for the dying patient. The Gold Standards Framework was started by a Macmillan GP facilitator in 2001. The aim is to improve care provision through team working for dying patients. The Liverpool Care Pathway was jointly developed by the Marie Curie Hospice Liverpool and the Royal Liverpool University Hospital eight years ago as a tool to enhance education programmes for care of the dying (Ellershaw and Wilkinson, 2003). To date, little has been written about collaborative work between learning disability nurses and specialist teams caring for terminally ill PPLD. Evidence suggests that terminally ill PPLD are not receiving the attention due to them (UK Learning Disability Consultant Network, 2006; Brown et al 2002; McEnhill, 2004; Disability Rights Commission 2006; Mencap 2004).

Several writers share the view that there is a lack of equity and parity of palliative care services for PPLD (McEnhill, 2004; Ahmed et al, 2004; Brown et al 2002). There is the perception that palliative care services are for cancer patients only. This shows that there is still a misunderstanding about who or which specialist teams patients ought to be referred to. The inaccessibility of services proves that collaborative work may not be happening in learning disability nursing practice. More to the point, why are terminally PPLD not offered the same palliative care services as the rest of the population? A possible reason may be that this group of people is not high on the agenda for scientific attention from the public and/ or funding bodies. Another argument put forward is that there is the perception that there is resistance from some professionals to involve palliative care specialists for this group of patients (Ahmed et al, 2004). Nevertheless, why this is so has not been explained. I feel that there are missed opportunities between learning disability nurses and specialist palliative teams to work collaboratively. What's more, I feel that perhaps there is a

tendency to give priority and to promote specialist palliative teams in cancer care work within the general population. In addition, based on my personal experience and observations during my research work, terminally ill PPLD who needed specific intervention are generally not hospitalised. This is contrary to an article (Bracegirdle, 2010) which states that patients suffering from terminal illness needing treatment are admitted to hospital for treatment.

In the next section, I shall explore the implementation of social policy and its application to care for terminally ill PPLD in residential care settings.

### **3.3 Social policy**

To date, several government policies such as The National Institute for Health and Clinical Excellence (NICE, 2004), The NHS Cancer Plan and the New NHS (DOH, 2004) and the NHS End of Life Care Program (<http://www.endoflifecare.nhs.uk;2006>) have emphasised the need to respond to patients' end-of-life care needs. The aims of these social policies can be traced back to the Calman Hine Report (A Policy Framework for Commissioning Cancer Services, DOH, 1995c). The Calman Hine Committee was set up to outline the direction in which cancer services in England and Wales should be developed. This was at the time when the overall prevalence of cancer and other terminal diseases was rising (DOH, 1995c). One of the fundamental aims of the Calman Hine Report (DOH, 1995c) was to create a network of care in England and Wales, which will enable a patient to access a team of professional carers from differing disciplines.

The National Institute for Health and Clinical Excellence is an independent organisation responsible for providing guidance on health technologies and on clinical practice in England and Wales (NICE, 2004). NICE's task is to reduce inequalities in healthcare provision brought about by local variations in prescribing practice, sometimes referred to

as the postcode lottery. It also aims to reduce inadequacies in clinical practice as well as to provide faster access to treatment.

The NHS Cancer Plan and the New NHS (DOH, 2004; DOH, 2000) provides a comprehensive strategy to improve cancer services. The aims of the NHS Cancer Plan were to:

- ensure better prevention and detection of cancer
- ensure people receive the right care and treatment for cancer
- tackle inequalities in health and research
- invest in planning and co-ordinating the drive on cancer research

Reflecting on the aims of NICE (2004) and the NHS Cancer Plan and the New NHS (DOH, 2004; DOH, 2000), I do not doubt the principles that govern the implementation of the policy. These are important documents to ensure that first class services are given to all patients. The emphasis is on the word “all”. Does “all” imply and include PPLD? Studies already show that this has not been the case. PPLD are being overlooked (Brown et al 2002; McEnhill, 2004). Moreover, numerous governmental policies, such as “The NHS Cancer Plan and the New NHS” (DOH, 2004) and “The Calman-Hine Report” (DOH,1995c) appear not to take into consideration PPLD; rather these reports set out the agenda for palliative care for adults with severe mental health problems and the population at large. However, all these documents clearly indicate that the development of cancer services should be patient-centred, high quality care should be made accessible to all patients wherever they live, including pre-symptomatic screening, initial diagnosis through to care and follow-up on death and bereavement (DOH, 1995c). These policies also recognise that good communication is important between professionals and their clients.



So far, these policies/ reports are generic in nature. In fact, little attention is given to addressing those PPLD who suffer from a life-threatening illness. By this, I mean there is no clear guide about the way people with PPLD are provided for. It is worth remembering that when diagnosed with a life limiting and threatening illness, the symptoms of the disease in PPLD are no different from those in the normal, non-disabled patient. In Addington-Hall's executive summary report, she speaks of 'the [patient's] right to terminal care, to have their physical symptoms relieved and to receive appropriate psychological and spiritual support' (Addington-Hall, 2000). Yet, PPLD did not appear to get a mention in any of these documents.

It is therefore questionable whether access to high quality healthcare services is fairly implemented. PPLD are considerably at a disadvantage, specifically in relation to screening services and palliative care services (Foundation for People with Learning Disabilities, 2002; Brown et al 2002; McEnhill, 2004). It has been reported that the uptake rates for breast cancer and cervical screening are especially poor for people with learning disabilities, generally (Foundation for People with Learning Disabilities, 2002; McConkey and Truesdale, 2000). It was reported in one health authority that out of 389 women with learning disabilities aged between 20-64 years who were eligible for cervical cancer screening, only 49, that is, 13% of these women were recorded as having the test in the previous five years (Stein and Allen, 1999). It was not clear how many other health authorities actually provided adults with profound learning disabilities any screening services for life threatening illness. It seems that the uptake of screening services for PPLD is unknown. PPLD are unlikely to fully participate, unless through an advocate. Several studies concur with my observations that it is difficult for this group of people to access services due to their physical and cognitive limitations (Stancliffe et al 1999; Coombes et al 2001). So, although there is a generic National Service Framework for Cancer Care

which serves every citizen in England, it is questionable whether it serves PPLD. In the cancer context, I wonder if screening services could be improved for PPLD.

The principle encompassed within the White Paper-Valuing People (DOH 2001a) fits in with the idea that PPLD have control and choice in exercising their rights. Given that PPLD simply are not able to communicate, it is likely that they have little influence to challenge government social and health policy. This view was supported in Persaud's (2006: 71) writings where she points out: "government health policy has traditionally excluded learning-disabled people from mainstream services". The aim to ensure people receive equal treatment and the right to care and treatment for cancer are contentious issues for PPLD. If policy makers are to achieve the stated objectives of non-exclusion as laid out in the report, "Valuing People" (DOH, 2001a), consideration must be given to provide a knowledgeable and skilled workforce to care for PPLD who have a terminal illness.

Evidence suggests that there were concerns about the response of NHS mainstream healthcare services for people with severe learning disabilities (Mencap, 2004; Mencap 2007a, 2007b). This claim led to an independent inquiry, under the chairmanship of Sir Jonathan Michael in July 2008 (Michael 2008). His report found that there was evidence of good practice, but there were dreadful examples of discrimination, abuse and neglect across the range of health services in England. An example was highlighted in the case of a severely disabled person, named "Emma", who had a 50% chance of survival from cancer with treatment. "Emma" was not given the treatment that she was entitled to because healthcare professionals in the acute hospital were worried it would be difficult to treat her because of her learning disability and therefore she would not co-operate with treatment. This case suggests that it is possible that accessibility to

services is no better or easier for terminally ill PPLD. The issue about treatment and care meted out to terminally ill PPLD is far from over. The focus of most reports (Mencap, 2004; Mencap, 2007a, 2007b; Michael Report, 2008) has been on people with severe, moderate and mild learning disabilities. I believe that the Mental Capacity Act must be used to support people with PPLD, given that this group of people have great difficulty communicating. I believe the lived experience of PPLD is an area worthy of further research.

The NHS end-of-life care programme, not unlike The NHS Cancer Plan and the New NHS (DOH, 2004), is an overall strategy to improve end-of-life care for all patients, irrespective of their diagnosis. The programme also considers the issue of preferred priorities for care and place of death (The Preferred Priorities for Care National Review Team Document, 2007). This initiative recognises that those wishing to die at home should be provided a high quality end-of-life care. For this, the programme supports the use of the Liverpool Care Pathway (LCP) to deliver a “gold standard of care” (Gold Standards Framework) (GSF) ([www.goldstandardsframework.nhs.uk](http://www.goldstandardsframework.nhs.uk)) (2009) for all people nearing the end of life. The aim and design of the LCP promotes care that is of a high standard. It includes outlining the expected and realistic course of a patient’s care, to ensure a multidisciplinary approach to care is acted upon. A fundamental element of practice is to support the person who is dying, enabling him or her to die pain free, both physically and psychologically.

As yet, little has been written about the implementation of the LCP for terminally ill or dying PPLD in residential care settings. The only known programme is the project – “Growing Older with Learning Disabilities” (GOLD) (Foundation for People with Learning Disabilities, 2002) that shows some commitment in recognising and acknowledging how best to facilitate a comforting end of life for people with profound learning disabilities. I believe that policy makers as well as implementors need to be

practical and realistic when drawing up policy for PPLD. They need to recognise that a “one size fits all” philosophy is not realistic for PPLD.

The culture of learning disability nursing and practice is in the community (DOH, 2001a). This means using mainstream or primary health care services. There is evidence that PPLD do not use primary care services as much as would be expected (DOH, 2001). Evidence also suggests that some of these individuals still continue to have difficulty accessing primary care services (Michael Report, 2008; Todd, 2005; DOH, 2001; DOH, 1998; Stanley and Ng, 1998). Even with the implementation of the Human Rights Act of 1998 (OPSI, 1998) and the Disability Discrimination Act of 1995 (DOH, 1995b), PPLD are still discriminated against in terms of service provision such as the inaccessibility of screening services (Mencap, 1999; Pearson, 1998; Ganesh, et al, 1994; Lindsey, et al, 1993; Wilson and Haire, 1990). Governmental policies do not appear to be explicitly clear in addressing terminal care and support for PPLD, their families and carers. These policies are generic in nature and there is no clear guide about the way the needs of PPLD are provided for.

Because of communication difficulties experienced by PPLD, I feel that learning disability nurses need to find a voice within the strategic planning of palliative care to ensure high quality care is delivered to this group of patients with end-stage disease. The document “Valuing People Now”, written by Professor Jim Mansell (DOH, 2009) sets out the key issues for the NHS. The aims of this report are to ensure a reduction of health inequalities and to ensure high-quality evidence-based specialist health services are made available to all. Yet, “Valuing People Now” has not explicitly made clear how the needs of terminally ill PPLD are to be met. Perhaps policy makers may need to recognise that this group of people, that is, terminally ill PPLD have multiple health needs.

I therefore argue that the lack of specific care for terminally ill PPLD may be an expression of discrimination towards them. Here, the implication is that the needs of terminally ill PPLD are considered not important in comparison to those of non-disabled patients. It seems PPLD are considered a less worthy recipient of palliative care and palliative care services. Several early reports revealed that nurses do not have the expertise to care for these patients (see Chapter 2) (Li and Ng, 2008; Todd, 2005; Black and Hyde, 2004; Ng and Li, 2003; Lindop and Read, 2000); Bycroft, 1994). It appears that death and dying is an area of expertise that is not well covered within the learning disability nursing curriculum. Learning disability nurses may need support and training to understand the complexity of looking after dying or terminally ill patients in residential care homes. After all, knowledge and skills in palliative care are not the focus of the learning disability nursing curriculum.

### **3.4 Conclusion**

In concluding this chapter, I have shown three areas of concern pertaining to terminally ill PPLD. Firstly, terminally ill PPLD may be discriminated against within “normal” arenas of care, for example, the offer of basic screening (Mencap, 1999; Pearson, 1998; Ganesh, et al, 1994; Lindsey, et al, 1993; Wilson and Haire, 1990). Secondly, this discrimination is even more apparent within the arena of providing specialist care and support. Third, there is less care or expertise offered when the need for care is more extreme among terminally ill PPLD. Overall, it seems that PPLD are falling through the net in the NHS in terms of receiving specialist palliative care. The aims contained in the NSFs, and within social policy must not be seen simply as “paper exercise”. Several reports have already shown that deaths from cancers (Hollins, et al 1998; Cooke, 1997) continue to rise, in particular, deaths from gastro-intestinal tract (Cooke, 1997) and colorectal cancers among PPLD (Black and Hyde, 2004). For these reasons, it is essential that specialist palliative care teams and resources are easily reached. This is to ensure that the period before death is as

comfortable as possible. This means wherever a patient lives, he or she would be certain that the prescribed treatment and care given is of a uniformly high standard. This means nurses in learning disability residential homes caring for terminally ill PPLD need to have education and training in the principles and practice of palliative care. In order to address this issue, I will examine the learning disability nursing curriculum in the next chapter (Chapter 4).

**Chapter 4**  
**Literature review**  
**Learning disability nursing, education and training**

## **4.0 Introduction**

The aim of this chapter is to review the literature on learning disability nursing and nurse education and training. Section 4.1 starts with a brief discussion of the history of learning disability nursing and how the role of the learning disability nurse has evolved in response to policies. I then discuss learning disability nursing as a discipline with characteristics of a competent profession. Benner's (1984) conceptual framework will be explored and discussed in relation to the concept of a profession. This is followed by an exploration of the nature of learning disability nurse education and practice, including what preparation learning disability nurses receive in their training to care for terminally ill PPLD in residential care homes. The focus will be on the student nurses' programme based on the 1974 to 1985<sup>6</sup> syllabus and the pupil nurses' programme, based on the 1982 to 1985<sup>7</sup> syllabus. I attempt to unpack what preparation learning disability nurses received to help them to care for terminally ill PPLD, using Carper's (1978) conceptual framework of the 'four patterns of knowing'.

### **4.1 What is learning disability nursing?**

The general history of learning disability nursing is sparse. Historically, learning disability nursing was about caring for a group of people categorised as 'mentally defective' (Mitchell, 1998), in large long stay hospitals/ institutions or asylums. The mentally defectives were deemed to not require nursing care, but to be shown compassion, kindness and understanding (Northway et al 2006). At the time, professionals such as learning disability nurses played an important role in caring for the health and welfare of the mentally defectives (Mitchell, 2001; Alaszewski, 1983). The role of the learning disability nurse was to meet the health needs of his or her patient. They provided basic day-to-day

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<sup>6</sup> The majority of participants (RNMS/RNMH) in this study were trained during this period.

<sup>7</sup> One participant (EN) in this study received her nurse training during this period.



care, supervised, supported and helped their patients with activities of daily living (Alaszewski, 1983). These activities were considered necessary in the care of an ordinary patient in a hospital. Essentially, these were also attributes of Nightingale's (1970) nursing and caring values.

Abel-Smith (1960) argues that historically anyone involved in care work could call himself or herself a nurse. Yet, learning disability nurses were not accorded the status "nurse". Instead, the title "keeper", then "attendant" was given (Mitchell, 1998; Alaszewski, 1983). Some writers describe the long and often difficult campaign for learning disability nursing to be recognised, which the GNC eventually agreed to in 1920 (Mitchell, 1998; Alaszewski, 1983). At the time, the nursing staff recruited to work with the mentally defective were considered ignorant, heavy-handed disciplinarians who were unemployable elsewhere (Dingwall, et al, 1988). Perhaps this was the reason why the then General Nursing Council (GNC) had reservations about taking on board the registering of this group of workers as nurses. It seems then that the issues related to the registration of learning disability nursing as a profession were due to the "characters" employed at the time - that is, unintelligent staff, and the lack of capacity to claim identifiable skills. Some argue that the positioning of learning disability nursing as a second-class profession (Mitchell, 1998; 2001; Craft, Bicknell & Hollins, 1985) continued, even after it was accepted into the nursing profession. Literature shows that learning disability nursing could not be recognised as a branch of the nursing profession by the General Nursing Council, because there was no need for a specialty of nursing for the mentally defective (Mitchell, 1998; 2001; Craft, Bicknell & Hollins, 1985). The question raised here is: is learning disability nursing a "profession" or "occupation"?

#### **4.1.1 Learning disability nursing - a “profession” or “occupation”?**

The campaign for learning disability nursing to be considered a “profession” has never been far from the minds of those who work in this field of nursing. The term “profession” refers to an occupation, or a line of work that normally involves the application of specialised knowledge of a subject. In addition, it implies academic training, formal qualifications and membership of a professional or regulatory body (Scambler, 2005). The term “profession” derives from the Latin: "to swear (an oath)". The oath referred chiefly to three properties: standards of conduct, performance and adherence to ethical standards. In nursing, all of these three must also be practiced for the benefit of the client/patient. It is the requirement of every nurse to work competently and professionally, the emphasis being on accountability and fitness for practice, thus embracing the professional codes and regulation (NMC, 2008).

Several writers argue that in any definition of “profession”, the key factor is the extent or degree of “knowledge” (Torstendahl, 1990). This notion is also supported by a well known philosopher - Alfred Schutz (1966). Schutz (1966) says that knowledge has various degrees of clarity, distinctiveness, precision, and familiarity. One can be an ‘expert’ in one’s field, and a “layman” in many others.

Meerabeau (2001) points out that the process for attaining professionalism is not straightforward. Meerabeau (2001) says that nursing still occupies a marginal place in higher education in England for many reasons, one of these reasons being that nursing is still a “new” academic discipline situated within the academic world of higher education.

Traditionally, the preparation of learning disability nurses was carried out within a school of nursing based in large hospital for the mentally handicapped (Mitchell, 1998;

Alaszewski et al, 2000; Alaszewski et al, 2001). All nursing schools were located in the NHS hospitals. The co-existence between schools of nursing and the hospitals with their emphasis on an apprenticeship approach to nurse education can be traced back to the time of Florence Nightingale (Roxburgh et al, 2008). Most of the learning was gained from practice settings on the wards within the hospital. It was also a form of paid vocation for student nurses, who learnt their “trade” under the close supervision of an expert practitioner and counted in the nurse staffing rosters. They were an important part of the workforce for care delivery on the wards within the hospitals. This system of training also functioned to socialise these nurses into the role of a hospital carer / worker and to instill in them nursing's value systems (Mitchell, 1998).

The training syllabus was designed to equip learning disability nurses to care and assist their patients to learn life skills such as occupational therapy, crafts training and industrial therapy (Mitchell, 1998; Craft, Bicknell & Hollins, 1985). These aspects of caring would not necessarily require high powered skills or theoretical knowledge input. The system of training was based on conformity, service and hard work. It provided a ready supply of skilled, efficient, inexpensive and loyal ‘hands-on’ workers and continued to do so into the early part of 1970s.

The perception that learning disability nursing was not considered a “profession” was highlighted by a group of nurses in a study on the role of the learning disability nurse and learning disability nursing (Alaszewski, 2001). This revealed that learning disability nurses described themselves as the poor relation or the Cinderella of the nursing profession, felt they did not quite fit in with the image of a profession and felt undervalued. This finding raises important questions. For example, firstly, why the lack of confidence in valuing one’s profession? Perhaps one of the dilemmas for learning disability nurses in developing an image of a profession is the nature of theoretical knowledge. Accordingly, the

construction of a 'profession' is dependent on certain characteristics. The following are some of the essential characteristics of a "profession" (RCN, 2003):

- A unique body of knowledge - the assumption that the individual person or professional has extensive theoretical knowledge and possesses skills based on that knowledge that they are able to apply in practice.
- Licensed, professional association: this refers to a professional, organised body which would enhance the status of their members and have carefully controlled entrance requirements.
- Testing of competence: admission to a professional body will require the person to pass prescribed examinations based on integrated theory-practice knowledge.
- Extensive period of education: this refers to a period of study at a higher level at a university.
- A strong service ideal - this refers to the services rendered in the interest of the patient [or public], hence the well-being of the patient is of primary importance.
- Code of professional conduct or ethics: this refers to the ability to exercise autonomy and control in their care of patients, guided by the ethical codes and frameworks, and to be able to justify decisions and be accountable for one's actions.

Basically, in considering these characteristics, I argue that learning disability nursing has the hallmark of a profession. Gates (2009) says that learning disability nursing is unique and is one of the pure forms of nursing. The reason given is that learning disability nurses work with a range of people with learning disabilities, from birth through to death (Gates, 2009). Like all professions, learning disability nurses are required to observe and adhere to the code of ethics and the standards of performance. They are required to renew their licence annually to practice in specific areas in accordance with their expertise. In being granted the licence to practice, the learning disability nurse must be able to demonstrate

that he or she has appropriate knowledge and skills and the ability to perform his or her role. One such system to ensure that the nurse can demonstrate the ability to perform his or her task is through professional education. This means the learning disability nurse is expected to develop and refine his or her knowledge as long as he or she continues to practice. In this sense, a key characteristic of a profession is its emphasis on educational preparation, expertise and skills.

Learning disability nurses do possess specialist skills including communication, health education, health assessment, promotion and facilitation, behavioural change, advocacy and service coordination (Gates, 2007). Learning disability nurses skills also centre on maintaining a home-like environment with its emphasis on the concept of “social role valorisation” (see also chapter 2) that views PPLD as equal citizens (Jukes, 2009; O’Brien and Tyne, 1981). A learning disability nurse, regardless of his or her status, is expected to have relevant knowledge and understanding that will allow him or her to achieve and work competently. To this end, the emphasis of training and educational courses is to ensure that the workforce has the required “expertise” reflecting the image and role of a profession. So, does the profile of the learning disability nurse’s role fit the image of a profession? In the next section, I will examine the role of the learning disability nurse.

#### **4.1.2 What do learning disability nurses do?**

In the 1970 General the Nursing Council (GNC, 1970) booklet, the function of the learning disability nurse was to “skillfully assist the individual patient and his family, whatever handicap, in the acquisition, development, and maintenance of those skills that, given the necessary ability, would be performed unaided, and to do this in such a way as to enable independence to be gained as rapidly and fully as possible, in an environment that maintains a quality of life that would be acceptable to fellow citizens of the same age”. 30 years on, this statement still rings true today. Learning disability nurses still provide and

assist the individual patient and his family in an environment that maintains a quality of life. Learning disability nurses are involved in everyday tasks, helping the patient with their basic needs and attending to personal care such as dressing, undressing, washing, feeding and toileting.

The majority of learning disability nurses now undertake residential or community work since the implementation of the care in the community policy (DOH, 1991; DOH, 1990). Many learning disability nurses work within a multidisciplinary team, supporting people of all ages that have complex learning disabilities. Their main role is to support the well-being and social inclusion of PPLD by improving or maintaining their physical and mental health (DOH, 2001a). In other words, the role of the learning disability nurse is towards the direction of health surveillance, health promotion and health care. They play a key role in the detection of ill health that might compromise the health of PPLD (DOH, 2001a, DOH, 1991). Importantly, they work on a one-to-one basis, sometimes referred to as the named nurse concept, or the “key worker” system (Gates, 2009). Learning disability nurses are PPLDs’ immediate and primary carers. They often work with people from birth through to death. This means it is usually an ongoing process and often a slow one. It is not like working in a surgical ward or accident and emergency department.

The Community Care Act (DOH, 1990) officially introduced the idea of personal care being administered by unqualified nurses. However, qualified LD nurses were equally involved in doing simple tasks daily, for example, helping a patient to dress, helping to feed or helping to toilet. Consequently, both the qualified and unqualified LD nurses’ work means giving personal and intimate care. This includes help with eating and drinking, bathing, dressing, toileting, skin care, hair care and other personal care. Ultimately, their role is to ensure that their patients are comfortable in every way such as physical,

psychological (emotional) and social. On this basis, it seems that the skill involved does not require advanced clinical skills or knowledge. If any, clinical skills are almost “invisible”. Nonetheless, learning disability nursing’s strength is in meeting the total care needs of PPLD; physical, psychosocial and educational (Brown, 1994).

In 1991, the Cullen Report outlined learning disability nurses’ skills; recommending that learning disability nurses’ role be widened to include specialist roles such as in behaviour therapy, forensic care, or as counsellors with PPLD. Since then, the role of the learning disability nurse has changed. For example, it is recognised that many PPLD have multiple pathology, including life-limiting illnesses and diseases (DOH, 2001a). The future work of many learning disability nurses will increasingly focus on complex health needs (Jukes, 2009; DOH, 2008; Gates, 2009; 2007; DOH, 2001). For example, learning disability nurses are now caring for terminally ill PPLD in residential care settings. They are also likely to experience and provide care to PPLD requiring percutaneous endoscopy gastrostomy (PEG) feeding. PEG is a method of artificial feeding whereby nutritional requirements can be delivered by means of a pump connected by a tube to a plug in the patient’s abdominal wall. From my observations during my fieldwork in conducting this project, I encountered two patients on one site requiring PEG feeding. Thus, I argue that the role of the learning disability nurse will require him or her to develop and refine his or her knowledge and competence in a range of skills in order to provide quality end-of-life care for PPLD. The questions raised are (i) are learning disability nurses adequately prepared to care for terminally ill PPLD? (ii) are learning disability nurses appropriately skilled, trained and qualified in caring for terminally ill PPLD in community-based care settings? (iii) are they culturally competent to care for dying patients in community-based care settings? In the next section, I shall explore the meaning of a competent nurse in learning disability nursing.

## 4.2 Defining a competent and knowledgeable nurse

There is no precise definition of a competent nurse (Rowden et al, 2000). Most definitions include reference to appropriate knowledge and skills for a particular task. In other words, there must be appropriate balances of knowledge and skills. Additionally, a summary report (DOH, 2008) by Lord Darzi says that all nurses' titles, roles and responsibilities must reflect their title 'nurse'. The framework for defining and assessing the competence of the learning disability nurse can be found in the United Kingdom Central Council's regulation, Rule 18A (UKCC, 1999). Normally, the approach adopted to assess whether someone is competent or a professional expert is by using a system of assessments such as Bloom's taxonomy<sup>8</sup> or Benner's (1984) framework. Benner's (1984) framework maps a trajectory of competence from novice to expert<sup>9</sup>, sometimes referred to as the 'gold standard' in nursing. Table 3 shows an example of a nurse's progression, from level 1 to level 5, from novice to becoming an expert.

**Table 3- Level Descriptors adapted from the work of Benner (1984) from Kingston University's Nursing Curriculum (permission to use granted by the Dean, FHSCS, 2010)**

Level 1	Level 2	Level 3	Level 4	Level 5
Novice	Advanced Beginner	Competent Practitioner	Proficient	Expert
<b>Characteristics of Performance</b>				
Inflexible, rule - governed behaviour. Works within clearly defined guidelines and not likely to challenge ideas. Still lacking in confidence.	Demonstrates increasing confidence, but still needs prompting. Begins to develop own professional principles and judgement.	Demonstrates increasing confidence and able to apply own professional judgement and experience to make clinical judgments. Needs minimal prompting.	Demonstrates ability to make decisions based on past experiences, lets the situation guide the nurse's actions /responses.	Demonstrates rapid response based on introspection knowledge and past experiences. Demonstrates intuitive awareness.
<b>Theoretical Knowledge</b>				
Little superficial knowledge without linking it to practice.	Some knowledge of key aspects linking to/with practice.	Good background knowledge, linking to/with area of practice.	Has depth of understanding of discipline / area of practice.	Authoritative knowledge of discipline and deep tacit understanding across area of practice.

<sup>8</sup> Benjamin Bloom (1956), identified three domains of educational activities: cognitive: mental skills (*Knowledge*), affective: growth in feelings or emotional areas (*Attitude*), psychomotor: manual or physical skills (*Skills*)

<sup>9</sup> Level 1 - 3 apply to a learner (pre-registration student), but levels 4 -5 apply to a qualified nurse (post-registration nurse).



Benner (1984) contributed much of her work to understanding professional competence in acute clinical nursing. Her studies showed that the experienced nurse or the professional expert performs at different levels to a “beginner” and a “novice”. The “expert” nurse has greater knowledge, a result of his or her background of experience in clinical practice.

Benner’s framework for assessing nurses’ competency appears to be generally accepted without much criticism. I do not refute that Benner’s work helps to clarify the difference in the characteristics of performance between the novice and the professional expert nurse who performs skillfully and knowledgeably. In my view, Benner’s work has provided a good insight and description of the expert nurse, but no explicit explanation has been given as to why some nurses will not become experts. Besides, English (1993) points out that Benner does not demonstrate what actually happens to the nurse in transition, that is, the move from novice stage to expert stage. In other words, it is still not clear as to what or how the nurse is guided or enabled to become an expert. The five stages; from novice to expert, are merely merging points on a continuum. What has been demonstrated is the principle of distinction for each of the stages. Benner's study used a qualitative- narrative approach. I feel strongly there is an over use and interpretation of the narratives, that is, a disproportionate attention has been paid to narratives. Furthermore, the nurses recruited to Benner’s studies were based on peers’ or managers’ evaluations of the experienced nurse or the expert nurse. This pre-sorting by peers or managers may be unsound particularly as it might affect validity or credibility, thus a degree of difficulty generalizing the findings. Another observation made about Benner’s studies is that Benner’s work appears to accentuate excellence, success and beneficence. Benner’s studies also indicate that experienced nurses’ or the expert nurses' decisions and judgment are normally accurate and seldom flawed. The good of the patient is always the focus, yet the relative’s point of view is never put forward or expressed. The patient’s stories or versions of events are never put across. In this day and age of nursing, patients are supposedly to be the best judge about

whether a nurse is competent or not. Perhaps, it might be possible that not all experienced nurses are experts or competent.

Another point worth noting is that Benner's work (which was undertaken in the United States of America (USA)) did not pay attention to nurses or care workers who are without a nursing qualification. Today, in the UK, the proportion of health care support workers to qualified nurses employed within learning disability services is higher (see also chapter 2, section on "skill mix"). It is possible that some of these health care support workers have many years of experience and that they do perform competently in their nursing job.

There is no denying that Benner's studies provide a foundation to understand how a nurse may be viewed as competent and a professional expert. However, I remain to be convinced that all experienced nurses are 'experts' because Benner's work was conducted with nurses in acute settings where changes in the patient's physiological status were rapid, whereas learning disability nurses' work is mainly in community-based residential care settings.

Another method used to assess whether a nurse is competent and knowledgeable is the 'behavioural objectives' tool. This tool was developed by Benjamin Bloom (1956). Bloom identified three domains of activities: (i) cognitive (mental skills) - this refers to knowledge structures or 'knowing the facts'. (2) Affective (attitude) - this is concerned with values or with perception of value issues. It ranges from mere awareness, through to being able to distinguish implicit values through analysis. Basically, this concerns growth in feelings or emotional areas. (3) Psychomotor (skills) - this refers to manual or physical skills acquisition.

Bloom's taxonomy is a useful tool to assess learning disability nurses' competencies. From my experience, Bloom's taxonomy was briefly implemented; however, the effectiveness of

this tool and the associated question of assessing the competence of a learning disability nurse were under-explored. Nonetheless, in learning disability nursing, adequacy of knowledge and skill are no doubt important. The therapeutic role of a learning disability nurse cannot be described in terms of tasks or procedures, but in terms of values, attitudes, feelings, understanding and relationships. This view is also supported by Turnbull (1997) who argues that it is important that learning disability nurses deal with the physical aspects of patients' care, but more significantly, their role is about providing understanding, comfort and support for their patients. What Turnbull was referring to was that learning disability nurses' role is about valuing and caring for "people". Thus, "people" or "being things" are often more important than the "doing things" (Turnbull, 1997). For this reason, sometimes competencies or the 'doing things' are not the be all and end all because of the "value" placed on people.

There is a need to rigorously examine the educational curriculum to investigate the content, process and outcome. This leads to my next point of discussion regarding the organisation of nurse education and training of learning disability nurses. I will explore the 1970s and 1980s training syllabi, and attempt to unravel what preparation learning disability nurses received to help them to care for terminally ill PPLD. The reason for exploring the 1970s and 1980s training syllabi was because one participant involved in my research project was trained in the 1970s (Roll of Nurses [State Enrolled Nurse]) syllabus and the remaining 16 participants during the 1980s (Registered Nurse for the Mentally Handicapped).

In the next section, I will examine the relationship between theory and practice concerning the education and training of learning disability student nurses within the changing context of care delivery for terminally ill patients who are profoundly disabled. I will also briefly examine the National Vocational Qualification (NVQ) in health and social care, designed

for unqualified nurses, that is, health care support workers within the field of learning disability nursing profession.

### **4.3 Educational influences - learning disability nursing registration and NVQ in health and social care**

In the last three decades, the education and training of all nurses in this field of nursing have changed to reflect the needs of PPLD in community-based care settings. As reviewed in Chapter 2, there is evidence that PPLD experience greater health needs than the non disabled population, with many needs being unrecognised and unmet (DOH, 2001a; Mencap, 2004). This means for learning disability nurses, the ability to understand and care for a profoundly disabled person with a terminal illness is now all the more pressing.

There are no clear statistics to suggest that the number of expert or qualified learning disability nurses is on the increase. According to the document Valuing People (DOH, 2001a), it is estimated that 75% of staff working in this field of nursing are unregistered. Many learning disability nurses work as health care support workers, but may hold the National Vocational Qualification (NVQ). The NVQ in health and social care qualifications at level 2 to level 4 are a nationally recognised course, which aims to improve a healthcare support worker's skills in doing a job. The course comprises four mandatory and two optional units. A range of topics is offered. They include supporting individuals with daily living, supporting individuals to meet their domestic and individual needs, providing food and drink, helping individuals to eat and drink, supporting individuals with personal care needs, administering medication and contributing to moving and handling individuals. The design of the programme did not appear to consider the inclusion of knowledge and understanding about diseases or skills about end-of-life care.

Reflecting on this type of training course, I do not doubt the benefits and value offered to the individual health care support worker. The NVQ assessment is directly related to performance at work, therefore it is largely task-specific competence driven. At the end of the course, the health care support workers will be assessed. This means a health care support worker who holds the NVQ qualification is deemed competent in his or her nursing job.

A report by the Qualifications and Curriculum Authority in 2005 ([www.qca.org.uk](http://www.qca.org.uk)) found areas of concerns including a lack of specific occupational and assessment expertise and assessors among training service providers. It also revealed a lack of consistency concerning internal verification. What this report suggests is that the assessment method may be lacking in rigour. The lack of rigour in the assessment might imply that nurses undertaking the course may be out of their depth when caring for terminally ill PPLD. In the next section, I will examine learning disability nursing curricula.

#### **4.3.1 The 1970s syllabus**

From the late 1960s and throughout the 1970s, as attitudes towards and services for people with learning disabilities changed, so too did the preparation and training of the learning disability nurse. However, the 1970s system of nurse education and training was still largely linked to the requirements of the hospitals in the National Health Service. An example, of the training syllabus for the student nurses' training for the RNMS/RNMH (Registered Nurse for the Mentally Subnormal/ Registered Nurse for the Mentally Handicapped) qualification covered three major streams as shown in table 4.

**Table 4 - Three streams taught in the student nurses' training in the GNC 1970 syllabus.**

<i>AN INTRODUCTION TO THE STUDY OF MAN AND HIS ENVIRONMENT</i>
Human development and behaviour in the family and society
Introduction to psychological concepts
Human biology
Human behaviour in relation to illness
Psycho-physical disturbances and physical illness
<i>PRINCIPLES AND PRACTICE OF MENTAL SUBNORMAL NURSING</i>
General care of the patient
Ward administration
Nursing aspects of the training and care of the mentally subnormal
First aid and applied anatomy
Nursing procedures
<i>CONCEPTS OF MENTAL SUBNORMALITY, TRAINING AND TREATMENT OF THE MENTALLY SUBNORMAL</i>
Theory of mental subnormality
Legal and administrative aspects
Education and training of the mentally subnormal, including socialisation and rehabilitation

These three streams of learning were taught side-by-side during the three years training. This was developed, elaborated and integrated during the practical experience which ran concurrently. The course followed a pattern of study with an initial introductory block or period. Recounting my student nursing training experience, the introductory block was devoted to initiating and familiarising students in some of the basic nursing values and hospital ward routine. These included learning and understanding about nurse's etiquette and behaviour. Other subjects covered were a nurse's professional code of conduct and nursing procedures such as first aid and emergency treatment. The sessions on first aid were on how to put on a dressing or a bandage. The first aid emergency treatment consisted of how to care for a patient with a seizure.

Following the introductory block, the student nurse was expected to be out in placement for a period of twelve weeks nursing experience. Thereafter, the students would return to the school of nursing for a two-week study block. This was to consolidate what was learnt

on the wards before going out onto a different ward for another ten to twelve week placements. This pattern of study and work experience would be repeated for the next three years. The teaching and learning strategies were mostly didactic. The nursing components were delivered by a clinical teacher or nurse tutor; subjects related to genetics would be given by the hospital doctor or medical superintendent. Much of the clinical skills learning took place on the wards where the student nurse worked alongside experienced nurses on hospital wards (Alaszewski et al, 2001).

#### 4.3.2 Practical experience

The practical experience of the nurse's work in the hospital for the mentally subnormal/handicapped and in the community was supposed to be closely related to the theoretical preparation. Opportunities for experience included care of newly admitted patients, care of subnormal and or severely subnormal adults, care of subnormal and or severely subnormal children, care of physically handicapped patients or physically ill patients, night duty, school training methods, social therapy, occupational and industrial therapy training. The number of weeks in practice in each of the area ranged between four and 36 weeks, totaling 88 weeks to 120 weeks during the three year training course as indicated in table 5 below.

**Table 5 – A summary of practical experience associated with the student nurses' 1970 syllabus**

TYPE OF PRACTICAL EXPERIENCE	NUMBER OF WEEKS
Care of newly admitted patients	12
Care of subnormal and/severely subnormal adults	12
Care of subnormal and/severely subnormal children	12
Care of physically handicapped patients or physically ill patients	12
Night duty	12-36
ESN* School training methods (*educationally subnormal )	12
Social, Occupational and Industrial therapy training	12
<b>OTHER TRAINING SITUATIONS</b>	
Local authority (optional)	4-12
<b>TOTAL(minimum to maximum)</b>	88-120

During practice, the clinical nurse teacher would visit students on the wards. The main function of the visit was to ensure that the students were achieving relevant practical and clinical skills according to the “schedule” contained within the syllabus. At the end of the three years training, the student nurse would be assessed on his or her clinical competencies, with a written state final examination and a practical examination. The practical examination consisted of testing experience and knowledge of “laying up trays and trolleys”, for example, a student might be tested on setting up a tray for neurological examination of a patient. On passing both components, the student would be awarded the registration “Registered Nurse for the Mentally Subnormal” (the title was changed to Registered Nurse for the Mentally Handicapped in the latter part of the 70s) by the GNC.

For those on the pupil nurse’s programme (State Enrolled Nurse), the training was shorter, lasting two years. Their practical experiences each ranged between three and 12 weeks, totaling 79 weeks during the two year training course as indicated in table 6 below.

**Table 6 – A summary of practical experience associated with the pupil nurses’ 1970 syllabus**

TYPE OF EXPERIENCE	NUMBER OF WEEKS
<b>PRACTICAL EXPERIENCE</b>	
Care of more able patients	12
Care of less able patients (subnormal and/severely subnormal adults)	12
Care of subnormal and/severely subnormal children	12
Care of physically handicapped patients or physically ill patients	8
Care of patients with behaviour problems	8
ESN* School training methods (*educationally subnormal )	8
Social, occupational and industrial therapy training	8
General nursing	8
Community	3
<b>TOTAL</b>	79



At the end of the two years training, the pupil nurse were required to pass practical tests and a written examination, in the form of a multiple choice objective test, prior to enrolment.

### **4.3.3 Reflecting on the 1970 syllabus**

The 1970 syllabus was not without criticism; one of these criticisms was whether learning disability nurses were appropriately trained for their job. Questions were raised about whether learning disability nursing should belong to a health discipline or a social discipline. Some argued that the teaching-learning method of nurse training at the time consisted of negative features of patient care (Alaszewski et al, 2000). For example, the pattern of patient care consisted of adhering to “rigid routines” and “block treatment” of patients. “Rigid routine” means nurses learnt the routine on one ward, and with minimal adjustments, they would apply the same principles and work on all wards in the hospital. “Block treatment” refers to patient care which was determined by the ward routine. For example, patients were treated as a homogeneous group without the opportunity for personal choice such as at meal times or bath times. Activity was undertaken en masse. ‘Block treatment’ inadvertently suggested that the focus was not learning or knowing about the patients as individuals. In fact, at the centre of nurse education and training, the student nurse learnt to manage groups of patients on the wards. It seems the training strategies bore little relationship to “personalised or individualized” care.

Moreover, at this time, a number of social and political changes ([Briggs Report<sup>10</sup>] DHSS, 1971; DHSS, 1971; DHSS, 1979) proposed changes in patterns of employment and the

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<sup>10</sup> In 1970 -1972, the Briggs Committee was set up to review the training of nurses and midwives, which led, in 1976, to the formation of the Briggs Co-ordinating Committee. The work of this committee led to a new statutory framework for nursing education. The Nurses, Midwives and Health Visitors Act 1979 dissolved all statutory and non-statutory training bodies, including the GNC and Central Midwives Board. They were replaced by the United Kingdom Central Council for Nursing, Midwifery and Health Visiting, with the four National Boards for Scotland, England, Wales and Northern Ireland (Roxburgh et al, 2008.)

role of learning disability nurses. It was recognised that the existing services concerning the traditional custodial care in large hospitals were inadequate. The development of the multi professional team to provide care and services in the community based on the principles of normalisation (Wolfensberger, 1972) also meant that the education and training of the learning disability nurse were subject to scrutiny. Consequently, changes in nursing people with learning disabilities affected the direction of nurse education.

Against this background, several models were proposed: a model based on shared training between the GNC and Central Council for the Education and Training of Social Workers (CCETSW), or sole responsibility for all by the GNC, but to provide the mental handicap programme only as post-registration training for general, children's and mental health nurses; or a completely new training body; or sole responsibility given to CCETSW (DHSS, 1979: 87) based on the Certificate in Social Services (CSS). The proposed models were rejected due to major disagreements about the ways and levels of training. For instance, the models proposed would see the demise of learning disability nursing and nurses. To avert the uncertainty of the learning disability nursing workforce, the GNC had to respond, which resulted in the 1982 syllabus.

#### **4.3.4 The 1982 syllabus**

The design of the 1982 syllabus took into account the consequence of the rapid developments and changes in knowledge, attitudes and skills in the care of people with mental handicap (DHSS, 1971; DHSS, 1979). It was expected that this generation of student nurses would have the appropriate attitudes and abilities to work and care for people with a range of mental handicaps in the community.

The structure and content of the 1982 educational curriculum were underpinned by the principles of normalisation (Wolfensberger, 1972). This approach was seen to be of significant importance in the provision of services for people with mental handicap and their families (Ayer, 1997). The syllabus was designed to prepare the student nurse to work with other healthcare professionals to meet the demands implicit within the principles and philosophy of care for the mentally handicapped. Thus, the emphasis on nurse education and training was on a multidisciplinary team working in partnership, inclusion and advocacy (Sines, 1993). The training syllabus was divided into two main sections which were to be further subdivided into sub-sections as indicated in table 7.

**Table 7 - The 1982 RNMH training syllabus (ENB, 1982)**

<b>Sections 1 to 9 - Core concepts</b>	<b>Sections 10 to 19 –major areas of practical everyday care</b>
The nursing process	Developing care and training programmes
Communication – skills and methods	Maintenance of living environment
Education and mentally handicapped people	Children
The sociology of organisations	Adolescents
Normalisation and human rights	Adults
Management	The elderly person
Principles of development	People with multiple handicaps
Causation, nature and effects of mental handicap	Facilitating integration and rehabilitation into the community
Partnership with families	Maintaining optimum health
	Professional development

The first section comprised nine sub-sections termed the ‘core concepts’. The second section had ten sub-sections relating to major practical everyday nursing care activities. The contents under the core themes were to develop the student nurse’s professional knowledge and skills to register with the UKCC. It was envisaged that student nurses would learn and practice in each learning unit at the appropriate level; to expand and increase in complexity as one progressed in the course.

Based on the core concepts (sections 1-9) and units of learning in practice (sections 10-19), each college of nursing had the freedom to interpret students' learning. One such programme is indicated in table 8.

**Table 8 - An interpretation of the 1982 training syllabus for the Registered Nurse for the Mentally Handicapped in one school of nursing**

CONTENTS	
History of mental handicap care	Schedule writing
Nursing process	Normalisation
Communication skills	Mental handicap nursing
Multiple handicaps	Mental handicap-nature/causes
Makaton	Occupational therapy
Speech therapy	Physiotherapy
Ward administration	Community aspects
Principles of education	Legal aspects
Special education	Human rights
Adult education	Environment management
Training programmes	Sociology
Physical/recreational training	Psychology
Rehabilitation	Counselling/interviews and seminars
General nursing (secondment)	Human development
First aid	Professional development
Behaviour modification	Clinical teaching

At the end of the course, the student's theoretical knowledge would be assessed by means of part multiple-choice questions and part unseen written examination paper.

#### **4.3.5 Practical experience**

Practice placements consisted principally of residential care "homes" experience. These 'homes' were previously wards converted into a "home-like" environment, but contained within the old hospital wards. In this type of placement, it was envisaged that student nurses would develop skills in caring for patients in the 'home' to live a healthy life. At the end of the three year course, the student nurse would be effective in planning the nursing care, providing the nursing care and evaluating the results of the nursing care of their

patients. They would also be able to work collaboratively with other healthcare professionals. The outcome of the clinical experience would mean that the student nurse should possess nursing knowledge and have the skills of assessment, planning, implementation and evaluation. Other practical experiences included working with other professionals such as in social and further education centres, an occupational therapy department and a behavioural unit. The student nurse would also be placed in the local general/ district hospital for eight weeks. Through this type of experience it was hoped that nurses would gain some insight into care of the sick, but it transpired that not all nurses were given this experience. The majority of student nurses were placed on the medical wards, but not on a specialist ward. At every placement, the student nurses' performance or achievement would be assessed by means of a continuous assessment scheme (ENB, 1982). An example of a student nurse's practical experience is presented in table 9.

**Table 9 – A summary of practical experience associated with the 1982 mental handicap training syllabus**

<b>TYPE OF EXPERIENCE</b>	<b>NUMBER OF WEEKS</b>
<b><i>WARD EXPERIENCE</i></b>	
Care of the more able mentally handicapped	14
Care of the less able mentally handicapped	20
Care of children with mental handicap	12
Care of the mentally handicapped with behaviour problems	11
Care of physical handicap	11
Night duty	6
<b><i>THERAPY ENVIRONMENTS</i></b>	
ESN* School training methods (*educationally subnormal )	12
Social therapy, Occupational therapy and Industrial therapy training	12
<b><i>OTHER TRAINING SITUATIONS</i></b>	
General nursing	8
Community	12
<b><i>TOTAL</i></b>	118

#### **4.3.6 Reflecting on the 1982 syllabus**

The main aim of the re-organisation from the 1970s syllabus to the 1980s syllabus was to develop a knowledgeable workforce in alignment with the changing philosophy of care

embedded in the principles of normalisation (Wolfensberger, 1972) and government policies (DHSS, 1971; DHSS, 1979). This philosophy incorporates the promotion of normal living conditions and equal rights for people with mental handicap. The focus of nursing care was on the role of the nurse in the education and welfare of the mentally handicapped.

Reflecting on the list of subjects taught in the 1980s curriculum, nursing care of the dying would be considered an integral part of general nursing care of the mentally handicapped. It was not clear in what depth these particular topics were taught. Care of the dying patient was not written as a large component within the mental handicap training syllabi. Death education was therefore not high on the list of subject taught. This means then that learning about death and dying, or the pathophysiology of illnesses or diseases and the physical aspects of care may not have been considered highly significant. I argue that for a learning disability nurse to be able to care for a dying patient, a nurse's knowledge about the likely prognosis of an illness is important. By acquiring knowledge about the disease trajectory, for example, the course of decline, the nurse would be able to give the appropriate care where necessary.

For learning disability nurses, there is even more reason why it is important and necessary to understand the nature of the patient's disease and its process. In learning disability nursing, PPLD have little understanding about the concepts of illness and death. They have no awareness of the seriousness of their illness because of their substantive mental or cognitive impairment (DOH, 2001; Dodd, 1999; March 1991). A person with a profound learning disability is unable to feel their angst or anxiety, or report any symptoms. Hence, learning disability nurses' knowledge about illnesses or dying trajectories and learning to recognise patients' problems associated with the disease is highly significant.

Much literature has established that a significant number of PPLD have specific syndromes and conditions that are linked to life limiting or threatening illnesses/ diseases. Yet, theory and practice in this area is somewhat limited. Some writers (Li and Ng, 2008; Ng and Li, 2003) (see chapter 2, section 2.2) have established that learning disability nurses lack advanced knowledge and skills in nursing care for terminally ill or dying PPLD. These findings have support in a recent report - the Michael Report (2008), which states that training and education relating to care of dying patients provided to undergraduates and postgraduates across the NHS is still very limited. It seems there is still little attention given to teaching and learning about care of the dying. This highlights the issue about whether care of the dying or recognition of ill health and changing conditions feature in nurse education programmes.

Insofar as clinical nursing care is concerned, caring for patients with a terminal illness may not be considered an everyday activity for nurses within learning disability practice. Consequently, learning disability nurses may not be used to providing specific clinical care. A report on “nurse training and education in mental handicap” (Brown, 1990) revealed that learning disability student nurses themselves identified a lack of confidence in some physical areas such as first aid. The report also revealed that learning disability nurses were unhappy with the term “nurse” because of their lack of knowledge in the physical aspects of care. This then raises the following questions (i) were learning disability nurses equipped to meet the needs of terminally ill PPLD in residential care homes? (ii) did they consider that “community-based care” also meant care for patients with a terminal illness? In other words, how does the move from long stay hospitals to community-based care (residential care homes) affect the learning disability nurse’s ability to recognise disease-related illnesses?

Based on my observations, the majority of learning disability nurses' student experiences during the 1980s curriculum were outside the hospitals. Their placements consisted mainly of non-nursing or non-clinical environments, for example, a placement of 14 weeks in a home caring for the more able mentally handicapped, or 12 weeks experience in a day care centre. The lack of suitable clinical placements would prevent learning disability student nurses from becoming a reflective nurse or practitioner. A reflective nurse is someone who is able to develop his or her practice through critical analysis and the appropriate use of evidence (Alaszewski et al, 2000). Has the training programme prepared learning disability nurses adequately to fulfill their role in caring for terminally ill PPLD in community-based care settings?

Could the 1980s training syllabus with its focus on the principles of normalisation and on working in community settings inadvertently place learning disability nurses at a disadvantage concerning care of terminally ill PPLD? For example, issues relating to death and dying may not arise so frequently because of the nature of learning disability practice placements, outside the hospital. Non-nursing environments offer few opportunities in care for dying or terminally ill patients. Several studies found learning disability nurses to lack confidence in this type of work due to a lack of preparation in knowledge and skills relating to death and dying (Tuffrey-Wijne et al, 2010; Bradshaw and Merriman, 2008; Li and Ng, 2008; Ng and Li, 2003; Carlisle, 1997). Furthermore, the focus of post-registration training during this period was more towards management of resources, leadership and risk assessment, to name a few. It seems then that advanced nursing knowledge and skills would not have covered issues relating to death and dying. The implication is whether community-based care models produce appropriate attitudes and aptitude in nurses caring for terminally ill/dying PPLD.



Donald Schon (1930-1997) a philosopher, made a remarkable contribution to our understanding of the theory and practice of learning. Schon's (1983) model provides an understanding concerning how in a profession such as nursing, knowledge is derived from empirical science that is based on facts and or observations. This means that learning disability nurses must be credible in the way they practice. For example, in learning disability nursing, recognition of changed behaviour in PPLD cannot be learnt from a nursing textbook. Understanding about a patient's behavioural pattern or physical characteristics can only be gained from experience or practical situations involving observations, "reflection-in-action" and "reflection-on-action" (Schon, 1983). The ability to compare and make qualitative distinctions about a patient's behavioural pattern can only come from experience of clinical variations (Benner, 1984).

#### **4.4 Fit for purpose and practice?**

Nurse education and training programmes are designed to provide nurses with relevant and appropriate knowledge and skills. Education and training programmes are also aimed at developing the competencies of nurses in a work environment. Accordingly, if the 1980s educational programme was meant to be an improvement, would it be true then that learning disability nursing knowledge has developed and improved since the 1970s? Are learning disability nurses fit for purpose and practice? More to the point, can learning disability nurses claim to have the ability to care for terminally ill PPLD in residential care homes? It appears not. Already there are many instances and studies to show that learning disability nurses do not have the knowledge or skills to care for dying patients or patients dying from a terminal illness (Tuffrey-Wijne et al, 2010; Bradshaw and Merriman, 2008; Li and Ng, 2008; Ng and Li, 2003; Carlisle, 1997).

Another issue concerns the approach used in facilitating and teaching learning disability student nurses on nursing programmes. For example, what model or framework is used to

teach and prepare learning disability nurses in the integration of death and dying nursing knowledge and nursing practice? Surely, Carper's (1978) "four patterns of knowing" is relevant and applicable in learning disability professional practice. It has been pointed out that a person's basic knowledge in a particular discipline proceeds through pattern recognition and development in the areas of: empirics, ethics, personal knowing and aesthetics (Cody, 2006).

Carper describes (i) "empiric knowing" as competence or a competent action grounded in scientific theories and knowledge. As a pattern of "knowing", knowledge is expressed through facts, theories, models and descriptions. It is demonstrable and publicly verifiable. (ii) "Ethical knowing" involves nursing decision-making or clinical judgments about what ought to be done. 'Ethical knowing' therefore guides and directs personal and professional conduct in life and work, and is expressed through moral codes and ethical decision-making. It helps a person to determine what is most important, what is good, what is right. Learning disability nurses often have to make choices for PPLD and they have to be aware of the dilemmas involved. (iii) "Personal knowing" comes from experience, as sympathy and empathy and understanding. It is about knowing self, requires full self-awareness and promotes respect in the nurse patient relationship. (iv) "Aesthetic knowing" refers to the "art" and "act" of nursing. It involves deep appreciation of the meaning of a situation and understanding how and why one does something and integrates and links the other three ways of knowing. It is individual and unique involving intuition, interpretation, empathy, understanding and valuing.

Accordingly, several writers (Chinn and Kramer, 1999; Carper, 1978) pointed out that each of the four patterns of knowing are an essential component of the integrated knowledge base for practice, and no one pattern of knowing should be used in isolation from the

others. Naturally, these four ways of knowing may overlap, but all should be considered in each care situation.

Having examined Carper's fundamental ways of knowing, I now discuss the application of Carper's patterns of knowing in learning disability nursing. Can Carper's work be reasonably justified on a theoretical and practical level considering the philosophical (normalisation) and organisational changes (community care) within learning disability nursing? Is a community-based care setting the best place to learn about observations of the signs of impending illness and or changing health condition? Could learning disability nurses' experience in the community-based care setting be properly integrated with knowledge? Is this approach appropriate and adequate in the preparation and training of learning disability nurses because of the diverse and multidisciplinary work within learning disability nursing practice? Or would this framework compromise learning disability nurses' or the students' learning strategies? In other words, is there a possibility that care of the terminally ill patient may be sub-optimal due to the lack of an appropriate and relevant nursing framework? I believe it is important to consider using a framework such as Carper's (1978) in learning disability nursing practice. It should provide a useful and meaningful nursing framework for learning disability nurses within community /residential care settings. Insofar as learning disability nursing is concerned, these four patterns of knowing will allow learning disability nurses to consider what they have learnt through reflection on experience. It is a coherent framework as knowledge acquisition, comprehension, and application, together with the skills of integration, evaluation, analysis and synthesis, are threaded through the patterns of knowing (Cody, 2006).

The literature review suggests that for a profession to demonstrate expertise in a particular field, knowledge, skills and experience are essential ingredients, and reflection forms an

important part of the whole learning process (Benner, 1984). Fundamentally, an educational programme should provide opportunities and experiences for student nurses to observe and to reflect on their learning. A similar method or approach would be one based on Schon's (1983) reflective practice model. This refers to how a student nurse develops reflective abilities during the course of their experience on placement. Schon (1983) points that "reflecting on action", after the experience, or by "reflecting in action", during the experience, are important strategies of developing professional practice. Reflection is certainly an essential element of learning (Kolb 1984).

Overall, the pre-registration nurse education and training in the 1970s and 1980s syllabi was meant to improve the education and professional expertise of learning disability nurses. At the end of their training, they would be considered to be academically sound and "fit for practice" (UKCC, 1999; Peach Report, 1998). The main question regarding a learning disability nurse is: has the training syllabus prepared this group of nurses sufficiently to care for terminally ill PPLD in community-based care settings such as in a residential home? Thus, has the learning disability nurse education and training curriculum prepared learning disability nurses to care for their patient "from cradle to the grave" [literally]?

#### **4.5 Conclusion**

In this chapter, I have shown that throughout the history of learning disability nursing, a great deal has happened, a result of some of the socio-political influences (Briggs, 1972; DHSS, 1979; DOH, 1990; DOH, 2001a). The reports in a way force learning disability nurses to re-focus their vision regarding nurse education in providing services to their patients in community-based care settings (Sines, 1993). They now work in nursing care homes, residential care homes, respite care services or day care services. They work in

collaboration with the multidisciplinary team<sup>11</sup>. In effect, the policy of inclusion means learning disability nurses today will need to consider how to care for terminally ill /dying PPLD in community-based care settings. Learning disability nurses are more likely to experience care of PPLD with different types of life-threatening illnesses or diseases as this group of people living in the community increases (DOH, 2001a). The changes in policy and location of nursing care practice have impacted on the nature of learning disability nursing. Therefore, it remains to be seen how learning disability nurses care for terminally ill PPLD in residential care homes. Thus, in the next chapter, a literature review will be carried out to examine how and what processes nurses use in the recognition of patients' problems or changing health conditions.

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<sup>11</sup> Multidisciplinary team – comprises medical, nursing and other health care professionals. They are there to help, support and facilitate the patient's progress.

**Chapter 5**  
**Literature review**  
**Sources of nursing knowledge**

## **5.0 Introduction**

This chapter provides a literature review on sources of nursing knowledge about early recognition of signs and symptoms of illnesses/ diseases. The review of literature includes the concepts of ‘knowing the patient’, ‘intuition’ and ‘commonsense’ knowledge. As there is a lack of literature about these concepts in learning disability nursing, I shall draw on the work of several researchers on nurses caring for adult patients in acute settings (Radwin, 1996; Minick, 1995; Tanner et al, 1993; Benner, 1984). Additionally, literature on decision-making processes used by mothers in relation to recognition of their child’s health is included. The reason for the inclusion is that they involve interpretations of behaviour in young children who are unable to voice their symptoms (Hunt, 2003; Callery, 1997; Irvine and Cunningham-Burley, 1991).

### **5.1 The concept of “knowing the patient”**

I present table 10 that shows a selective review on “knowing the patient”. The selection of each article was based on the size of the study. I have therefore excluded studies that were too small or presented as a one-off case study or opinion papers. The findings in each study showed that “knowing the patient” was important to nursing practice; through “knowing the patient”, nurses were able to recognise patients’ problems. The findings from these studies consistently showed that nurses must get to know their patients as a “person” if they were to make sound clinical judgements about patients’ problems. The studies identified several strategies of “knowing the patient” (Radwin, 1996; Minick, 1995; Tanner et al, 1993; Benner, 1984). They include nurses’ experience with caring for patients and involvement or a sense of closeness between the nurse and patient. Following table 10, I proceed to review and analyse the concept of “knowing the patient”.

**Table 10 – Selective literature review on “knowing the patient”**

Reference	Country and Settings	Sample	Methods	Aim	Findings	Type of study
Hunt (2003)	United Kingdom (i) A neuro-disability centre, children’s hospital (ii) a charitable trust , long term care and school children (iii) two hospices for children	Parents of 21 children (one parent had two children) and 26 nurses	Interviews	To explore the diagnostic /clinical decision-making processes used by parents and healthcare staff in relation to pain in children with severe to profound neurological impairment.	Findings: forms of knowledge required  (i)Knowing the child (ii)Familiarity with children with the same or similar conditions (iii)Knowing the science (of pain).	Qualitative
Callery (1997)	United Kingdom  Parents’ own homes	Parents of 24 children	Interviews	To explore parents’ knowledge about their sick children	Mothers know their child best. Mothers’ intimate knowledge of their child allows them to make a judgement about their child’s changing health condition. The child’s normal behaviour is used as baseline, to compare against the personality and the abnormal patterns exhibited.	Qualitative
Radwin (1996)	USA  Acute setting	18 nurses	Interviews, participant observation, field -notes and documents.	To explore nurses’ decision - making process.	‘Knowing the patient’ emerged as the core decision- making process in nursing. One important condition that enhances ‘knowing the patient’ is closeness between the nurse and patient. Experience also counts as another factor that helps nurses to make clinical judgments about patients’ changing health conditions.	Qualitative
Minick (1995)	USA  Acute setting	30 critical care nurses	Interviews	To examine how nurses recognise patients’ problems.	Nurses learn to know and recognise patients’ problems through ‘caring and connecting’ with the patients.	Qualitative
Tanner, Benner, Chesla and Gordon (1993)	USA  Acute settings	130 nurses	Group Interviews	To explore the meaning of knowing the patient.	‘Knowing the patient’ gain through ‘involvement’ with the patient is an essential ingredient. Pattern recognition of similarities and dissimilarities also contributes to early recognition and detection of patient’s problems.	Qualitative
Irvine and Cunningham-Burley (1991)	United Kingdom  A community in a new town in Scotland.	56 women	Interviews	To identify the ways in which mothers recognise children’s illnesses.	‘Knowing the child’ - the child’s behavioural changes were noticeable to mothers in this study; therefore behavioural changes are precursors or results of illness.	Qualitative
Benner (1984)	USA  Acute settings	48 nurses	Interviews	To explore the different strategies used by nurses to know their patient.	‘Knowing the patient’ results from nurses’ involvement with the patient and observation made about the patient. Information gained from patients’ families/friends about patients’ habits also helps the nurse to understand the patient.	Qualitative



“Knowing the patient” has been defined as “knowing the patient’s typical pattern of responses and knowing the patient as a person, their individual characteristics, habits, preferences and capabilities” (Benner and Wrubel, 1989: 273).

Hunt (2003) uses a grounded theory approach to explore clinical decision-making processes in the assessment and management of pain in patients with severe neurological impairment. Hunt suggests that knowing the child allows the parents to recognise behavioural and physical changes. The assumption here is that mothers learn to compare and contrast the child’s behaviour, when well and when unwell. For example, a mother could deduce a particular pain from the appearance and pattern of behaviour that a child displays. Interestingly, in this study, Hunt (2003) suggested that some mothers also reported that “knowing the child” was not instantaneously acquired. For example, she reported that there were times when some parents did not realise the child was in pain because “they did not yet know their child” (Hunt, 2003: 175). Hunt, claimed that doctors and nurses sometimes dismissed parents’ description of the child’s pain experience. She stated that several parents portrayed the professionals (doctors and nurses) as finding ways “to discount the child’s pain with the consequence that the process of referral to a specialist centre could be delayed” (Hunt, 2003: 178). She claimed that doctors’ knowledge about a patient (the child) was based on occasional visits; therefore, it was not possible for the doctor to know what the child was like, to see a difference in them. Hunt shows that for this reason, parents find it difficult to communicate to the doctor about the child’s pain (2003).

Callery’s (1997) study also endorses Hunt’s study (1991) that “knowing the child (patient)” is an important feature of mothers’ judgments about their children. For

example, mothers judged the behaviour and symptoms of the children against the personality and the normal patterns they exhibited, leading them to seek medical advice. In Callery's study (1997), "knowing the child" also appears similar to the concept described by others (Radwin, 1996, Tanner et al, 1993) as "knowing the patient". This study shows that the skill of recognition of early signs of illness is through daily contact between parents and their children. He shows that mothers' knowledge develops through intimate contact with the child, referring to this knowledge as "private" knowledge. He shows that a mother knows her own child intimately and so is able to notice and interpret the slightest variations in behaviour when the child is unwell. The analysis of Callery's study therefore shows that a deviation from the 'normal' behaviour pattern is perceived as a precursor to an illness.

Callery like Hunt (2003) found that mothers in his study had difficulty persuading the professionals (that is, doctors and nurses) of the seriousness of their child's problems. He suggests that professionals' ("public") knowledge develops from knowledge based on science. Therefore, professionals' knowledge by definition is scientific. He claims that professionals typically observe for deviations from the norm for a population rather than an individual. He found that professionals could only respond to visible physical signs; therefore, behaviour changes in itself were not enough to convince them. Reflecting on this study, it seems that "private" knowledge of the child is not enough to convince professionals, unless mothers translate their concerns into physical signs and symptoms that are recognisable. It seems that the mothers' judgement is by definition non-scientific.

A study conducted in Scotland by Irvine and Cunningham-Burley (1991) examined mothers' perceptions of their children's health and illnesses. Irvine and Cunningham-Burley (1991) provided similar evidence as that found in Hunt (2003) and Callery

(1997) where they explored mothers' concepts of normality, behavioural change and illness in their children. Irvine and Cunningham-Burley's (1991) findings show that recognition of illness is grounded in knowing the child's behaviour. They claim that mothers' noticing the child's unusual behaviour alerts them that something is wrong with the child. Additionally, this study also shows that some mothers claim that not all "unusual" behaviour is interpreted as a symptom of an illness.

In this study, the writers also report instances of conflict between mothers and professionals'. For example, mothers in Irvine and Cunningham-Burley's (1991) study describe their difficulties in convincing the doctors that something is wrong with their child. This illustrates that differences do arise between "private" knowledge (mother's knowledge derived from intimate contact with the child) and "public" knowledge (professional knowledge based on science) resulting in conflicts between two parties. This distinction can also be found in Hunt (2003) and Callery's (1997) studies when they reported that professionals' responses to the relief of pain were different from the parents', that is, "public" knowledge was prioritised over "private" knowledge.

Radwin's (1996) study shows that nurses' decision-making is characterised by "knowing the patient". Her study shows that nurses' experience and a sense of closeness between the patient and nurse are important factors to knowing the patient. She defines nurses' experience as "the application of that learned from previous practice situations" (p591). In this instance, "experience" with patients with similar conditions sharpens a nurse's ability to know the meaning of a given situation. The nurses' "caring experience" allows them to compare and contrast patterns learned from past patients in similar situations. This view is similar to pattern recognition and knowing the patient as a person in Benner and Tanner's study (1987).

Minick (1995) carried out a study on the early recognition of patient problems by nurses working in critical care units. Interview data consisted of narrative accounts related by these nurses. The study demonstrates that “caring” for the patients helps nurses to recognise subtle changes in patients’ health status. The nurses in this study describe “caring” as involvement with the patient. In this study, Minick shows that nurses through their “caring” are more able to recognise patients’ problems. The study shows that nurses’ “caring” allows them to “connect” or bond with their patients. Minick’s study shows that “connecting” with patients can occur within a few minutes. Therefore, the length of time or temporal understanding is not a vital component of assessing and recognising subtle changes about patients’ conditions in this study. Yet, in other studies caring for and knowing the patient over time have been identified as important in the recognition and assessment of subtle changes in patients (Tanner et al, 1993).

Tanner et al (1993) in a qualitative study of nursing practice also suggest that “knowing the patient” is central to nurses’ work. Tanner et al (1993: 275) define “knowing the patient” as “understanding the patient’s situation in context with salience, nuances and qualitative distinctions”. They show that direct involvement with patients allows nurses to get to know their patients, to understand their patients as individuals. Direct involvement helps the nurses to understand and deal with their patients’ concerns and hopes.

In this study, Tanner et al (1993) also point out that experience and familiarity with the “population” enhance nurses’ ability to recognise similarities and differences. In other words, experience and familiarity with illnesses give the nurse a broader understanding of the variations of types of illness from which they can draw different conclusions depending on the individual aspects and nuances of each case. Tanner et al (1993) also

show that nurses often learned about the patient through the patient's family, for example using the family's ability to recognise subtle changes in the patient.

One observation made about this study is that Tanner et al (1993) maintain that "knowing the patient" is achieved through close relationship and direct involvement; however what is not clear is the length of time involved in nurturing this or the extent of the relationship between the nurse and the patient. It could be argued that nurses in acute settings can only glean a superficial knowledge of a patient's needs and foibles.

"Knowing the patient" is central to Benner's (1984) study in how nurses recognise patients' problems in the acute settings. She describes, "knowing the patient" as knowing the patient's typical pattern of responses and knowing the patient as a person. She suggests that knowing the patient requires involvement. In this study, Benner did not define the term "involvement". She also found that nurses got to know their patients by observing them, for example, knowing patients' preferences and habits. She also found that information obtained from patients' families and friends was necessary if nurses were to get to know their patients. This was congruent with Tanner et al (1993) studies who stated that it was necessary to obtain information from patients' relatives for nurses to get to know their patients.

Reflecting on Benner's study, "knowing the patient" is a result of (i) dialogue with the patient and the patient's families and friends and (ii) nurses' observation about the patient's usual habits or usual behaviour. However, what is not clear is if there is a baseline from which nurses are able to compare what is the 'usual' habits or behaviour. The term "usual" is not clearly defined. Moreover, in Benner's study, it seems that information about the patient is "ready-made", obtained directly from the patient or the patient's family.

The key results of the studies highlighted several enhancing factors that are necessary if nurses are to get to know their patients. These include nurses' experience and involvement with the patients. "Knowing the patient" creates the opportunity for early recognition of patients' (/children's) problems thus preventing adverse events. "Knowing the patient" is integral to good nursing practice, an essential aspect of practice in the early recognition of patients' problems. The above studies demonstrate that nurses must know their patients, patients' preferences, patients' behaviours and patients' habits if they are to make sound clinical judgements. Similarly, studies on mothers and children (Hunt, 2003; Callery, 1997 and Irvine and Cunningham-Burley, 1991) showed that prior knowledge of a child's behaviour was a great predictor of accurate assessment decisions. The emphasis is on behaviour cues. They demonstrate that parents know their children's habits and behavioural patterns. Therefore, any behavioural change noticeable to these mothers is considered as precursor or result of illness.

An observation made of the studies reviewed suggests that it is easier for nurses to diagnose illness in acute settings. For example, a change or deterioration in the patient's condition can be swift and often tangible. Furthermore, non-disabled patients would normally be able to articulate the changes themselves. Alternatively, as shown in the studies, families would often provide the information or they could report their observations of changes on the patient's behalf. However, in learning disability nursing, PPLD are not able to communicate verbally. Thus, self-reporting is out of the question. At most, for a profoundly disabled patient, his or her behaviour does not fall within the realms of "normality". Furthermore, the majority of PPLD in the study do not have relatives / families, thus, the reporting of signs and symptoms of illnesses rests with LD nurses.

Furthermore, the studies reviewed indicated “involvement” as the basis of knowing the patient. What is not clear is the meaning of “involvement” or duration of involvement. Nurses in acute settings do not normally spend years caring for one specific patient; they also have high patient load. A lack of time often means nurses do not get opportunities to engage fully with their patients. Additionally, patients do not spend a long time in the acute setting. Consequently, long-term contact and involvement is not sustainable. In comparison with learning disability nursing practice, learning disability nurses are permanent staff and have long-term contact and involvement with their patients. They know their patients as “a person”. They are constantly involved in daily activities with their patients. Here, for a learning disability nurse, involvement means they participate and play a part in the patient’s everyday life. In addition, a patient with a profound learning disability normally lives in the residential home most of his/her life; hence, the place is a “home” as opposed to a “ward” in the hospital /acute setting.

So far my literature review shows that “knowing the patient” is how nurses recognise patients’ problems or illnesses. In the next section (section 5.2), I shall review and analyse studies that focus on “intuition”.

## **5.2 “Intuition”**

According to several authors (King and Macleod Clark, 2002; Cioffi, 2000; Davies-Floyd and Davies, 1996; Rew, 1990; Rew, 1988; Schraeder and Fischer, 1987; Pyles and Stern, 1983; Benner and Tanner, 1987) there is a general agreement that “intuition” is another approach that nurses use to determine patients’ illnesses or changing health conditions. Table 11 shows a selection of reviews on the concept of “intuition”, and precedes my review on the subject matter. The selection of these studies for my review

is because of the size of the study. Therefore, studies that are too small or presented as a one off case study or opinion papers are excluded.

**Table 11 – Selective literature review on “intuition”**

Reference	Country/Settings	Sample	Methods	Aim	Findings	Type of study
King and Macleod Clark (2002)	United Kingdom  Acute settings	61 qualified nurses	Interviews and non-participant observation	To explore the different levels of expertise and the use of intuition in clinical practice.	Experienced nurses (expert nurses) tend to be more intuitive.	Qualitative
Cioffi (2000)	Australia  Two sites: 4 wards in one teaching hospital and 3 wards in a peripheral hospital.	32 female registered nurses	Interviews	To examine the experiences of nurses involved in calling the Medical Emergency Team (MET) to their patients.	Showed that ‘experienced nurses’ did not ignore the ‘feelings’ they may have about the patient’s condition even though they were not able ‘to put their finger on it’. But less experienced nurses had to seek opinions from the more experienced colleagues. Other strategies used included ‘knowing the patient’. The ‘experienced’ nurse is more able to compare or contrast experiences and other patterns developed from past patients in similar situations.	Qualitative
Davis-Floyd and Davies (1996)	USA  2 conferences	22 midwives	Interviews	To explore the role that intuition plays as a guide to action and decision making during homebirths.	Midwives learn to trust their intuition. The CNMs regard intuition with mistrust to begin with, and then move on to trust through lived experience. The empirically trained midwives had trust in intuition to begin with and then move into confirmation of that trust through lived experience.	Qualitative
Rew (1990)	USA  Critical care setting	25 critical care nurses	Structured interview	Research question: How nurses describe intuitive experiences in practice and within the nursing process and what physical sensations are associated with intuition.	Nurses’ intuition increases as they gain experience. Descriptions of intuition include knowing, gut feeling, sixth sense, perception and ability to anticipate. Physical sensations - mouth feeling dry, skin flushing, muscles tightening and pulse racing.	Qualitative study



Rew (1988)	USA 5 home health agencies, 5 hospital critical care units and a university student health centre.	56 registered nurses	Interview schedule	To explore how nurses described intuitive experiences in critical care and home care settings.	Nurses describe their intuition as 'feeling'. A 'feeling' is manifested as 'physiological', e.g. fearful or nagging feeling.	Qualitative
Schraeder and Fischer (1987)	USA Neonatal intensive care unit (critically ill newborns)	15 nurses and the medical director	Interviews, participant observation, examination of primary documents, researchers' field notes.	To describe the experiences, actions, rationales and consequences involved in decision-making in the neonatal intensive care nursery.	Four factors that influence intuitive knowledge: (i) characteristics of the nurse, (ii) feeling of relatedness to the patient, (iii) cue recognition – sensing subtle changes and (iv) recognition /linking present perceptions with past experiences.	Qualitative
Pyles and Stern (1983)	USA Critical care setting	28 critical nurses	Interviews	To find out how critical care nurses determine if a patient is developing cardiogenic shock.	Identified a matrix termed 'nursing gestalt', i.e., nurses linked together knowledge, past experiences, patient cues and gut feelings. Gut feelings refer to 'falling out of the pattern' - this is a discrepancy between what they saw and what they expected.	Qualitative
Benner and Tanner (1987)	USA Coronary care unit	21 expert nurses (nurses with 5 years experience in a single area)	Interviews	To examine the nature of intuition as a component of professional expertise.	6 aspects of intuitive judgements- 'pattern recognition', 'similarity recognition', 'commonsense understanding', 'skilled know-how', 'a sense of salience', 'deliberative rationality'. The study found nurses develop 'intuitive grasp' (intuitive responses) because of a combination of factors such as years of experience, functioning at a higher level, hence demonstrate a greater confidence and competence in practice.	Qualitative

The word “intuition” comes from the Latin word “intueri” – “to look inside” or “to contemplate” (Carlin, 2007). Carper (1978) first highlighted the importance of intuition in nursing practice. Gut feelings, sixth sense and premonitions are some of the words used to refer to intuition. The author most credited with developing the intuitive model in nursing is Patricia Benner (1984). Benner demonstrates the use of intuition in her study on nurses in acute settings. She demonstrates that as nurses gain experience in practice and proficiency, they develop an “intuitive grasp” to analyse most clinical problems.

There is no unanimous agreement that describes “intuition”. For example, Benner and Tanner (1987: 23) define intuition as “understanding without a rationale”. Schraeder and Fischer (1987: 45) describe intuition as “immediate knowing of something without the conscious use of reason”. However, all studies suggest that when nurses’ experience grows in clinical practice, their intuitive feelings also increase.

King and Macleod (2002) show that the more experienced group of nurses (expert nurses) tend to be more intuitive. The researchers show that “intuition” relates to the depth of a nurse’s knowledge, ability and confidence in their practice. Some examples in their study show expert nurses are more intuitive. This is illustrated by one nurse: *“I can look at a patient and know how there’s something not right with them....at the same time you have a feeling when you are not happy.....”*. In another example: *“It’s more than a gut feeling..... you always feel you would know it straight away ... its tied up with gut feeling, and you can just see it.”* (King and Macleod, 2002: 326-327). The examples imply that decision-making is due to a “feeling” or “sensing”. This study supports other nursing studies that demonstrate intuition as an aspect of nursing decision-making and clinical judgments, with experts using it most (Benner and Tanner, 1987).

Cioffi (2000) conducted a study on 32 female nurses concerning their experiences of making decisions to call emergency assistance to their patients. The study shows that experienced nurses do not ignore the “feelings” they have about the patient’s condition even though they are not able “to put their finger on it” (Cioffi, 2000:112). Like Benner and Tanner’s (1987) study, it goes to show that experienced nurses do not devalue their feelings. Cioffi shows that “experience” and “knowing the patient” support nurses’ intuition in their clinical decision-making skills. The study reveals that less experienced nurses seek opinions from the more experienced colleagues in nursing decision-making. In this study, the meaning of “less experienced nurses” and “more experienced nurses” is not clear even though both terms are extensively applied throughout.

Reflecting on the concept and use of intuition in adult acute nursing, there is no doubt intuition is a useful strategy in the early recognition of patient’s problems. However, other healthcare disciplines besides acute nursing also suggest that intuition has an important role. For example, Davies-Floyd and Davies (1996) conducted a study between 1992 and 1993 on midwives. The objective of the study was to examine the role of intuition in midwives’ roles during homebirths. The researchers’ goal was to elicit as many good “intuition stories” from the midwives as they could, using interviews and a tape-recorded workshop. The population consisted of twenty-two white middle class American midwives who were selected on the basis of their “good stories”. Seventeen of them were empirically trained midwives and primarily attended homebirths. Empirically trained midwives are those who learn their skills through the one-to-one interaction of apprenticeship. The remaining five were medically trained midwives (CNM). Of the five medically trained midwives, three carried out homebirths as well as hospital births. The remaining two midwives were hospital-based. Most of them had three to 16 years of midwifery experience; only three had less than a year. All

(CNM) were highly literate and competent in technological skills and biomedical diagnosis.

In this study, Davies-Floyd and Davies (1996) report that midwives described “intuition” as “making a connection”, which involved the body, psyche, and spirit, but not the rational mind. The midwives perceived intuition as a valuable diagnostic tool that guided their actions. The findings from this study show that the medically trained midwives first regarded intuition with mistrust, but began to trust it through lived experience. The empirically trained midwives started by trusting intuition and then confirmed that trust through lived experience. Reflecting on Davies-Floyd and Davies’s (1996) study, intuition is the act of knowing which cannot be explained logically. In this study, midwives learned to listen to their “inner voice” because of experience (Davies-Floyd and Davies, 1996; 237). “Intuition”, according to the midwives emerged through their contact with the mothers during births - it was an “inner connection” with the mother and child.

My criticism of this study is the fact that the researchers only interviewed midwives for their good stories, and the criteria for the selection of stories were not clear. One would have thought that sometimes it would be worth considering “deviant” cases or negative instances because they offer a crucial test of a theory (Silverman, 2000).

A study by Rew (1988) examined the experiences of nurses in critical care and home settings. The sampling population consisted of 56 nurses; five males, and 51 females. The majority of the nurses held a baccalaureate degree in nursing. On average, the nurses had 12 years clinical experience. The study showed that the majority of nurses described their intuition as “feelings”, for example, “fearful” or “nagging” feelings. The writer acknowledged the different types of feelings associated with intuition, but was

unable to explain the difference in the terms used. However, on deeper analyses of the study, the variations in how nurses used the terms to associate “intuition” may be due to previous experience in clinical practice. For example, one nurse stated: “*the longer I’m in nursing, the more my hunches are right*” (Rew, 1988, p152). This study (Rew, 1988) provided further insight about nurses’ experiences, highlighting the notion that intuition has its link to knowledge that derives from clinical and past experience.

In 1990, Rew published another research which complemented her earlier work (1988) on intuition. The 1990 study showed that nurses described intuition as knowing, gut feeling, sixth sense, perception and the ability to anticipate situations. The nurses reported that intuition mostly occurred during the assessment and implementation stages of the nursing process. Rew also showed that nurses described intuition as including physical sensations. These included muscles tightening, the mouth feeling dry, skin flushing, and the pulse racing. It seems here that Rew’s concept of intuition suggests physiological changes.

Schraeder and Fischer (1987) conducted an ethnographic study of nurses with four years of experience working in the neonatal intensive care unit (NICU). In this study, the researchers include the Myers-Briggs Type Indicator (MBTI) (Myers, 1980) to investigate and identify nurses’ decision-making processes. Schraeder and Fischer (1987: 49) showed that nurses who had in-depth knowledge of their field and a wide experience with similar clinical problems applied intuition more in clinical situations. They showed that these nurses were better at making qualitative distinctions in a given situation. The study also showed that nurses developed a feeling of relatedness to the infant. Relatedness in this study included feelings of love for the infant, feelings of loss and feelings of commitment, that is to say the anticipation of coming in to work, to care for the baby. In this study, the researchers were surprised to find that technically skilled

nurses who normally relied on logic and hard data turned to using intuitive thinking when making clinical decisions. Nevertheless, the findings need to be treated with caution because some academic psychologists have criticised the use of the MBTI instrument, claiming that it lacks convincing validity data (Hunsley et al, 2004).

In summing up Schraeder and Fischer's study (1987), it seems that nurses develop intuition as a result of feelings of knowing the individual (infant), observation of qualitative changes that link present perception with past experience. It seems to me that all these elements are prevailing features of intuition. This is similar to what Pyles and Stern (1983) refer to as "gestalt nursing" - a matrix operation whereby nurses link together basic knowledge, past experiences, identifying cues presented by patients, and sensory cues including what nurses call "gut feelings".

Pyles and Stern (1983) undertook a study with 28 critical care nurses. The aim of their study was to understand how nurses determined if a patient was developing cardiogenic shock. Their findings showed that nurses' past experience, observation of patients' cues and gut feelings were important features in determining a patient's situation. They referred to these as "nursing gestalt"- a matrix in which all of the features were linked together. In this study, experience was fundamental to the development of intuitive feelings. Pyles and Stern also suggested that nurses placed great emphasis on patients' cues, which served as early warnings of potential changes or deterioration. I interpret gestalt nursing in this sense as a combined action of logic and intuition involving both conceptual and sensory cues, for example, the "ah ha" experience when learning occurs suddenly and the "penny drops" (Bevis, 1978). In other words, "gestalt" is said to have taken place when all the pieces of information are taken into consideration and the data "harmonise" or "add-up" (Bevis, 1978). Pyles and Stern also reveal that some physicians do not support nurses' use of intuition.

Benner and Tanner (1987) investigated the nature and role of intuition in expert clinical judgment in coronary care units, based on their interviews with 21 nurses with five years of experience in a single clinical area. Their findings identified several aspects of intuitive judgment that nurses used in decision-making. They are (i) pattern recognition - this is illustrated in an example when a nurse interprets the patient's current situation in the light of the patient's history. (ii) Similarity recognition - this refers to an awareness that the patient reminds the nurse of a similar patient thus raises new questions and possibilities (Benner and Tanner, 1987:24). (iii) Commonsense understanding - this refers to the nurse's ability to grasp an understanding of the patient's illness experience from the nurse's own cultural and personal perspectives. For example, nurses in Benner and Tanner's study describe knowing the "stupid" stuff, knowing what the patients look like and how they eat (1987: 25). (iv) Sense of salience - this refers to important cues and the subtleties as illustrated by two nurses' descriptions of a patient's problem - "*she (patient) moves her left side... she always has her left hand at her tracheostomy... when you deal with her mouth she will reach up...*" (Benner and Tanner, 1987: 27). (v) Skilled know how - this refers to integration of experiential knowledge. (vi) Deliberative rationality - this means the nurse's ability to reflect using past experiences to guide alternative views of the current situation. This study therefore demonstrates that nurses' decision-making and clinical judgments rest on a combination of methods. They are indicative of a commonsense approach and experience which ultimately led nurses to develop an intuitive awareness of the situation.

Reflecting on the literature, intuition may be summed up as a series of complex interactions of traits or attributes, which include experience and personal knowledge of the patient's history and the interaction and relationships built over time. The studies

reviewed also showed that nurses with more years of experience used intuition most. I would therefore argue that intuition is a skill and an art that nurses learn how to observe, what to observe and in time know how to deal with a situation. In this sense, I mean intuition is a result of experience, and personal and professional reflection on the job in hand.

Many of the examples shown so far have been in acute nursing with the exception of one being in midwifery (Davies-Floyd and Davies, 1996). These studies have demonstrated that nurses in acute settings and in midwifery have well developed “intuition” - a kind of unspoken personal knowledge that is not easy to express or explain. Overall, all these studies appear to demonstrate that “intuition” as a nursing decision strategy is associated with expert nurses’ nursing experience. The key finding is that “past experience” leads to mastery, thus, early recognition of patients’ problems is the hallmark of expertise. It is also possible that nurses will use other strategies in decision-making in nursing practice. In the next section, I will review some literature on the concept of “commonsense” knowledge, another source of knowledge that might be used in nursing decision-making and clinical judgments.

### **5.3 “Commonsense knowledge”**

It is difficult to give an exact definition for “commonsense” knowledge. Various definitions have been put forward. An example was one proposed by an English philosopher, John Locke, sometimes known as the master of “*commonsense*” (Lowe, 1995). Locke first published his work, ‘An Essay Concerning Human Understanding’ in 1689, in which he proposed that commonsense knowledge means “sense that is common to the others”. He proposes that each of our senses gives input, is integrated and then united into a single impression. This is what he meant by “common” sense.



Locke proposed that ‘each person makes abstract general ideas and made them up in our minds with Names, or Patterns or Forms and they become to be regarded as of that particular Things’ (Lowe, 1995: 164).

The concept of “commonsense” knowledge can also be found in Alfred Schutz's writings. He refers to commonsense knowledge as organised “typified” stocks of taken-for-granted knowledge based on our everyday activities (Schutz, 1966). In other words, commonsense knowledge is a social product developed through an ongoing process, which is knowledge acquired through everyday life routines or activities (Schutz, 1966). This means “commonsense” knowledge consists of knowledge or facts or the kind of things that people generally leave unstated in conversation because they are obvious.

Others have similar viewpoints (Sternberg et al, 2000; Stacey, 1993; Dingwall, 1977). These writers claim that “commonsense” knowledge comes from our everyday personal life experience. This type of knowledge consists of statements that most people would agree with (Anacleto et al, 2006a; Anacleto et al, 2006b). For these writers (Sternberg et al, 2000; Stacey, 1993; Dingwall, 1977), the phrase “commonsense” knowledge is also called “people knowledge” or “practical knowledge” or “lay knowledge”.

“Commonsense” knowledge is not codified in textbooks, it is not systematised and generalised (Stacey, 1993). On reflection, “commonsense” knowledge is a set of facts known by most people living in a particular culture. However, commonsense varies, for example, by different cultural background, values, attitudes or geographical location. Furthermore, several studies have found commonsense knowledge increases as people mature and gain more experience in life (Cornelius and Caspi, 1987; Williams et al, 1983; Denney and Palmer, 1981).

There is little information on how commonsense knowledge is used in acute nursing and even less in learning disability nursing. A qualitative study (Harper et al, 2007) was conducted on 29 British military surgical and non-military orthopaedic registered nurses. The aim of the study was to identify taken-for-granted assumptions and commonsense cultural knowledge used in postoperative pain assessment. The findings from this study showed that military nurses belonged to a military culture and had different pain attitudes, and therefore reporting pain differed between the two groups of people. These findings demonstrated that a lack of consensus between nurses and patients was a result of different cultural backgrounds and attitudes to pain. What this study has demonstrated is that all nurses need to be aware of different nursing cultures as “commonsense” knowledge will influence pain assessment.

A study by Hanson (1994) with a group of cancer nurses revealed that their world is rich with meaning, knowledge, skills and values. The findings showed that these nurses’ commonsense knowledge was derived from both professional practice and educational experiences. However, interestingly, the study showed that cancer nurses in practice often failed to rely on commonsense knowledge, because of the mainstream influence of the medical model. The study recommended that cancer nurses must bring their commonsense knowledge and values to the fore in order to provide holistic care of persons with cancer. The presumption here is that cancer nurses are expert nurses, although this was not made clear to readers.

What these studies have shown is that commonsense knowledge is socially distributed (Dingwall, 1977) based on practical experience (everyday activities) and socialisation processes, not based on specialised knowledge. Ultimately, for a person to interact in a meaningful manner, a suitable language is developed. In other words, the characteristic of “commonsense” knowledge lies in the use of language. Along this line, I raise the

issue about the usefulness and application of “commonsense” knowledge in learning disability nursing practice.

#### **5.4 Conclusion and research questions**

This chapter highlights how nurses make decisions in the recognition of ill health. So far, the literature review showed that the concept of “knowing the patient” (Hunt, 2003; Callery, 1997; Irvine and Cunningham-Burley, 1991; Tanner et al, 1993) was considered to be important nursing knowledge related to nursing decision making and clinical judgments of patients’ ill health. Furthermore, the art of nursing decision-making and clinical judgment may also take place on an intuitive level as well as embedded in commonsense knowledge.

How applicable these types of knowledge or methods are to learning disability nurses in their decision-making and the recognition of patients’ health condition is still an unexplored area. The concepts of “knowing the patient”, “intuition” and “commonsense” knowledge have not been tested in learning disability nursing. It is important to understand how learning disability nurses assess and recognise PPLDs’ changing health conditions. The lack of research focusing on this area represents an important gap in current knowledge, particularly in the profoundly disabled population when patients are unable to communicate linguistically and /or physically. Therefore, the aim of my research is to examine learning disability nurses’ experiences of caring for terminally ill PPLD in residential care homes. My study sought to answer three questions:

Question 1: How and what processes do learning disability nurses use in the recognition of a patient’s changing health condition?

Question 2: How do learning disability nurses care for terminally ill PPLD in residential care?

Question 3: What services and resources do learning disability nurses use to support them in caring?

In addition, the thesis has the following objectives:

1. To build new knowledge of learning disability nurses caring for dying patients with profound learning disabilities.
2. To develop a practice-based assessment tool as a reference point that will enable learning disability nurses to assess a person with profound learning disability's changing health status.
3. To inform nurse educators in the future planning and developments of nursing curricula.

**Chapter 6**  
**Research design and methodological choices**

## **6.0 Introduction**

The aims of this chapter are to justify my research design and methodological choice. The chapter begins with an overview and discussion of qualitative research methods. Within this section, I discuss the different qualitative approaches and methodological tools. Thereafter, I discuss the rationale and justification for my research study, including a description of the study setting, how the data are collected and analysed, using a grounded theory approach. I present a reflexive account regarding my entry into the research sites and the challenges experienced in my role as an “insider” researcher (Arber, 2006; Seale, 1999). Issues relating to consent, confidentiality and validity are also critically explored.

### **6.1 The value of qualitative research**

Qualitative research is used to develop new insights, hypotheses and theories (Clark, 1997). It involves seeking in-depth information about a subject. It seeks to describe people’s experiences, often looking at attitudes, behaviours and perceptions. Burns (2000) claims that qualitative research methods allow researchers to describe and define meaningful events in a naturally occurring setting. Qualitative research methods therefore attempt to capture and understand what people do or think and to understand the meanings of events or the nature of lived experience (Burns, 2000; Silverman, 2000; Polit and Hungler, 1999; 1987). The essence of qualitative study concerns the depth of information/data rather than statistical analysis (Miles and Huberman, 1994), therefore it is appropriate to concentrate on a small sample, yielding more focused and richer data (Parahoo, 1997). The nature of qualitative research differs from quantitative research, in which the process of measurement is central. The quantitative research method follows a deductive research process and involves the collection and analysis of quantitative (numeric) data to identify statistical relations between variables. Thus, the focus is on

gathering information that is easily coded into a numeric form, such as a survey (Flick et al, 2007; Burns, 2000).

Qualitative research methods are essentially concerned with processes and meanings, rather than statistical inferences (Eisner, 1991). Qualitative research uses individual in-depth interviews, focus groups or questionnaires to collect, analyse and interpret data by observing what people do and say. It reports on the meanings, concepts, definitions, characteristics, metaphors, symbols and descriptions of things.

Qualitative research therefore is inductive, and can provide rich, descriptive detail into certain topics of which little is known (Parahoo, 1997). This means using qualitative research methodologies can provide opportunities and ways that lead to the discovery of deeper levels of meaning. But most importantly, one feature that stands out in qualitative research is the reflective capability of the researcher, that is, “the researcher’s actions and observations in the field of investigation is taken to be an essential part of the discovery” (Flick et al, 2007, p 8). This also means that the investigator or the researcher is an integral part of the investigation (Jacob, 1988). This claim has its support in Heidegger, a student of Husserl, suggesting that the researcher is as much a part of the research as the participant, and that their ability to interpret the data is reliant on previous knowledge. Heidegger (1962) called this prior understanding fore-structure.

The use of qualitative methods has gained acceptance beyond the confines of sociology (Silverman, 2000; Clark, 1997; Glaser, 1978). Nursing research making use of qualitative methodologies has increased considerably as more and more nursing researchers recognised its usefulness (Wimpenny and Gass, 2000). Qualitative research methodologies have provided much insight into the human side of nursing (McConnell-

Henry et al, 2009). As discussed in previous chapter, several nurse researchers have used this method to explore nurses' recognition of patients' problems in acute settings. Benner (1984) used qualitative research methods to explore how nurses function, from novice to expert. Others such as Hunt (2003), Minick (1995) and Tanner et al (1993) used this method to examine nurses' ability to recognise patients' problems in acute settings. While other nurse researchers such as Clark (1997), Field (1994), Hockey (1991) and James (1986) also adopted qualitative research methods to further understand the work of healthcare professionals in palliative care settings.

Additionally, social scientists have also used qualitative methodologies to investigate topic areas such as human behaviours and actions. They included Garfinkel (1967) and Goffman (1961). Garfinkel's (1967) study used the ethno-methodological method to demonstrate the pre-conditions and rules that govern the production of everyday processes of understanding and doing. Goffman's (1961) work on patients in psychiatric institutions and prisoners was regarded as one of the notable studies of organisational sociology.

The phrase qualitative research is a generic term for different research types or approaches to doing qualitative research, for example, phenomenology, discourse analysis and grounded theory (Starks et al, 2007; Denzin and Lincoln, 1998; Morse and Field, 1995; Forsythe et al, 1984). These three qualitative research methodologies are thought to be useful methods in health research (Starks et al, 2007). I provide a brief background of each type in the following section (section 5.1.1).



### 6.1.1 Types and differences in qualitative approaches

(a) Phenomenology, one of the many qualitative methods, seeks to capture how people think, feel and behave in their naturalistic environments (Polit and Hungler, 1987); it has its roots in the philosophy of Heidegger. At the heart of Heidegger's hermeneutic phenomenology, this method seeks to shed light on human experience, as it is actually lived (van Manen, 1990). The goal of phenomenology is therefore to study how people make meaning of their lived experience (Starks et al, 2007). For example, the researcher collects data from individuals who have experienced a phenomenon such as bereavement. Data may be collected by observations, interviews or journals. The researcher then develops a composite description, representing the "essence" of the experience or "core" commonality of the individuals' experiences. A descriptive passage is produced describing the common experiences of the participants. This description would normally consists of "what" was experienced and "how" the phenomenon was experienced (Moustakas, 1994).

This method involves the use of "thick description" of lived experience (Wilson and Hutchinson, 1991). Furthermore, for this method, Heidegger suggests that the researcher is as much a part of the research as the participant. He believes that we construct our reality and our comprehension from our experience of "*Being-in-the-world*" as our "Dasein", as we are unable to separate ourselves from these (Waterhouse, 1981). "Dasein" in colloquial German means human existence (Waterhouse, 1981). From this perspective, Heidegger viewed humans as entities with the awareness and the ability to ask ontological questions, that is, the researcher's ability and intention of reporting realities based on the actual words of different individuals and presenting different perspectives from individuals (Cresswell, 2007). Importantly, the emphasis then is about acknowledging the cultural aspects of the individual's experience (Dilthey, 1988). This view is translated into the Gadamerian metaphor "fusion of horizons" where

participants and researchers as individuals are brought together through dialogue to produce a shared understanding of the phenomena (Gadamer, 1975), thus bridging the familiar and the unfamiliar. Hence, it is befitting to consider phenomenology as a vehicle for exploring the experience of nurses caring for patients. However, there are some who would say that Heidegger's hermeneutic phenomenology is one of the least understood methodologies, probably because of the nature of the language used, as it is both overwhelming and exclusive.

(b) Discourse analysis has its roots in linguistic studies. It is concerned with examining how language-in-use, that is, written, spoken or signed language shapes and reflects personal, cultural and social values and practices (Starks et al, 2007). The goal of the researcher using the discourse analysis method is to identify and analyse commonly shared use of language or a conversation whereby meaning is created. One of the prominent and early discourse analysts was Michel Foucault (1972 in English edition) who wrote "The Archaeology of Knowledge", among other topics. Another researcher using this approach was Patricia Kaufert (1988) who was interested in how the subject "menopause" was constructed. She used different materials, for example, medical texts, reports, and epidemiological studies in constructing the meaning of the menopause. Kaufert's study shows how using documentary sources or secondary analysis of research reports can contribute to the production of medical "knowledge". She shows how the "facts" produced through one such methodological process come to have a life of their own as "knowledge".

(c) Grounded theory (GT) has its origin in sociology. According to some writers, grounded methodology and methods are now among the most significant and widely used approaches to carrying out qualitative research (Strauss and Corbin, 1998). Grounded theory is described as an approach to collecting and analysing qualitative data

with the aim of developing theories and theoretical propositions “grounded” in real-world observations (Polit and Hungler, 1987: 530). Consequently, generating theory is the researcher’s principal aim. The purpose of grounded theory is to discover what is going on (Glaser, 1978; Glaser and Strauss, 1967). Grounded theory was developed by two American sociologists, Anselm Strauss and Barney Glaser (1970). They looked at how and when professionals and their terminal patients knew they were dying and how they handled the news. Later, Strauss and Corbin explored the different kinds of illness work people do as patients and as family members (Corbin and Strauss, 1988). In their study, families were observed to provide a great deal of care for the chronically ill. They also found that when illness strikes, not only sick persons face difficulties, but it also affects the immediate family. Their studies had an impact on health care systems, especially for chronically ill patients in hospitals (Corbin and Strauss, 1988).

Since the publication of *“The Discovery of Grounded Theory”* in 1967, Glaser and Strauss have disagreed on “how to do” GT. Their differences of opinion resulted in a split in the theory between Glaserian and Straussian paradigms. Glaser emphasises the emergence of theory by data conceptualisation, with a less structured approach, while Strauss suggested a more structured approach to analysis through the constant comparative technique. An example of a nursing study that uses the constant comparative method was Forsythe et al (1984). The researchers used the constant comparative method to investigate the perceptions of hospitalized chronically ill patients (how patients framed the challenge their disease presented and the attitudes developed to meet that challenge).

In their writings on the GT approach, Strauss and Glaser did not explicitly state the underpinning criteria or principles of the GT method. It has been pointed out that there is no prescription for the writing of grounded theory specifically (Sandelowski, 1998).

However, a significant feature and strength of the grounded theory approach lies in the “cyclical process of collecting data, analysing it, developing a provisional coding scheme, using this to suggest further sampling, more analysis, checking out emerging theory until data reaches saturation when no new constructs are emerging” (Green and Thorogood, 2004: 180). The process therefore involves the collection of data and data analysis occurring concurrently (Polit and Hungler 1987), based on the constant comparative method (Wimpenny and Gass, 2000) which result in the generation of categories, thus shaping the researcher’s development of theories and theoretical propositions grounded in the data (Field and Morse 1985; Polit and Hungler 1987; Green and Thorogood 2004). Data obtained using the grounded theory approach may be inferred from listening to what participants have to say about themselves and others, from participant observation and from reading notes or literature or maintaining field notes (Field and Morse, 1985; Payne 1997; Eaves, 2001; Green and Thorogood, 2004).

So, what are grounded theory methods? Charmaz put it simply as: “grounded theory methods provide systematic procedures for shaping and handling rich qualitative materials” (Charmaz, 1996: 28). Basically, grounded theory methods consist of systematic and flexible guidelines for collecting and analysing qualitative data to construct theories "grounded" in the data themselves. The products of this methodology make a theoretical contribution in their own right and also add to existing theory and knowledge (Strauss, 1987). The guidelines offer a set of general principles and heuristic devices rather than formulaic rules (Dey, 2008). In other words, the task of the grounded theorist is to collect data and to develop theoretical analysis from the start of an investigation or study. The ultimate and principal aim of grounded theory methodology is to generate theory based on comparative analyses between or among groups of persons within a particular area of interest (Morse and Field, 1995). This is

why grounded theory research is also referred to as the constant comparative method (Glaser & Strauss, 1967).

In principle, the researcher using the grounded theory method does not start with existing theory but builds concepts up from the data. The researcher normally starts with collecting data and uses the data to generate a theory (Charmaz, 1996; Strauss, 1987; Glaser, 1978). The suggestion here is that similar data are grouped and conceptually labeled, then concepts are categorised. Categories are linked and organised by relationship; conditions and dimensions are developed, and finally a theory emerges (Strauss & Corbin, 1990; Glaser, 1978; Glaser & Strauss, 1967). Below, I list the features of the grounded theory approach:

1. A data collection and analysis stage is carried out simultaneously in a sequential series of phases.
2. Analytic notes and categories are developed from data; further data collection (or sampling) is based on emerging concepts.
3. Theoretical sampling refines, elaborates and exhausts conceptual categories.
4. Categories obtained from the data are constantly compared with the data obtained earlier so that commonalities and variations can be determined.
5. The processes and outcomes of the research are both shaped from the data.
6. Theory construction is derived from data acquired through interviews, observations, and documents.

Reflecting upon the three types of qualitative research methods, each has its own integrity, but there is no significant difference among these different modes in qualitative research (Flick et al, 2007; Burns, 2000). Principally, they all have similar features, namely, the purpose, area of enquiry, nature of data, research question,

sampling method, sample size, data collection instrument, and method of data analysis. They all collect data, code data, and search for themes and theory building. Most importantly, in order to obtain desired results in any research study, it is critical that the researcher selects a suitable method (Starks et al, 2007; Seale and Silverman, 1997), one that fit the needs and abilities of the researcher (Birks et al, 2006).

### **6.1.2 Methodological tools - value and limitations**

There is an array of techniques that make up the “toolkit” of qualitative research (Clark, 1997). Data collection strategies can include a mix of interviews (structured, semi-structured, or unstructured), observation (direct observation, participant observation, non-participant observation), texts or documents. Not all topics or phenomena are amenable to observation methods. Some researchers suggest that psychomotor activities and non-verbal activities are more suited to observation methods, while knowledge, attitudes and beliefs are better studied by either questionnaire or interviews or both (Parahoo, 1997; Polit and Hungler, 1999). However, much of human knowledge is obtained from observations, a particularly useful method for nurse researchers (Parahoo, 1997).

The observation method has its place in nursing research; for example, observations can be a rich source of data (Starks and Brown-Trinidad, 2007). However, this method has its limitations. For example, it can be impractical especially in health research settings because of the potential intrusiveness. Observation may create anxiety to the observed, including the patients and their families. It can also be disruptive to participants’ work routine and the environment. Observation can pose a challenge to the researcher as observer, and to the observed, especially when a researcher tries to blend into the work routine/ activities in the setting (Burns, 2000). Hostilities and resentment may be experienced by the researcher. For example, Li (2002: 121) says that she was “cold-

shouldered” by one of the nurses while conducting her study on psychosocial care in palliative care setting. A review of her study showed that direct or participant observation offers a comprehensive method to ascertain how nurses manage interactions with patients /relatives and others through talk. In this respect, I argue that in using observation methods, whether by direct observation or participant observation, the researcher must pay careful attention to his or her role in a particular setting under study.

Interviews, whether structured, unstructured or semi-structured, are probably one of the most used methods for obtaining information from participants in qualitative research (Burns, 2000; Fontana and Fey, 1998; King et al, 1994; Polit and Hungler, 1999). The objective of interviews in phenomenology and grounded theory is to draw out the participant’s story. Typically, the researcher is the listener and the participant is asked to give an account of their experience. Where necessary probing questions are used to encourage the participant to elaborate on details, and to make sure clarity is achieved. Therefore, the researcher will need to ask clarifying questions about the meaning the participant intends to convey. Multiple data collection methods such as participant observation, researcher reflection or journaling (memoing) and focus groups may be used, but these may play a secondary role to interviewing in grounded theory studies (Creswell, 2007).

There are benefits and disadvantages to using interviewing techniques. One of the main advantages of the qualitative interview is that it allows the participants to tell their own story, conveying their own particular experiences. Participants can provide powerful stories to illustrate and create meanings to their actions. Furthermore, an important feature of interviews is their flexibility. The interviewer has the opportunity to observe the participants in a given situation such as in a residential home. Furthermore,

observations can be made on the participants' non-verbal communication and the environment. Such observations may provide valuable information and give an added dimension to data collection (Burns, 2000). Additionally, questions and their meanings can be explained and clarified. The researcher (or interviewer) can also request additional information when a response needs further clarification. According to Gubrium and Holstein (2003), the interview conversation is a pipeline for transmitting knowledge. Even though interviews are taxing, this technique allowed for a higher response rate and allows for rich in-depth data to be collected. For example, participants are more hesitant to decline to talk to an interviewer who is directly in front of them than to discard or ignore a questionnaire (Polit and Hungler, 1987). One such example is Brennan's study (2008) using open-ended interviews to examine men's pregnancy-related feelings, physical and psychological symptoms. Brennan's study yielded rich data even with a small number of participants. Thus, the advantage of using the interviewing method is that face-to-face interaction is productive (Denzin and Lincoln, 1998; Polit and Hungler, 1999; Patton, 1990).

There are also disadvantages. Data collection by means of interviewing means that data had to be transcribed, analysed and coded at the same time, which is time consuming. Other shortcomings can be that participants may choose not to expose or reveal their true stories, even though interviewing is likened to prospecting for true facts and feelings from within the interviewees (Creswell 2007: 69). I present similarities and differences concerning the goal, methodology (strategy), analytic methods and the outcome of the three methods (see table 12).



**Table 12 - Similarities and differences concerning the goal, methodology and analytic methods of the three qualitative methods.**

<b>GOAL</b>		
<b>Phenomenology</b>	<b>Discourse analysis</b>	<b>Grounded theory</b>
Describe the meaning of lived experience of a phenomenon	Understand how people use language to create identities and activities	Develop a theory of social processes
<b>METHODOLOGY</b>		
Observation - observe participants in the environment where the phenomenon is experienced	Observation- observe participants in conversation in their natural environment	Observation- observes participants in a setting where social process occurs.
Interview - the participant describes experiences. Interviewer probes for detail and clarity	Interview- dialogue between the participants and the interviewer. Interviewer probes for meaning and clarity	Interview - the participant describes his/her experience. The interviewer probes for clarity and detail
<b>ANALYTIC METHODS</b>		
Identify descriptions of the phenomenon. The researcher then develops a composite description, representing the 'essence' of the experience or 'core' commonality of the individuals' experiences	Examine how meanings are created through language (interest is in the words, language)	Steps to follow- process of coding: open, axial and selective coding. Examine concepts, categories and integrate into a core category

## **6.2 Selecting my research design**

According to several writers (Green and Thorogood, 2004; Seale, 1999; Parahoo, 1997; Mason, 1996; Polit and Hungler, 1999), the main influences on any research design in nursing are the research question itself, the aims of the study, and the impact the study will have on nursing (changing) practice. Therefore, in order to meet the aims and objectives of my thesis, I addressed the following:

- the research approach: qualitative, using the constant comparative method,
- the methods of data collection: interviewing participants in a setting where social process occurs (residential homes),
- the resources: two sites, time and accessibility were negotiated with participants

### **6.2.1 Rationale for qualitative approach - the grounded theory method**

My reasons for adopting this methodological approach are twofold:

a) there is no research or information about the experiences of learning disability nurses caring for people with profound learning disabilities who are terminally ill in residential care homes. Most studies are on people with mild, moderate or severe learning disabilities (Chapter 2). This approach is likely to reveal insights into learning disability nurses' experiences and their perceptions of caring for people with profound learning disabilities who are terminally ill in residential care settings, b) learning disability nurses are significant carers in the lives of this group of people at the time of their terminal illness. Through their voices, solid and rich data can be obtained to elicit detailed and accurate conceptual and analytical issues.

My research study is modelled on the grounded theory approach as advocated by Glaser and Strauss (1967). This simply meant that data were gathered and analysed using the constant comparative process. The purpose of using this approach was to construct theory from the data. I thought it appropriate to employ a method modelled on the GT method to investigate the meaning that participants hold about their nursing experience; to explore from an emic perspective, understanding life from the perspective of the participants in the setting under study (Morse and Field, 1995). Moreover, I believe this methodological approach allowed me to contextualise what participants said in relation to their everyday experience. This is particularly important in this study where participants' views and experiences were central to the research. I wanted a clear framework in which there was a clear process which allowed me as the researcher to manage myself and the data in a style compatible with my personal characteristics, my

needs and ability as a researcher (Birks et al, 2006; Green and Thorogood, 2004).

Hence, my rationale for using this method.

Below, I list the features that best described my research design:

- I used the constant comparative approach modelled on grounded theory to generate concepts, categories and theory building. I adapted my interview guide to add areas to explore and to delete questions, after interviewing the first seven participants. This was done because I realised I could combine two of the questions. I adopted the 'zig'zagging' process (Creswell, 2007). This refers to the process where I was doing two things simultaneously, that is, data collection and data analysis were carried out at the same time. For example, I was out on site conducting interviews with participants, then back to base to analyse the data collected. Within this approach, I constructed frequency tables to show the distribution rate of occurrences of categories (seen in Chapter 7 on 'presentation of results'). The inclusion of frequency or numbers safeguards against criticisms of subjectivism (Seale, 1999). A systematic thematic content analysis of data from the transcripts was carried out manually and imported into the NVivo7 program.
  
- I engaged in theoretical sampling. Seale (1999: 93) says that "theoretical sampling is the process of data collection for generating theory, whereby the researcher collects, codes and analyses his/her data and decides what data to collect next and where to find them in order to develop his/her theory as it emerges". This process was repeated until the data reached saturation (Seale, 1999; Glaser and Strauss, 1967). Saturation means that no additional or new data are being found (Seale, 1999). Additionally, theoretical sampling is concerned with the selection of groups to a study that is meaningfully theoretically, because

it builds in certain characteristics or criteria that help to develop and test theory and explanation (Silverman, 2001; Seale, 1999). Mason (1996) argues that as researcher, one must overcome the tendency to select a case that is likely to support one's argument. Silverman (2001) suggests a way to avoid this is to search for negative instance (s), sometimes known as deviant case (s) that contradict or seem to contradict, the emerging data (theme or sub-themes) of the study. This approach will determine whether the theory holds up, thus confirming or disconfirming a given theory and offering a test of a theory (Patton, 1990).

In keeping with grounded theory, a total of 36 learning disability nurses comprising qualified and unqualified nurses were selected. The sampling population was learning disability nurses selected from a variety of residential homes from two NHS Trusts. Participants were those who had first-hand experience in looking after people with profound learning disabilities with a terminal illness.

- I engaged in a self-reflective process, also referred to as reflexivity. Several explanations have been put forward for the meaning of the term. Creswell (2007) defines "reflexivity" to mean that the researcher is conscious of the biases, values, and experience that he or she may bring to a qualitative study. Another definition is that reflexivity is the capacity to reflect upon one's actions and values during the research when producing data and writing accounts, and to view the beliefs we hold in the same way that we view the beliefs of others (Seale, 1999). Arber (2006) says that a reflexive approach enables one to understand how the researcher who is also a practitioner has an impact on those researched. Additionally, reflexive accounting enhances the credibility of one's

research findings (Seale, 1999; Coffey and Atkinson, 1996). Based on these statements, as a researcher, being reflexive, I examine my motives, my viewpoints and assumptions concerning my study. This means that at all stages in my fieldwork research, I documented my observations of the environment and participants' non-verbal communication. Because I was undertaking research in familiar environments, I was therefore privy to "insider" information. This was yet another good reason to keep notes in my reflective journal during my fieldwork. I included interpretations of observed activities during my personal interaction with participants in the care settings. Thus, an "audit trail" was maintained; a good approach for reflexive accounting (Seale, 1999). Brennan (2008) suggests that "audit" is useful for tracking and checking the researcher's research process and own status in the research sites.

- Seale (1999) suggests that the "audit trail" may involve peer auditors to check the research process. A peer auditor may be the researcher's supervisor, that is, if the researcher is a PhD student. Seale (1999) says that a student researcher's supervisor is suitably fitting to conduct such tasks. This way the researcher's approach would be checked for evidence that includes close scrutiny of the interview guide and amendments to it if necessary, examining the transcripts, derivation of categories and sub-categories and themes. Seale (1999) claims that this approach is less time consuming than conducting another or replicate qualitative study to establish reliability. To ensure reflexivity, I consulted my supervisors throughout the research process. My second supervisor was involved as an independent researcher in validating and auditing the research process.
- In addition, by keeping a journal, I was able to track the emerging impressions of what the data meant, how they related to each other, and how engaging with

the data shaped my understanding of the initial research questions. Additionally, the journal helped me to keep track of my thoughts and own emotional reactions (Gilbert, 2001). Arber (2006: 154) said: 'it is about how one feels, and not simply about the experiences and reflection of field work'. As a matter of fact, this happened in the first month of my project, when my brother died unexpectedly. I wrote in my research journal at the time how I felt and the tension about whether I was going to be able to cope with the grief and whether I should continue with the project. Being thousands of miles away from home it was difficult. This event struck me quite hard. I was reluctant to pick up books about death and dying, I did not want to talk about dying. This is an example which illustrates the benefits of keeping a reflective journal, for self-reflection, self-checking of one's emotion and journey throughout the project.

- Heidegger (1962) says that most researchers cannot possibly enter the field without possessing preconceived notions. Some claim that knowledge on the part of the researcher is a valuable guide to the research inquiry and makes data collection a meaningful undertaking (Lopez and Willis, 2004). In this instance, "bracketing" is an effective process to follow. It means suspending one's views, experiences, preconceptions, prejudices and beliefs (Parahoo, 1997). Taking into account the claims made, I observed the technique of 'bracketing' or setting aside (but not abandoning) one's background of understanding, knowledge and assumptions. For example, several participants talked about ensuring that their patients were comfortable and went on to describe how comfort was achieved. As a nurse, I am familiar with the expression 'comfortable', but bracketing the word helped me to take a fresh perspective, from the participants' viewpoint.

### **6.2.2 Rationale for using semi-structured interviews**

There were two principal reasons why I favoured the interview approach. Firstly, for many years people with profound learning disabilities were treated as little more than objects of scientific interest. In view of this, I wished to avoid being accused of reinforcing such stereotypical behaviour towards people with profound learning disabilities. Hence, I avoided the direct observation method and instead decided on the interview method. Secondly, I was aware that participants might use language common to them, for example, “challenging behaviour”, a term commonly used and understood among learning disability nurses (but this word did not arise during the interviews); therefore using interviews gave me the flexibility to rephrase the questions in interviewing some of the participants. Several researchers (Barriball and While, 1994; Hutchison and Wilson, 1992) support the claim that using this approach allows the interviewers the opportunities to change the words but not the meaning of the questions.

Below, I list my reasons for choosing semi-structured interviews as the tool for collecting rich and meaningful data from participants:

1. Clarification of ambiguous questions was instantaneous.
2. There was flexibility in the order of questions and phrasing of words and usage.
3. I was able to probe and tease out information from the participants, for example “in what way?”, or “what do you mean?” or “how can you tell?”
4. Face-to-face interviews allowed me to make observations regarding participants’ level of understanding as well as their action through non-verbal behaviour.

### **6.2.3 Choosing my research settings**

The choice of research setting depends much on the researcher's intentions (Green and Thorogood, 2004; Mason, 1996). My original research question was – “how does a learning disability nurse care for terminally ill patient with profound learning disability in residential care settings?” In view of the research question, I needed to situate myself in settings where I could locate learning disability nurses who had the experience of caring for this particular group. To find potential participants who were willing and had the interests and the specific experiences, I relied on my extensive local network. My experience of working in this field of nursing spans over 30 years; since then I have established extensive networks within my speciality (learning disabilities), both professionally and personally. I chose two large local NHS Trusts' residential care settings where I knew there would be sufficient learning disability nurses<sup>12</sup> who would be able to answer my research question. The term “learning disability nurse” was applied to include both qualified and unqualified care workers (nurses).

### **6.2.4 The setting profiles**

The residential care settings were located in South East England, identified as T1 and T2, managed by the National Health Service Trusts. The term “residential home” is deliberately used in this study to reflect the provision of care for people with profound learning disability in the settings. A “residential home” is a permanent substitute family home for the majority of the PPLD<sup>13</sup>. Learning disability nurses in the residential homes are the main carers, providing much of the care needed by their patients. Most of these

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<sup>12</sup> LD nurses now work in a range of community based setting such as nursing homes, residential homes and day care centres, among others. In this study, my focus is on LD nurses working in residential homes.

<sup>13</sup> In residential settings, the term ‘people’, ‘service users’, ‘clients’, or ‘residents’ are used interchangeably, but for the purpose of this study, they are referred to as patients because of their physiological changes or health condition.



homes comprise a large sitting room, dining room, kitchen, utility room, two or more toilets, bath and shower suitable for wheelchairs, an office and staff room which may be used as a staff sleeping-in room. Each patient enjoys the privacy of his or her bedroom, well furnished and decorated to the individual's choice and preference. The home routine is likened to a normal home environment (Wolfensberger, 1972).

The nursing organisational structures of each of the homes comprise a home manager, deputy home manager, care team leader or senior support worker and support workers (also known as care assistants). The home manager is normally a registered nurse for people with learning disability (RNMH/RNLD [the current title for a qualified registered LD nurse is Registered Nurse for Learning Disability - RNLD]). The deputy manager may or may not be a registered nurse. All other nurses, that is, care team leaders (also known as senior support care workers) and support workers (care assistants) are unqualified, but some possess job-related NVQs at Level 2<sup>14</sup>. All learning disability nurses work shift patterns. Normally, the morning shift starts at 07.00 hours and ends at 14.30 hours, the afternoon shift starts at 14.00 hours and ends at 21.00 hours and night shift starts at 21.00 hours and ends at 07.15 hours. Each learning disability nurse is responsible for his or her patient. This means the identified learning disability nurse is also the key worker or the named nurse<sup>15</sup> for the patient. The administrative tasks normally fall to the home manager and this responsibility is shared with the deputy home manager. Besides their administrative role, the home manager and the deputy home manager also have other nursing responsibilities; sometimes acting as a patient's nursing care coordinator. Most managers and deputy managers also have the added responsibilities of direct involvement in caring for their patients, but this may be

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<sup>14</sup> National Vocational Qualification Nursing (Level 2 or 3) - these qualifications are work based awards in England, Wales and Northern Ireland. NVQs are based on National Occupational Standards.

<sup>15</sup> Refer to Chapter 4, section 4.1.1 - what do learning disability nurses do?

dependent on the demands and complex health needs of the patients. The nurse manager, deputy manager and all other levels of nursing staff are located within the home with the patients.

There were similarities concerning the nursing organisational structure in both T1 and T2. The composition of nurses in each shift was a mixed population of female and male, qualified and unqualified nurses and from a variety of cultural backgrounds. The ratio of nursing staff to patients on average stood at 1 to 2, but sometimes 1 to 3 (full time equivalent). T1 and T2 maintained at least one psychiatrist and a team of psychologist who were normally located in the main administrative building.

T1 had 10 registered residential care homes for male or female adults with PLD. Out of these 10 homes, six were bungalows and the remaining were old large two storey buildings. There were not more than 10 patients, male and female, living in each of the homes.

T2 consisted of 15 residential care homes across two counties. The physical environment of each of these homes was similar to T1. The homes were either two storey or single storey building with gardens (see section 5.2.4) and usually had not more than 12 patients of both sexes.

In both T1 and T2, each individual patient had a nominated key worker matched as closely as possible to the individual's needs. Twenty-four hour patient care was provided on a shift basis, with one waking nurse at night and one nurse who "slept-in". Access to mainstream services in the community included the local GP for general routine health conditions, and the dentist.

### **6.2.5 Ethical considerations: entry, consent and confidentiality**

The study did not involve the collection of data from patients (PPLD). Learning disability nurses were the main focus of my study. The ethical principles outlined by Ramcharan and Cutcliffe (2001) were used as a framework to underpin this study. This was to ensure that my research study was properly conducted and monitored in accordance with professional, legal and moral principles throughout the whole research process, in order to protect participants' rights and prevent unjustifiable physical, psychological or emotional harm. I observed the principles as outlined:

- To respect participants' autonomy
- To promote and maintain beneficence and non-maleficence
- To observe the natural rules of justice

In addition, permission was sought from the ethics committee prior to commencement of my research in the field. Ethical approval was sought and granted from the University Research Ethics Committee (Appendix 7) and Local Research Ethics Committee (LREC) (Appendix 8). On entry to each of the research sites, I presented a brief paper to the gatekeepers, explaining the purpose of my research. For their information, I also showed them my research protocol (Appendix 2) which was part of my submission to the LREC. A gatekeeper within health care research has the power and control and responsibility to protect potentially vulnerable people (Holloway and Wheeler, 2002; de Raeve, 1994). However, it is also right that professionals are considered vulnerable if they are asked to participate in research. Therefore, observing and following the principles of gate-keeping, permission was sought and granted from both organisational and professional levels in the two NHS Trusts, that is, the Research and Development coordinators and the Directors of Nursing.

All participants were included on the basis of informed consent. A Participant Information Sheet (PIS) (Appendix 3) was provided to participants telling them of the purpose, aims and objectives of my research study. A consent form (Appendix 4) was provided for participants to sign as an agreement prior to interviews. All participants were given time to read through the PIS and any questions were answered prior to the start of the interviews.

Participants were informed and their permission sought regarding the use of audio tapes to record the interviews. Participants were advised that data collected would be used for the stated purpose, thus adhering to the Data Protection Act (1998). Since participants were asked to describe their experience of a given situation which might prove to be traumatic or emotional for some, arrangements for counselling on-site were made accessible if needed. Prior agreement had been made with the Directors of Nursing on both research sites. Participants were also informed of their right to withdraw from the study at any time and that data collection would be terminated. They were also assured of confidentiality and anonymity, and that audio-tapes / recordings and transcripts were stored safely under lock and key, and would be destroyed on completion of my thesis.

Participants were informed that quotes used in the “results” section of the research were anonymised. I also informed the participants that their identity and their patients’ would not be revealed in my research journal or in my final project (thesis) or future publications. Additionally, they were informed that a copy of the main study would be made available if they so wished. The publication of the study findings in future nursing literature would also be made available to them on completion of the project, if they so wished. However, they were informed at the start of the interview that any issues that might be detrimental to, or impact on the care, or health and safety of any persons with

learning disabilities may be brought to the attention of the Director of Nursing, care home manager or nurse in charge of the home.

### 6.2.6 The participants

The participants selected were those who had first-hand experience of caring for terminally ill people with profound learning disabilities in residential care homes. 36 participants were interviewed from two separate residential care homes. Participants in this study were learning disability nurses, but some were without a nursing qualification<sup>16</sup>. In T1, there were nine qualified learning disability nurses, of whom two participants had dual nursing qualifications. One participant held the sick children's nursing qualification [RSCN] and was a state registered nurse [SRN]), but without a learning disability nursing qualification (RNMS/RNMH). Another, a registered learning disability nurse (RNMH), also held the mental nurse qualification (RMN). In T2, there were eight registered nurses in learning disability nursing (RNMH). This included an SEN (MS) who did a conversion course to RNMH. The table (table 13) below shows the breakdown and demographic variables of participants.

**Table 13- Demographic variables of nursing staff interviewed**

Setting	Female	Male	Nursing Qualification	Average years of experience in the setting
T1	8	8	<b>(Qualified nurses = 9)</b> RNMH = 7 SRN and RSCN = 1 RNMH and RMN =1	12.5
			<b>(Unqualified nurses)</b> Health care support workers= 7	10.2
T2	13	7	<b>(Qualified nurses = 8)</b> RNMH(1 x SEN conversion to RNMH)	7
			<b>Unqualified nurses)</b> Health care support workers= 12	7.3

<sup>16</sup> For the purpose of this study, all participants were categorised as learning disability nurses.

### ***6.2.6 i Recruitment of participants***

The recruitment of participants was sought via gate-keepers (see also in section 6.2.5). The use of gate-keepers (Holloway and Wheeler, 2002; deRaeve, 1994) was necessary in this instance to ensure that participants were fully aware of the meaning of my research, and to ensure there was no unnecessary intrusion into the much-needed privacy of participants (and patients) in the residential homes.

All participants were in full time employment. The average length of qualified nurses' working experience for the participants in T1 were 12.5 years and T2, 7 years, while for those without a nursing qualification, the average number of years were 10.2 years and 7.3 years, respectively. In both settings, all participants had experience of caring for patients diagnosed with life-limiting illnesses/diseases. The most commonly reported types of life-limiting illnesses /diseases included breast cancer, bowel cancer, cervical cancer, prostate cancer, ovarian cancer, cancer of the oesophagus, pancreatic cancer and non-specific cancer.

The suitability, screening and identification of all participants was therefore carried out by me and the Director of Nursing, thereafter with the care home managers or nurse in charge of each of the residential care homes. The process by which I recruited and identified potential participants was as follows:

- i) visiting the Trust to discuss with the Director of Nursing potential learning disability nurses as participants (see footnote 17)
- ii) contacting the care home manager or nurse in charge for permission to talk to potential participants who were eligible for interview
- iii) setting up informal meetings with participants and handing out Participant Information Sheets about the research project

- iv) setting up an individual meeting with each participant to obtain signed consent to the interview

The above process was important to establish a level of trust and comfort in the relationship between all participants and myself.

**6.2.6ii Inclusion and exclusion criteria**

- I. Participants must have experience in caring for terminally ill patients with profound learning disabilities in residential care settings (homes) within the last two years.
- II. Only competent English speaking participants were included.
- III. Participants who did not have experience in caring for terminally ill patients with profound learning disabilities were not included.
- IV. Non-English speakers or those who had communication difficulties/communication needs were not included.

**6.3 Data collection**

**(a) Interviews**

I spent a total of eight months interviewing (audio-taping) participants, as shown in table 14 below.

**Table 14 - Data collection: timeline**

	7 <sup>th</sup> March 2007	Research protocol granted and approved by LREC
T1	April to August 2007	Conduct interviews
T2	February to April 2008	Conduct interviews

There were two parts to the interview guide (Appendix 1). All interviews included closed and open-ended questions. The first part of the interview guide consisted of questions related to the participant’s demographic information. It was anticipated that

obtaining such information would allow me to understand the nurses' educational and training background. The second part related to my research questions, but there was flexibility in the phrasing and order of the questions. It also allowed me to "probe" deeply (in-depth) and clarify issues (Parahoo, 1997). I was careful in how I used probes because I wanted to ensure that participants were not led nor influenced in any way during the interviews.

In both settings, T1 and T2, most interviews were conducted in a quiet corner of the sitting room. The interview was organized to take place around either mid-morning or mid-afternoon. The reason was because most of the patients would be out in the day centre and it was considered as the quiet period when most nurses were free to be interviewed. Throughout the interviewing, participants were asked to talk through their experience of caring for a particular patient. Participants were interviewed in a sensitive manner, using the in-depth approach. Interviews lasted between 40 to 60 minutes and were transcribed verbatim. Silverman (2001) says that the use of audio tape recordings is an increasingly important part of qualitative research which provides an excellent record of natural occurring interaction.

*(b) The reflective journal*

This was done promptly after each interview, as I wanted to capture the immediacy of the experience. In writing my journal, I would describe my observations made about the different participants' approaches, their mannerisms, reactions and responses. I also noted how I was received during the interviewing process as well as a description of the ambience of each of the homes I went. This approach is also suggested by writers such as Charmaz who believed that as researchers, one 'learns nuances of your research participants' language and meanings' (Charmaz, 1996: 36).



## **6.4 Methods of data analysis**

The interviews produced large amounts of rich data, which was managed systematically during the analytical process. I used the NVIVO 7 software package to help with processing the data. Using the constant comparative method, three stages were closely followed (Dey, 2008; Strauss and Corbin, 1998), namely open coding - this means examining, comparing, and categorising data; axial coding - this means re-assembling data into groupings based on patterns within and among the categories identified in the data, and selective coding - this refers to identifying and describing the categories or themes in the data.

### **6.4.1 Content analysis**

Transcribing - I transcribed the audiotapes (verbatim) after each interview.

Sensing - With the help of my second supervisor, we went through the first five transcripts. Thus, “sensing” the data was crucial; this is an important part of the process of analysis (Li, 2002; Payne, 1997). Each of the transcripts was scanned line-by-line. Each piece of transcript (alongside the notes) was read at least three times to get a sense of the script in search of data patterns from words and phrases, and to ground myself in participants’ lived experiences. Key words and phrases were highlighted with coloured highlighters. These key words were then written on the right margin of the each of the transcripts. Reflexive notes were also used to form the initial concepts and categories.

Sorting - With the help of my second supervisor, all similar data segments were identified, and grouped together to formulate a category and transferred onto an A3 flip chart. We spent half a day organising the data into category headings; for example, “longitudinal knowing” was to become my main theme. Following the format set, I proceeded in applying the same principle in my data collection across the two research

sites. Using the constant comparative method (Glaser and Strauss, 1967) data was collected and analysed in one setting and then used to compare to the interview data collected in the second setting. Using this method allows testing the reliability of a set of data generated from one setting to see whether it is supported in the second setting (Li and Arber, 2007; Silverman, 2000; Hammersley and Atkinson, 1983). This procedure determines patterns or categories in the data.

At this point, I like to add that I borrowed the technique of conversation analysis (CA) (Drew and Heritage, 1992) in categorising the data. By this, I meant that I identify data consisting of words/ phrases used by participants at their place of work. Drew and Heritage (1992) say that language or words used by people at their place of work, such as in a health care setting is a useful analytic tools for validating categories that would lead to the generation of theories. However, they did not assign specific headings, labels, or classifications to words or phrases.

In my content analysis, I was interested in how learning disability nurses present themselves as “knowing the patient well” in their assessment and recognition of patients’ changing health conditions. I looked for words/ phrases used in participants’ verbatim accounts. This involved establishing categories which linked participants’ verbatim accounts and counting the number of instances (simple word counts). Li (2002) and Silverman (2001) say that counting (frequency) shows the importance of each category as topics in participants’ talk. I created six different sub-categories (not in any priority order), labelling them as “markers”. Each of these “marker” were shown to be relevant to how learning disability nurses recognise and assess their patient’s changing health status (see table 15). For example, participants to show qualitative distinctions in the patients’ behaviour pattern over a period used temporal devices (“normally”, “had”, “used to”, “before”). Maximum markers showed the severity or

intensity of a patient’s health condition, for example, “very, very”, or “an awful lot”. Contrast markers “but” or “until” were presented to describe a difference about patients’ changing health conditions. Measurement markers were indicative of the degree or extent of patients’ health conditions, for example, “suddenly”, “quite”, “massive”, “just”. Observation markers demonstrated the act of paying attention, for example, “notice”, “see”/ “seen”. Uncertain markers such as “might”, or “possibly” were to demonstrate that participants were unsure of patients’ changing health conditions.

**Table 15 - ‘Markers’ and frequency distribution - learning disability nurses’ talk in constructing the “normal and the pathological” continuum**

Markers		Words/phrases	Number of times	
Categories	Temporal devices - past and present tenses	“used to”	19	
		“before”,	25	
		“had”	8	
		“normally”,	27	
		“now”	7	
		“one minute”,	3	
		“next minute”,	1	
		“usual”	25	
	Maximum marker		“very, very”	4
			“constantly”	3
			“always”	11
			“an awful lot”	1
			“all”	25
			“quickly”	6
			“never”	10
			“lost”	5
			“a lot”	9
	Contrast marker		“so quickly”	11
			“but”	1
		“until”	5	
	Measurement marker		“just”	8
			“quite”	12
			“suddenly”	6
			“massive”	1
	Observation marker		“notice”	28
			“see/ seen”	19
	Uncertain marker		something”	2
			“seem”	2
			“possibly”	3
			“maybe”	1
		“suspected”	1	
		“might”,	2	
		“not quite sure”	1	

Furthermore, I noticed participants talk included the use of figurative language or metaphors to demonstrate meanings about a patient’s health condition, and to express the image of a patient. For example, “going downhill” implied the worsening of a

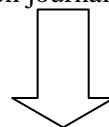
patient's health condition; while "hibernation" implied withdrawal from the outside world (this was specific to a patient who isolated herself from others). According to Lakoff and Johnson (1980), a metaphor is a mental construction that helps us to structure experience and to develop our imagination and reasoning. In other words, the reasons for using metaphors are to conceptualise, to represent and to communicate one's thoughts. This has support in Froggatt's (1995) thesis in which she says that using metaphors has its place in death and dying situation. Thus, metaphors are important devices, and a useful strategy in learning disability nurses' work in caring for dying patients, within residential care homes.

Little research has been conducted to test the use of linguistic devices in learning disability practice and PPLD. However, attention has been paid to the importance of language and use of metaphors in others (Froggatt, 1995; James, 1986; Hockey, 1991). It is beyond this PhD thesis to provide a detail analysis of metaphors or use of language as my methodological choice is not on discourse analysis.

I present a simple diagram - figure 1 (page 153), to show the process of my data analysis.

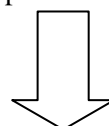
### **Figure 1: Analytical sequence for generation of data and formulation of a theory**

Immediately after each interview, data was transcribed and reflexive notes made from my research journal.

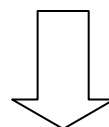


Sensing the data - interview transcripts scanned line -by- line in conjunction with my research journal to form initial patterns and emerging themes.

Use of NVIVO 7 – qualitative software to process data and assign labels to annotations.

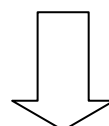


Reflect and group similar phrases and key words and label to form categories, sub categories and themes. Use large (A3 size flipchart) paper to lay out categories, sub categories in order to get a clearer picture and to gain a sense of ‘the whole’ in answer to my research question.



Emerging categories renamed as themes, identified and validated with independent researcher and selected participants. Formulation and re-formulation of several categories, sub-categories (sub-themes) by sorting out, cutting and pasting words and phrases under each of the headings.

Reviewing and collapsing and finally formatting the main theme and sub-themes



Presentation of the themes (in chapter 7), thus constructing a theory.

### **6.5 Methodological rigour of the research study - reliability and validity**

Seale (1999) and Silverman (2001) say that rigour and validity are important in qualitative research. Tuckett (2005) suggests several ways of ensuring rigour and validity of research. These include keeping a field journal, audio recording and transcript auditing. Additional strategies included negative case(s), and member checking and thick descriptions. Below, is a list of how I achieved rigour in my study as outlined in Seale and Silverman’s (1997) principles:

- Supporting generalisations - Seale (1999) and Silverman (2001) point out that simple counting is a good way to enhance validity, and avoid being accused of anecdotalism. This was addressed in my presentation of a table that shows frequency for using intuitive knowledge (Chapter 7, table 20) and how learning disability nurses established and constructed the “normal and the pathological” continuum (chapter 6, table 15). Another dimension which adds rigour to the research is to ensure that my findings can be generalised beyond the setting in which they were generated. In other words, the range of settings chosen was representative of a wider population. One way of achieving this is the use of theoretical sampling (see below).
- Ensuring representativeness - theoretical sampling was adopted. The selection of participants and settings addressed my research questions, aims and objectives. I also paid attention to negative or deviant cases. Deviant cases help to refine the analysis, a method for improving the quality and rigour of research (Silverman, 2001; Seale, 1999). I searched for, and discussed elements in the data that contradicted, or seemed to contradict, the emerging explanation of the emerging theme and subthemes (final theory), but none was found in this study.
- Using computer assisted analysis - NVIVO 7 (Lewins and Silver, 2007) was used to input data collected, for coding and categorising purposes. This ensured systematic analysis of data. The use of NVIVO 7 also provided the possibility in conducting a search and analysis of deviant case (s), but none was found.
- Examining transcription through “member checking”, also known as ‘respondent (participant) / validation’ (Sines and McNally, 2010; Silverman, 2001; Seale, 1999). Interestingly, Morse and Field (1995) suggest that member

checking as an indicator of validity is nonsense, unless implemented and approached in a manner that follows step by step, piece by piece checking, during the research process. Hence, member checking occurred at a follow-up in-depth interview after my initial coding and categorising of transcripts/ data. Selected participants from each research site were involved in checking interview transcripts, to check for accuracy, verify categories and sub-categories. My second supervisor also scrutinised the transcripts/data (five transcripts) independently. We then met and discussed our respective coding and categories derived from data analysis.

- Research field notes (analysing my documents) - “Thick” description is proposed as advancing the claim for transferability or generalisability of a qualitative study (Miles & Huberman 1994; Lincoln & Guba 1985). Classically, “thick” description is achieved in participant observation, where long periods of fieldwork in the setting are likely to provide an adequate level of detail. Thick description refers to detailed understanding and accounting of field experiences in which the researcher makes explicit the patterns of cultural, social relationships and the use of languages in natural settings (Flick et al, 2007; Creswell, 2007; Seale, 1999). It was not possible for me to engage in long periods or detailed observational research work due to limited resources in terms of time required to be at the research sites, in addition to my other reasons as indicated in section 6.2.1. Thus, I adopted the interviewing method using audio tapes to record data comprehensively. I kept a research journal throughout the process. This included reflexive accounting that contained detailed notes about the whole research process. I noted down my research process, my role as the ‘insider-outsider’ researcher, my observations of the settings, information about the participants, my perceptions and

interpretations of interactions and impressions formed in the field. All information was typed-up in hard copy and filed.

### **6.6 On being an “insider” and an “outsider” researcher**

The term “insider researcher” is used to describe a researcher who has direct involvement or connection within the research setting (Robson 2002; Hockey, 1993; Stephenson & Greer, 1981). In setting T2, I was the visiting link nurse tutor for students on practice placements. Therefore, I knew and was known to the staff in most of the homes. From this perspective, I was a researcher on the “inside”. There are advantages being an “insider” researcher. Hockey (1993) claims that the “insider” researcher shares the social world of the research participants and that there is less likelihood of his or her experiencing any culture shock or disorientation. In this respect, I concur with Hockey; I understood and was familiar with the participants’ language, the terms and phrases used in the settings. I knew the hierarchical position of members within the group, and their work. Being an “insider” researcher, I was able to short-cut much of the mutual familiarisation stage. I was able to establish a good working relationship easily. Participants were enthusiastic about my research, and were able to speak freely, honestly and openly during the interviews. There were laughter and crying (emotion shown by two participants) (see chapter 9, reflections) when they recounted their stories during the interviews. Hockey (1993) suggests that participants are more likely to reveal details to someone considered empathetic. In addition, Tierney (1994) says that an “insider” researcher has the potential to increase validity due to the added richness, honesty, fidelity and authenticity of the information acquired.

While there are benefits to being an “insider” researcher, there are also pitfalls. One potential difficulty with being an ‘insider’ researcher is over-rapport between researcher and participant. The issue of over-rapport is that the researcher might lose sight or



objectivity of the research. For example, if the researcher was too sympathetic with the participants, this might potentially distort the data, thus discrediting the information obtained (Green and Thorogood, 2004). One of the ways of overcoming this difficulty is that the researcher manages the situation by ensuring an acceptable distance or stepping back (Arber, 2006), but still continues to show active listening and interest and keeping the interview focus.

In T1, I considered myself an “outsider” researcher. By this, I mean I had no direct involvement, personally or professionally in the homes. However, some staff knew me as a nurse lecturer and research student undertaking a research project towards a PhD. Schutz (1976: 100) describes the “outsider” researcher as a “stranger”. He says that it is important for the researcher to be ‘accepted or at least tolerated’ in order to carry out one’s research. Several writers (Le Gallais, 2003; Hockey, 1993) are in also agreement with Schutz’s claims. Le Gallais (2003) and Hockey (1993) suggest that the “outsider” researcher needs to gain the trust of staff, convince them of one’s integrity and trustworthiness, and not be considered a “spy”. Initially, I wondered how I was to be perceived by staff because of their experience with the Healthcare Commission, namely negative comments made about their delivery of care some twelve months earlier. I did not want to cause unnecessary concern to staff nor did I wish to be perceived as a “spy”, or someone from the education camp attempting to evaluate the work in the setting. In view of this, I was prepared that staff might choose to refuse to participate in the study. To overcome the potential for such concerns and feelings of social distancing, after consulting the Directors of Nursing, I called a meeting with the home managers and staff in each of the homes prior to conducting my interviews. Staff were informed of the aim and purpose of my research and were assured that information given would be treated with respect and confidence. In addition, I assured the participants that I was not there to criticise their work, nor an expert in caring for terminally ill PPLD. I worked at

making the staff comfortable and relaxed during the interviews. Following Arber's (2006: 150) approach and attitude as the "outsider" researcher, "I did not ask too many questions, I attempted to look engaged, alert and interested". This approach worked because participants in T1 volunteered to talk as much as those participants in T2. Adopting a relaxed and approachable stance avoided being perceived as threatening to some people. Arber (2006: 150) says "access to data often depends on keeping on good terms with people". I spent about four months in this setting interviewing participants. I showed willingness by joining in the social activities in the home, depending on the time of day. There were occasions where staff invited me to join them (staff and patients) for morning or afternoon tea. Throughout the time spent conducting my fieldwork, I felt the staff were helpful, welcoming, and genuinely interested in my research. I did not feel that staff were trying to impress upon me or influence the perception of their image. I suspect self-presentation (Goffman, 1959) becomes important when people (staff in this case) want to obtain sympathy or want to show that they are competent and doing well on a job. Goffman (1959) says that sometimes individuals will present or act in calculating manner. Thus, keeping a research journal was crucial, recording my own actions and observations made each time I visited and when interviewing staff in the home. Taking into account what Goffman says, I did not detect feigned attitude, behaviour, or statements made. I believe participants genuinely wanted to partake because the research was worthwhile.

### **6.7 Methodological contributions**

The aim of using grounded theory is to generate or discover a theory (Dey, 2008). To achieve this aim, Seale (1999) claims that one must ensure credible evidence. To make sure the research is credible, the researcher must approach the development of a theory using the cyclical process of collecting data, analysing it, and developing a provisional

coding scheme. From here, the researcher can only then proceed to further sampling, more analysis, checking out emerging theory, until a point of saturation is reached. This is when one can justifiably claim that evidence has been obtained and verified through dense and rich theoretical accounting. However, to do justice to my piece of research, I adhere to the constant comparative method where the key principles are the same as those advocated within the pure grounded theory approach. Using both the inductive and deductive methods, I moved back and forth between emerging theory and data, until no new data was revealed. Li (2002: 293) points out that a good piece of research produces data that is “reflexive” and not “journalistic” or “anecdotal”. Following this pattern, I was aware that I should not stop or dismiss any categories of data. Every bit of data counts toward generating a theory. I constantly re-visited my original data, comparing and contrasting nurses’ accounts to provide empirical evidence about their experiences of care for terminally ill PPLD. Thus the dynamic of nurses’ talk was a big part of generating as many codes, potential or concrete. There was no one right code or categories at the stage of collecting or analysing data because it was about refining concepts throughout the whole process. So the constant checking of data, comparing both within and between cases, and asking the general question – “what is going on here” is important (Green and Thorogood, 2004, p 181).

I have shown that I have increased the reliability of my findings in the following ways: I highlighted participants’ expressions and use of terms in their descriptions of events and situations, for example using temporal devices, “normally”, “used to”, “before”. I also showed the characteristics of expressions used in participants’ talk, for example the use of markers to indicate intensity (maximum marker), measurement, and uncertainty of events or situations. These markers are constructed and shown in table 15 (see

section 6.4.1, content analysis). I also showed key words and phrases used by participants; these are evidence of their expressions, thus authenticating the data.

Thus, using the constant comparative method, supported by evidence of participants' own expressions and language leads to increased confidence in the validity of the analysis (Li, 2002).

## **6.8 Conclusion**

In this chapter, I provided an overview of some qualitative methods. I then proceeded to discuss my methodological choices, the process and procedures of data collection and data analysis. I showed that the methods chosen for my study were consistent with my research questions, aims and objectives. This is reflected and demonstrated in theoretical sampling. I described the steps taken in collecting my data. I demonstrated that my theory is grounded in the data using multi-methods within this qualitative study. I showed that I have incorporated audiotape recordings, interviews, member validation and research journals. I showed that my final theory was data driven using the constant comparative method. Finally, I described how I ensured rigour of my research study, and my role as both an "insider" researcher and an "outsider" researcher, thus increasing the validity of my data.

## **Chapter 7**

### **Presentation of Results**

## 7.0 Introduction

This chapter presents the results of the study. The main theme and sub-themes are shown in table 16 below. Illustrative extracts with direct quotes from participants (data) are then presented and interpreted in section 7.1 to section 7.5.3.

Table 16 - Themes and sub-themes emerging from data analysis

MAIN THEME	SUB THEMES			
	1 “KNOWING THE PATIENT WELL”	2 “UNCERTAINTY OF KNOWING”	3 “CERTAINTY OF NOT KNOWING”	4 “COMFORT” CARE
“LONGITUDINAL KNOWING”	<ul style="list-style-type: none"> <li>• <i>Strategies “Intuition”- ‘sensing and noticing disease-related behavioural change’ and ‘sensing and noticing disease-related physical changes’</i></li> <li>• <i>“Commonsense” knowledge</i></li> <li>• <i>“Commonsense” knowledge and “formal” knowledge</i></li> </ul>	<ul style="list-style-type: none"> <li>• <i>LD condition masking illness / disease (diagnostic overshadowing)</i></li> <li>• <i>Lack of experience</i></li> </ul>	<ul style="list-style-type: none"> <li>• <i>Gaps in knowledge about the pathophysiology of illness/disease</i></li> <li>• <i>Lack of skills in using a syringe driver to manage pain in cancer</i></li> </ul>	<ul style="list-style-type: none"> <li>• <i>Longitudinal presence of the nurse</i></li> <li>• <i>Physical comfort - positioning and personal cleanliness of the patient</i></li> <li>• <i>Pain relief</i></li> </ul>

As shown in the above table (table 16), “knowing the patient well” (sub-theme 1) means “knowing” what is “normal” for the individual patient. In this study, the concept of “knowing the patient well” derives from “personal knowing” and experience over time. I named this way of knowing as “longitudinal knowing” (main theme). LD nurses in this study learnt to know their patient well through years of close contact and direct involvement. On average, an LD nurse spent more than seven years caring for PPLD in residential care homes (chapter 6, table 13). In-depth knowledge of the patient gained over time therefore allows them to establish a baseline of the physical appearance, characteristics and behavioural patterns of what is “normal” and what is not. “Knowing the patient well” allows LD nurses to separate out the signs and symptoms that are attributed to the physiological effects of diseases from the “normal” types of behaviour that are attributed to the nature of the person’s LD condition. The strategy of “knowing

the patient well” therefore makes it possible for LD nurses to capture the early onset of illness and disease.

In this study, participants also revealed that they relied on other strategies for the recognition of patients’ changing health conditions. They are “intuition”, “commonsense” knowledge and a combination of “commonsense” knowledge and “formal” knowledge (table 16). In this study, participants (LD nurses) described “intuition” as knowledge based on “gut instinct”, “feeling”, “strange feeling”, “an inkling” (see also table 21). This knowledge - “intuition” strengthened by “knowing the patient well”, served as a warning signal that something was not right with the patient. This study also showed LD nurses used “lay language” and “technical language” to describe patients’ changing health conditions. My study also showed that four out of the 36 participants had difficulty recognising symptoms of ill health. These included two qualified and two unqualified LD nurses. I labeled this difficulty as “uncertainty of knowing” (sub-theme 2, table 16). “Uncertainty of knowing” means LD nurses were not sure whether the observed change in behaviour was a sign of an illness / disease.

Sub-theme 3 relates to “certainty of not knowing”. In this study, “certainty of not knowing” refers to gaps in knowledge. Participants were clear that they lacked knowledge about the nature of pathophysiology of illness / disease. They also identified a lack of skills in using a syringe driver to relieve a patient’s pain associated with cancer (table 16).

Sub-theme 4 relates to “comfort” care. This refers to the actions performed by participants to relieve patients’ discomfort. I showed that giving “comfort” care was dependent on how well participants knew the patient longitudinally. Participants described the three actions performed in relieving patients’ discomfort. They were (i)

longitudinal presence of the nurse (ii) positioning and personal cleanliness of the patient and (iii) pain relief (table 16) (this aspect will be presented in section 7.5.3 under “certainty of not knowing”).

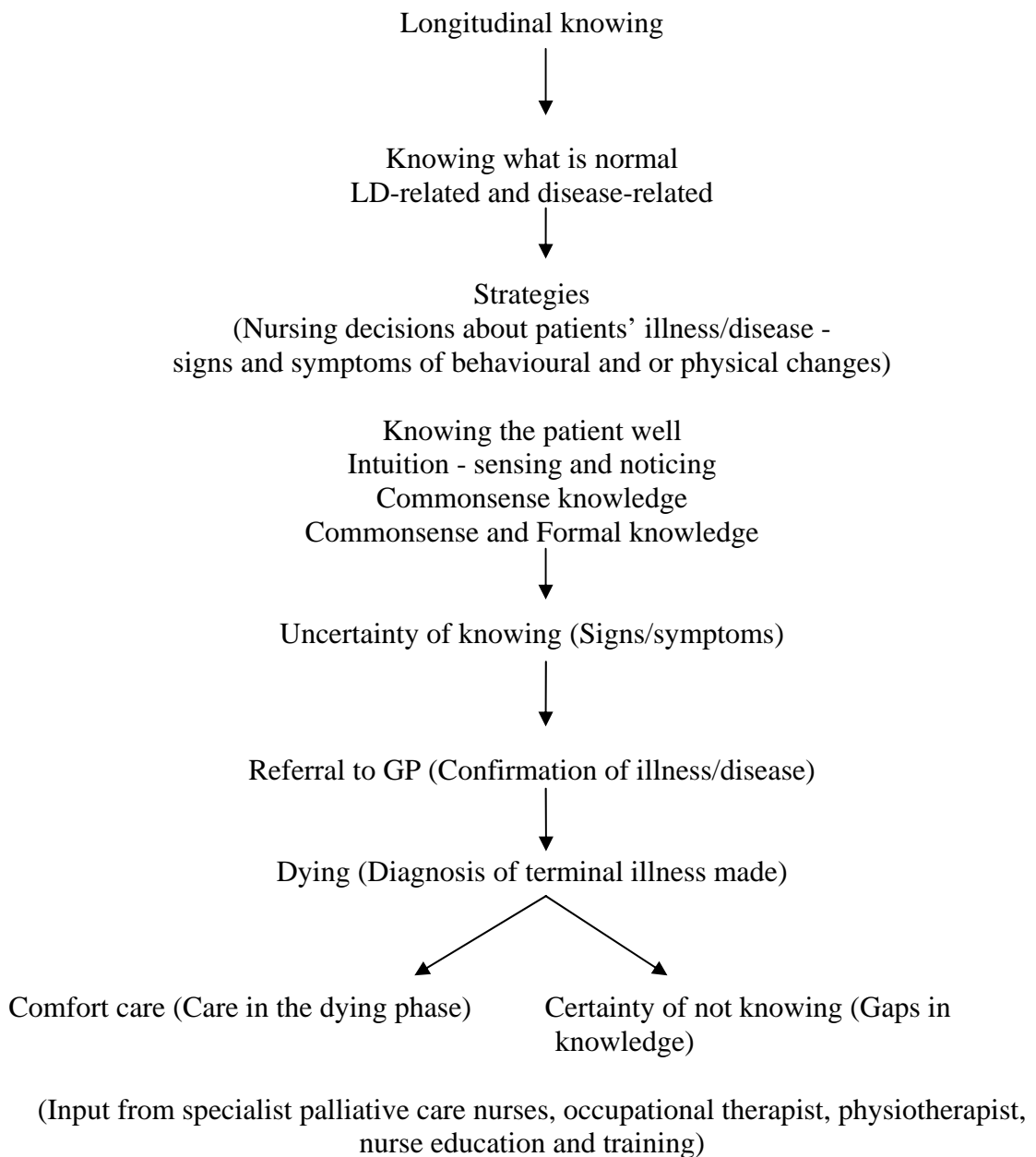
From the main theme and sub-themes, I developed a pathway of assessment - the “normal and the pathological continuum” (figure 2, page 165). This “continuum” has been a useful method to establish a systematic approach for LD nurses to achieve timely and comfort care. “Longitudinal knowing” enables LD nurses to notice patients’ habits and behaviours. Their noticing helped them to locate health deviation from LD-related behaviour. The continuum shows how LD nurses construct different ways of knowing a patient’s changing health status. I showed that LD nurses acted on their intuition, derived from “knowing the patient well” and took immediate actions on observing physical changes and behavioural changes. I showed that “lay” and “technical” language gave LD nurses a vocabulary to describe and report patients’ changing health status.

The continuum shows that “uncertainty of knowing” means LD nurses are not sure whether observed changes in behaviour are due to LD-related or disease-related conditions. Some patients’ illnesses /symptoms may not be easy to identify because they do not show particular characteristics. In addition, diagnostic overshadowing (Hendren et al, 1990) occurs where the assumption is made that the way the patient presents symptoms is due to their learning disability condition. The continuum shows “certainty of not knowing” means LD nurses could locate gaps in their knowledge about patients’ illness/diseases. The gaps in knowledge are addressed through education and training and filled by specialist palliative care nurses, occupational therapist and physiotherapist. This continuum shows that “comfort” care is delivered through collaboration between



LD nurses, specialist and palliative care nurses, occupational therapist and physiotherapist.

**Figure 2 - The Pathway of Assessment - the “normal and the pathological continuum”**



I also provide operational definitions for the categories, presented in table 17 below. The table includes the main theme and sub-themes generated derived from data analysis in this study.

**Table 17- Operational definitions of the analytic categories**

Longitudinal knowing	The concept refers to knowing the patient well, derives from in-depth personal knowing and experience of the patient over time.
Knowing the patient well	This means knowing what is 'normal' for the individual patient, that is, establishing a baseline of the physical and behavioural patterns of what is the 'normal'. I categorise these as noticing disease-related behavioural changes and noticing disease-related physical changes.
The normal and the pathological continuum	The concept of 'normal' is described as the state of health which is free from medically defined disease, while a change to the normal healthy state, its bodily functions or behaviour, is termed 'pathological', a response to an illness (Canguilhem,1989).
Noticing disease-related behavioural changes	This refers to moments when participants (LD nurses) observe a change in the patient's behavioural patterns, in comparison with how the patient normally behaves. The changes in the patient's behaviour suggests the presence of a disease affecting the patient's actions or conduct.
Noticing disease-related physical changes	This refers to the moment when participants notice clinical signs or physical changes to the patient's body. Noticing a clinical sign or signs of a physical change means a change to the patient's normal healthy state and bodily functions.
Uncertainty of knowing	This refers to the moment when participants are not sure whether physical changes are due to disease or learning disability related conditions.
Intuition	This refers to participants' knowledge based on "gut instinct/ reaction", a method participants drew in the recognition of patients' changing health conditions, supported by longitudinal knowing.
Commonsense knowledge	This refers to the use of lay language that is commonly used to describe and report signs and symptoms.
Formal knowledge	This refers to the use of technical language which is academically based; knowledge developed and acquired from experience and practice of a particular discipline. In this study, nursing is the focus of the discipline.
Certainty of not knowing (gaps in knowledge)	This refers to moments when LD nurses know for sure that they lack knowledge about the pathophysiology of illness/disease and the use of a syringe driver. They identified several strategies to fill these gaps, for example, use of expertise of specialist palliative team, attending study days, accessing websites, nursing journals and nursing books.
Comfort care	This refers to the actions performed by participants to relieve a patient's physical discomfort. They are longitudinal presence of the nurse, positioning and personal cleanliness of the patient and relief from pain associated with the patient's disease throughout the illness trajectory.

## 7.1 Constructing “Longitudinal knowing”; “knowing the patient well” and “intuition”

The analysis of data demonstrated that the source for recognition of patients' (PPLD) changing health condition began with LD nurses' longitudinal association and experience of working with their patients. Longitudinal association refers to the length of time that spanned a number of years of knowing the patient well. Through

longitudinal (temporal) knowing and understanding, it was not difficult for participants to distinguish signs and symptoms of ill health. “Knowing the patient well” has positive outcomes. Following on from this, participants in this study showed that “knowing the patient well” strengthened their “intuition”. I sub-divide this category into (i) “sensing and noticing” disease-related behavioural changes and (ii) “sensing and noticing” disease - related physical changes.

The analysis of data showed 24 out of 36 participants reported “sensing and noticing” disease-related behavioural changes. The behaviours described comprise positive as well as negative changes. Table 18 below shows indicators of marked behavioural changes observed by participants. Indicators included patients refusing food, not drinking, rejecting fluid, being withdrawn, lethargy, less vocal, more active, more interactive and more alert.

**Table 18- Indicators of marked behavioural changes observed by participants.**

Lethargy	Withdrawal	Refusing food
Loss of laughter	Unable to do things	Not eating
No longer smiling	Becoming less vocal	Not drinking
No longer enjoying food	No longer interested in food	Becoming more accepting
Rejecting fluids	Becoming unsociable	Becoming more interactive

Extract 1 below is an illustration that showed how “knowing the patient well”, supported by “intuition”, enabled participant Q2 to recognise a change in health had occurred.

Extract 1

1. “He normally likes to have a rough and tumble, used to have a cheeky
2. grin. I now noticed a difference - he lost that smile completely, never
3. saw the smile once returned when he became ill. All the years of
4. knowing him, he was someone who loved his food, enjoyed his food,
5. but now he is different, I noticed he started refusing food, refusing
6. fluid, rejecting fluid and started throwing-up. I thought it was unusual,
7. it’s not like him to refuse food. I sensed something wasn’t right, so
8. referred him to the doctor and he was diagnosed with cancer of the
9. pancreas”. (Q2)

Here, participant Q2 presented himself as someone who knew his patient well. For example, he knew his patient “normally” likes to have a rough and tumble, “used” to have a cheeky grin, “loved his food” and “enjoyed his food”. The phrase “all the years of knowing” (longitudinal knowing) (between lines 3 and 4), led him to “sense” that something wasn’t right (between lines 7 and 8) about his patient’s health condition. He reported that he “noticed” a “difference” in his patient’s behaviour. All these behaviours – “likes to have a rough and tumble, have a cheeky grin, loved his food and enjoyed his food” “now” appeared to have been lost. He presented his patient as someone who “lost that smile completely”. Furthermore, he noticed that the smile “never once returned” (between lines 2 and 3).

Here, temporal devices (past and present tense) were used to show qualitative distinctions in the behavioural pattern. The terms “normally”, “used to”, “before” were used to reflect past behaviours, prior to becoming unwell. The word “now” represents the moment in time when a change in behaviour had occurred, while contrasting words such as “but” and “different” (Drew and Heritage, 1992) were used to represent a significant change to behaviour.

Participant Q2 also used maximum markers (Drew and Heritage, 1992) to represent the loss of previously known behaviour that cannot be recovered. The terms included “completely”, “lost” and “never”. Furthermore, signs of “refusing food”, “refusing fluid”, “rejecting fluid” and “throwing-up” are clear indications of a person who is not well. The display of such behaviours was considered not ‘normal’ when comparing to how he would normally behave.

In this extract, a behaviour that was “unusual” (line 6) was viewed as uncharacteristic for this patient. Here, “sensing and noticing” a difference in the behavioural pattern functions as a warning signal that “something wasn’t right”. In this case, the participant’s “intuition” strengthened by “knowing the patient well” led him to believe that his patient’s health had altered (Canguilhem, 1989). It was therefore necessary to “refer him to the doctor”.

This extract showed that the source for recognition of a patient’s changing health condition was based on “knowing the patient well” which was supported by “intuition” (King and Macleod Clark, 2002; Cioffi, 2000; Davies-Floyd and Davis, 1996; Rew, 1990; Benner and Tanner, 1987; Benner, 1984). This extract showed that these finely tuned abilities come from many years of direct involvement, observation and care. This way of involvement is regarded as “longitudinal involvement”.

Another participant (Q7), extract 2 below, also demonstrated the actions he followed after he “noticed” and “sensed” that his patient was becoming unwell. Here, participant Q7 described having to respond to his “intuition”.

#### Extract 2

1. “She was slightly mobile, used to move from chair to chair,
2. she was normally withdrawn- a quiet lady who liked her own
3. company, liked her own space, and she would normally cover herself
4. up with the duvet, a sort of hibernation, sort of not wanting to interact.
5. These were her normal patterns of behaviour. When you got to know
6. her enough you soon picked up, and you noticed she would not
7. immediately pull the duvet over her head, but out of the blue she was
8. putting her head out, so suddenly she was accepting contact, more active,
9. more than what she was before, more alert than she was and more
10. interactive, so when that sort of thing changed, you sensed something
11. was not right. You know you just couldn’t ignore this type of strange
12. feeling, but thought best to call the doctor.” (Q7)

In this extract, participant Q7 presented himself as someone who knew his patient well. For example, using temporal devices of past tenses, he described his patient as someone who “was” slightly mobile, “used” to move from chair to chair, “normally” withdrawn, “normally” covered herself up. The use of past tenses demonstrated how well participant Q7 knew his patient, that is, how his patient normally and typically responded. He also used comparative devices to compare and contrast the manifestation of behavioural patterns observed. For example, from someone who was ‘normally withdrawn’ to someone “more accepting”, “alert” and “active” (alert and active usually would be regarded as the person becoming better, but this was not the case in this situation). Here “sensing and noticing” a difference in behaviour suggests “something was not right” with the patient. This way of “longitudinal knowing” then, enabled participant Q7 to notice the qualitative differences between what was normal and abnormal behaviour for this patient before the onset of illness.

The analysis of the above data shows that “knowing” the patient’s typical pattern of responses created a “feeling” that guided the participant’s perceptions and actions. Here, participant Q7 was able to pinpoint certain aspects of behaviour as salient when compared to this patient’s typical picture. Tanner et al (1993) state that this type of qualitative distinction occurs through “knowing the patient”. They suggest that this type of knowledge derives from the nurse working closely with the patient. However, in the above extract, I demonstrated that “longitudinal knowing” enabled participant Q7 to not only know his patient, but know his patient “well”.

Participant Q7 also used metaphors to describe a marked difference, for example, ‘hibernation’ (line 4). The term “hibernation” represented someone [patient] who “liked her own space”. The expression “out of the blue” represented unexpectedly or without

warning. The term “suddenly” was applied to pinpoint that a noticeable change of behaviour had unexpectedly occurred. As such, observations of behavioural changes clearly indicated that his patient was unwell. Here, using metaphors provided visual images that characterised social action.

The analysis of data also showed that participant Q7 presented himself as someone who used his intuitive ability to home in on the signs and symptoms of ill health. For example, the phrases “sensed something was not right” and “strange feeling” represented intuition. Furthermore, the expressions “got to know her enough” and “soon picked up” conjured up meanings of understanding gained from “knowing” the patient over time. This clearly suggested that participant Q7’s intuitive ability was gained from experience and time spent with his patient. Here, “intuition” served as a function in the recognition of the patient’s changing health condition, linked to “experience” and “knowing the patient well”. The extract above demonstrated that intuitive knowing also relied on “longitudinal knowing”. This way of knowing can also be seen in the next extract (extract 3).

#### Extract 3

1 “All these years when you are with the person you somehow know, a feeling  
2 that something wasn’t right. I notice a massive change in her behavior - not  
3 her usual self. I mean you get to know the different types of laughs, the sort  
4 of cries, the looks when she gets tired. You get to know all these little things  
5 about her. It is also something that you see from experience, from seeing lots  
6 of cases. I have been to so many homes, so well, I can only say it did make  
7 me think and feel that something was happening, so I called the doctor.  
8 We (nurses) were later told she had cancer and there was nothing more they  
9 could do for her.” (U12)

Here, participant U12 presented herself as someone who knew her patient well, through a long and established relationship. This was shown in line 1- “all these years with the

person". The word "all" represented the extent of time, which accounted for her understanding about her patient's actions such as the "laughs", the "cries" or the "tiredness". She prided herself in knowing the different types of laughs - this meant she could reason and differentiate the sound of cries. She could distinguish the different "sort" of laughter and the "looks" when she [patient] was tired. Participant U12 described noticing a "massive change" in the patient's behaviour, but did not clarify what she meant by massive. Here, a linguistic device was used to signify a "big" or "substantial" change in the patient's behaviour. The phrase "massive change in behaviour" could be interpreted as an effect of pathology or a disease which altered the state of the patient's health. In this case, "a massive change of behaviour" appeared to be not learning disability-related, but a reaction to a disease - "pathological".

In this extract, the analysis of data showed that knowledge of the patient's manner and behaviour were key factors that led participant U12 "feeling that something wasn't right" with the patient. This way of knowing required "longitudinal knowing". For this participant, "feeling that something was happening" was linked to past experiences of "seeing lots of cases" and having "been to so many homes". Here, it was also clear that past situations stood out. This type of recognition and assessment of a patient's changing health condition is often a result of several experiences of similar cases and remembering similar situations (Benner, 1984). Consequently, as demonstrated in this extract, "longitudinal knowing" supported by "intuition" and past experiences enabled participant U12 to recognise that her patient was unwell.

In this extract, "intuition" emerged from a longitudinal process of learning and knowing about the person, that is, "knowing the patient well", heightened by past experiences of similar cases. This type of "knowing" has been referred to as "gestaltist" or nursing gestalt (Davies-Floyd and Davies, 1996; Rew, 1990; Benner and Tanner, 1987;



Schraeder and Fischer, 1987; Benner 1984; Pyles and Stern, 1983) (chapter5). Thus, for this participant, on “sensing and noticing” a change in behaviour, a decision was made. She acted – “I called the doctor”.

Regrettably, among PPLD, the diagnosis of cancer is often too late (Mencap 2007b; Tuffrey et al, 2005; McEnhill, 2004; Brown et al, 2002; Mencap, 2001). A delay in diagnosis means a delay in treatment and risk to patients’ lives. Here, participant U12’s description fits several cases reported in early studies (Mencap 2007b; Tuffrey et al, 2005; McEnhill, 2004; Brown et al, 2002) where “nothing more could be done” concerning late cancer diagnosis.

A similar theme can also be seen in the next extract.

Extract 4

1. “Yeah, I had an inkling that he was ill. I mean having known him
  2. for a good number of years. He liked to sit at the table with the
  3. others at meal times. He was sociable you know. You could see
  4. the difference - I noticed he didn’t look well, looked withdrawn, no
  5. longer want to sit with the others, isolating himself from the others. It’s
  6. not like him. All these things together makes me feel that something
  7. was the matter. I had a feeling that something was not right, so rang the
  8. doctor to have further tests to find out what was wrong. He was
  9. diagnosed with bowel cancer. We were told it was the late stage”.
- (U32)

Here participant U32 described having an “inkling” that his patient was ill. In this extract, “inkling” represented “intuition” - a type of knowledge that could only be gained from the accumulation of personal knowledge and experience of the patient. On this basis, participant U32 was able to establish that his patient was unwell through “longitudinal knowing” demonstrated in his phrase: “a good number of years” (line 2). He described his personal knowledge and experience about his patient’s behaviour based on “a good number of years”. The emphasis was on the adjective “good” - this

suggested “quality”. This extract clearly showed that “longitudinal knowing” was an important factor based on a good number of years (quality and quantity of time) which increased the participant’s level of intuitive awareness about the patient.

He also described his patient as someone who “used to sit at the table with the others at meal times” and was “sociable”. This suggested he knew what his patient was like, before the onset of illness. This showed a contrast of behaviour, a picture of someone who was previously “sociable”, but “now” “isolates himself from others”. Thus, the perception of a changed behaviour, together with how he felt –“an inkling” and “feeling that something was the matter” led him to conclude that his patient was unwell.

In addition to “knowing his patient well”, using the power of observations, participant U32 “noticed he [patient] didn’t look well”, “looked withdrawn”. He interpreted his observations as signals that “something was the matter” with his patient. Thus, “sensing and noticing” a change of behaviour and a change in the physical appearance served as warning signals that his patient was unwell. The above description supports several studies (Benner and Wrubel, 1989) whereby knowing the patient’s characteristics, habits and preferences were important for nurses in the recognition of ill health.

The data presented so far demonstrated that LD nurses learned to use intuition, reinforced by “knowing the patient well” to discover a change in a patient’s health status. Indeed, “sensing and noticing” is a function, a way of assessing and recognising a patient’s changing health condition that demands immediate attention. Consequently, “longitudinal intuition” enabled LD nurses in this study to recognise changes to patients’ health status.

The data showed participant U32 did not ignore his “intuition”. A “feeling” associated with intuition led him to ring the doctor to ‘have further tests’ to find out what was wrong with his patient. Here, nursing decision-making was due to “intuition”, reinforced by how well he knew his patient, that is, through “longitudinal knowing” – “a good number of years”.

In this extract, participant U32 also reported a late diagnosis of cancer, for example, “we were told it was the late stage”. Here, it seems that detection of an illness was too late for the patient. Several studies showed that too often cancers among PPLD were not picked up quickly (Mencap 2007b; Tuffrey et al, 2005; McEnhill, 2004; Brown et al, 2002).

### **7.1.1 Sensing and noticing disease - related physical changes**

30 out of 36 participants reported “sensing and noticing disease-related physical changes” as the clear onset of an illness. For example, they included “the presence of a lump” on the breast, “haemorrhaging”, “physical deterioration”, “constipation”, “diarrhea”, “incontinence of faeces”, “loss of weight” and “raised temperature”. Table 19 shows indicators of marked physical changes observed by participants.

**Table 19 - Indicators of marked physical changes observed by participants.**

Change in bowel habits	Changes to shape of nipples	Fever
Blood in urine	Presence of a ‘lump’ on the breast	Loss of mobility (unable to walk)
Urine retention	An area of enlargement on the breast	Loss of appetite
Constipation	Hardness of the breast	Weight loss
Incontinence of faeces	Flatulence	Jaundice
Diarrhoea	Physical deterioration/weakness/fatigue	Bleeding

The following extract provides an example of how participant Q33 ‘sensed’ and ‘noticed’ disease - related behavioural and physical changes.

Extract 5

- 1 “You could see he was becoming disinterested in things around him.
- 2 I mean normally he was quite jolly, and excitable. I used to look after
- 3 him when he was in another home. He used to eat well, now he was not
- 4 eating - you could see he was losing weight, the look of him, the
- 5 changes, he was becoming weaker and becoming inactive. I
- 6 sensed something was wrong.” (Q33)

Here, participant Q33 demonstrated that he knew what his patient was like before, for example, “normally jolly and excitable”, “used to eat well”. The terms “normally” and “used to” were temporal devices which function to indicate “normal” health status, while the word “now” was used to convey the moment in time when a change in behaviour had occurred.

Added to the observation of behavioural changes, participant Q33 also noticed changes in the patient’s physical wellbeing such as “losing weight”, “becoming weaker” and “becoming inactive”. Here, “noticeable physical changes”, together with observations of behaviour changes were sufficient indicators of someone becoming unwell. The participant’s ability to assess his patient was based on “longitudinal knowing the patient well” from past experience when he “used” to look after him in another home. Consequently, “knowing the patient well” included “intuition” which enabled LD nurses in this study to recognise changes to the patient’s health status.

So far, it seems that past experiences and “longitudinal knowing” are essential strategies in the development of intuitive knowledge. This is also demonstrated in the next extract (extract 6):

#### Extract 6

1. “She wasn’t the girl I knew, she used to walk about and now she
2. never goes out. She has lost a lot of weight. She lost her appetite for
3. eating. Before this, she used to enjoy food. She was going downhill so
4. quickly. I remember a similar situation with another patient in another
5. home whom I looked after for several years. You know it is this type of
6. experience that gives you this kind of feeling - a gut reaction that
7. something is wrong with the patient. I reported to the GP on the same
8. day when he visited the home” (Q9)

Participant Q9 also presented herself as someone who knew her patient well. Participant Q9 used temporal devices to describe what her patient was like before the onset of illness. For example, she used past tenses “used to” and “before” and present tense “now” to represent the time-frame of “longitudinal knowing”.

Participant Q9 also described her patient as someone who “used to” enjoy her food, “used to” walk about. She further described that these behaviours no longer existed. She also reported that her patient had “lost her appetite for eating” and “never” goes out “now”. These behaviours appeared to have been lost. She also observed several physical changes such as “lost a lot of weight”, “lost her appetite for eating”. Thus, “longitudinal knowing” enabled participant Q9 to notice changes that indicated that the patient’s health had altered; from the normal to the pathological status.

Participant Q9 also used maximum markers such as “never”, “lost”, “a lot” to emphasise the level and degree of changes identified. She also used metaphors, to represent the image of someone becoming suddenly unwell. For example, “going downhill so quickly” implies that the patient’s health had deteriorated very rapidly. The function of metaphor in this case helps us to understand the speed of change in her patient’s condition from a well person to an unwell person.

Here, participant Q9 also showed that identifying a patient's changing health status was based on past experiences through "longitudinal knowing". For example, she claimed that she remembered "a similar situation" with "another patient whom she looked after for several years". This supports Benner's study (1984) relating to "similarity recognition". However, my data shows that "longitudinal knowing" is the principal process for LD nurses' early recognition of patient's changing health status. This is where my study differs from Benner's work.

The next extract also shows how a participant uses a patient's documented history to identify a patient's changing health condition.

#### Extract 7

1. "I have known him for several years, he has a history of manual
2. evacuation. This was also documented in his care notes. We noticed
3. he had a change of bowel habits, he had an awful lot of wind, and
4. he just looked very, very uncomfortable. We discussed amongst
5. ourselves, check out his records again and thought he is not right. So,
6. my gut reaction was to get him check out by the local doctor, then at
7. the hospital."(Q21)

In this extract, participant Q21 explained that he knew his patient "for several years" (longitudinal knowing), but "knowing" the patient's "history" added to his knowledge in establishing the patient's changing health condition. It seems therefore that a patient's "history" (past record) is an important resource which this participant Q21 drew on to make an assessment of his patient's condition. It allowed him to make a comparison of what was "normal" for his patient and what was not. For example, the documented "history" gave us an insight that this process of habitual manual evacuation was 'normal' for this patient. Consequently, the descriptions such as "a change of bowel

habits”, “an awful lot of wind”, “looked very, very uncomfortable” were noted as anomalies in light of the patient’s past “history”.

In this extract, participant Q21 also reported involving members of staff in the home to make a nursing decision about the patient’s changing health condition. For example, participant Q21 used the term “we”, a collective pronoun to refer to the nursing team being involved. Here, confirmation of the patient’s illness from the nursing team - “amongst ourselves” and checking out his [patient] records “again” were ways of reaffirming that his patient’s health had altered.

In this extract, participant Q21 used a maximum marker to illustrate the level of discomfort experienced by the patient. For example, expressions such as “an awful lot” and “very, very “ were used to demonstrate the intensity of the patient’s condition. He also used a combination of technical language and lay language to describe his patient’s physical condition. For example, “manual evacuation” is a technical term for the manual act of emptying the bowel. “Wind” is a non-technical term, that is, lay language. The term “wind” suggested that the patient suffered from flatulence, a formation of gas in the digestive tract.

In relation to the above extract, participant Q21 claimed he had “to convince” the doctor that his patient was not well. (Extract 8 below is a continuation of extract 7):

#### Extract 8

1. “Got one of the nurses to take him to the doctor.
2. You know, it took a few weeks to convince the doctor that
3. my patient was not well. You know these doctors, they don’t believe
4. you, you know. So, by the time he was seen, it was too late, his
5. cancer was already at the last stage” (Q21)

This extract demonstrates that nurses sometimes encounter problems in their attempt to convince doctors when a patient is not well. It seems then that the risk of not being believed by others such as the “doctor” is detrimental to the patient’s health condition as shown in this extract.

This extract is an example of how a nurse’s “personal knowledge” through “longitudinal knowing”- “I have known him for several years” (see extract 7, line 1) is crucial to the identification of a patient’s changing health condition. Furthermore, it also shows that it is difficult to convince doctors without hard clinical evidence as they appear not to accept nurses “intuitive knowledge”. Rew (1988) claims that even though intuition is a respectable and an important function of the assessment process, some doctors might not understand the significance of it. Using intuitive knowledge is supported by several writers who argue that intuition aids nurses in anticipating interventions (Cioffi, 2000; Rew, 1990). It is crucial then that nurses’ continuous and long relationship (longitudinal knowing) with the patient serves an important role in making clinical judgements. Thus, “intuition” supported by “longitudinal knowing” complemented by knowing the patient’s “history” were important components in how nurses identify and recognise a change to the patient’s changing health condition.

A similar theme that shows “longitudinal knowing” strengthens “intuition” in the recognition of a patient’s changing health status can also be located in the next extract.

#### Extract 9

1. “He moved into this home about more than five years ago or so, settled
2. in well. This is a friendly place, a small home. There is good
3. relationship between nurse and patients. Whenever you are on duty he
4. would be there with a smile, all ready for you. Just one day like, I
5. noticed he wasn’t himself, he looked unwell, one minute he was fine,
6. and next minute, I mean it happened so quickly, he had difficulty



7. passing water, there was blood when he passed water. I had this feeling
8. there was something not right, so called the doctor". (U31)

The analysis of this data demonstrated that participant U31 had a "good relationship" with her patient. She claimed that relationship was established when his patient moved in five years ago. In this sense, a good relationship is premised on establishing a longitudinal relationship with patients. Here participant U31 described her patient as someone with a "ready smile" whenever she was on duty. She also presented the home as a "friendly" place where "good" nurse-patient relationships could flourish easily. Here, participant U31 implied that it was easier for patient to "settle well" in a small home. From the above description, the suggestion is that a small home allows greater opportunity and time for nurses to get to know their patients well.

Through "knowing her patient well", participant U31 "noticed" that the patient "looked unwell", had "difficulty passing water", and there was "blood" when he [patient] passed water. The behavioural changes and physical changes were signs and symptoms interpreted as altered bodily functions - "something not right", a deviation from "the normal to the pathological continuum".

She further described that her patient's health condition occurred unexpectedly and speedily - "so quickly". Here, temporal devices - "one minute", "next minute" - were used to indicate "timeframe" when the patient's physical situation had taken a turn for the worse.

Here, participant U31 demonstrated that her action taken inferred the sense of salience (Benner and Tanner, 1987), and a response to "intuition" - "feeling something was not

right”. Guided by her “intuitive knowledge” and sense of salience, participant U31 took action- “so called the doctor”.

The analysis of data showed that even though participants were not asked what they did with their intuitive knowledge, through “longitudinal knowing”, their intuition has led them to take immediate nursing actions, thus averting delays in diagnosis. They either “referred”, “reported” or “called” the doctor. Table 20 below shows some examples of the consequences of “intuition” experienced by learning disability nurses in residential care homes.

**Table 20 - Examples of what learning disability nurses did in response to experiences of intuition**

“referred him to the doctor.” (Q2)
“called the doctor.” (Q7)
“called the doctor.” (U12)
“reported to the GP.” (Q9)
“get him check out by the local doctor, then at the hospital.”(Q21)
“called the doctor.” (U31)
“rang the doctor”. (U32)

So far, the analysis of data shows that participants’ responses about patients’ changing health conditions are fundamentally to prevent delay in diagnosis and treatment. Such actions might have enabled patients to receive timely treatment and appropriate care, thus avoiding unnecessary suffering and early deaths (Mencap, 2007) (Chapter 2).

Table 21 below shows the number of instances (frequencies) and key phrases spoken by participants, which in the contexts used, can be interpreted as expressions that showed intuitive knowledge.

**Table 21 - Descriptors and frequency for using intuitive knowledge**

<b>Intuitive knowledge</b>	<b>Frequency</b>
1 Had a feeling that something was happening	3 (8.3%)
2 Got a feeling that something was not right	3 (8.3%)
3 Somehow know within yourself	1 (2.7%)
4 Sensed something wasn’t right	5 (13.8%)
5 Somehow know something wasn’t right	5 (13.8%)
6 Sensed something was going to happen	4 (11.4%)
7 An inkling	7 (19.4%)
8 A feeling that something was the matter	6 (16.6%)
9 Gut instinct	4 (11.4%)
10 Strange feeling	4 (11.4%)
11 A bit strange	4 (11.4%)

## 7.2 “Commonsense” knowledge

The analysis of data in this study demonstrates that “commonsense” knowledge is premised on “longitudinal knowing”. “Commonsense” knowledge served as a tool to help nurses make decisions about a patient’s changing health condition. The notion of “commonsense” is seen in the layman’s language nurses used. Both qualified and unqualified LD nurses used lay language to describe patients’ changing health status.

Extract 10

1. “I was bathing her one morning and noticed a very, very hard lump on
2. the client’s right breast, different from the left one. So straight off to
3. the phone, I rang the senior nurse on duty and told her that I found a
4. lump on (named patient) right breast, and immediately make an
5. appointment for her to see the doctor. Shortly, she was diagnosed with
6. cancer of the breast.” (U13)

In this extract, participant used lay language to describe a change to her patient’s breast. For example, a “very, very hard lump” is lay language, commonly used to describe a swelling, indicative of a tumour. Participant U13 also used a maximum marker to describe the severity of her patient’s condition - “very, very”.

Here, participant U13 presented herself as someone who acted quickly on observing signs of abnormalities on the patient’s right breast. The hardness of the right breast signified “abnormality” - a “pathological” reaction. It is common knowledge that a healthy breast would not feel “very, very hard” when touched. So, for this participant, “noticing” a “very, very hard lump” led her to take action, that is, to “ring the senior nurse on duty” and “make an appointment for her [patient] to see the doctor”.

This data also demonstrates that noticing a change to the patient’s physical appearance such as “a very, very hard lump” necessitates urgent attention. This was shown in

participant U13's use of the word "immediately". Furthermore, this data shows that when a nurse knows her patient well (this participant had spent 11 years caring for the patient), it is not difficult to differentiate bodily changes to a patient's appearance. In this extract, "commonsense" knowledge derived from "longitudinal knowing" ("very, very, hard lump") alerted LD nurses to notice a deviation from the "normal" health status. Thus, participant U13's immediate nursing action was clearly a result of knowing what was "normal" and what was not for the patient.

This data shows that early identification can prevent early deaths (Mencap, 2007b; DOH, 2003a; DOH, 1995a). Generally, breast self-examination is not possible for PPLD. Reports also suggest that PPLD are not offered routine screening due to consent issues (DOH, 2003a) (Chapters 2 and 3). It is therefore necessary that all staff must be vigilant and committed to ensuring that monthly routine checks are in place in residential homes. The above extract shows "longitudinal knowing the patient well" becomes even more important in preventing adverse or unnecessary delays in diagnosis. Significantly, "longitudinal knowing" enables nurses to recognise and notice illnesses/diseases, thus averting serious consequences.

The combined use of "longitudinal knowing" and "commonsense" knowledge can be located in the following extract.

Extract 11

1. "She looked tired, she would sit or lie down in a curled-up position. She
2. wouldn't eat, and she was off her food, started to refuse her pudding.
3. Normally she preferred her pudding over other food. You see she has a
4. sweet tooth. For her to refuse her pudding- a favourite, well this was not
5. right. Also, we noticed she was bleeding heavily from down below. She
6. was admitted to A&E and we were told she had cancer. I think they
7. confirm cervical cancer" (U23)

In this extract, participant U23 presented herself as someone who through “longitudinal knowing”, knew that her patient’s health status has changed. She knew what her patient was like. She knew her patient’s “favourite” food and preference. For example, she knew her patient “preferred eating pudding” and had a “sweet tooth”. This statement implied that participant U23 knew her patient well. Here, participant U23 used “lay language” to describe her patient’s behaviour. She presented an image of someone who really enjoyed eating puddings. This data showed that this way of personal “knowing” is longitudinal.

Participant U23 revealed that her [patient] started to “refuse her pudding- a favourite”. In this extract, a contrast to the patient’s behaviour, denotes a change to the patient’s health condition. This became more apparent with additional physical signs such as “looked tired”, “sit or lie down in a curled-up position” and “bleeding heavily from down below” (“down below”- euphemism/ lay language). The signs and symptoms observed present a distinctive physical clue that the patient was in a poor state of health. Thus, the display of a change in behaviour and changes to bodily functions when observed to be not “normal” showed that a change to the patient’s normal healthy state had taken place - a reaction to the “pathological” state. This extract showed that through “longitudinal knowing”, participant U23 learned to understand the consequence of the signs and symptoms presented.

In this extract, participant U23 also drew on “lay language” to describe a change to the patient’s health status. For example, the expressions - “bleeding heavily” and “down below”. This data shows that LD nurses working in residential homes commonly use “lay language”. However, my data also shows LD nurses do use a mix of “lay language” and “technical language” to describe and report patients’ changing health

conditions. The use of a mix of lay and technical language can be located in the next extract below.

#### Extract 12

1. “Yeah, he was a noisy and a cheerful chap most of the time. Normal
2. for him really. He had no speech, but noticed he wasn’t eating and
3. looked uncomfortable and tensed. I mean you could see the facial
4. expression, he was grimacing, he was holding and rubbing his tummy,
5. his abdominal region. His ‘poo’ was like watery and the unusual stench
6. whenever he went to the toilet. We all commented on how horrible the
7. smell was. I remember reading nursing journals about various
8. diseases(we keep them for students) and eventually going to the doctor
9. with him to find out what was wrong. Stool samples were taken, came
10. back with the result that he had bowel cancer.” (U22)

In this extract, it was apparent that early intimate knowledge of a patient’s behaviour gave rise for concern. Intimate knowing relies on “longitudinal knowing”. Here, participant U22 described his patient as someone who was “noisy and cheerful most of the time”. This implied he knew what his patient was like before the onset of the illness which allowed him to notice a difference in the patient’s behaviour, for instance, signs and symptoms of discomfort included “looked uncomfortable”, “facial expression”, “grimacing” and “holding” and “rubbing his abdominal region”. Such a description represented the image of someone who was without doubt in distress - an unwell person.

The analysis of data showed that participant U22 used a combination of “lay language” and “technical language” to describe his patient’s symptoms. For example, lay language included words such as “tummy”, “poo”, “watery”, “stench”. Technical language included terms such as “abdominal region”, “stool” and “bowel cancer”. It is possible to hypothesise that “reading nursing journals” allowed participant U22 to become familiar

with using technical terms, hence the description. On the other hand, unqualified nurses working in a nursing culture are mostly familiar with specific-nursing words and situations, especially if they are also working closely with qualified nurses. Specific nursing words may be picked up and learned easily, provided the nurse is encouraged to do so. In this extract, participant U22 presented himself as someone who seemed to have taken the step of “looking up nursing journals” to find out what was wrong with his patient.

The analysis of data shows that LD nurses sometimes use a mix of languages, that is, “lay” and “technical” knowledge when describing and reporting a change about their patients’ changing health. The data shows that “longitudinal knowing the patient well” is as important and necessary as understanding and knowing the typical signs and symptoms of illnesses. Table 22 shows some examples of lay language and technical language used by unqualified LD nurses to describe the signs and symptoms of illnesses/diseases.

**Table 22- Some examples of lay language and technical language used to describe signs and symptoms by unqualified LD nurses**

	<b>Lay language</b>	<b>Technical language</b>
<b>Unqualified nurses</b>	a very, very hard lump	abdominal region
	curled-up position	stool samples
	bleeding heavily down below	bowel cancer
	tummy	cervical cancer
	“poo”	epilepsy
	watery	rectal
	stench	autistic spectrum
	smell	prostate cancer
	painkiller	dementia
	fits	

Table 23 below presents some examples of lay language and technical language used by qualified LD nurses to describe the signs and symptoms of illnesses/diseases.

**Table 23- Some examples of lay language and technical language used to describe signs and symptoms by qualified LD nurses**

	<b>Lay language</b>	<b>Technical language</b>
<b>Qualified nurses</b>	a lump	peritonitis
	nipple	tonsillitis
	fits	appendicitis
		Down's syndrome
		Alzheimer's disease
		dementia
		plateau
		quick decline
		fever
		loose stools
		deteriorating progressively
		marked deterioration
		anatomy
		underarm nodes
		enlarged
		inverted
		thickening in one area
		quick decline
		fever
		epilepsy
	biopsy	
	mastectomy	

My data also shows LD nurses using both “formal” and “commonsense” knowledge to describe signs and symptoms of illnesses/disease. This can be located in the following examples:

### **7.3 “Formal” knowledge and “commonsense” knowledge**

Extract 13

1. “This was a lady with Down’s syndrome who died of Alzheimer’s
2. disease last year. Nursing literature shows that Downs are prone
3. to Alzheimer’s with typical signs and symptoms. Of course for her it
4. was a typical case. I had nursed another patient several years ago.
5. At first there was no significant changes or signs, but then a marked
6. deterioration soon after, then a plateau, followed by a quick decline in
7. the last 6 months. She couldn’t move, she had to be nursed in bed all the
8. time. If you put her in a position, she will stay like that. She used to sit
9. up and move back and forth to music. From what I saw, I knew she
10. wasn’t going to last long and the doctor did confirm it anyway.” (Q18)



The above extract clearly showed that participant Q18 knew her patient well. She described her patient as someone who “used to sit up and move back and forth to music”. Additionally, participant Q18 clearly showed that she kept abreast with “nursing literature”. She revealed that her experience gained from “nursing another patient several years ago” helped her to see [“saw”] that her patient “wasn’t going to last long”. So, through “longitudinal knowing” and formal knowledge about the disease (Alzheimer’s disease) she knew her patient’s condition was terminal.

The above extract reflects participant Q18’s use of technical language to describe a patient’s health condition, for example, “Down’s syndrome”, “Alzheimer’s”, “plateau”. She also presented herself as someone who “knew how” (theory-based) the disease would develop, for example “a marked deterioration soon after”, then a “plateau”, followed by a “quick decline in the last 6 months”. It seems that this participant is familiar with the language; she talks fluently about Down’s syndrome and Alzheimer’s disease.

This data also demonstrates the value of “knowing” based on past experience (Benner, 1984) and learning obtained from formal nursing education. What Benner suggests is that past experience, in addition to formal education preparation, is required to understand illnesses. However, the data presented above shows that “longitudinal knowing”, in my study, provides the foundation for decision-making about a patient’s changing health condition. The emphasis in my study is on “longitudinal knowing”. This differs from Benner’s work (1984). Thus, in my study, “longitudinal knowing” enabled the participant to identify and describe her patient’s changing health condition in a technical manner.

The extract demonstrates a mixture of theory (knowing the science) (Carper, 1978) and past experience (Benner, 1984). However, as illustrated in this extract, past experience and knowledge relies on “longitudinal knowing”. It guides the participant’s perceptions and actions and allows for a rapid grasp of the situation as a whole.

Another example representing the application of technical language to describe physiological changes can be located in the descriptions below:

Extract 14

1. “I have known him for a long time and it’s usual for him to be noisy.
2. I mean he had no speech, but only noises, always liked to be with
3. one of us. I noticed he is now quiet, noticed that he was
4. progressively deteriorating physically, he was losing weight, and
5. other symptoms included like passing loose stools. He didn’t look
6. well. Quickly, we made an appointment for him to see the GP.
7. There tests were carried out, stool samples were taken for testing,
8. and blood test to find out why he was deteriorating.” (Q19)

Here, participant Q19 presented himself as someone whose intimate knowledge of his patient was one based on length of time. Here, temporal understanding was the crucial factor that contributed to “longitudinal knowing” the patient as a unique person. Knowing the patient for “a long time” allowed him to notice that his patient’s behaviour had altered. This was supported by his next statement where he compared his patient’s “usual” behaviour of someone “noisy” to someone who was now “quiet”. So, noticing his patient to be “quiet”, meant a change in behaviour had occurred. The word “quiet” implied a departure from “noisy”. This description suggested a display of contrasting behaviours. In this case, personal/intimate knowledge and understanding of his patient allowed for rapid perceptual grasp of the patient’s changing health status. Using the strategy of “noticing”, he reported that his patient was “deteriorating physically”,

“losing weight” and “passing loose stools”. These physical signs were obvious clues that his patient’s health was indeed on the decline.

The analysis of data showed participant Q19 was at ease about using technical language to describe his patient’s physical condition: “progressively deteriorating physically”. Other words used included “loose stools”, “stool samples”. These words were normal to someone involved in nursing work. In nursing, an observation of loose stools always requires stool samples for testing. Similarly, the reason for doing blood tests was to find out the underlying causes for physical deterioration. This was indicative of someone who had some pathophysiological knowledge, thus following the nursing process.

As illustrated above, noticing a change in the patient’s personality required the nurse to know the patient well through “longitudinal knowing”. Participant Q19 took immediate action. The term “quickly” was used to demonstrate swift action. Here, timely intervention was imperative.

As illustrated also in extract 15 (participant Q16), “longitudinal knowing” enables LD nurses to take timely action concerning a patient’s rapidly changing health condition. The extract also shows evidence of the LD nurse using both “formal” and “commonsense” knowledge in reporting a change to a patient’s health condition.

#### Extract 15

1 “I was bathing her one morning and noticed part of her body, her anatomy  
2 looked different. I then examined her closer, noticed a lump, I could see that  
3 her underarm nodes were slightly enlarged, her nipple looked inverted and  
4 also there was thickening in one area. I thought - oh my goodness the poor  
5 girl - I knew her cancer had returned. I had looked after her before when she  
6 was younger in another bungalow, so I knew what she was like. She had  
7 cancer three years ago, so I knew the signs. The signs were bad news.

- 8 Immediately, I rang the senior nurse on duty, informed the oncologist, and  
9 she was admitted to the hospital the same day.” Q16)

This extract demonstrated that participant Q16’s ability to make an assessment of the patient’s changing condition was “personalized”. She knew her patient well. This was reflected in her statement - “I had looked after her before when she was younger and knew what she was like”. Here, “knowing” about the patient developed over time (“before”), featuring temporal understanding, based on longitudinal knowing.

Using a combination of “lay” language and “technical” language, she described the signs observed about the patient’s breast. For example, “lump” (line 2) indicated lay language. While “underarm nodes”, “enlarged”, “nipple looked inverted” “thickening in one area” represented technical language. Here, a mix of languages was applied to describe someone with a tumour on the breast - “a lump”, “anatomy”, “underarm nodes”, “enlarged”, “nipple inverted”, “thickening”. The descriptions match the signs of breast cancer. For example, enlargement of nodes on the underarm, inverted nipple and an area of thickening are all features of cancer of the breast. In describing the features of breast cancer, participant Q16 seemed to be at home with using technical language and primarily nursing-specific language. This should not be a surprise as participant Q16 was a qualified nurse, who also had formal training in general nursing.

The evidence presented above showed that “longitudinal knowing” in my study, and the background knowledge of the patient and the disease contributed to the identification of a patient’s changing health condition. Additionally, the analysis of data showed that the participant’s observation reflected her knowledge about breast cancer awareness (The NHS Cancer Plan and the New NHS,` DOH, 2004). In this case, observations of “lump”, “enlarged nodes”, “inverted nipple” and “thickening” were signs of breast

abnormalities. The signs observed “were bad news”. They were clear indications of breast cancer. This extract showed that “longitudinal knowing” of the patient’s past history (the patient had cancer three years ago) allowed the nurse to notice changes from baseline.

Guided by her understanding that the signs were indicative of breast cancer, participant Q16 responded and acted immediately. A sense of urgency was detected in participant Q16’s tone - “immediately”, “the same day”. She showed that it was urgent to respond to the situation. She knew from her observations that her patient’s health condition had relapsed - “her cancer had returned”. This demonstrated that participant Q16 was someone who knew the urgency of seeking medical attention when a patient had a relapse, from cancer. Using a maximum marker, the tone of urgency could be located in the phrase “immediately” and “same day”. This data showed that the nurse’s personal in-depth knowledge (“longitudinal knowing”) of the patient served as a basis for prompt action that was necessary for preventing late treatment for the patient.

The analysis of data showed qualified nurses sometimes used a mix of lay language and technical language in establishing and describing patients’ changing health conditions. I showed that participants with a nursing qualification had a propensity to use technical language, probably due to formal nurse education and training. I showed that unqualified nurses working in LD setting use of lay language comes from the person’s practical knowledge (Dingwall, 1977; Schutz, 1966). This study illustrates the importance of “formal” knowledge relating to the use of technical language. Using technical language also shows that LD nurses understand appropriate nursing terms relevant to nursing care and treatment of symptoms so that patients would not suffer undue pain. In addition, the use of lay language for identifying and describing signs of ill health is equally valid in residential homes. Importantly, my data shows that LD

nurses ability to describe patients' changing health status is only relevant if the nurse possesses good personal knowledge about their patient ("longitudinal knowing").

So far, I have shown that recognition of patients' changing health conditions was reflected in the way language was used. I have shown that both approaches, that is to say, "formal" knowledge and "commonsense" knowledge about disease facts and physiological states enhances nurses' recognition and intervention abilities, thus allowing appropriate and high quality end-of-life care.

However, my data also showed that some nurses, qualified as well as unqualified, were likely to hazard a guess about a patient's illness even though nurses have developed in-depth knowledge ("longitudinal knowing") about the patient. The following extract shows that even with the display of visible signs, participants may find it difficult to recognise ill health.

#### **7.4 "Uncertainty of knowing"**

Extract 16

1 "She has a temperature for about 3 to 4 days and was not quite herself.  
2 I called the GP and he came over to the bungalow and saw her every day.  
3 The GP and I thought it might possibly be a throat infection, but on the 5<sup>th</sup>  
4 day she got worse. We suspected she might possibly have contracted  
5 something. We thought perhaps it was appendicitis or maybe peritonitis. I  
6 actually panicked a little. I have not known this to happen, not sure what  
7 to make of it. Her fever was like on and off. So, got the GP back again to  
8 see her. She was admitted to the local hospital and when they opened her  
9 up they found she had cancer of the bowel." (Q5)

In this extract, participant Q5 revealed she had difficulty understanding what was wrong with her patient. Even with an array of signs, she could only "suspect" that her patient

might have contracted “something”. “Uncertainty of knowing” was reflected in the following words - “might”, “suspected”, “possibly”, “something”, “thought”, “maybe”, “perhaps”. She also speculated that a raised temperature “might possibly be throat infection” and “thought”, “perhaps” it may be appendicitis or may be peritonitis.

With participant Q5’s accounts, “a raised temperature” (line 1) beyond a few days and a “fever that was on and off” (line 7) were taken seriously. Furthermore, participant Q5 did not hesitate to follow up her suspicion. She “got the GP back again to see her [patient]”. Sadly, for the patient, “cancer of the bowel” was established when “they opened her up”. In this extract, delayed diagnosis was evident even though action by the nurse may be fast.

In this extract, participant Q5 in this situation may have performed well by calling the doctor a second time, but her action in handling the situation was presented through a veil of anxiety – “I panicked a little”. With this participant’s account, it was possible to consider that her anxiety about the situation was linked to a lack of clinical experience - “I have not known this to happen” (line 6). In addition, this extract showed that even though the participant knew the patient well, signs might be passed off as LD-related behaviour - “not sure what to make of it” (between lines 6 and 7), thus diagnostic overshadowing (Hendren et al, 1990) might have occurred in this instance. This is where the tension occurs. This “tension” may be resolved by ensuring that LD nurses working in residential homes have the opportunity to update their knowledge concerning advanced illnesses/diseases through education and training. Each patient’s illness trajectory may be different despite similarities concerning medical problems. Knowledge of the processes of diseases could only mean better control and management of pain and other distressing symptoms.

This extract showed that reporting of signs using layman's language or technical language are both valid, but the emphasis concerning the use of either language rests on the nurse's intimate knowledge of his or her patient ("longitudinal knowing"). The way LD nurses report signs of disease-related physiological changes and physical changes can only be made easier if the nurse knows the patient well ("longitudinal knowing").

"Uncertainty" about patient's changing health status can also be located in the next extract:

Extract 17

- 1 "She was a bad epileptic and you could see she was weakening,
- 2 but until you get a diagnosis it's a fine line, and unfortunately for
- 3 her it was cancer". (U15)

This extract represents someone suspending a nursing judgment about a patient's health condition. Participant U15 did not describe additional signs or symptoms, other than that her patient was "weakening". She was not clear whether "weakening" was attributed to physiological responses to epilepsy. Here, participant U15 also used metaphors - "a fine line" to highlight the vagueness described in relation to her patient's condition. The words "until" [a diagnosis was made] and "but" are contrast markers used to underpin ambiguity about a patient's health condition.

The data is not substantial enough to provide additional reasons for participant U15's lack of certainty about a patient's changing health condition. However, it is possible to consider that this participant, being an unqualified nurse, did not have sufficient educational background about disease processes. It is highly unlikely that the content at NVQ level 2 for an unqualified LD nurse includes the pathology of advanced illnesses/diseases (see chapter 4, section 4.3).



“Uncertainty of knowing” concerning recognition of the patient’s illness is also described in the following extracts (extract 18 and extract 19):

Extract 18

- 1 “She lost a lot of weight and I reported this to the nurse in charge, but
- 2 whether her weight loss was medical or whether it was just her not
- 3 wanting to eat, it was just very, very hard to tell. She was a lady who I
- 4 knew well and she had a mind of her own, still I think it was very, very
- 5 difficult to say. I like to say that I knew her well enough to say she was
- 6 not herself, but then again it was really guess work.” (U27)

In this extract, participant U27 presented herself as someone who knew her patient well. She described her patient as someone who “had a mind of her own”. Here, she implied that the patient had a strong personality. This extract shows that this type of personal knowledge about a patient’s character can only happen if a nurse knows her patient well (longitudinal knowing).

The analysis of data showed that even though participant U27 knew her patient well, she had difficulty understanding that the patient’s health had altered. She used the terms “guess work”, “very, very hard”, “very, very difficult” repeatedly to emphasise the problem she had in identifying her patient’s state of health. The phrase “very, very” reflects participant U27’s great concern about the patient’s health. Here, a maximum marker was used to indicate the extreme situation.

The above data shows that nurses’ professional duty is to embrace moral and professional commitment to our patients (Carper, 1978). So, even though participant U27 was vague about what to make of the external bodily signs such as “loss of weight”, she acted and reported her observations to the nurse in charge. This showed that participant U27 did not disregard the possibility that her patient was becoming

unwell. Her uneasiness about her patient's loss of weight was on the basis of "longitudinal knowing". This could be seen in her foreword: "I knew this lady well enough to say she was unwell".

The data analysis showed that participant U27 described two reasons for her "uncertainty of knowing". She was uncertain if her patient's loss of weight was due to personality ("she had a mind of her own") or that "not eating" was due to a "medical" cause. This extract showed that sometimes there were difficulties in recognising ill health relating to PPLD (Tuffrey et al, 2010; Li and Ng, 2008; Bycroft, 1994; Hendren et al, 1990) due to diagnostic overshadowing (see Chapter 2). Emerging from this analysis, I showed that nurses did not downplay the possibility that their patients might be experiencing illnesses even if they were unsure about patients' symptoms. The issue raised here is that there should not be a delay in diagnosis and intervention (Read, 2005). The next extract presented also reflects "uncertainty of knowing":

Extract 19

- 1 "He appeared jaundiced, not sure what to make of it. I mean
- 2 I have not seen him like this before. I have no previous experience in
- 3 this either. There were no other signs or symptoms. He was diagnosed
- 4 with cancer and had only two weeks to live" (Q1)

In this extract, participant Q1 described the reason for his uncertainty, for example, he reported that there were "no other signs or symptoms". Yet, the patient "appeared jaundiced". He was "not sure what to make of it" when presented with this symptom. Here, the extract shows that "uncertainty of knowing" is due to lack of experience - "not seen him like this before" and "I have no previous experience in this".

The extract clearly shows participant's lack of knowledge about illnesses and disease. This could lead to conflation between LD-related and disease-related behaviour. In this

data, “jaundice” is a sign that can occur in many different diseases. Hence, in this data, jaundice signifies that the patient’s health has altered. Here, the above extract shows that the lack of ability to grasp the problem about a patient’s changing health condition has serious consequences for PPLD (the patient had only two weeks to live). The Michael Report (2008) makes a strong point stating PPLD may be at risk when nurses lack knowledge and skills about illnesses/diseases. “Uncertainty of knowing” then may contribute to a delay in diagnosis and timely treatment.

The presentation of my data above shows the importance of “longitudinal knowing”. It alerts nurses to early warnings of patients’ (PPLD) changing health conditions. Through “longitudinal knowing”, nurses are able to make qualitative distinctions, comparing the current picture presented by the patient with the behavioural and physical changes, prior to the onset of becoming unwell.

My data also showed the importance of trusting “intuition”, derived from “longitudinal knowing”, which reinforced participants’ nursing decisions about a patient’s changing health condition (King and Macleod Clark, 2002; Cioffi, 2000; Rew, 1990; Benner and Tanner, 1987 and Benner, 1984). I showed that intuitive knowledge gained from experience enhanced LD nurses’ approach of the nursing assessment and that recognition and assessment of patients’ changing health was characterised by increased intuitive links and noticing the salient issues [sense of salience] in each situation (Benner, 1987). I therefore showed that “longitudinal knowing” enabled LD nurses to use intuition to recognise PPLD’s changing health condition.

I showed that LD nurses use a combination of “lay language” and “technical language” in making a nursing decision about patients’ changing health conditions. Using a mix of languages is common in LD nursing practice. I showed that LD nurses with experience,

particularly those with a nursing qualification, developed a specialised “formal” knowledge using “technical” language to describe their patients’ changing health conditions. I showed that the way nurses reported signs and symptoms of disease-related physiological changes and physical changes could be made easier if the nurse knew the patient well (“longitudinal knowing<sup>2</sup>). This meant that “longitudinal knowing” was integral to the way nurses report and describe patients’ changing health condition.

I also showed that “uncertainty of knowing” occurred among qualified and unqualified LD nurses even though they might know the patient well. The condition of PPLD often overrides and obscures their physical illness (‘diagnostic overshadowing - Hendren et al, 1990) Thus, a lack of experience and lack of knowledge about advanced cancer and their illnesses may cause illnesses to go undetected. This ‘tension’ could be addressed through formal nurse education and training (see chapter 8). Not knowing the pathophysiology of illnesses should not excuse LD nurses from decision-making about the specificity of individualised interventions. My data showed that LD nurses had reasons to act and seek medical interventions if and when they “noticed” and “sensed” that their patient was unwell. By following the baseline of “knowing” what was “normal” and what was not for the individual patient, LD nurses had the knowledge to recognise PPLD’s changing health conditions.

The presentation of my data so far showed that “longitudinal knowing” allowed LD nurses to recognise PPLD’s changing health condition, thus seeking appropriate interventions. By the same token, ‘longitudinal knowing’ allowed LD nurses to provide intimate comfort care. PPLD like non-disabled patients are vulnerable when ill. “Longitudinal knowing” therefore helps LD nurses to personalise care. Indeed, “longitudinal knowing” leads to the achievement of “comfort” care in PPLD. The

results of my data showed LD nurses value “comfort” care to be the primary end-of-life care nursing activity. According to several writers “comfort” care is highly significant in nursing practice, in critically ill or dying patients (for example, Saunders, 1978; Nightingale, 1970). Hence, I argue that providing high quality end-of-life care implies care given to patients by a nurse who knows the patient well, given their longitudinal understanding of the patient. Longitudinally knowing the patient well allows LD nurses to treat a PPLD as a unique person.

In the next section, I present my data that refers to the way LD nurses spoke about how they provided “comfort” care to terminally ill PPLD in residential homes. “Comfort” care in this study refers to the actions performed by participants to relieve a patient’s physical discomfort. Participants in this study described specific actions that they would take to ensure that their patient was comfortable right to the end stage of life. I showed that nurses who were familiar with each patient, knowing their likes and dislikes by virtue of “longitudinal knowing” could individualise “comfort” care. I show that giving “comfort” care, for example, mouth care, repositioning, and skin care was repeatedly highlighted as a component of high quality end-of-life care, achieved through “longitudinally knowing the patient well”.

## **7.5 Comfort care**

In this study, the analysis of data demonstrated three components contributing to “comfort” care. They are (i) the ‘longitudinal presence of the nurse’ (ii) “positioning and personal cleanliness of the patient and (iii) “relief from pain” associated with the patient’s disease. The first two aspects of “comfort” care are illustrated in the following extracts in sections 7.5.1 and 7.5.2. The third aspect “pain relief” will be presented and

analysed under section 7.5.3 labeled as “certainty of not knowing”. I present table 24 below to show some examples of the properties of “comfort” care.

**Table 24- Some examples of the properties of “comfort” care**

Longitudinal presence the nurse	Provide clean linen - daily
Nurses take turns to sit with the patient/ always someone with the patient day and night	Ensure patient is physically comfortable in bed, for example, correct position in bed to prevent pressure sores
Spending time with the patients, for example, ‘to cheer her patient up’, ‘to say hello’	Provided extra sheepskin and cushioning to prevent pressure sores
Presence of a friendly / familiar face (nurse)	Provide waterbed to relief bed pressure
Making sure patients’ rooms are ‘normal’, with pictures, ornaments, photos, vases of flowers	Provide pain relief, for example, installation of syringe driver to deliver morphine and oral medications such as paracetamol
Give small sips of water	Maintain fluid intake
Maintain personal cleanliness and hygiene - wash and dry properly, change of clothes daily	Getting the right bed for patients, involving occupational therapist
Keep mouth moist	Plumping up pillows
Keeping the room at the right temperature	Correct ways of moving and handling patients, involving physiotherapist
Correct /soft lighting in the room	Provide soft music in the room

### 7.5.1 “Longitudinal presence of the nurse”

Several reports suggest that terminally ill patients at the late stage of the disease can experience confusion and disorientation (Payne et al 2008; Walker, 2002; Aikens, 1908). I showed that the “longitudinal presence of the nurse” is comforting and reassuring for terminally ill PPLD in residential homes. The following extracts illustrate this viewpoint:

#### Extract 20

- 1 “when we knew her condition was definitely terminal she had to be
- 2 looked after in the room, so we make sure there was always one of us
- 3 with her, you know someone who knew her well [ patient’s name]. We
- 4 would take turns to sit with her, to be with her, so that when she wakes
- 5 up she is not anxious, she is not baffled, it’s sort of reassuring in a way to
- 6 have a friendly face. We tried to make her room as how she normally
- 7 liked - things like photographs, pictures, ornaments, vases of flowers to
- 8 make the room smell and look nice as well.” (Q4)

The above extract demonstrated that for this participant, it was important that her patient should find it reassuring and comforting to have a “friendly face” when “she wakes up”. Here, the participant believed that her presence would alleviate her patient’s anxiety.

This can be seen in her words: “so that when she wakes up she is not anxious, she is not baffled” (between lines 4 and 5). The presence of the nurse is a concept that is not alien to nursing. As such, this concept relates to nursing as an art (Carper, 1978), as well as a skill that feature as a significant nursing care theme in Florence Nightingale’s work (1970) and the theory of the humanistic approach to care for dying patients (Saunders, 1983; 1978; 1963).

Here, participant Q4 also demonstrated that it was important to ensure they “take turns to sit with her [patient]”, “to be with her”. The need for the presence of the nurse at this moment depended on the likelihood of distress or behavioural problems. Behavioural signs were specific to the particular patient who had profound learning disability. It is through “longitudinal knowing the patient well” that a nurse like participant Q4 would notice and interpret variations in behaviour that seemed important in her judgements about a patient when unwell. “Longitudinal presence of the nurse” therefore suggested that participant Q4 understood her patient as an “individual”, with fears and anxiety. This showed that participant Q4 took into consideration the patient’s psychosocial care needs. The reduction of anxiety is linked to psychological care, one of the principle aims of palliative care (WHO, 2008; Radwin, 1996).

The above extract also showed comfort care included providing and creating an environment that resembled normality. For example, participant Q4 described, “we tried to make her room as how she normally liked - things like photographs, pictures, and ornaments, vases of flowers to make the room smell and look nice as well”. This is a reflection of one of the aims of palliative care - to normalised death (WHO, 2008). This data also showed that through “longitudinal knowing”, participant Q4 knew how to maintain the patient’s room as near normal as possible.

This extract so far illustrates the participant's understanding about comfort care through "longitudinal knowing". Importantly, the extract demonstrates that at the very heart of caring for terminally ill PPLD, longitudinal relationship between the nurse (participant) and patient is crucial. Here, the longitudinal relationship allowed the participant to be aware that a patient's anxiety varies from person to person.

The above data also shows that LD nurses' expertise of "longitudinal knowing" was essential in providing individualised comfort care. Thus, the "longitudinal presence of the nurse" is crucial for caring for the terminally ill PPLD. Another example that illustrates "longitudinal knowing" offers "comfort" can also be located in the next description below:

Extract 21

- 1 "You know, before he became ill, he used to tag along one of us in the
- 2 home. He never did like to be on his own. So when he became ill
- 3 he was more or less confined to his room and just seem so lonely. To
- 4 make sure he was not alone in his room we make sure there was
- 5 always one of us present at the bedside every second of the day." (Q19)

Here, participant Q19 demonstrated knowing what his patient was like. He reported that his patient "never did like to be on his own". This showed he had a good understanding about his patient's behaviour, likes and dislikes through "longitudinal knowing". Additionally, he showed the significance of someone being "confined" to a room. "Confinement" shows exclusion and loneliness. Such actions demonstrated that it was necessary to tackle patients' different experiences, anxiety and loneliness. The extract also showed that the participant was demonstrating sensitivity towards the patient (Carper, 1978). To lessen the patient's anxiety, for this participant, it was necessary to be present at the bedside "every second of the day". This data was also indicative of thoughtful regard for the patient.



So far, evidence presented in this study has demonstrated that participants, through “longitudinal knowing”, were able to anticipate and meet patients’ “comfort” needs. LD nurses also show that they have the ability to anticipate and prevent distress through perpetual / “longitudinal presence of the nurse”. Early writers (McNamara, 2001; Nightingale, 1970; Saunders, 1983; 1978; 1963; Sheldon, 1977) (chapter 3) have identified “presence of a nurse” as an important concept of comfort care. However, where my study differs from them is that LD nurses’ presence is “longitudinal”. Early studies were conducted in acute settings where nurse-patient contact was minimal (McNamara, 2001; Nightingale, 1970; Saunders, 1983; 1978; 1963; Sheldon, 1977). My study on the other hand, emphasises permanent, long-term nurse-patient relationships based on continuous contact and interaction. Consequently, the concept “longitudinal presence of the nurse” in my study aids the accomplishment of “comfort” care.

The following extract describes how “longitudinal knowing” allows participants to do “personal comfort” nursing care for a terminally ill PPLD in residential homes. Participants described this aspect of “comfort” care as “positioning and personal cleanliness of the patient”.

### **7.5.2 “Positioning and personal cleanliness of the patient”**

Extract 22

- 1 “I have worked in this home for the best part of 10 years, so I know
- 2 her and other patients well. It’s good in a way because like now she sees a
- 3 familiar face, so every half an hour I would go to her room, check on her,
- 4 let her know she is not alone, we are close by, check she is ok in bed and
- 5 change her position if need be.” (Q10)

In this extract, ‘longitudinal knowing’ (line 2) was given prominence in nursing descriptions of how ‘physical comfort’ care was provided. Participant Q10 implied that

knowing her patient for 10 years constructed 'longitudinal knowing' and familiarity. Here, the participant believed that working in the home for 10 years gave her the privilege to know her patient (and other patients) well. "Familiarity" through "longitudinal knowing", allowed her the privilege to see her patient "every half an hour", to "check on her" and to "change her position". This extract showed that ten years of direct involvement and contact with an individual patient undoubtedly allowed participant Q10 to understand her patient's needs and responses. This view has support in Radwin's (1996) study. Radwin points out that personal knowledge about a patient assists the nurse to interpret concerns or anticipate needs. This data therefore shows that longitudinal knowing is central to achieving quality end-of -life care as it ensures patients are treated as individuals. This also follows my data where participant Q10 claims that "knowing her patient well" allows her to "change her [patient] position if need be", "check she is ok in bed", but importantly "let her know she is not alone", and "we are close by". Here, a sense of "closeness" ensured patients were treated as individuals. It also gave assurances that the patient was safe. The above extract demonstrated that participant Q10 was providing more than "physical comfort" care.

A similar theme where physical "comfort" care is given through "longitudinal knowing" can also be located in the next extract - participant U11's description:

Extract 23

1 "When we were told she had cancer we knew we had to make sure she  
2 was going to be comfortable, not suffering again. I mean to have cancer is  
3 bad enough. We got her the waterbed to make her more comfortable like.  
4 And whenever I come in on duty, I would make sure I pop round to say  
5 hello to cheer her up a bit. Some days I would come in when I am off-  
6 duty to sit with her, to keep her company." (U11)

The above extract showed that participant U11 was acting on experience and personal knowledge that “cancer is bad”, and that her patient should not ‘suffer again’. To relieve discomfort, she got a “waterbed” which would make her patient “more comfortable”. It was through “knowing the patient well” over a period of time that the nurse was able to distinguish and interpret signs of distress from “normal” behavior, thus lessening suffering. Through “longitudinal knowing”, the nurse knew the different ways of relieving the patient’s discomfort. Here, the participant’s action was to “get a waterbed”. The extract also showed that when a nurse knew her patient well, she could comfort her patient with her presence. For example, the participant would “pop round to say hello to cheer her up a bit” or “sit with her [patient] to keep her company”. These are all essential “comfort” care, yet basic nursing care. Here, spending time with the patient even when one is off duty shows the caring nature of the nurse and continuity of care at the end of life. This type of action supports the notion that nursing care is “knowing” how to keep a patient comfortable in “body and mind” (Aikens, 1908). Additionally, the extract represented “comforting” action in spite of an adverse situation. “Popping round” and “to say hello”, meant she acknowledged her patient’s presence. Here, the data shows that the participant’s actions highlight that achievement of quality care is through “longitudinal presence of the nurse” and “longitudinal knowing”.

Making a patient physically comfortable at the end of life can also be located in the extract below:

Extract 24

- 1 “She was a small person to begin with, I mean she was a lady I knew
- 2 well anyway, but when she had cancer she lost so much weight, she was
- 3 all just skin and bone. Extra sheepskin and cushioning was brought in to
- 4 make her more comfortable, to prevent pressure sores, and we also called
- 5 the physiotherapist to show us how to move her. We didn’t want to move

6 her not knowing how because she was so fragile by then, didn't want to  
7 break her bones, you know." (Q6)

In this extract, participant Q6 obtained "extra sheepskin and cushioning". This was to make sure that her patient was "more comfortable". Obtaining "extra sheepskin and cushioning" also prevents "pressure sores". This demonstrates that there is some understanding that weight loss is part of the disease (Payne et al, 2007) and extra bedding can relieve discomfort. In addition, the participant also revealed that it was necessary to know "how to move" the patient. Here, this participant showed she was someone who knew about the correct method for moving and handling an immobile patient in bed. Thus, by seeking the assistance of a physiotherapist on this occasion was important so as not to "break any bones". Seeking the support of a physiotherapist also suggested that this participant knew whom to contact for performing a correct procedure such as moving and handling in this situation.

In the above extract, the actions performed by the nurse and the physiotherapist showed that physical "comfort" may be provided through collaborative working (End-of-life Care Programme, 2006). Similarly, other participants in this study also reported that they worked closely with other members of the health care team (physiotherapist and occupational therapist) to ensure the patient's physical comfort was met. This is shown in the following description (extract 25):

Extract 25

1 "We involved the physiotherapy and the occupational therapy just to  
2 make sure we have got the right bed so that he would be in a  
3 comfortable position when we move him. We didn't want to have  
4 to strain him. I knew him so well, he was one of those patients  
5 who didn't like to be touched and if we need to move him, get him up  
6 or off the bed we have got to be so careful how we move him so as not  
7 to distress him in anyway, and so getting a special bed" (U32)

Here, participant U32 demonstrated that it was necessary to enlist the support of a physiotherapist and occupational therapist because they “didn’t want to have to strain him”. Knowledge and skills of moving and handling are essential in ensuring quality physical comfort care for the patient. Also, “knowing” that his patient “didn’t like to be touched” means the participant (nurse) knew his patient’s dislikes; and, therefore had to be “careful how to move him”. Also, in obtaining a “special bed”, participant U32 shows that discomfort could be prevented, thus lessening unnecessary “distress”. This extract thus showed that “longitudinal knowing” is vital to knowing how to manage PPLD when they are vulnerable.

The description above illustrates how a patient’s physical comfort may be relieved through “longitudinal knowing”, and collaborative work involving other health care professionals. This type of care delivery reflects and underpins the framework and principles of palliative care (Payne et al, 2008; NCHSPCS, 2002).

The following descriptions that show giving “personal cleanliness and hygiene care” constitute “comfort” care are shown below:

Extract 26

2 “When she became ill she spend most of the time in bed, but we  
3 make sure she is helped to get out of bed a little everyday with help.  
4 In the home we make sure her personal cleanliness was maintained at  
5 all times, to make her feel good and clean. We always make sure she  
6 was washed, dried properly and a change of clean clothes every day,  
7 and this is done every day, sometimes more than once depending on  
8 her condition.” (Q3)

This extract illustrates the importance of keeping the body clean. Here, participant Q3 knew giving personal care was important for someone who is terminally ill – “she was

washed, dried properly and a change of clean clothes”. She also knew the reasons for performing these nursing actions – “to make her feel good and clean”. Patients with cancer are subject to sweating which can cause discomfort, distress, fatigue and confusion (Watson et al, 2005).

The analysis of data also suggests that this participant is aware that prolonged bed rest is not necessarily a good thing. She reported that the patient was “helped out of bed a little everyday with help” (line 3). Other measures taken to provide “physical comfort” care included mouth care. This is also demonstrated in participant Q2’s description below:

Extract 27

1. “Giving him small sips of water and sometimes use a cotton swab to
2. moisten the mouth because by that time he couldn’t take any sort of
3. solid foods, he couldn’t eat, he lost that appetite and we had to just
4. give him fluids. We kept a chart and so making sure he was not
5. dehydrated and because he spent his last few weeks in his room we
6. didn’t want him to be anxious and isolated so we make sure there was
7. always someone with him, day and night.” (Q2)

In the above extract, actions such as using a “cotton swab to moisten the mouth” and “giving sips of water” are essential nursing care for a sick/ dying patient. Giving “small sips of water and “use cotton swab to moisten the mouth” showed that participant Q2 knew what she was doing. She showed that “giving sips of water” prevented dehydration. She also demonstrated knowledge about nursing procedure and the importance of keeping “a chart” to monitor fluid input and output.

Other physical care actions comprise maintaining good mouth care. Studies show that cancer patients experience loss of appetite and it is important to ensure that the patient does not dehydrate and mouth care helps to prevent problems before they start (Payne et al, 2007). Maintaining mouth care is imperative especially in cases when patients are

too weak and are no longer able to take food. Mouth care also helps to control unpleasant symptoms and signs of dry mouth, soreness and halitosis (Payne et al, 2008).

The analysis of the above extract (extract 27) also demonstrates that it is important that the patient is not “anxious” and “isolated”. This description demonstrates that the participant is aware of promoting physical care as well as psychological care at the end of life. This supports the notion that both physical needs as well as psychological needs are integral part of terminal care (NCHSPCS, 2002). The extract shows that through “longitudinal knowing”, the participant is able to meet the patient’s physical and psychological care needs.

The data presented so far shows that “longitudinal knowing” is how LD nurses provide “comfort” care for terminally ill PPLD in residential homes. To ensure quality end-of-life care is the business of all nurses regardless of the care setting. My data in this study shows that LD nurses’ work differs from nurses working in the acute settings. LD nurses normally work on a one to one basis according to the key worker system (see chapter 4). Clearly, long exposures to the patient allow them to develop and establish the process of knowing what makes the patient comfortable. For example, repositioning the patient in bed, or providing extra sheepskin. It is possible that nurses working in the acute/general hospitals spend less time in one single transaction with the patients when compared to LD nurses in residential homes. It is therefore difficult for nurses working in the acute settings to get to know the patient in any depth within a short period. So far, there is little information / research about “longitudinal knowing” and the impact this has on “comfort” care.

Further data analysis in this study shows that a significant number of participants felt they lacked expertise in specific nursing knowledge and skills relating to pain relief.

They described how they had to use the expertise of specialist palliative teams to relieve patients' physical pain associated with their diseases. I referred to this as "certainty of not knowing" (gaps in knowledge about pathophysiology of illness /disease and pain relief).

### **7.5.3 "Certainty of not knowing" - (gaps in knowledge about pathophysiology of illness /disease and pain relief)**

All 36 participants revealed that physical pain was a concern and the ultimate goal of "comfort" care at the end of life is to be pain free (NHS-End-of-Life Care Programme, 2006). The analysis of data showed that LD nurses were certain that they lacked knowledge about the pathophysiology of illnesses and pain relief. The analysis of data illustrated that the most commonly reported source of knowledge was specialist palliative care team/nurses, and through nurse education and training. The next description (extract 28) demonstrated participants using the expertise of a specialist palliative team to relieve patients' physical pain:

Extract 28:

- 1 "We had to call the palliative care (pc) nurse. We knew who and how
- 2 to contact the pc nurse. She gave us her number, 24/7. They were the
- 3 experts and they have the skill and I don't. This equipment (referring
- 4 to the syringe driver) is something new to me. As a qualified nurse I
- 5 can still continue to give her normal pain relief like paracetamol, but
- 6 not give morphine by using a syringe driver, because I don't know how
- 7 to use it." (Q4)

Here, participant Q4 accepted that he had no knowledge in using a technical device, referring to the syringe driver. For this reason, the palliative care nurse was called upon because "they were the experts". However, participant Q4 provided an account that as a qualified nurse in the home, he could still continue to administer "normal" medication. This shows that LD nurses in residential homes are not familiar with using a syringe



driver. They have little knowledge of the nursing procedures in using syringe drivers, but have knowledge of local palliative care facilities.

The Liverpool Care Pathway (LCP) (Ellershaw and Wilkinson, 2003) and GOLD Standards Framework (GSF) ([www.goldstandardsframework.nhs.uk,2009](http://www.goldstandardsframework.nhs.uk,2009)) for care homes recognised that staff involved in the palliative care of terminally ill patients need to have adequate training in symptom control. It is possible that the training of LD nurses does not involve using and setting-up syringe drivers. “It is a new thing” as participant Q4 claims. It is also possible that LD residential homes do not stock advanced equipment such as syringe drivers (Tuffrey et al 2010; Li and Ng, 2008; Todd, 2005; Black and Hyde, 2004; Bycroft, 1994). This is due to the implementation and philosophy of a social care model that underpins the LD nursing curriculum. A residential care home is a “home” for PPLD, not like a ward in a hospital. Whereas an LD nurse lacks specialist knowledge in the administration of pain relief, he or she has the ability to envisage pain. It is through “longitudinally knowing the patient well” that an LD nurse would be able to assess and judge the behaviours of a patient against the normal patterns they exhibited.

A similar example of certainty of knowing where gaps of knowledge are can be located in the following extract:

Extract 29

- 1 “I could tell he was in pain. He had a bad tooth once and he was in agony.
- 2 So, this time we knew he needed pain relief. The nurse from the palliative
- 3 care team came in regularly and was available 24/7. We needed more
- 4 information about the cancer and she would be there to tell us, but yeah
- 5 they would come in to give her morphine. They use the syringe driver to
- 6 administer the morphine. We wouldn’t be able to do that” (Q7)

The above extract showed that participant Q7 could recognise that his patient was suffering from pain. His understanding was based on “knowing the patient well” from past experience when the patient “had a bad tooth once”. Here, “knowing” what the patient looks like when in pain may not be possible for an outsider such as a palliative care nurse. Pain signs were specific to the particular patient and could only be interpreted by someone who knew the patient well. Nonetheless, because of the participant’s lack of skill in administering pain relief medication, specialist services were sought from the palliative care nurse. This extract showed that the participant knew he lacked knowledge and skills about cancer and pain relief. This was evident in his forewords: “we needed more information about cancer” (between lines 3 and 4) and “we wouldn’t be able to do that” (that is, use a syringe driver) (line 6).

This extract shows that the specialist palliative care team not only “come in to give morphine”, but they were also there to support and provide participants with “information about cancer”. Furthermore, participant Q7 explained that palliative care team services were accessible and available “24/7” if they “needed more information about cancer”.

The above extract shows that palliative care team offers a range of services (Payne et al, 2008). The description given also showed that specialist palliative care services have now moved to patients in all settings (End of Life Care Strategy, 2006) even though it had been claimed that some of the LD nurses working with PPLD still continued to have difficulty accessing primary care services (Michael Report, 2008).

Similarly, because of a lack of knowledge on the part of LD nurses, using and accessing the support of specialist palliative care is also illustrated in the next extract:

### Extract 30

1 “This lady her cancer had spread and they (palliative care nurse) had to  
2 come in to manage and increase her morphine, but in the end she didn’t  
3 need it because she died overnight. They were also giving us advice  
4 about the sort of things we needed to know about the disease. In fact they  
5 came in for a couple of hours training staff, explaining to us the course of  
6 the disease, and like what to expect, how to deal or cope during the  
7 patient’s illness. We were grateful to them.” (Q6)

This extract demonstrated that LD nurses relied on “experts” with specialist knowledge, to manage opioid medication for cancer patients. Here, participant Q6 showed where gaps of knowledge were – “needed to know about the disease” (line 4), the “course of the disease (between lines 5 and 6), what to expect, how to deal or cope during the patient’s illness” (between lines 6 and 7).

The extract also showed that “training staff” in how to cope with the patient’s illness was one of the many functions of the palliative care team (NCHSPCS, 2002); for example, “they came in for a couple of hours training staff”, “explaining to us the course of the disease, what to expect and how to deal or cope during the patient’s illness”. Hence, they (LD nurses) were “grateful” for the support and knowledge from the specialist palliative care nurse. In addition, the participant reported that palliative care team had to “come in to manage and increase” the patient’s morphine. Again, this statement was indicative of a lack of knowledge among LD nurses in managing pain experienced by terminally ill PPLD in residential homes.

So far, my data has shown LD nurses were reliant on specialist palliative care nurses to relieve patients’ pain. They were clear that they lacked the expertise in using a syringe

driver and knowledge in a specific area, that is, the nature of terminal disease/illness. The analysis of data also shows that in the context of palliative care, an interdisciplinary care approach is important to ensure full support for terminally ill patients and nurses in residential homes. This approach embraces the philosophy of palliative care in which specialist palliative care services are involved to provide specialist advice, and in administering pain relief in a variety of settings ([Goldstandardsframework.nhs.uk,2009](http://Goldstandardsframework.nhs.uk); End of Life Care Strategy, 2006; Ellershaw and Wilkinson, 2003; NCHSPCS, 2002).

The presentation of data clearly shows that collaboration between LD nurses and specialist palliative nurses is paramount in the treatment and relief of pain symptoms associated with terminal diseases/ illnesses in PPLD. Importantly, my data in this study shows that LD nurses “longitudinal knowing” contributed to giving collaborative “comfort” care. Even though specialist palliative nurses are experts in cancer knowledge and pain relief, they need to rely on LD nurses to tell them if their patients are in pain. Specialist palliative care nurses do not have the opportunity to work or get to know PPLD. Hence, I argue that LD nurses also have “specialist” nursing skills in caring for terminally ill PPLD in residential homes. Based on the accounts provided, the participants showed that they did not have sufficient knowledge and skills in caring for the patient at the end of life. They knew that they needed to update their knowledge in this area of terminal care.

The analysis of data shows that knowledge about cancer and the use of syringe drivers to relieve pain (Carper, 1978) have indeed filtered through to the working culture of learning disability nurses in a residential home through collaboration with specialist palliative care nurses. Within residential homes, the LCP and GSF provide valuable ways for improving quality of care at the end of life. The End of Life Care Strategy (2006) identified the need for palliative care teams to provide education to supplement

the skills of those caring for dying patients in care homes. Also sharing information between healthcare professionals is necessary for LD nurses to provide high quality end-of-life care for terminally ill PPLD in residential homes as shown in my data.

My findings showed that participants used a variety of strategies to keep themselves informed about patients' disease. They included accessing the internet, nursing books and journals and going on extra courses to keep up to date with new information. This can be seen in the next extract (extract 31):

Extract 31

- 1 "The palliative nurse gave us lots of information which was very helpful,
  - 2 but I put myself down for a study day to keep myself updated so that if I
  - 3 do come across another similar incident I would know what to expect."
- (U13)

Here, participant U13 reported that the palliative care nurse gave "lots of information" (line 1) which was "helpful" (line 1), but attending a "study day" and keeping herself "updated" (line 2) were equally important and would help her to know what to expect if she were to come across "another similar incident" (line 3). This meant she was aware of the importance of keeping herself informed with new knowledge about cancer and terminal illness in this type of setting for PPLD. The above extract shows that the participant knew where the gaps in her knowledge were.

This data also demonstrated the importance of imparting and sharing of information between health professionals concerning cancer knowledge (Addington-Hall, 2000). Using other sources to increase one's knowledge about a patient's illness can also be located in the extract below:

Extract 32,

- 1 “we were looking up cancer websites and nursing journals so that we can
- 2 try and understand what treatment options were there.” (Q25)

Here participant Q25 revealed that “cancer websites” as well as “nursing journals” were sources of information. In this extract (extract 32), it was quite clear that the reason for “looking up cancer websites and nursing journals” was to “understand treatment options”.

The data in my study shows that “certainty of not knowing” functions to identify gaps in knowledge. This means LD nurses know where their knowledge gap is and what action to take to fill this gap.

## **7.6 Conclusion**

In this chapter, I show “longitudinal knowing” is central to the way LD nurses recognise PPLDs’ changing health condition. It is crucial to how LD nurses plan and deliver “comfort” care at the end of life. My thesis shows that it is important for LD nurses to collaborate with the specialist palliative care team to provide comfort care at the end of life ([Goldstandardsframework.nhs.uk,2009](http://Goldstandardsframework.nhs.uk,2009); Payne et al, 2008; End of Life Care Strategy, 2006; Ellershaw and Wilkinson, 2003; NCHSPCS, 2002; Bury, 1982). My study shows that comfort of the patient is the primary concern for LD nurses (Aikens, 1908, chapter 3). Despite the fact that “comfort” care is the central goal of LD nurses in caring for terminally ill PPLD in residential homes, some nurses are still uncertain whether a change in behaviour is due to LD-related or disease-related conditions. The masking of an illness is often due to PPLD’s condition that may override and obscure their physical illness (‘diagnostic overshadowing’- Hendren et al, 1990). Nevertheless, I show LD nurses seek to address the lack of knowledge about pathology of diseases by searching for relevant internet resources and updating their knowledge through nurse

education and training. I show LD nurses through longitudinally knowing their patient well, and in working collaboratively with specialist palliative care nurses, occupational therapists and physiotherapists, are able to achieve high quality comfort care for terminally ill PPLD in residential homes.

**Chapter 8**  
**Discussion and Conclusion**



## **8.0 Introduction**

The aims of this chapter are to present the discussion of results in the context of my research questions. I consider my findings in the context of the literature reviewed. The discussion centres on the themes and strategies (figure 2) LD nurses used in recognising a patient's changing health condition. The main theme is "longitudinal knowing". It is the process through which LD nurses come to know their patients well. "Knowing the patient well" then forms my first sub-theme. Other strategies used include "intuition", "commonsense" knowledge and "formal" knowledge. The second sub-theme "uncertainty of knowing" reveals a lack of clinical experience and knowledge about the pathophysiology of illnesses /diseases. LD nurses in my study showed that they "know the patient well" as a person, but do not necessarily understand the pathological changes. The third sub-theme is "certainty of not knowing". This refers to moments when LD nurses know for definite where the gaps in knowledge are. The gaps in knowledge relate to lack of knowledge about the pathophysiology of illness/disease and the use of a syringe driver. The strategies used to address the gaps are through nurse education and training. They also access support from specialist palliative care nurses and other healthcare professionals. The fourth sub-theme is "comfort care" and the categories generated include the "presence of the nurse" and "physical comfort". I discuss the relationship between "longitudinal knowing" of the patient well and "comfort care". My study demonstrates that "longitudinal knowing" the patient well informs and allows LD nurses to give appropriate and timely "comfort" care to terminally ill PPLD. Finally, I address limitations of the study and contributions to new knowledge, ending with implications for nursing practice and policies and recommendations for future research.

### **8.1 Research question: how do learning disability nurses recognise a patient's changing health condition?**

Several reports have highlighted that deaths from cancers (Hollins, et al 1998; Cooke, 1997) are on the increase, in particular, deaths from gastro-intestinal tract (Cooke, 1997) and colorectal cancers among PPLD (Black and Hyde, 2004). Yet, the experience of learning disability nurses and their care for terminally ill PPLD have never been fully investigated. However, there have been several studies on the care needs of people with mild, moderate and severe learning disabilities (Black and Hyde, 2004; Ng and Li, 2003; Tuffrey-Wijne, 2003; Lindop and Read, 2000; Read, 1998; Bycroft, 1994; Hendren, et al, 1990). Some of the issues identified included delay in diagnosis because of poor communication between healthcare professionals and PPLD (McEnhill, 2004; Brown et al, 2002; Mencap, 2000), while other studies showed difficulties in recognising symptoms of ill health due to insufficient knowledge about the nature or pathophysiology of illnesses and diseases (Li and Ng, 2008; Todd 2005; McEnhill, 2004; Brown et al, 2002; Mencap, 2000; Bycroft, 1994) (Chapter 2).

My study set out to investigate the experiences of LD nurses caring for terminally ill PPLD in residential homes. My aims were to establish how LD nurses assess and detect signs of illness in PPLD and the support required to help them in caring for patients with profound learning disability at the end of life. My study showed that learning disability nurses had the ability to recognise PPLD's changing health status. The analysis of data suggests that "longitudinal knowing" enables LD nurses to develop "intuition" which helps them to recognise patients' changing health status. Other strategies used included "commonsense" knowledge, "formal" knowledge and a mixture of both.

In this study, “longitudinal knowing” refers to LD nurses (qualified and unqualified) who are patients’ immediate and main carers. In most LD residential homes, LD nurses routinely work with a system that operates on a one-to-one basis. It is referred to as the key-worker system. As the patient’s key worker, the LD nurse is the patient’s immediate and principal carer and is the patient’s first point of contact (Gates, 2007). Each nurse provides and supports patients with activities of daily living (see Chapter 4, section 4.1.2). My study therefore shows that “longitudinal knowing” is crucial in how LD nurses recognise signs and symptoms of illnesses/diseases. Ultimately, “longitudinal knowing” the patient well shapes how “comfort” care is delivered, at the end of life.

The result of this study provides evidence that LD nurses’ nursing decision-making and actions are characterised by “intuition”, strengthened by “longitudinally knowing” the patient well. They draw on “intuition” to provide confirmation that their patient’s health is deteriorating. In my study, LD nurses define intuition as a “feeling”, “gut instinct” or “inkling” (table 21).

The results of this study also provided evidence that LD nurses used lay language (“commonsense” knowledge) and technical language (“formal knowledge”) in describing and reporting the signs and symptoms of patients’ illnesses. This study also showed a small minority of participants were uncertain about their patient’s cause of illness. My findings showed that some registered (qualified) LD nurses (Q1 and Q5) as well as those who were unqualified (health care support workers, U15 and U27) experienced “uncertainty” about their patients’ changing health status. They might hazard a guess about a patient’s illness. Several reasons also contributed to “uncertainty” of knowing about a patient’s changing health status. They included (i) diagnostic-overshadowing (NPA, 2004; Hogg et al, 2001; Hendren et al, 1990), a term that refers to characteristics associated with PPLD masking diseases-related signs and

symptoms, (ii) a lack of knowledge about the pathophysiology of illnesses and diseases (Tuffrey et al, 2010; Li and Ng, 2008; Hendren et al, 1990; Bycroft, 1994) and (iii) poor communication skills between healthcare professionals and PPLD (Ng and Li, 2008; Bycroft, 1994) (see Chapter 2).

The results in this study also provided evidence that “longitudinal knowing” the patient well allowed participants (LD nurses) to be directly involved in providing “comfort” care for their patients. This study showed agreement that “comfort” care was the most important component of terminal care for PPLD. In this study, participants identified two types of “comfort” care. They were (i) the “presence of the nurse” and (ii) “physical comfort” which referred to positioning and personal cleanliness of the patient.

The results in this study also showed that LD nurses knew they lacked knowledge about the pathophysiology of illness/disease and pain relief. I referred to this sub-theme as “certainty of not knowing” about gaps in knowledge bridged by others.

### **8.1.2 Contextualising “longitudinal knowing the patient well” in the recognition of the patients’ changing health condition**

The concept of “knowing the patient” can be seen in the work of others to explore nursing experience, but in acute settings (Callery, 1997; Radwin, 1996; Minick, 1995; Tanner et al, 1993; Jenny and Logan, 1992) (see chapter 5). In my study, the concept of “knowing the patient well” means LD nurses know their patients intimately. Their relationship with their patients is long lasting; they spend many years in getting to know the same patient whose LD condition is permanent (see chapter 4). The emphasis is on the phrase “longitudinal knowing” the patient well. My findings showed LD nurses actively constructed a temporal baseline knowledge and understanding about their

patients' behavioural and physical patterns. In this study, the average time span of an LD nurse's experience of caring for a profoundly disabled patient in a residential home is more than seven years. I called this process of knowing as "longitudinal knowing", based on long-term association with the same patient. The prolonged time therefore offers LD nurses the opportunity to get to know their patients even before the onset of an illness. For example, terms such as "normally", "used to", "before" were used to denote personal knowledge about their patients. These terms were used to reflect participants' (LD nurses) knowledge and understanding of what their patients were like before the illness, and what they were like now. Then, when a subtle change occurred, it was recognised as a deviation from baseline. Ultimately, a change in behavioural pattern or physical appearance served as a signal that their patients were unwell.

In my study, LD nurses' working environment differs from nurses who work in acute settings. Under the social policy directives (see Chapter 2), LD nurses' working environment is like a "home". This means that the ambience of residential homes is often relaxed and informal. "Knowing the patient well" is easier and less complicated. The working environment encourages working patterns that are regular and consistent, thus adding a sense of continuity, familiarity and informality in the homes. This type of environment allowed nurse-patient relationships to flourish, and promoted easier interactions between the nurse and patient. This, in turn, allowed LD nurses to build a good relationship with their patients and to understand them intimately, knowing their habits, moods and behaviours as "individuals".

This is in contrast to Benner's and others work (Radwin, 1996; Tanner et al, 1993; Benner 1984) that focuses on acute nurses working in the hospitals; their work is at a much faster pace. Any information and experience nurses had about their patient was based on a small window of opportunity; gleaned from a limited time period. Moreover,

nurses in acute settings do not get to look after one patient repeatedly. Thus, this is where my study differs.

LD nurses routinely carried out a number of basic and personal tasks such as washing patients, getting them up and dressed, feeding them and attending to toilet needs. Thus, helping to meet a patient's basic and personal needs may appear insignificant, but over a prolonged period allowed LD nurses the opportunity to establish a close relationship with their patients. The result of routine personal care work offered LD nurses the opportunity to get to "know" and understand their patients well. Personal care also gave LD nurses opportunities to increase their "private" (Callery, 1997) or "personal" knowledge of their patients (see Chapter 5). Thus, personal knowledge is premised on "longitudinal knowing". Therefore, any changes however slight or apparent would be easy to detect. Consequently, through "longitudinal knowing", a patient's changing health condition would be more easily recognised.

Previous studies (Minick, 1995; Tanner et al, 1993) claim that "knowing the patient" is gained through nurses' involvement and communication with the patients and families. In these studies, nurses' work is with normal adult patients in acute settings. Information is normally gathered directly from patients or the patients' relatives. Normally patients in Western societies would know changes to their body. The presumption here is that normal adults have the ability to self-report any signs and symptoms of illnesses, unless they choose not to act or report a change. However, for PPLD, self-reporting of a change to their health status is not possible due to substantial cognitive impairment (see chapter 1). For the same reason, they are not aware if there is a change in their health status. Hunt (2003) acknowledges the difficulty inherent in distinguishing the expression of distress in severely disabled patients in general settings. My findings show that distress is often expressed in atypical ways such as behavioural

change, from being ‘quiet’ to ‘more active’ or even a ‘type of laugh’ or ‘cry’. So, through ‘longitudinal knowing’ the patient well LD nurses developed the ability to differentiate between disease-related and LD-related conditions.

In my study, LD nurses have no direct contact with patients’ relatives, and if they do, any communication between them is rare. It is therefore not possible to obtain information from patients’ relatives. This is where my study departs from Minick’s (1995) and Tanner and other’s work (Tanner et al, 1993).

My study also departs from Benner (1984) and Benner and Tanner (1987) where she discusses the phenomenon of “expert’ nurses” recognition of patients’ problems/ changing health conditions. Here, an “expert” nurse is someone who has obtained a nursing qualification and has more than five years experience. She shows that expert nurses are more able to recognise a patient’s problems. Her studies implied that five years experience is linked to levels of progression, from “beginner” to “expert”. For Benner, longitudinal understanding was therefore not part of pattern recognition, but rather nurses’ ability to recognise a patient’s problem was strengthened by familiarity with the clinical situation (Benner, 1984; Benner and Tanner, 1987) (see Chapter 5, sections 5.1).

My findings demonstrated that LD nurses have the ability to recognise illnesses through “longitudinal knowing”, a consequence of personal contact and close involvement with individual patients. “Time” is of the essence. “Quality” and “quantity” of time with individual patient are crucial in my study, rather than Benner’s (1984) notion of familiarity with the clinical situations. I showed that LD nurses who had built up a longitudinal relationship with patients over time were alerted to significant changes such as behavioural change or a change to physical appearance.

My findings demonstrated that a small minority (two out of 18 participants) of qualified LD nurses (see chapter 6, section 6.2.6, table 13) were uncertain (see chapter 7, section 7.4) about patients' changing health status; the two LD nurses identified had their training based on the 1982 syllabus (RNMH). The data support the views of Tuffrey et al (2010), Li and Ng (2008), Todd (2005) and Bycroft (1994) in that a lack of certainty or under identification of illness may be a result of insufficient knowledge about the pathophysiology of illnesses or diseases. There was little emphasis particularly within the 1982 learning disability nursing education and training syllabus on terminal illness or palliative care (Li and Ng, 2008). Furthermore, the lack of clinical placements that offered learning opportunities also contributed to poor nursing skills and knowledge. In some ways, the data presented also supports the view proposed by Hendren et al, (1990) which suggested that in PPLD, their condition often overrides and obscures their physical illnesses, thus masking signs and symptoms. Hendren et al (1990) called this 'diagnostic-overshadowing' (chapter 2). There was also evidence to show that unqualified nurses made presumptions about a patient's illness because of confusion between LD-related condition and illness-related behaviour. My findings suggest that both qualified and unqualified LD nurses may benefit from undertaking joint training with hospice staff/specialist palliative teams, to gain a deeper insight into the pathophysiology of terminal diseases.

Evidence from my results revealed that 30 out of 36 participants (83% of the participants, both qualified and unqualified) (see chapter 7, section 7.1.1) were able to identify a physical change in their patients, interpreting such changes as signs of illnesses. In other words, changes in health involve changes in the body, appearance or behaviour, for example, the "*presence of a lump on the breast*", "*physical deterioration*", "*constipation*", "*diarrhea*", "*loss of weight*" (see chapter 7, table 19).



I showed that very often more than one change was considered to be an indication of ill health. My findings showed that through 'longitudinal knowing', 24 out of 36 participants (66% both qualified and unqualified) (chapter 7, section 7.1) perceived a behavioural change in their patients as a sign of impending illnesses or diseases.

The results in my study provide evidence that LD nurses have good knowledge about patients' personal history and profile through longitudinal knowing. Often, the patient's individual history was an important source that LD nurses drew on to make an assessment about the patients' health. The patient's individual history often documents what was 'normal' for a patient and what was not. My data revealed that 'longitudinal knowing' the patient's personal history takes on significance in the light of patient's current situation. Benner's (1984) study also shows that patient's history is a good resource. However, her study was conducted in the acute settings, where documentation of the patient's history may be brief. In LD nursing, a patient's longitudinal history includes the biography of the person, since birth. Personal records kept on them were detailed. Changes in the patient's behavioural and physical patterns occurring over a longer period were documented. This raises an important insight in that nursing notes or clinical records of a patient's behavioural change or previous signs and symptoms are critical in helping LD nurses to notice and distinguish illness or disease related behaviour. My study shows that "longitudinal knowing" the patient's intimate or detailed personal history constitutes a unique contribution to how LD nurses plan timely and appropriate end-of-life care. The issue raised here then is about knowing a patient's history and profile that are both relevant to the detection and recognition of altered health condition. Consequently, attention to this area in terms of maintaining good documentation of a patient's history is a valuable strategy.

Another factor that contributed to LD nurses' ability to recognise changes in their patient's health was that they had knowledge of the nature of PPLD. Carper (1978) calls this 'empiric knowing' (see chapter 4, section 4.4). LD nurses in my study are specialists in their own right, trained exclusively in LD nursing. Their understanding and knowledge about LD conditions were grounded in knowing the facts about learning disability conditions. For example, it is considered 'normal' for a patient with Down's syndrome to appear cyanosed in cold weather. This is because the patient has peripheral circulatory disturbances. Additionally, they understood that PPLD have substantial cognitive and often complex physical deformities and many of their patients' disabilities have organic origins, caused by physiological impairments (Martens et al, 2008; Heaton-Ward, 1973). They know that their patient's specific syndrome may be associated with a particular profile or behavioural traits that fall outside the accepted norms and expectations in society. Thus, longitudinal knowledge about LD conditions enabled LD nurses to make qualitative distinctions about the patient's changing health condition. I argue that LD nurses' ability to recognise signs and symptoms of ill health requires personal and intimate knowledge of the patient and knowledge of the population group (Callery, 1997; Benner, 1984; Carper, 1978). This kind of knowing is premised on longitudinal knowing. Nurses working in acute settings do not have this specific knowledge (Northfield and Turnbull, 2001; Read, 1998).

### **8.1.3 Contextualising "intuition"**

The results of my study also showed that LD nurses used intuitive knowledge to make nursing judgements about their patients' changing health status. LD nurses defined intuition as a "feeling", "gut instinct", "inkling". However where it differs from previous studies is that my study showed that LD nurses' intuition was based on "longitudinal knowing" which helped to add and deepen their experience and knowledge of "knowing the patient well". Pyles and Stern's study (1983) showed that

nurses placed a great emphasis on patients' cues. Information provided by the patients about their feelings served as an early warning for potential deterioration (chapter 5, section 5.2). It was difficult for nurses in acute settings to read and interpret patients' cues because patients' stay in hospital was brief. Nurses in this type of situation had to rely on information passed down from patients or relatives. Therefore, nursing decisions were based on information from patients who had the ability to talk. In my study, through "longitudinal knowing", LD nurses were able to read patients' cues consistently and correctly.

LD nurses' working situation is different (Pyles and Stern, 1983). They work with patients who have substantial cognitive impairment (Chapter 1, section 1.2; WHO, 1999). PPLD have limited ability to communicate and have no spoken words or language. Recognition of the state of health of PPLD who are without spoken words depends on nurses' ability to recognise the onset and the processes of illnesses and diseases. Through "longitudinal knowing" LD nurses are able to "intuitively" grasp any changes that have occurred.

My study also differs from Benner's work (1984). She claims that "expert" nurses who reached the level of expertise are more intuitive. She suggested that nurses who had at least five years of nursing experience in one clinical area were more intuitive as they progressed from being a "beginner" to a "competent" practitioner. Thus, the ability to intuitively grasp and identify situations rested on nurses' clinical abilities as they advanced. She also suggested that expert nurses' intuition was derived from practical nursing knowledge based on "pattern recognition" and "similarity recognition" (Chapter 5, section 5.2).

My results depart from Benner's notion that "intuition" should only occur among expert nurses. Evidence in my study shows that "intuition" occurs among both qualified LD nurses and unqualified LD nurses. My findings show that LD nurses' idea of "intuition" relates to a sense of "feeling", which underpins "longitudinal knowing". I showed that "longitudinal knowing" enables LD nurses to pinpoint when their patients were becoming unwell. For example, their notion of having a "strange feeling" was built on accrued knowledge about a patient over time. I also showed that LD nurses used past experience to enrich their knowledge and interpret new situation about a patient's changing health condition. So, "longitudinal knowing" provides a tool for recognising a patient's changing health condition.

My study also departs from Rew's (1988) study. Rew shows that "intuition" has a physiological base. For example, nurses in her study describe "intuition" as sensations such as muscle tightening, pulse racing, mouth feeling dry, and skin flushing. I argue that the difference in how nurses describe intuition could well be due to the busy hospital setting of Rew's study, for example, critical care units and patients who may be deteriorating rapidly. This is in contrast to LD nurses who work at a much slower pace that is more relaxed. I show that LD nurses recognise changes in patients' health through "longitudinal knowing".

In line with the views of English (1993) and (Rew (1989), I argue that "intuition" plays an important role in helping LD nurses to make decisions when caring for PPLD who have little or no communications. I show that nurses take nonverbal cues seriously. They are willing to act on their "strange feelings". By extension, my findings show LD nurses do not hesitate to act on their "intuition". Thus, intuition is crucial for LD nurses and therefore relevant in the education of LD nurses.

My findings show that LD nurses' "intuition" prompts them to take actions immediately by referring their patients to doctors for further investigations. My results also showed that doctors did not take LD nurses' intuition seriously. For example, resistance to a nurse's intuition was demonstrated in one extract 8 (participant 21) - "they don't believe you". Some doctors in PPLD setting seem to have difficulty accepting nurses' 'intuitive grasp' for a particular patient's situation. Their scepticism or rejection of nurses' "intuition" may be due to a lack of understanding. They tend to respond to clinical manifestation of visible signs (Callery, 1996, chapter 5). The issue raised here is that doctors should take PPLD nurses' personal knowledge about their patients seriously.

My findings point to the importance of developing a system whereby LD nurses could use their intuitive insights without fear of being disbelieved or ridiculed. My findings show that LD education and practice need to foster the development of intuitive thinking in the classroom. At present, LD nurses are taught to obtain only objective data in the classroom, following the nursing process. Small case scenarios could be used to re-enact this type of situation in small groups in the classroom. This would foster development of the specific skill of using intuition. Additionally, discussions or feedback at the end of a shift between nurses in practice (residential homes) are a good way to explore and compare experiences of intuition. Learning through careful record keeping of situations is also one of the important means for documenting the significance of intuition in nursing practice.

The results of my study also demonstrate that LD nurses draw on other sources of knowledge to help them to recognise patients' changing health status. They showed

that the combined use of “commonsense” knowledge and “formal” knowledge helped them to make appropriate assessment about the patients’ health condition.

#### **8.1.4 Contextualising “commonsense” knowledge and “formal” knowledge**

In my study, I show that “commonsense” knowledge enables LD nurses to notice and report patients’ signs and symptoms. The evidence presented in this study shows that qualified LD nurses (Q16, Q18, Q19) tend to use technical language more (see chapter 7, table 23). In these instances, technical language was the focus in the description of changing health symptoms. I argue that technical language underpins “formal” knowledge which is acquired through nurse education and training.

Hanson’s (1994) study shows that nurses in the acute settings use technical language in the clinical situation. Hanson suggests that in a clinical setting, the use of technical language increases (Chapter 5, section 5.3). However, this is not surprising. Moreover, Hanson’s study did not indicate whether nurses in the study were qualified nurses or health care assistants.

The results of my study provide evidence that unqualified LD nurses are more inclined to draw on lay language to describe and report signs and symptoms of illnesses. My findings revealed that the use of lay language was a natural and spontaneous activity within learning disability nursing practice (see chapter 7, table 22).

In my thesis, LD nurses use lay language in their practice for a reason. LD nurses work in an ordinary home living environment (Chapter 2). PPLD are primarily regarded as a ‘person’ not a ‘patient’. In this sense, PPLD are patients only when they become ill (see Chapter 1). LD nursing practice is based on a social care model, underpinned by the philosophy of social role valorisation (Wolfensberger, 1976). Moreover, LD nurses

work in a non-clinical setting; therefore, medical terms are not used frequently. This means that there is limited reason for using technical language.

The use of lay language may however distort the seriousness of patient's illness. Several reports point out that a lack of clarity in describing illnesses or diseases (see chapter 2, section 2.3.4, Tuffrey-Wijne et al, 2005; Ng and Li, 2003; Foundation for People with Learning Disabilities (GOLD), 2002) may delay LD nurses in getting patients seen by doctors. Some healthcare professionals may misinterpret and misunderstand signs and symptoms, delaying intervention and treatment. Also, there is the risk of de-professionalising LD nursing. I argue that "formal" knowledge and education should be maintained to reflect a competent and professional nursing workforce (chapter 4).

My findings pose a challenge for academics whose language often differs from that in the actual workplaces. For example, the use of lay language is a natural approach among LD nurses in residential homes. However, considering that "lay language" is an important strategy found in this study, it is imperative to plan a variety of teaching activities. I argue that "lay language" should be built into the curriculum.

### **8.1.5 Contextualizing (a) "uncertainty" of knowing and (b) "certainty of not knowing" (gaps in knowledge)**

#### **(a) "Uncertainty of knowing"**

My findings also demonstrate that some LD nurses have difficulty in recognising the onset of patients' illnesses. "Uncertainty of knowing" is reflected in the words/ terms they used. For example, "might", "possibly", "maybe", "suspected", and "something". However, "longitudinal knowing" enabled them to notice and sense that something is not quite right with their patients and that a change in patient's behaviour had occurred. Nevertheless, patients' diagnosis of a disease was sometimes still delayed (extract 8,

Q21, chapter 7) resulting in early death (Ng and Li, 2003). The reason for the delay in diagnosis was because doctors did not take LD nurses' suspicions seriously (see chapter 7, extract 8, Q21). The issue raised here concerns timely diagnosis and intervention (Li and Ng, 2008; Black and Hyde, 2004; Tuffrey-Wijne, 2002) which has consequences for the patient's care and treatment.

LD nurses are "key" workers in residential homes. They are patients' immediate carers. Therefore, this means LD nurses would be the first to pick up early signs and symptoms of illnesses. However, "uncertainty of knowing" creates a tension between "knowing the patient well" and "comfort" care. This supports the notion that learning disability conditions often override and obscure physical illnesses (diagnostic overshadowing) (Hendren et al, 1990).

Also, another the reason for "uncertainty in knowing" was a lack of clinical experience because of the nature of LD setting. Consequently, LD nurses had little practical learning opportunity to learn about end-of-life care / care of the dying.

Gaps in pathophysiology knowledge suggest that LD nurses may be out of their depth when caring for LD patients who suffer from specific cancers. "Longitudinal knowing" then serves to alert LD nurses that something is not quite right with their patients. They report their "noticings" which then lead to referrals to the doctor. Through "longitudinal knowing", they are able to articulate that their patients are unwell, but cannot yet eloquently express what is wrong with their patients in clinical terms. Thus, the identification of a lack of this knowledge represents a tension between "longitudinal knowing" and "uncertainty of knowing". This means that sometimes LD nurses know the patient well as a person, but does not necessarily understand the pathological changes. Thus, to address the "tension" in "uncertainty of knowing", LD nursing



education and training needs to include the pathophysiology of advanced diseases and illnesses within the learning disability nursing syllabus. There should also be a systematic assessment tool to identify disease-related illnesses. A simple observational tool (table 25, attached at the end of this section) is developed from this study. It can help LD nurses to identify disease-related changes in PPLD. This would perhaps prevent the problem of late detection and diagnosis of illnesses and diseases. I recommend that this simple observational tool needs trialing and suggest a future study on it.

Another option is to introduce short courses or shared programmes that focus on pathophysiology of advanced diseases and illnesses for nurses across all nursing disciplines. A shared course could be introduced for nurses from acute settings, hospices and LD nurses in residential settings. This type of joint-learning also encourages partnership and sharing of information (GOLD Standards Framework, 2009; Ellershaw and Wilkinson, 2003).

**(b) “Certainty of not knowing” (gaps in knowledge)**

My findings show that LD nurses know where their knowledge gap is. They identified a lack of knowledge about cancer and the use of a syringe driver to relief pain experienced by the patients. They address these deficits through education and training. They attended study days and short courses. They also accessed the internet and nursing journals to increase their nursing knowledge about advanced diseases. They accessed the services of specialist palliative care nurses to provide them with information on cancer diseases and in the management of pain relief. A discovery of a lack of knowledge and recognising the need to update knowledge in pathophysiology of diseases helps to reduce the tension created by “uncertainty of knowing”.

In concluding this section, recognition of a patient's changing health condition comes from longitudinal experience of knowing the patient well. Using a grounded theory approach, "longitudinal knowing" enabled them to identify critical moments when their patients' health deteriorated. In addition, my findings showed that LD nurses' assessment of a patient's changing health status included using various types of knowledge, namely "intuition", "commonsense" knowledge and "formal" knowledge. "Intuition" is not only limited to the domain of "expert" nurses in acute nursing settings, but also extends to residential settings. I showed that these types of knowledge are important in the recognition and assessment of PPLD's changing health conditions. I also showed that "longitudinal knowing" alerted LD nurses that something was wrong with their patients even though they were uncertain whether the changes were LD-related or disease/illness-related.

**Table 25- A checklist for identifying disease-related changes in patients with profound learning disabilities**

Residential care home:		Patient's name:				Name and signature of attending nurse/s:			
Date started:		Time started			Date completed:		Time completed:		
OBSERVATION	INDICATORS	DESCRIPTION: PLEASE CIRCLE THE APPROPRIATE BOXES						INTERVENTION	REVIEW DATE
APPEARANCE	Facial expression	relaxed	tense	frowning	cringing	distress			
	Skin	normal	pale	sweaty	cold	hot			
	Mental alertness	Alert	anxious	confused	irritable/ restless	cheerless	unable to do things/inactive		
HABITS/MANNERISMS	Smiles	always	occasionally	rare	rarer	no longer smiling	lacklustre		
	Likes to be cuddled/hugged	always	occasionally	rare	rarer	refused	withdraws from people		
	Interested in people and surroundings	active eye and head movement	become more accepting	become more interactive	withdrawn	covering head with clothes or hands	withdraws if touched		
	Vocal expression	normal	lost of laughter/ less vocal	moaning/groaning	whimpering	crying	screaming /shouting		
	Eating habits/Appetite	normal	'off food'	eating less and less/ taking longer to eat	refuses favourite food/pudding	refuses favourite drinks	uninterested in food and drinks		
	Sleep	normal	wakeful	lethargic	sleepy				
PHYSICAL / PHYSIOLOGICAL CHANGES	Weight	normal	thin	muscle wasting	marked weight loss	progressive weight loss			
	Pain	None	frowning	whimpering	fretful	in obvious distress			
	Bowel movement	regular	irregular/change of bowel habits	diarrhoea/watery	constant flatulence	no bowel movement	(faeces) unusual smell/ colour		

	Breathing	normal	slow	breathless at rest	panting	gasping			
	Temperature	normal	low	pyrexia	hyper-pyrexia		purple fingers and toes		
	Pulse	normal	fast	irregular	slow				
	Respiration	normal	fast	irregular	slow				
	Blood pressure	normal	raised	high	very high				
	Urine	clear and odourless	cloudy	output: reduced/increased/retention	blood in urine	smell			
	Skin	normal	dry/flaky/patchy/swelling	ulcer:healing/bleeding/malodorous/fungating	bruising under the skin	jaundiced	oedema:localised/widespread		
	Nausea /vomiting	None	retching	vomiting	projectile	vomiting of blood			
	Weakness/ fatigue	None	floppy	lethargic	constant tiredness				
	Breast	fluid discharge from nipple: clear/ bloody	nipple retraction or indentation	change in size and shape of breasts	compression or dimpling of the skin over breast	redness and dimpling of the skin over breast	feels hard to touch		

## **8.2 Research question: how do learning disability nurses care for terminally ill PPLD - “Comfort” care**

The results of the study show that “comfort care” derives from personal knowledge gained through accumulated experience and longitudinal knowing of individual patients. In other words, “knowing the patient well” is the foundation for giving comfort care to terminally ill PPLD in residential homes. In this study, “comfort care” means relieving a patient’s physical discomfort. This involves (a) the “presence of the nurse”, (b) providing good personal hygiene and positioning of the patient to achieve physical comfort and (c) to relieve pain and discomfort associated with the patient’s disease.

There is evidence in Saunders’ (1963) work that suggests dying patients’ physical and physiological needs are equally important (see Chapter 3). These aspects of care are in keeping with the principles of the palliative care approach for terminally ill people (NCHSPCS, 2002) (Chapter 3). In my study, even though LD nurses may not have the knowledge of palliative care, their accounts suggest that it is important to make sure that their patients are “comfortable” at the end of life. Reducing discomfort and responding to bodily dysfunction is a strong message in LD nurses’ descriptions of caring for PPLD at the end of life. At present, there is no specific assessment tool that may be used to assess and evaluate end-of-life care for PPLD. However, the general principles of end-of-life care (NCHSPCS, 2003) could be fine-tuned and used in caring for PPLD in residential homes.

I showed that participants were good at providing basic nursing care in comforting terminally ill PPLD. They took pride in giving basic care. I also showed that caring for terminally ill PPLD requires nurses to deliver holistic care. The results of my study show that the “longitudinal presence of the nurse” is an important concept for nursing practice. It adds nuance to the delivery of “comfort” care at the end of life.

“Longitudinal presence” means a familiar presence over time and provides opportunities for LD nurses to reassure, comfort, diminish anxiety, loneliness and vulnerability. This is highlighted in the descriptions discussed in chapter 7 (section 7.5.2). Aikens (1908) refers to “presence of a nurse” as a practical activity, a necessary condition for comfort care. My study differs from these writers in that it is a longitudinal presence of the nurse. My results do not suggest that “longitudinal presence of the nurse” is just a practical activity; but it serves as a psychosocial / emotional activity (NCHSPCS, 2003). This suggests that longitudinal presence enhances a patient’s security when they are vulnerable at the end of life (Stanley, 2002, chapter 3). In my study, therefore, the notion of “longitudinal presence of the nurse” is similar to the “presence of another”, as an important aspect of comfort care (NCHSPCS, 2002).

The results of my study also showed that “longitudinal presence of the nurse” relates to “caring”. Every LD nurse is expected to care for his or her patients; it is their moral and nursing duty (NMC, 2008; Carper, 1978) (see chapter 4). The findings showed that they did not openly talk about or use the term psychological care; however the word “distress” implied both physical and psychological elements of care of the dying. The prevention of distress is central to Saunders’ (1963; 1978; 1983) concept of ‘total pain’ in the care for terminally ill / dying patients (chapter 3). The analysis of data showed that LD nurses respected the patient as an individual. The analysis of data also demonstrates evidence of a caring attitude for another as a human being as opposed to a stigmatised person with blemishes (Todd, 2006; Goffman, 1963; see chapter 2). Personal knowing then relies on “longitudinal knowing” and “longitudinal presence”.

The analysis of data showed that LD nurses were also concerned about unspoken pain and suffering in PPLD. One of the nurses priorities is to relieve physical pain and discomfort. My findings revealed that LD nurses knew that they were not necessarily

skilful in administering pain-relieving medications with a syringe driver. However, through ‘longitudinal knowing’ and ‘longitudinal presence’, they acquired skills in noticing signs that might indicate that their patients were suffering. Several authors also identified a lack of nursing knowledge and skills regarding pain and symptom management in caring for terminally ill PPLD (Tuffrey et al, 2010; Todd, 2005; National Patient Safety Agency 2004; Read, 1998) (see chapter 2). Thus, it raises another issue for education in PPLD nursing.

LD nurses in my study reported their reliance on specialist palliative care nurses to administer a syringe driver to relieve pain (Tuffrey et al, 2010; Todd, 2005; National Patient Safety Agency 2004; Read, 1998). The issue of using a syringe driver to manage and control pain is linked to the lack of formal training in this subject area. In addition, LD residential homes are not equipped with life maintaining and saving technical equipments. It may be necessary for example to develop an educational programme for qualified LD nurses to use the syringe driver and monitor pain sensitivity. As a nurse educator, I was well aware that, despite current teaching about nursing assessment and care for PPLD, there was not enough emphasis placed on nurses who work in residential homes to learn to use such equipment.

Currently, several pain assessment tools are in place in general nursing. For example, the Abbey Pain Scale (Abbey et al, 2004) and the McGill Pain Questionnaire (Melzack, 1975). The Abbey Pain Scale (Abbey et al, 2004) could be introduced in PPLD settings as PPLD like people with late stage dementia, cannot speak or have no speech. The Abbey Pain Scale is designed to assess pain in patients who are unable to articulate their needs. The assessment markers for pain in this scale have six areas. They are (i) vocalizations such as whimpering, groaning, crying, (ii) facial expression, for example, looking tense, frowning, (iii) change of body language: fidgeting, rocking, (iv)

behavioural change; refusing to eat, confusion, (v) physiological change, for example temperature, pulse or blood pressure outside the normal limits and (vi) physical changes such as skin tears, arthritis. The McGill Pain Questionnaire (Melzack, 1975) is not appropriate for PPLD. This is because it consists of groupings of words that describe pain. This requires verbal articulation not suitable for PPLD who have no spoken words or language. There has been a suggestion that PPLD demonstrate pain insensitivity (Dodd, 1999). Furthermore, Hunt (2001) reported that there was difficulty in distinguishing the expression of physical pain from expression of emotional pain. Nonetheless, it is accepted that pain among PPLD is likely to be present, but may be expressed in behaviour. There is therefore a need for using pain assessment tools to guide LD nurses in determining the different levels of pain.

### **8.3 Research question: what services and resources were used by learning disability nurses to care for terminally ill PPLD – “*knowledge gaps filled by others*”**

PPLD with a terminal illness may have multiple disabilities. This means that multiple interventions are needed. Once diagnosis was known, appropriate care and interventions could be delivered through collaboration, between LD nurses and other healthcare professionals. This included the specialist palliative care team and occupational therapist and /or physiotherapist and doctors.

My findings showed that where LD nurses lacked knowledge and skills in cancer nursing, support was sought from a combination of expertise from specialist palliative cancer nurses (Payne et al, 2008). This was particularly evident where specialist skills were required to administer a syringe driver. The findings confirmed that there was a gap in LD nurses’ knowledge and skills in managing terminal illness and cancer (Li and Ng, 2008; Jones et al, 2007; Todd, 2005; Black and Hyde, 2004; Ng and Li, 2003; Lindop and Read, 2005; Tuffrey-Wijne, 2002; Bycroft, 1994). My thesis revealed that



“comfort care” was achieved through collaborative division of labour between LD nurses and specialist palliative care nurses. For example, where LD nurses lacked knowledge and skills in cancer nursing, the palliative care nurses were on hand to fill this knowledge and skills gap. I argue that giving “comfort care” is an interdisciplinary effort.

My findings suggest that not enough emphasis was placed on the management of pain in the 1980s education and training programme in learning disability nursing. On the other hand, one could also argue that learning disability nurses are trained to work in a social environment. The use of clinical knowledge and skills is rare because of the nature of the nursing environment. Given this observation, specialist palliative care nurses have an important role in achieving pain control in cancer (NHS-End-of-Life Care Programme, 2006; The NHS Cancer Plan and the New NHS, 2004). I propose that joint education and training for LD nurses and hospice specialist palliative care nurses may be necessary. The joint training initiative has already occurred in one local healthcare setting. There are benefits to having joint training sessions between nurses from a variety of discipline. Joint training allowed a deeper understanding of each other’s discipline, to improve the collaborative delivery and understanding of effective treatment and intervention at the end of life for patients (Li and Ng, 2008; Tuffrey-Wijne et al, 2007; Cardy, 2005) modelled on the Liverpool Care Pathway (Ellershaw and Wilkinson, 2003). A robust ongoing joint education and training programme should include integrated and advanced care planning, management and control of symptoms, care after death and bereavement process ([Goldstandardsframework.nhs.uk](http://Goldstandardsframework.nhs.uk), 2009; NHS-End-of-Life Care Programme, 2006; Ellershaw and Wilkinson, 2003).

My findings showed that LD nurses were motivated in pursuing their own knowledge to fill knowledge gaps in cancer nursing (NMC, 2008). For example, they accessed the

internet for more information about cancer diseases and were willing to learn from the specialist palliative care nurses/ teams. They recognise that joint knowledge is the right approach to achieving good quality care for terminally ill PPLD. LD nurses are appraised once a year and clinical supervisions are compulsory part of Post-Registration Education and Practice (PREP) (NMC, formerly UKCC standards). In some NHS Trusts, LD nurses held regular one-to-one sessions with a supervisor from an associate discipline (for example, community nursing).

My findings suggested that when LD nurses described “comfort” care, they did not explicitly refer to the Liverpool Care Pathway (LCP) and GOLD Standards Framework (GSF) in caring for terminally ill PPLD. Fitness for Practice (UKCC, 1999) stipulates that nurses should have sound knowledge and skills in maintaining quality care in practice. The aim and design of the LCP and GSF is to deliver a high standard of care for patients at the end of life, through team working (see chapter 3). This means enabling and supporting the dying patient to the end without pain (McNamara, 2001; Saunders, 1983, see chapter 3). Historically, the “gold standard” of care for PPLD nearing the end of life was not a central theme in LD nurse training. Additionally, there was little or no research conducted in residential homes for terminally ill PPLD.

In my study, LD nurses did not indicate whether they had any formal training about using end-of-life care tools such as the LCP and GSF. The LCP and GSF are recognized nationally as major initiatives to improve care of the dying within healthcare. The LCP and GSF appear to be exclusively taught for those caring for non-disabled patients. These programmes could be adapted for use in LD nursing. LD nurses working in residential homes where they are likely to experience care of terminally ill people should be taught these programmes. Understanding and implementing both LCP and GSF are crucial for terminally ill PPLD. Fitness for Practice (UKCC, 1999)

recommends that nurses, regardless of their field of nursing, must be competent and 'balanced', in knowledge, attitudes and skills. At the same time, LD nursing curriculum developers and implementers ought to review their theoretical content to include rigorous discussion of LCP and GSF. LD nurses could adapt the LCP and GSF and implement them in residential homes for terminally ill PPLD. NICE (2004) recommends that regardless of care setting and patient group, nursing staff are required to meet the needs of palliative care patients. A robust continuous learning and teaching programme underpinned by LCP and GSF ethos must be implemented in LD residential homes where residential homes are now the preferred place of death. Training of the LCP and GSF should therefore be made available and a priority, to qualified and unqualified nurses. The training programme could include the properties of "comfort" care identified in this thesis such as mouth care and turning of the patient to avoid pressure sores. It is also important to include other essential aspects underpinning the principles of palliative care, for example, advanced care planning, symptom and pain management and therapeutic / communications skills to help patients cope with their illness.

#### **8.4 Limitations of my thesis**

My research was conducted in two community-based care settings, both located in the South East of England. The size of my sample and location of the homes may therefore limit my research. I had initially wanted to also interview nurses in private/independent care settings, but had to abandon the idea, because I would not have the resources in terms of time and organisation. It would be interesting to find out if learning disability nurses differ in different settings, in the way they make nursing decisions about patients' changing health conditions and comfort care. Also, my study is based on accounts of care, not direct observations, and self presentation (Goffman, 1959, see chapter 6) is likely to be an issue. The study needs to be replicated in other settings. It may yield

further insights into the experiences of this group of nurses as LD care is variable in community-based settings.

### **8.5 Contributions to new knowledge**

My thesis has generated new thinking about the experience of LD nurses caring for terminally ill PPLD in residential care homes. It explicates the strategies and sub-strategies concerning how LD nurses recognise signs and symptoms of changing health status. Figure 2 (chapter 7) represents the pathway of assessment - “the normal and the pathological continuum”, a concept adapted from Canguilhem (1989). This “continuum” helps LD nurses to establish ways of “knowing” disease-related signs and symptoms, leading to accomplishment of “comfort” care for their patients at the end of life (figure 2). The continuum constructs different ways of knowing, particularly “longitudinal knowing”. I showed that LD nurses could identify early signs and symptoms of illnesses using ‘markers’ (see Chapter 6, Table 15) to pinpoint when a patient’s health had noticeably deteriorated. I showed that a deviation from the normal behaviour pattern and/ or physical appearance along the “normal and the pathological continuum” was perceived as a precursor to illness or disease. In addition, accounts in this study showed that LD nurses drew on different ways of “knowing the patient well”. These were “intuition”, and a combination of “commonsense” knowledge and “formal” knowledge. These strategies helped LD nurses to recognise changing health conditions in PPLD. Through ‘longitudinal knowing’, LD nurses were able to pick up clues and refer their patients to doctors for further investigations.

In my thesis, I showed that LD nurses’ personal knowledge about their patients and past experiences allowed them to notice qualitative distinctions about patients’ changing health conditions. My work shows that LD nurses’ personal knowledge is premised on ‘longitudinal knowing’. LD nurses also relied on “intuition” to establish the distinction

between disease-related and LD-related signs and symptoms. Because they were permanent staff in an informal environment, the opportunity to be present and to get to know the patient was increased. I showed that the development of “intuitive” knowledge among LD nurses derived from ‘longitudinal knowing’.

My study also showed that “intuition” occurs among LD nurses at all levels. This is where my study departs from others (Benner and Tanner, 1987) (chapter 7). In my study, LD nurses have considerable experiences in caring for PPLD. I showed LD nurses were aware of, and subsequently act on their intuition. It was an inherent working knowledge developed through longitudinal knowing. LD nurses trusted and used their “intuition” to make decisions about patients’ health conditions. This means they did not ‘downplay’ their ‘intuition’. Instead, I showed LD nurses acted on their “intuition”, and sought medical diagnosis about their patients’ changing health conditions.

My thesis also showed that sometimes LD nurses use a combination of “commonsense” knowledge and “formal” knowledge as strategies to assess patients’ health conditions. Building on Schutz’s work (1976, 1966, see chapter 5) on the concept of “commonsense” knowledge, that is, routine knowledge people have of their everyday world, I showed that the framework of “commonsense” knowledge is represented by LD nurses’ use of ‘lay language’ in residential homes. My thesis showed that “lay language” was a representation of LD nurses’ practical, routine knowledge, naturalised within LD nursing. The emphasis on a social care model (see chapter 4) affected the way LD nurses presented themselves in the way they spoke. I showed that LD nurses’ “commonsense” knowledge then derives from “longitudinal knowing”.

My thesis also proposes that “the normal and the pathological continuum” (figure 2, chapter 7) be used to trace the illness trajectory. It helps to pinpoint the patient’s changing health condition and identify an area of “uncertainty of knowing” which could be a barrier to timely and appropriate care and treatment. This area would be best addressed through nurse education and training. This should include the LCP and GSF in the LD nursing curriculum. “Uncertainty of knowing” refers to moments when LD nurses are not sure whether the observed changes in the patient’s behaviour is a sign of an illness or disease or if it is LD-related. Sometimes patients’ symptoms cannot be easily identified because they do not show particular physical characteristics. “Uncertainty of knowing” creates a tension between “longitudinal knowing” and “comfort” care. LD nurses may regard the signs as LD-related, that is, diagnostic overshadowing. My work has contributed to nurse education in terms of identifying gaps in knowledge and skills and how these could be addressed.

My thesis put forward the view then that “uncertainty of knowing” reflected a lack of pathophysiological input in the 1982 learning disability nursing education and training syllabus. The 1982 syllabus was underpinned by the principles of normalisation (Wolfensberger, 1972) that promoted social care (see chapter 4, section 4.3.4). In this syllabus, there was little input relating to knowledge about pathophysiology of diseases and illnesses. In addition, learning to observe the signs and symptoms of progressive diseases and illnesses in practice was also questionable because of a lack of clinical experience. A deficit in knowledge and skills about the pathophysiology of diseases and illnesses therefore creates a ‘tension’ in the sequential accomplishment of comfort care at the end of life for terminally ill PPLD in residential homes.

My thesis contributes to new knowledge in terms of tracing the pathway along “the normal and the pathological continuum” (figure 2) to assess, plan, implement and evaluate care so that comfort care can be achieved. It is also applicable to people who suffer from progressive diseases like Motor Neurone Disease, stroke, dementia or Alzheimer’s disease. The “normal and the pathological continuum” can also be adapted to the assessment of non-disabled patients in acute settings.

My thesis establishes a checklist (table 25) that can be generalised and applied to patients who have speech difficulties or loss of speech or loss of mobility. This is now adopted by one NHS Trust (LD service) as an assessment tool for PPLD in residential homes.

My thesis contributes to the production of a teaching and learning package which is informed by both the LCP and GSF. I introduced the programmes to LD nurses, occupational therapists, physiotherapists and speech therapists during a two-day seminar with positive results (see chapter 9, section 9.5). This package now forms part of my teaching plan within my end-of-life care module at level 6 and above.

My thesis contributes to the development of a method that helps LD nurses to make decisions about patients who cannot articulate their wants and needs. It would be interesting to explore the relationship between “knowing the patient well” and “uncertainty of knowing” at different levels (that is, qualified and unqualified nurses) of practice in the care for terminally ill PPLD to identify knowledge and practice gaps. Nurses in all settings need to demonstrate their ability to recognise patients’ changing health conditions. Nurses in the acute settings may not have the opportunity to establish a longitudinal relationship with their patients in critical care settings. However, they

have opportunities to get to know their patients in settings in which patients with long-term conditions are cared for. Sines et al (2001, p 3) point out insightfully that nursing care is “dependent on the acquisition and development of competence”. This is because learning disability nurses now work in different care environments, demanding different sets of new skills.

Finally, the aim of my thesis is not to criticise how learning disability nurses care for terminally ill or dying patients in residential care homes. It aims to demonstrate how learning disability nurses make decisions about observed signs and symptoms which inform their actions. A body of learning disability literature in palliative care tends to focus on people with mild, moderate and severe learning disability (Todd, 2005; Tuffrey-Wijne et al, 2005; GOLD, 2002; Bycroft, 1994). The literature tends to emphasise what skills and knowledge learning disability nurses do not have. My study reveals that LD nurses do have knowledge and skills. What they do not have is knowledge about the nature of pathophysiology of advanced illnesses/diseases.

## **8.6 Implications for nursing practice**

Since the implementation of care in the community, the role of LD nurses in residential homes remains largely unchanged. “Longitudinal knowing” is an important process in LD nursing to achieving comfort care in all LD settings. It is vital that nurse educators include the LCP and GSF in the nursing curriculum. Using the title ‘nurse’ has implications for the profession. It implies that a person with an RNLD (Registered Nurse for Learning Disability) should have the right knowledge, the right skills and is competent to practice expertly and professionally. I propose that teaching should include open discussions and scenario-based activities in the classroom. Students should be encouraged to discuss their notion of “intuition” and “commonsense” knowledge. I



also propose adopting ‘virtual reality’ learning to be used for discussions in the branch programme. This method could be useful for students away from the classrooms, suited to those in clinical situations. I propose that student nurses are encouraged to learn and discuss with their mentors in practice the process of knowing the patient, and to document what they have observed in practice. I also propose that nurse educators encourage learning disability nurses to undertake research work in death and dying issues, for example, Alzheimer’s disease and Down’s syndrome and end-of-life care. PPLD with Down’s syndrome and end-of life care is an important area that is still relatively unexplored.

Nurses holding the NVQ may not have the same levels of expertise concerning nursing knowledge and skills as their counterparts (RNMH/RNLD) but it is important that their practice is sound. Unqualified care staff need to keep themselves adequately prepared and knowledgeable in this area of work. They would benefit by attending in-service training or joint training with hospice palliative care nurses, or seeking information from qualified or trained colleagues.

Additionally, despite growing research around end-of-life care for people with learning disability, social policy in England has yet to address the needs of PPLD. Care pathways for PPLD with a terminal illness should be developed jointly between LD and hospice specialist palliative care teams. Joint training was one of the objectives introduced in the LCP and GOLD Standards Framework.

### **8.7 Recommendations for future research**

Little is known about the strategies that I have identified in my study in learning disability nursing practice with PPLD. Future research could include an investigation of

nurses in the private sector. It would be interesting to examine whether my main concept of “longitudinal knowing” is applicable in settings where chronically ill patients with Alzheimer’s disease or Motor Neurone Disease are located. It would also be interesting to examine the resources or support provided by the private sector to enhance comfort care for their patients.

## **8.8 Conclusion**

My thesis showed that “intuition”, “commonsense” knowledge and “formal” knowledge derived from “knowing the patient well longitudinally”. The strategies enable LD nurses to discover patients’ changing health status so that appropriate resources can be provided. The strategies also help LD nurses to provide timely “comfort” care for terminally ill PPLD.

My study found that there was an area of “uncertainty of knowing”. This may impact on the achievement of comfort care. My study also found an area of “certainty of not knowing” - gaps in knowledge. LD nurses were able to identify these gaps and addressed their deficits through education and training. The identification of gaps in knowledge helps to defuse the tension between “uncertainty of knowing” and comfort care. Finally, I do not claim that my study is sufficiently comprehensive to capture the nuances of non-malignant diseases. I acknowledge that there are many possible disease trajectories. My study thus provides one insightful window into the reality of learning disability nurses’ world in caring for terminally ill PPLD in residential homes.

**Chapter 9**  
**Reflections**

## **9.0 Introduction**

The aim of this chapter is to bring my thesis to a close by reflecting on my research journey taken during this study. I consider reflection to be an important activity. As a nurse practitioner and lecturer, reflection has been part of my philosophy and practice for many years. Reflection is a human activity in which people re-capture their experiences, think about it, mull it over and evaluate it (Boud et al, 1985). The areas of reflections are as follow:

- preparation - my role as a researcher-interviewer
- experience concerning entry to research sites
- supervision and support
- participation by participants in practice
- seminar presentation - how participants responded to my findings
- using the computer software package
- why this research matters and achievements of the study.

### **9.1 Preparation - my role as a researcher-interviewer**

Preparation is a necessary part of any research work and significantly so during the interview process. Therefore, extensive preparation is a necessity before the interview to ensure that the interviewer does not leave out key issues relating to the investigation. Preparation enabled me to gain confidence during the interviews. Good interviewing skills rely on sensitive use of social interaction (Green and Thorogood, 2004) for example, to build a sense of trust and to establish good rapport with the participants. Even though I have interviewed nurses in my past research work, I felt that I ought to sharpen my interview skills. Thus, I arranged to interview two colleagues at work. The first practice interview was with my second supervisor. The second practice interview was with a specialist nurse lecturer in palliative care. The practice interviews allowed me to practice skills such as giving positive reinforcement, encouraging expansion and keeping the

interview focused (Flick et al, 2007). At the end of the pilot interview sessions, my colleagues were asked to comment on my interview techniques. They were also asked about the appropriateness of the research questions, the way in which they had been asked, questions that were sensitive, timing and whether the subject had been covered fully. The preparation also ensured that important issues were not left out and enabled amendment of the interview guide prior to data collection. Sines and McNally (2010) say that preparation helps to ensure that the interview guide addresses the research questions, an important part of the research process (see also chapter 6, methodology, issues of validity and reliability). They also suggest that pre-testing or preparation helps to improve the 'running order' of the questions. Feedback from my colleagues was useful. A change was made to a question, for example, instead of asking "when did you notice your patient was unwell?" The question was changed to "can you tell me what your patient was like before she / he became unwell, and how did you know she/he was ill?" The reason for the change was primarily to generate data, which gave an authentic insight into participants' experiences.

## **9.2 Experience concerning entry to research sites**

I encountered some difficulties prior to undertaking fieldwork in one of the research sites. The difficulties were mainly to do with communication between different people in the department. For example, below are two examples which I had noted in my personal research journal (pink book):

### 7March 2007:

- Research protocol granted and approved by LREC - happy days. I should be able to proceed with screening, selecting participants and collecting data.

### 25April

- Emailed R&D staff, explained research protocol was approved and granted by LREC. Request for permission to collect data on site.
- R&D replied - must complete forms (electronic copies - attachment).
- All necessary forms completed, returned to Head of Healthcare Standards.

### 1<sup>st</sup> week of December 2007: NO NEWS FROM R&D

- Rang R&D query about the progress concerning my request to site, to collect data.

- R&D says I must obtain official approval, ie. LREC approval/clearance (Appendix 8) Honorary contract (Appendix 5) and CRB check.
- My reply: forms already sent, provided email correspondence between Head of Healthcare Standards (Trust) and me as proof of evidence – all posted to R&D.

#### 2<sup>nd</sup> week of December

- Still no confirmation from R&D re entry to site. In the meantime, I rang a senior manager to find out if she could let me know of any learning disability nurses suited to my project, for interviews. I was told by her that I would not be allowed into site unless I have completed a CRB check, but she was not sure if I needed it. She promised to find out and let me know.

#### 19<sup>th</sup> Dec 2007:

- Still no news, the manager has not come back to me. Frustration! Ring R&D again, took it upon myself to proceed with CRB check.

#### 20<sup>th</sup> Dec 2007:

- Completed CRB forms. Drove down to Trust and delivered contract and completed CRB in person to department.

#### 16 Jan 2008:

- No news about CRB. Rang HR about progress. HR - CRB paperwork not sent due to staff sickness (administrator who normally dealt with CRB paperwork was on annual leave and subsequently on sick leave).
- Feeling sorry for myself by this stage! My forms were basically left in one of the tray in the office. HR promised to deal with the forms immediately.

#### 6 Feb 2008:

- Rang HR again, CRB returned, all cleared. At last entry granted and approved! What a long journey. It's like waiting for an elephant to be born!

Reflecting on my experience, the difficulty I encountered did not deter me in any way. Rather, the difficulties were about the frustrations linked to the slowness, the waiting, not hearing from those who had made promises. Fortunately, the quality of participants and rich data collected more than compensated for the disappointments. What I learnt also was the politically complicated situation that a researcher will have to endure when conducting research. I learnt to be patient, but also assertive. Most important, to seek support and discuss with my supervisors.

Based on my experience, it is important for students and supervisors to discuss pre-fieldwork 'issues' so that students are more prepared to face challenges, even though

students and their supervisors may not know exactly what difficulties may arise. I also think that perhaps it may be a good idea for researchers or PhD students like me prior to undertaking fieldwork to attend training courses. For example, pre-fieldwork workshops about relationship with people in the field, and how to manage, deal with or overcome challenges.

### **9.3 Supervision and support**

For me, supervision and support is one of the most important things throughout my journey as a PhD student. I was fortunate in that I was always able to discuss my work openly and honestly. Formal and informal support was provided at different times throughout my study. Most of my supervisions were negotiated on a regular basis and centred on the times of data analysis. These sessions were recorded. This proved to be useful because I was able to retrieve information easily and listen to the tapes repeatedly to check that I was doing the right thing. Below are two examples/ extracts from my personal research journal that showed the value of supervision and support given to me.

10<sup>th</sup> October 08 - this meeting showed some of the ‘action points’ that I had to act on after my supervision: I will make a summary of supervision action points (from meetings dated above)

Read around the theme ‘Knowing the patient well’ then write

- only analyse the first data ‘Knowing the patient well’, split into “behaviour “and “physical” and DO NOT DISCUSS, yet (just lay out the chapter as a formal chapter)
- Two weeks before the meeting on the 22 Jan 09 I will e-mail both of you (supervisors) 7,000 words on the first category, i. e. theme - ‘Knowing the patient well’

17<sup>th</sup> September 2009 - feedback on my work by one of my supervisors:

- some good bits of analysis which are supported by convincing data evidence some bits need more work
- organise and present all the data pertaining to one finding and all the data for another finding
- have linking sentence(s) when you present a new finding
- grammatical errors with occasional slip-ups, but much improved
- expression is a great deal clearer but some sentences are cumbersome
- on the whole, it is beginning to look like a proper data analysis chapter

#### **9.4 Participation by practitioners**

One of the major strengths of the study was the quality of the participants, who were interested and more than willing to share their experience with me. I was constantly surprised by their interest in the research. There were a couple of unqualified nurses who volunteered to be interviewed. They had heard about my project and wanted to share their experiences. Participants also willingly shared their patients' care plans with me. I was encouraged and thanked them for their generosity in their offer about reading patients' care plans (this option was not taken-up because ethics clearance was for conducting interviews). They were most generous with their time, making themselves available for the interviews and the interviews were taken seriously. This showed that the research topic was important and worthwhile. Because of participants' openness about their experiences, data collected was both rich (in-depth) and purposive.

Another factor that contributed to the success of data collection and quality of the research study is the relationship between me and the participant (Green and Thorogood, 2004). Participants in the study were people who I knew. I was careful in ensuring that the balance between my personal and professional role as 'insider' was in check. In her article on reflexivity, Arber (2006) points out that managing the boundary between closeness and



distance in terms of the researcher and participant roles must be adopted. Fortunately for me, boundaries were made clear from the beginning of data collection and there was mutual respect and trust. The rich and detailed data collected was sufficient evidence of learning disability nurses' experiences, contributing to the success of data collection.

Interacting and facilitating interviews can be quite astounding, because sometimes it is possible that 'doing' interviewing with participants may have an impact on the researcher. Moreno (1995) points out that sometimes risk and harm may accrue to the researcher more than the researched. I did not feel I was put under pressure or unduly affected on the two separate occasions when participants broke down during the interviews. I stopped the interviews immediately. Appropriately, for me as the researcher - interviewer, I had arranged with the Director of Nursing for on-site counselling /support services within the Trust should nurses require them. This was also a standard LREC requirement for sensitive topics. Clark (1997) points out that it is desirable for the researcher to ensure supportive and appropriate services are arranged. However, counselling was not required by either participant. In fact, both nurses considered the interviews to be cathartic (Heron and Reason, 1981). They told me that it was good to talk about their feelings, about their patient's death. They said that they had not had the opportunities to 'talk' about their experience of caring for patients whom they knew so well. I thought this was positive and so did the participants. It had transpired that both of them had moved into the care homes from institutions with their patients and had known the patients from an early age. In fact they thanked me for giving them the opportunity to tell their stories. On reflection, I guess the reason why participants were able to talk openly about their experience could be due to the fact that I had some previous knowledge about the patients. Hockey (1993) says that participants are more likely to divulge details to someone who shares the same world as the research participants.

All participants were interviewed sensitively. Interpretation of data was treated with sensitivity and I tried to represent the nurses' views as accurately and faithfully as possible.

### **9.5 Seminar presentation - how participants responded to my findings**

I presented a paper based on my initial findings to three separate groups of nurses at three separate venues, in London in 2008 and 2010 respectively. The first seminar presentation was to a group of 12 nurses working in acute settings. I had expected feedback about my findings at the end of the seminar. Instead, I was taken back when half of the group piped up, saying "we were not aware that this group of patients actually existed to require palliative care services". In response to this statement, the chief nurse, an attendee at this seminar declared "it is possible that the lack of awareness amongst you lot is because of the lack of contact with PPLD", she continued "in this hospital we do not and have not admitted PPLD with a terminal illness. It is not possible for us to do so because we do not have the resources nor can we admit PPLD because of their behaviour. Our staff will not be able to cope with this type of patient on the wards." Such comments just about sum-up Addington-Hall's speech (2000) when she says that nurses in the acute settings lack skills in dealing with patients with behavioural problems. This remark also signifies a necessity for reviewing the future training and education of nurses on the nursing programme across all branches.

Additionally, there seemed to be two messages from this seminar: (i) these nurses know very little about PPLD (ii) they presented a somewhat illogical view that PPLD are difficult people to look after. It is clearly important to find out their understanding about PPLD as it is likely that there will be an increase in the number of PPLD which will put a strain on services.

The second seminar presentation was to a small audience, including nurses from different areas of practice, for example, a specialist palliative care nurse and a psychiatric nurse. In their views, I had provided them with evidence that learning disability nurses could identify patients' illness and their ability to give appropriate care at the time of patients' illness.

My third seminar presentation was to a group of mixed healthcare professionals. They included a physiotherapist, a speech therapist and learning disability nurses. This was another interesting session. This group of professionals acknowledged their shortfall in view of the 'constant' change in learning disability services. One of them said that there was the constant pressure from the top to maintain "clinical" skills and knowledge in this area. Another said: "why are we not trained to use the syringe driver?" Another, "it seems that we (learning disability nurses) always have to rely on others to do our job." Their desire to provide appropriate end-of-life care was apparent when they asked me about courses to advance their knowledge and understanding relating to the topic. They also made pledges at the end of the seminar to make improvements concerning quality care for terminally ill PPLD in residential care homes. Some examples included: "I will be keen to get involved in the development of an end-of-life care pathway with other MDT colleagues", "I will think more carefully about my involvement in end-of-life care and in terms of developing guidance/policy in the home".

The message from this seminar (third seminar presentation) seemed to be that learning disability nurses would benefit from attending courses to update the knowledge, skills and attitudes needed for care of PPLD at the terminal stage of their lives. Darzi (2010) says the nursing professions need to be adaptive, proactive, flexible and responsive to change; this statement is applicable to LD nurses. There is little excuse for being less prepared in the care for PPLD with a terminal illness.

## **9.6 Using a Computer Assisted Qualitative Data Analysis (CAQDAS) software package**

Initially I was not sure if I should be using computer software for analysis of data. There is a suggestion that sometimes it is not worth the time and effort to use a computer software package especially if it is a small study (Bryman, 2001). After much thought about which is the best CAQDAS package, I opted to use NVIVO 7 to manage my dataset. I attended two workshops to familiarise myself in using the tool. NVIVO 7 was not too difficult to use, but I found that I still had to do certain tasks manually. By this, I mean I had to go back to basics like using coloured highlighters and pens to deconstruct coded data reports. On the other hand, using NVIVO 7 saved me a lot of time in organising and managing data quickly. It was a useful tool to uncover subtle connections in ways that might be missed if I had not used the software (Lewins and Silver, 2007).

## **9.7 Why this research matters and achievements of the study**

The Department of Health states that the number of people with severe learning disabilities is likely to increase by 1% in the next 15 years (DOH, 2001a). My motivation for conducting this research project originated from recognition that there is little research which explores how PPLD with a terminal illness are being cared for after transfer from long stay institutions into community care. Since completing the research I have concluded that the value of my research may be judged through answers to my research questions. I believe I have answered the three questions (Chapter 7 - findings and Chapter 8, discussion and conclusion) which I set out to find: question 1: how and what processes do learning disability nurses use in the recognition of patient's changing health condition? Question 2: How do LD nurses care for terminally ill PPLD in residential care homes? Question 3: What services and resources do learning disability nurses use to support them in caring for terminally ill PPLD?

I believe I have also achieved the study objectives. I organised a nursing module 'Life transition and end-of-life care for PPLD' for the pre-registration student nurses' programme and continuing professional development (CPD) programme, validated at level 5 and 6. As for the pre-registration student nurses programme, materials have been incorporated into the new curriculum for the first Degree student nurses intake starting this academic year (September 2011). A bespoke "Life transition and end-of-life care for PPLD" training programme was planned and delivered for qualified LD nurses some 18 months ago (CPD programme). This was fairly well attended, but could be better, as some attendees had to cancel due to shortage of staff in the homes.

As no one single profession will have expertise about end of life care, care pathways for PPLD with a terminal illness should be developed jointly with other healthcare professionals. This is particular evident when there are only 7197 learning disability nurses in England (2% of registered nurses) (DOH, 2008). I negotiated and established contact as the link tutor for one of the local hospice that provides in-patient care. I established contact and agreement with the local hospice's educational and training department to co-ordinate training and updating learning disability nurses on new knowledge and understanding on issues relating to terminal care and PPLD.

## **9.8 Conclusion**

In undertaking this research study, I have shown the strategies learning disability nurses used in recognising patients' ill health/ changing condition and the way they care for them (figure 2). I have shown how this might trigger and enhance nursing practice. This research has examined an important area in learning disability nursing, specifically PPLD, and might be used as a template for future research direction.

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## Appendix 1

Interview Guide for Participants - each participant will be asked to focus on the care of a particular terminally ill person with a profound learning disability (PPLD)

### Part One: Demographical Data

1. Nursing qualification
2. Year of training
3. Length of time working in the home

### Part Two: To establish

1. Recognition of patient's changing health status  
Can you tell me what your patient was like before she/he became unwell, and how did you know she/he was ill?
2. Knowledge of pathophysiology of illness / disease  
Can you tell me about the nature of the illness or disease? Where and how did you obtain information about your patient's illness/ from disease?
3. Establish how nurses care for a terminally ill PPLD  
Can you describe what you did for your patient, the types of services and resources that were available to you in caring for your patient?

## Appendix 2

### Research Protocol

Date: 31 Jan 2007

**Title: Investigating learning disability (LD) nurses' experience of caring for people with profound learning disabilities who are terminally ill in residential care settings.**

A person with a profound learning disability has an IQ score of below 20. The person has substantial cognitive and sensory motor impairments and requires total care throughout their lives. Many demonstrate severe physical handicaps and deformities that may restrict their capacity to cope with the demands of the environment. The person needs a greater level of care in comparison to those with mild, moderate or severe learning disabilities. For example, the individual will require help in all aspects of physical care, such as feeding, continence and other activities of daily living including dressing, washing, bathing. The person often has communication difficulties, difficulty in articulation, may not have spoken words or language, and many have hearing loss and poor vision.

**Objectives:** The objectives of the research are to:

- 1) Build a knowledge base for LD nurses who are caring for people with profound learning disabilities.
- 2) Establish how LD nurses develop ways of assessing and detecting the early signs of terminal illness in caring for people with profound learning disabilities.
- 3) Scope the range of services available to support LD nurses in caring for dying people with profound learning disabilities.
- 4) Develop a practice based model for LD nurses caring for people with profound learning disabilities who are terminally ill.

- 5) Inform nurse educators in the future planning and development of nursing curricula, specialist, inter-disciplinary palliative care and pre-registration nursing.

### **Rationale for Study:**

The Healthcare Commission report into the care of people with learning disabilities at Sutton and Merton Primary Care - learning disability service, recently reported that staff were not properly trained and care provided by staff was unacceptable (Healthcare Commission, 2007). Furthermore, the Commission claimed that few staff had specialist training in how to communicate with people with learning disabilities. With the closure of many long stay hospitals for people with profound learning disabilities, a social care model of service provision now predominates. Studies on the care needs of people with profound learning disabilities and life threatening illness/disease are becoming increasingly relevant as the number of this group of people living in the community increases (DOH, 2001). Generally for people with learning disability, there is evidence that diseases such as cancer, heart disease, stroke and respiratory disease have now overtaken the so-called 'institutional' illnesses such as asphyxia due to choking during seizure or from food bolting (Jancar and Jancar, 1977; Simpson, McFarland & Calvert, 1990; DOH, 1992; DOH, 1995; Patja, et al 2000), but there is no clear or explicit statistical evidence or studies to suggest how these diseases may affect people with profound learning disabilities. Yet reports claimed that people with profound learning disabilities tend to die younger (DOH, 2001; McGuigan, et al, 1995; Hoillins, et al, 1998; Patja, 2000). The aims of the 1971 White Paper 'Better Services for the Mentally Handicapped' (DOH, 1971) and 'Care in the Community' (DOH, 1990) have seen a reduction of long stay hospital places from 52,000 to 27,000, with an increasing number of residential care places in the community to about 53,400. Knowledge of the nature of terminal illness for people with profound learning disabilities has important implications for providers of health and social care. There is evidence to suggest that this group of people run the risk of their illness being overlooked by the fact that sometimes the display of challenging behaviour may mask or

be confused with signs of distress due to physical illness (Hendren, 1990). Often the delay in diagnosis and symptoms being overlooked until treatment is impossible are due to poor communication and communication difficulties. There is evidence to suggest that many people with profound learning disabilities have autistic traits, for example, they have difficulty relating to others. They are withdrawn and socially isolated and dislike changes and have difficulty in self expression. As such they have difficulty in co-operating with physical examinations (DOH, 2001). In addition the knowledge base of many LD nurses on the patho-physiology of illness and disease may be weak. Recognition of the state of health of people with profound learning disabilities who are without spoken words or those who cannot express themselves verbally or non-verbally rests with the nurses' ability to recognize the nature and process of illness and disease, in particular when the symptoms develop to the terminal stage when the relief of pain and other distressing symptoms associated with the disease is paramount.

Therefore, the aim of this research is to investigate and analyse the experience of LD nurses caring for people with profound learning disabilities who are terminally ill in residential care settings.

### **Gaps in the Research:**

As yet there is no known published data or empirical studies on people with profound learning disabilities or indeed the experience of LD nurses caring for people with profound learning disabilities who are terminally ill in residential care settings. There is research on people with mild and severe learning disability and palliative care, but these tends to be on the small scale and are based on reports and case studies (Hendren et al, 1990; Bycroft, 1994; Read, 1998; Lindop and Read, 2000; Tuffrey-Wijne, 2003; Ng and Li, 2003; Black and Hyde, 2004).

In view of the lack of research on people with profound learning disabilities who are terminally ill, a preliminary study was conducted. Seven LD nurses were recruited to start with, but ended up with a total of fifteen. The selection of LD nurses were based on their experience of caring for people with profound learning disabilities who are terminally ill. This was in agreement of relevant Director of Nursing services. The findings are based on a selected sample of fourteen LD nurses working in residential care homes in two private healthcare sectors. The findings are:

- i) many nurses employed in the care homes are healthcare support workers, but the home manager would normally be a qualified nurse.
- ii) some of these nurses, both qualified and unqualified, lacked knowledge in the patho-physiology of the disease/illness.
- iii) pain relieving medications are administered by district nurses. This was because qualified nurses in the care homes do not have the skills to administer syringe drivers to relieve pain and other distressing symptoms. The care homes are considered to provide only social care, the policy thus would not have allowed nurses to administer medications.
- iv) even though communication was an important aspect of terminal care, nurses had to rely on their gut feelings and guesses when trying to establish patients' needs. Use of spoken words or language are practically non-existent hence communication is deemed pointless. These nurses believed that their patients would not have understood what is wrong with them.

The preliminary study demonstrates that LD nurses need to have an understanding about the illness/disease, accurate assessment of terminal care needs and manage symptoms other than pain. The findings also suggest that understanding and interpreting non verbal communication with people with profound learning disabilities who have no spoken words is an important and fundamental aspect of terminal care. Nurses generally rely heavily on the patient's ability to recognise and report symptoms. However, this is not possible with people who are profoundly disabled. Consequently, the needs of people with profound

learning disabilities who require terminal/palliative care may be in danger of being ignored or neglected.

The current research proposes to build on the findings of the preliminary study and extend the investigation to the experience of LD nurses caring for people with profound learning disabilities who are terminally ill in residential care homes owned by National Health Service (NHS) Trust.

### **Design and Methodology:**

This is a qualitative study which is guided by the grounded theory approach as advocated by Glaser and Strauss (1967).

The theoretical framework that informs the design of this study will be based on the principles of palliative care (WHO, 2003). Palliative care has been defined as ‘an approach that improves the quality of the patients and their families facing the problem associated with life threatening and shortening illness, through the prevention and relief of suffering by means of early intervention and assessment and treatment of pain and other problems, physical, psychological and spiritual (WHO, 2003). The principles of palliative care involve alleviating pain and suffering, and meeting the psychosocial needs of the patient. The ultimate goal is to enable the patient to ‘die a good death’ (McNamara, 2001; Kuebler, et al, 2005).

### **Methods of Data Collection:**

The study will use semi-structured interview questions based on the following topic areas:

- i) Knowledge requirement of LD nurses in caring for people with profound learning disabilities who are terminally ill.
- ii) How LD nurses assess and meet the dying care needs of people with profound learning disability at the terminal stage of the illness.



- iii) The types of supporting services available to LD nurses in their care for terminally ill patients with profound learning disability.

These questions will be approached by asking participants to talk through their experience of caring for a particular patient. Interviews will be taped recorded and transcribed. A systematic thematic content analysis of materials from the transcripts will be managed with the use of NVIVO 7 package- a computer assisted programme for qualitative study.

A step by step approach will therefore be used (Silverman, 2006; Coffey and Atkinson, 1996)

- i) Transcribing the interview tapes
- ii) Importing the transcription to the NVIVO 7 program
- iii) Analysing for emerging themes and categories
- iv) Content Analysis
- v) Theory-building

#### **Sampling -Theoretical and Purposive Sampling:**

In this study, sampling will be purposive, selecting participants who have first-hand experience of a caring for a terminally ill person with profound learning disabilities. A set of between 30 and 40 interviews will be undertaken for data analysis, depending on the number of participants. Since this is a qualitative study, it can be argued that depth rather than statistical analysis is the essence of this research. In this instance, the sample size is less important than representation (Burns, 2000; Strauss and Corbin, 1998). In addition, small sample population will give rich, in-depth and focused data (Parahoo,1997).

#### **Ethical Considerations:**

Qualitative research requires involvement and a close relationship which will develop between the researcher and the researched which may generate ethical concerns (Field , et al, 2001). In this study, the principles of doing no harm, securing informed consent, not being intrusive and not practising deception will be observed (Bryman, 2001). Participants will be informed prior to being interviewed that any issues they reveal which may be detrimental to, or impact on the care, or health and safety of any persons with learning

disabilities may be brought to the attention of the Director of Nursing, care home managers or nurse in charge of the home.

It is recognised that participants are being asked to describe their experience of a given situation which might prove to be traumatic or emotional for some. This is another reason why it is important to approach gate keepers, namely home managers or nurse in charge prior to interviews. Data collection will be terminated if a participant becomes distressed. Access to counselling will be made available via the site counselling service should this prove necessary.

A Participant Information Sheet (PIS) will be provided to participants telling them of the purpose of the researcher's study. A consent form will be provided for participants to sign as an agreement to be interviewed. They will be assured of confidentiality and anonymity of identity (with the exception of disclosure of adverse events, as discussed above). Transcribed information and written work based on the researcher's published research thesis will not bear any person's name or any links to the residential care homes. The names of participants (LD nurses) or care settings or organisations will not be recorded. Quotes, when used in the 'results' section of the research will be anonymised. Care will also be taken that participants and patients cannot be identified from information provided in the quotes. Participating NHS Trusts will be acknowledged as part of the 'Acknowledgement', with the Trust name anonymised.

### **Conclusion:**

In this research study, the researcher proposes to investigate the experience of LD nurses caring for people with profound learning disabilities who are terminally ill in residential care homes. Data will be analysed guided by the grounded theory approach (Glaser and Strauss, 1997), following the process of data collection as developed by Strauss and Corbin (1998). JNg/31Jan07

## Appendix 3

Date: 31 January 2007

### Participant Information Sheet

#### Study Title:

Investigating learning disability nurses' experience of caring for people with profound learning disabilities who are terminally ill in residential care settings.

You are being invited to take part in a research study which forms part of my MPhil/PhD study at the University of Greenwich. Both the Director of Nursing and the manager of the house have agreed to the study, but you are free to consider whether or not to take part. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask me if there is anything you do not understand and take time to decide whether or not you wish to take part.

Thank you for reading this.

#### What is the purpose of the study?

This study aims to find out about your experience of how learning disability (LD) nurses care for people with profound learning disabilities who are terminally ill in residential care settings.

The objectives and purpose of the research are to:

- build a knowledge base for LD nurses who are caring for people with profound learning disabilities.
- establish how LD nurses develop ways of recognising, assessing and detecting the early signs of terminal illness/disease of a person with profound learning disabilities.
- find out the range of services available to support LD nurses in caring for dying people with profound learning disabilities.

I hope that the information gained from this study will be used to develop a practical model for learning disability nurses caring for people with profound learning disabilities. I also hope that the information will help to inform nurse educators in the future planning and development of nursing curricula, both specialist, inter-disciplinary palliative care and pre-registration nursing.

The study will last from June 2007 to June 2009.

#### Why have I been chosen?

You have been chosen because you have the experience of looking after a terminally ill person with profound learning disabilities. Your experience will provide me with rich and valuable information.

#### Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your employment.

#### What will happen to me if I take part?

If you decide to take part, you will have a copy of this information sheet and the signed consent form to keep. I will ask you to take part in an interview, with two parts. The first part is brief information about yourself, for example, your ethnicity, shift pattern, year of training and qualifications.

In the second part, you will be asked to describe how you have cared for a terminally ill person with profound learning disabilities in the care home. I will ask you to focus on only the patient (s) whom you have cared for the last two years.

You will be interviewed once for not longer than 60 minutes, but a second shorter interview may be required to clarify issues raised. An audio tape will be used to record the interview, with your consent.

The interview will take place at your workplace, namely, the care home, convenient to you and the patients' activities in the care home. The interview will be carried out in a quiet room. I will interview you using a guided semi-structured interview schedule.

What are the possible disadvantages and risks of becoming involved?

There are no risks or disadvantages associated with taking part although it is possible that recalling past events may be upsetting. If so, and if you wish, the interview will be terminated. If you wish, the counselling service within the Trust will be contacted to offer extra support should this be necessary.

What are the possible benefits of taking part?

There are no immediate benefits to taking part in this study. However, it is hoped that the information from this study will help me to develop a practical model for LD nurses caring for people with profound learning disabilities who are terminally ill. Other benefits will include future planning and development of nursing curricula, both specialist palliative care and pre-registration nursing.

What if something goes wrong?

If you are concerned about any aspect of the interview you should in the first instance contact my supervisor-Professor Liz Meerabeau. If you wish to make a complaint please do so in writing to Professor Liz Meerabeau, Head of the School of Health and Social Care, University of Greenwich, Avery Hill Campus, Avery Hill Road, London, SE9 2UG on 020 8331 9150.

Will my taking part in this study be kept confidential?

If you consent to take part in the research, all information which is collected about your experience in caring for people with profound learning disabilities who have a terminal illness will be kept strictly confidential. Only I and my supervisors will have access to the data. Your name will not be disclosed and you will not be identified in any report.

Quotes used in my research will be anonymised. Care will also be taken that you and your patient will not be identified. However, you will be informed at the start of the interview that any issues you reveal which may be detrimental to, or impact on the care, or health and safety of any persons with learning disabilities may be brought to the attention of the Director of Nursing, care home manager or nurse in charge of the home.

Who are the researchers who will interview you?

You will be interviewed by me, Julie Ng, a senior lecturer in the Faculty of Health and Social Care Sciences, Kingston University and St George's, University of London.

What will happen to the results of the research study?

The results of the study will be written up as part of the completion of my MPhil/PhD study. The results of the study will also be disseminated by peer reviewed scientific and academic journals, as conference presentations, presentations to participants and copies of the thesis will be lodged in the University library at St George's, University of London, Kingston University and the University of Greenwich.

Who should I contact if I want further information?

The contact name: Julie Ng, Faculty of Health and Social Care Science,  
Kingston University and St George's University of London,  
St George's, University of London, Grosvenor Wing,  
Cranmer Terrace, London,  
SW17 0RE

Telephone number: 0208 725 2438, Email address: [jng@hscs.sgul.ac.uk](mailto:jng@hscs.sgul.ac.uk)

Or

Professor Liz Meerabeau, who supervises my research study.

Her telephone number: 0208 331 9150

Thank you for reading this and for considering taking part.

## Appendix 4

Date: 31 January 2007

### CONSENT FORM

Title of Project: Investigating learning disability nurses' experience of caring for people with profound learning disability who are terminally ill in residential care settings.

Name of Researcher: Julie Ng

1. I confirm that I have read and understand the information sheet dated for the above study and have had the opportunity to ask questions.
  
2. I understand that my participation is voluntary and that I am free to withdraw at anytime, without giving any reason or legal rights being affected.
  
3. I agree to take part in the above study.
  
4. I agree for my interview to be taped.

-----  
Name of Participant

-----  
Date

-----  
Signature

-----  
Researcher

-----  
Date

-----  
Signature

## Appendix 5

### HONORARY CONTRACT

1. **Name** Julie Ng
2. **Appointment** Research and Development Project SBP040
3. **Accountable to** Sue Gurney (Trust personnel)
4. **Start Date** 18 December 2007

This honorary appointment is from 18 Dec 07 and will run until 18 Dec 2009 in the first instance.

The Trust reserves the unconditional right to withdraw your honorary appointment on any of the following grounds:

- personal and/or professional misconduct
- professional incompetence
- material breach of the terms of this appointment or any of the policies and procedures to which express reference is made in this document.

In considering any case falling under these heading the Trust will use such procedures as would be applied to a member of staff employed by the Trust.

5. **Location**  
You will be based at to be confirmed (Ashmount) within Surrey & Borders Partnership NHS Trust:

6. **NHS Indemnity Arrangements**  
You are covered by the NHS Indemnity arrangements as set out in HSG(96)48 in respect of claims of clinical negligence made against you in the course of your employment (copies of HSG(96)48 and leaflet on Indemnity arrangements issued in October 1996 may be obtained from the Human Resources Department. However, in certain circumstances such as when involved in work outside the scope of your NHS employment, the NHS Indemnity arrangements will not apply. Should you consider that you may be involved in work which is not covered by NHS Indemnity you should retain your own professional indemnity cover.

7. **Personal Property**  
The Trust accepts no liability or responsibility for the loss or damage of your personal property and you are advised to arrange for it to be insured.

The only exception would be where you have been required to hand your property to the Trust for safekeeping and have been issued with a receipt.

If you are required by your manager to use your own craft tools or any other equipment to carry out your tasks, you must provide your manager with a complete list and amend this as necessary.

**8. Health & Safety**

It is your duty while at work

- i) to take reasonable care for the health and safety of yourself and of other persons who may be affected by your acts and omissions at work, and
- ii) to co-operate with the Trust in ensuring that all statutory and other requirements are complied with
- iii) to observe the Safety Policy and other policies, codes of practice etc relating to Health and Safety and
- iv) not to intentionally interfere with or misuse anything provided for Health, Safety or Welfare.

You must comply with all statutory health and safety requirements which affect you. A copy of the Trust's current Safety Policy may be obtained from your Head of Department. The Trust may change or amend the policy from time to time.

**9. Security**

You are required to wear the photo identification badge as issued by the Trust, at all times whilst on duty, on Trust premises.

**10. Confidential Information**

In the course of your duties you may have access to confidential information relating to the Trust, its patients, employees and other parties. You must not use such information for your own benefit nor disclose it to other persons without the consent of the party concerned unless required to do so by law or your professional organisation both during and after the termination of your employment. If any member of staff is found to have revealed confidential information the disciplinary procedure will be applied. If you are in any doubt regarding the use of information in the pursuit of your duties you should seek advice from your manager before communicating such information to any third party.

**11. Concerns about Trust Issues**

If you wish to raise concerns about Health Service issues within the Trust you must follow the Trust's Grievance Procedure, copies of which are available from your manager or the Personnel Department.

**12. Standards of Business Conduct**

The Trust expects you to maintain the highest standards of personal and business conduct at all times. The Trust's rules are set out in its Code of Business Conduct Policy a copy of which is available from your Supervisor and in the Personnel Department. The policy covers conflict of interest, register of interests, awarding of contracts, acceptance of gifts and hospitality, sponsorship, rewards for initiative, and outside employment.

In particular you may not enter into another occupation or employment (paid or unpaid) or hold office in any professional body with the exception of recognised Trade Unions/Professional Organisations, or conduct any trade or business which is likely to interfere with the performance of your duties without the prior permission of your manager. Such permission will not be unreasonably refused.



You may not enter into any contract which is likely to result in a conflict of interest or loss of income to the Trust.

**13. Commercial Confidence**

The Trust wishes to protect its own position and those of other parties in relation to information or other material which is of a confidential nature or which is protected by copyright, patent, trade mark or other intellectual property rights. This must not be disclosed to any third party without the prior permission of your manager.

**14. Equal Opportunities**

The NHS Trust takes no regard (other than where legally required) of a member of staff's race, sex, age, physical disabilities, beliefs or lawful preference privately held, on any matter.

The Trust requires all its staff not to harass or discriminate against any other member of staff on any of these grounds and regards proven harassment and/or discrimination on such grounds as gross misconduct, which may lead to termination of this contract.

**15. Professional Registration**

You are reminded that it is your responsibility to renew your professional registration as necessary. The Trust is unable to continue to employ you if you do not renew your professional registration. Failure to renew will result in the termination of your employment.

**16. Health Clearance**

All appointments with the Trust are conditional on prior health clearance by the Trust's Occupational Health Service.

If you are appointed to a Honorary post designated as high risk under the Trust's Hepatitis B Policy or to any other position in relation to which there is a high risk policy, you will need to provide satisfactory evidence of your Hepatitis B Vaccination status or other appropriate status.

You must also continue to satisfy the Trust during the continuance of your Honorary Appointment, that you meet the health requirements for your job.

**17. Protection of Patients**

- i) You are obliged to divulge to the Occupational Health Department any concerns that you may have regarding your health which may affect patient care and, or the performance of your work. Any information given to the Occupational Health Department concerning your health will be kept in complete confidence. Where the Occupational Health Department considers your health to constitute a serious risk to patients and staff, they will have no alternative but to discuss your employment circumstances in the strictest confidence with your Director of Service and the Trust's Director of Human Resources.
- ii) You are also required to inform the Occupational Health Department in strictest confidence any concerns you have regarding the health of any colleague which

may seriously affect patient care / or the welfare of staff. Any information given to the Occupational Health Department will be kept in strict confidence except so far as is necessary to inform other members of management who have a proper interest in receiving the information.

**18. Criminal Convictions**

If during the course of this appointment you are convicted of a criminal offence you must report the matter in strict confidence to the Head of Personnel who will decide the appropriate action.

Additionally, if driving is a part of your duty and you are convicted of any traffic offence you must report the matter to the Head of Personnel who will decide on appropriate action.

Signed on behalf of the Trust

Name: \_\_\_\_\_ Title: Head of Personnel

Date: \_\_\_\_\_

I confirm my acceptance of the above Honorary Appointment on the terms and conditions of employment stated.

Signed: \_\_\_\_\_

Date: \_\_\_\_\_

## Appendix 6

### TRANSCRIPTION SYMBOLS

Sentences in double quotation marks in the data:

An example of a direct quotation from a participant's account - "*he had loose stools and there was obviously the weight loss*".

Q2, U22 etc in the data: indicates participants.

A registered nurse: the letter 'Q' preceding a number, for example, 2, in the data, indicates a qualified nurse.

A healthcare support worker: the letter 'U' preceding a number, for example, 22, in the data, indicates an unqualified nurse.

## **Appendix 7**

Attached - Letter of approval from Research Ethics Committee -  
University of Greenwich (04/5.4.3)

(This letter is in hard copy attached in bound thesis)

## Appendix 8

Attached - Letter of approval from Local Research Ethics Committee (LREC)  
(07/Q0806/15)

### London - Surrey Borders Research Ethics Committee

St George's University of London  
South London REC office 1  
Room 1.13,  
1st Floor, Jenner Wing  
Tooting  
London  
SW17 0QT

Telephone: 020 8725 0262  
Facsimile: 020 8725 1897

07 March 2007

Mrs Julie Ng  
Senior Lecturer  
St George's Hospital, Faculty of Health and Social Care Sciences  
2nd Floor Grosvenor Wing  
London  
SW17 0RE

Dear Mrs Ng

**Full title of study:** Investigating learning disability nurses' experiences of caring for people with profound learning disabilities who are terminally ill in residential care settings.  
**REC reference number:** 07/Q0806/15

The Research Ethics Committee reviewed the above application at the meeting held on 07 March 2007. Thank you for attending to discuss the study.

#### **Ethical opinion**

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation on the condition that the following points are addressed.

- Add to the Information Sheet how long the tapes will be stored for before being destroyed.

#### **Ethical review of research sites**

The Committee agreed that all sites in this study should be exempt from site-specific assessment (SSA). There is no need to submit the Site-Specific Information Form to any Research Ethics Committee. The favourable opinion for the study applies to all sites involved in the research.

## Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

## Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application		
	08 February 2007	
Investigator CV		
	31 January 2007	
Protocol		
2	31 January 2007	
Covering Letter		
	08 February 2007	
Interview Schedules/Topic Guides		
2	31 January 2007	
Participant Information Sheet		
2	31 January 2007	
Participant Consent Form		
2	31 January 2007	
Statement of Indemnity Arrangements		
	01 July 2006	
Honorary Contracts		
	20 April 1998	
Resume - Dr Sarah Li		
	01 February 2007	

## R&D approval

You should arrange for the R&D office at all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research at a NHS site must obtain final approval from the R&D office before commencing any research procedures.

## **Membership of the Committee**

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

## **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**07/Q0806/15**

**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

**Mrs Sheree Manson**  
**Committee Co-ordinator**

Email: [sheree.manson@stgeorges.nhs.uk](mailto:sheree.manson@stgeorges.nhs.uk)

*Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments*

*Standard approval conditions*

*Copy to: Research Office*  
*St Georges Hospital*

## London - Surrey Borders Research Ethics Committee

### Attendance at Committee meeting on 07 March 2007

#### Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present?</i>	<i>Notes</i>
Dr Steve Hyer	Consultant Physician	No	
Canon Christopher Vallins	Head of Pastoral Care	No	
Mrs Sylvia Aslangul	Lay Member	No	
Mrs Wendy Brooks	Stroke Nurse Consultant	No	
Mr Derek Cock	Chief Pharmacist	Yes	
Mrs Anne Davies	Chief Pharmacist	No	
Mr Eddy Digman	Lay Member	Yes	
Dr Rim El-Rifai	Consultant Paediatrician	Yes	
Mrs Nikki Evans	Cancer Research Nurse	No	
Mrs Sheila Jackson	Senior Sister	Yes	
Mr Christopher John	ENT Surgeon	Yes	
Mrs Sally Kerry	Senior Lecturer in Medical Statistics	Yes	
Dr Lawrence Webber	GP	Yes	

#### Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Mrs Sheree Manson	Committee Co-ordinator