

Abstract

There is a lack of understanding on how paramedic students develop their knowledge, skills and attitudes to support people living with dementia and their families in the community. This qualitative study used focus groups to explore paramedic students' perspectives. 1st and 3rd year paramedic students were recruited from two ambulance service providers in the South of England. Data were collected during 2017 and four themes emerged: 1) impact of dementia on all concerned 2) challenges of communicating with people with dementia 3) negative emotional response to dementia, and 4) lack of social care and pathways for people with dementia. A further two cross-cutting themes emerged: 1) Learning in the classroom and 2) Learning 'on the road'. Paramedic students did not discuss person-centered approaches to supporting people with dementia; however they all acknowledged the impact of dementia as unique to each person, their family and situation.

Keywords

Dementia, paramedic, qualitative, focus groups

Introduction

Globally many countries have developed the role of the paramedic through education and undergraduate programmes, which vary within and across countries (Colver, Fitzpatrick, Cooper, & Ward, 2016; Hou, Rego, & Service, 2013; Hickson, Williams, & O'Meara, 2015). In England national guidelines for paramedic education have been implemented (Brown, Kumar, Milins, & Mark, 2016; Fisher, Brown, & Cooke, 2006, 2013), alongside national standards for paramedic professionalism and a fit to practice register (College of Paramedics, 2015; Heath and Care Professionals Council, 2016) to support consistency across programmes and professional recognition of paramedic practitioners.

Paramedic programmes across and within countries need to respond to the changing population and population needs. The world population of people aged 60 years and over has been predicted to increase by 56% between 2015 and 2030, from 901 million to 1.4 billion (United Nations, 2015).

Dementia is not restricted to those within this age group; however the risk of developing vascular dementia or Alzheimer's disease doubles every five years from the age of 65 (Corrada, Brookmeyer, Paganini-Hill, Berlau, & Kawas, 2010; Jorm, & Jolley, 1998; Prince, Ali, Guerchet, Prina, Albanese, & Wu, 2016).

Ageing populations are strongly correlated with increasing healthcare costs, and a higher prevalence of chronic diseases, such as dementia (Caley & Sidhu, 2011). It is predicated that the care of people with dementia will utilise a greater proportion of health care budgets (LaMantia, Stump, Messina, Miller, & Callahan, 2016; Schaller, Mauskopf, Kriza, Wahlster, & Kolominsky-Rabas, 2015; Prince, Wimo, Prince, Ali, Wu, & Prina, 2015). An analysis of four days of data from across two counties in England demonstrated that a third of ambulance call outs were to patients over the age of 75 years, with 14.5% with a diagnosis of dementia and a further 7.0% with documentation suggesting dementia or cognitive impairment (Buswell, Lombard, Fleming, Ayres, Brayne, & Goodman, 2016).

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3 A recent review of urgent and emergency care services in England described the current service
4
5 delivery, policy and provision of care for people living with dementia as inadequate (NHS England,
6
7 2015). There remains an over reliance on treatment and transport to emergency departments for
8
9 older people presenting with injury or illness (Abrashkin, Washko, Zhang, Poku, Kim, & Smith, 2016).
10
11 In a crisis paramedics are in the optimal position to support people with dementia and their families
12
13 and to avoid hospital admissions where possible (Evans, McGovern, Birch, & Newbury-Birch, 2014).
14
15 NHS England have recommended a change of focus for undergraduate paramedic education, and the
16
17 need to concentrate less on emergency care and more on the treatment and referral of people with
18
19 mental ill health, dementia and minor injuries (NHS England 2013).
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22
23 However, recent studies have highlighted a lack of education in undergraduate paramedic
24
25 programmes on caring for older people and people with dementia (Abbey, et al. 2006; Annear,
26
27 Goldberg, Lo, Robinson, 2016). In the UK, the Department of Health (DH) has identified the need for
28
29 education providers to improve and facilitate learning, knowledge and skills in the area of aged care
30
31 (DH, 2010), with a view to reconfigure paramedic practice to ensure that care of the aged person
32
33 becomes a key aspect (Ham, 2017).
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36
37 Paramedic education needs to prepare students by providing them with relevant clinical and
38
39 interpersonal competencies to care for people with dementia. Traditional paramedic programmes
40
41 have focused on the acquisition of clinical skills and reasoning through clinical placements (Smith,
42
43 2016). This approach has led students to focus on clinical skills such as cannulation and resuscitation
44
45 (Ross, Bennett, & Perera, 2015), to the detriment of soft skills, such as communication (Jackson,
46
47 2009; Ross, et al. 2015). This traditional approach has led to patient interactions that are
48
49 operationalised into a series of sequential events (Halter, et al. 2011), where some paramedic
50
51 students experience difficulty with social interactions due to the lack of assessment tools (Voss, et al.
52
53 2015).
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3 A new initiative to support the development of paramedic students' interpersonal and
4
5 communication skills has included inter-professional education (IPE) with clinical placements in
6
7 aged-care to prepare not only paramedics, but medical and nursing students (Annear, et al. 2016).
8
9 This initiative found divergence in the outcomes experienced by nursing and paramedic students as
10
11 to the value of such programmes (Hallam, et al. 2016). The divergence was further amplified as
12
13 paramedic students viewed themselves as separate and not part of the wider health care system as
14
15 most care occurs within hospital or community settings (Williams, & Webb, 2015).
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19 Unfortunately, initiatives of placements within aged-care facilities for paramedic students have
20
21 remained focused on the development of processes and assessment tools. One initiative explored
22
23 the relevance of two pain scales for people with dementia, although this did inform students of
24
25 these tools and how they could be developed to become relevant for paramedic practice. This
26
27 approach did not focus on or support the development of students' interpersonal or communication
28
29 skills (Lucas, et al. 2016).
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32
33 Currently, there is limited understanding of how paramedic students develop interpersonal and
34
35 communication skills to support people with dementia and their families. Therefore this current
36
37 study seeks to understand the experiences of undergraduate paramedic students as they progress
38
39 through their programme and explore the impact of teaching and clinical placements on their
40
41 beliefs, and development of clinical and interpersonal skills when supporting and caring for people
42
43 who live with dementia and their families.
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46 **Methods**

47 **Design**

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49
50 An explorative qualitative interpretative phenomenological design was applied. Interpretative
51
52 phenomenology was deemed the most theoretically appropriate approach as both researchers are
53
54 experienced healthcare professionals, and understood they may not recognise all of their
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3 preconceptions to enable them to bracket these prior to facilitating focus groups and commencing
4
5 data analysis (Zahavi, 2003). Both researchers acknowledged their experiences as a nurse and
6
7 psychologist (JB), and a paramedic (MS) and from these perspectives interpreted paramedic
8
9 students' experiences, thus working within the framework of interpretative phenomenology as
10
11 developed by Heidegger (1962).
12

13
14 Data were collected via focus groups with 1st and 3rd year paramedic students. A number of carefully
15
16 planned group-based discussions were designed to support paramedic students to explore their
17
18 experiences and the development of their clinical and interpersonal skills to care for people with
19
20 dementia and their families (Krueger, & Casey, 2009). A deeper understanding of the topic was
21
22 further supported by the recruitment of paramedic students from a purposive sample, where
23
24 students were peers with existing professional and social relationships, and a shared culture (Brown,
25
26 2015; Githaiga, 2014). Paramedic students' shared culture of university education and clinical
27
28 experience fostered an environment where students were able to influence and be influenced by
29
30 each other, as they would in the clinical setting (Hollander, 2004). The group-based discussions
31
32 enabled small groups of students to share their experiences, whilst engaging with a large number of
33
34 students to gain an understanding of the range of their beliefs and experiences (Krueger, & Casey,
35
36 2009).
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41 Prior to the commencement of the study the University Research Ethics Committee provided
42
43 ethical approval. The study was introduced to potential participants at the end of a lecture, and each
44
45 student was provided with a participant information sheet and encouraged to ask questions. All
46
47 participants provided written informed consent. Confidentiality within the group could not be
48
49 provided, however confidentiality of discussions outside of the group was assured. All participants
50
51 were informed if any concerns were raised regarding the safety of patients or healthcare
52
53 professionals then confidentiality may be breached.
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57 Setting
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3 Paramedic students were recruited from one university in the South of England, students clinical
4
5 placements occurred within one of two ambulance service providers. The catchment populations of
6
7 the ambulance services ranged from just under 4 million to 8.6 million people.
8
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10 Participants

11
12 First (n=24) and third (n=33) year students completing a paramedic science degree, with male
13
14 students (n=29) and female students (n=28) being almost equally represented. The majority of first
15
16 year students had not completed any clinical placements, whereas third year students had
17
18 completed most of the required placements in their programme.
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22 Procedure

23
24 Focus groups were held in university classrooms, when students were in from clinical placements
25
26 and attending lectures. All focus groups were completed in January and February 2017, and
27
28 facilitated by the first author (JB) and observed by the second author (MS). A question route was
29
30 applied to ensure consistency and comparability of data. Six focus groups were conducted; three
31
32 with 1st year and three with 3rd year paramedic students (refer to Table 1). A number of students
33
34 self-disclosed they had a family member with dementia (n=18), even though this information was
35
36 not specifically requested. Each focus group was audio recorded and transcribed verbatim.
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41 Analysis

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43 Inductive thematic analysis was applied within the framework of interpretative phenomenology, as
44
45 thematic analysis is not a methodology, but an analytic method (Clarke, & Braun, 2013). The process
46
47 of thematic analysis as described by Braun and Clarke (2006) was adhered to: the data from each
48
49 focus group was read and re-read which lead to the identification of relevant text, initial codes were
50
51 assigned to text extracts, from these codes broad themes were identified, each theme and relevant
52
53 codes were reviewed and refined, this process was repeated until clarity within and across themes
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3 occurred, themes were then named, and finally, the construction of relationships across and within
4
5 themes.
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8 **Results**

9
10 Four themes emerged from the thematic analysis: 1) impact of dementia on all concerned 2)
11
12 challenges of communicating with people with dementia 3) negative emotional response to
13
14 dementia 4) lack of social care and pathways for people with dementia. Themes and subthemes
15
16 emerged from both 1st year and 3rd year paramedic students; with the exception of the last theme
17
18 that emerged only from discussions with 3rd year students. Two elements occurred across themes,
19
20 which included was the importance of theoretical knowledge provided in the university setting and
21
22 the importance of learning interpersonal skills in clinical placements (refer to Table 2). A pictorial
23
24 overview of the model demonstrates the four main and two cross-cutting themes (refer to Diagram
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26
27
28 1).
29
30

31 ***Impact of dementia on all concerned***

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33
34 Paramedic students discussed the wide ranging impact of dementia and the upsetting, stressful and
35
36 draining nature of dementia for all those involved, including people with a diagnosis, their family
37
38 members and healthcare professionals:
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41 'I think it is quite upsetting for everybody involved in the process, it seems to be quite
42
43 draining for everyone.' (Focus Group 4, Participant 1 [FG4, P1])
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46
47 Students related the negative impact of dementia to the untreatable and progressive nature of the
48
49 disease, and how their understanding of the impact of dementia was developed from their
50
51 experiences during clinical placements:
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54 'My understanding of dementia has greatly increased, I had never really met people who
55
56 had suffered from dementia before and it is very common to meet them on placements, so
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3 you get a really good understanding of what these people face every day and what their
4
5 families have to deal with.' (FG1, P5)
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8 *Impact on people with dementia*

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11 Paramedic students began by discussing the progressive nature of dementia and the continued
12
13 increasing negative impact on people with dementia, which included: changes to personality,
14
15 identity, independence, making people more reliant on others, and the emotional impact for the
16
17 person with dementia from 'being quite comfortable in their own bubble' to 'shear frustration' (FG2,
18
19 P6). Students viewed a diagnosis of dementia as a 'loss', with the loss of independence, and a global
20
21 loss of everything:
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24
25 'A huge loss in independence, I think that is a massive thing if you are quite independent
26
27 person that must be quite scary to sort of start to lose everything you have and not to be
28
29 able to rely on yourself for basic stuff.' (FG2, P5)
30
31

32 *Impact on family members*

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34
35 A common consensus amongst the students was the impact of dementia not only on the person with
36
37 the diagnosis, but on their family members and friends. Students felt that at the beginning of their
38
39 programme they had not realised the negative impact of dementia and 'how it affects other people
40
41 sometimes more than the person with dementia themselves' (FG1, P1). A 3rd year student discussed
42
43 how her focus had changed through clinical experience and the importance of including family
44
45 members:
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49 'I find I spend more time trying to communicate with the family than the person with
50
51 dementia than I used to, as I never realised how much of an impact it does have on the
52
53 family... I never realised they needed as much support.' (FG1, P2)
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56 *Untreatable progressive nature of the disease*

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3 All discussions included the untreatable progressive nature of dementia, as 'it is progressive, gets
4 worse, and there is not much treatment for it' (FG3, P4), this was reiterated throughout all focus
5 groups:
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10 'My understanding of dementia is that it is a degenerative disease, is that it causes
11 significant health decline in patients, and there is no cure.' (FG6, P7)
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14 ***Challenges of communicating with people with dementia***

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18 Paramedic students discussed the challenges of communicating with people with dementia,
19 including how this impacted on understanding their needs, obtaining informed consent and how
20 each person with dementia and their circumstances were unique, and therefore no generic rules
21 could be applied:
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28 'It is challenging in a different way, because when you go to a complicated trauma you are
29 focusing on the medical problems, the challenging side is the medical side, but when you go
30 to a patient with dementia the challenging bit during the visit is communication.' (FG5, P1)
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34 ***Understanding their needs***

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38 Paramedic students expressed concerns of not understanding the needs of patients with dementia
39 due to being unable to gain sufficient information, such as a medical history or levels of pain, and
40 felt this impacted on their clinical decision making, which 'can significantly disadvantage people with
41 dementia because they cannot communicate, and things can be left or not noticed' (FG2, P2). This
42 was a consistent discussion with all students:
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48
49 'It affects the way we communicate with them, but also the way they communicate with
50 us... for example they might be suffering with pain and they are unable to get that across to
51 you.' (FG1: P9)
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56 ***Obtaining consent***

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2
3 Paramedic students discussed the fluctuating ability of patients with dementia to provide consent,
4
5 'some patients with dementia seem to have capacity and then five minutes later they don't' (FG2,
6
7 P4). Students' felt their programme placed an emphasis on informed consent, which created a
8
9 barrier to supporting people with dementia. There was a general assumption among colleagues (but
10
11 not the students) that people with dementia do not have capacity to consent, but 'colleagues
12
13 haven't actually established whether they do or not' (FG2, P6). Students also discussed the difficulty
14
15 in understanding which decisions people with dementia did and did not have capacity to consent to:
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18
19 'Patients with dementia may have capacity for short term decisions, give consent for short
20
21 term things, but it is hard to try and judge how much capacity they do have and if they fully
22
23 understand what the decision involves.' (FG2, P5)
24
25

26 *Each person with dementia and their circumstances are unique*
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28
29 Paramedic students agreed that due to the uniqueness of the impact of dementia on each person
30
31 and their individual circumstances 'there are no set guidelines' (FG3, P6). Students related the
32
33 difference in supporting people with dementia and learning clinical skills:
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36
37 'When you are doing splints, for example, you think I have kind of got this skill now, but with
38
39 dementia there are so many different personalities in the world, you cannot generalise to
40
41 that degree, you do not have this algorithm and this is how I deal with this situation, there is
42
43 always going to be new ones, that will be idiosyncratic, that you are going to have to tailor
44
45 your support again for that person.' (FG5, P7)
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49 Students' also discussed the limitations of learning in the classroom, 'there is only so much you can
50
51 be taught in the classroom' (FG1, P9), and the importance of learning on the road:
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53
54 'In the classroom it is just a generic overview of dementia, but it is not until you go out on
55
56 the road and you see different people and how differently they present that you realise
57
58 there is a broad spectrum of the disease.' (FG1, P1)
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2
3 Students understood their development of learning clinical skills, through clear guidelines and
4
5 protocols, however found learning how to support people with dementia led to conflicting advice:
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7

8 'Some colleagues have said they tell them (people with dementia) exactly what is
9
10 happening, exactly what the situation is and why they are there. Whilst, others go along with
11
12 the situation that the patient is seeing in their brain, and they might go along with that to
13
14 make it easier to help them and find out what is going on and treat them accordingly. I don't
15
16 know whether that is the right thing to do or the wrong thing to do (FG1, P8)
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18

19 ***Negative emotional response to dementia***

20
21 Students felt dementia was sad and scary, and they experienced a feeling of helplessness when
22
23 trying to provide support and care for people with dementia and their families. A number of
24
25 students voluntarily self-disclosed information and incidents of family members with dementia.
26
27 Students' demonstrated the beginnings of self-reflective practice as they began to relate their
28
29 knowledge and attitudes of dementia towards their personal experiences:
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33
34 'I don't know if people are afraid of it (dementia), I am certainly afraid of it, if I was ever
35
36 diagnosed with it, I am just going to... I don't know what I would do, I would freak out I think.
37
38 The prospect of it is horrifying actually.' (FG4, P1)
39
40

41 ***Sad, scared and helpless***

42
43 Students described a negative emotional response to witnessing and being involved in providing
44
45 care for people with dementia:
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48
49 'The minute the nurses left her (person with dementia) she would be screaming for them
50
51 and saying she needed help or something and it was quite sad really.' (FG4, P1)
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55 'I think taking away their (person with dementia) choice because they don't understand; I
56
57 think that is difficult to watch.' (FG5, P4)
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3 Students expressed they could only support the symptoms of dementia, which left them feeling
4
5 helplessness as they were unable to treat the dementia:
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8 'I guess part of you feels slightly helpless, because you come away from a call and you have
9
10 treated the fall, you have treated something, but there is nothing you can really do for the
11
12 underlying cause (dementia) that may have caused the fall in the first place.' (FG5, P6)
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15 Students also expressed how feeling helpless to support people with dementia and their families
16
17 was a sad realisation for them:
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19

20 'It is sad, I think it is a bit doom and gloom, it is a bit of a sad realisation that there is only so
21
22 much we can do and only so much referral we can make. It is almost like you want to say,
23
24 this time we managed to get you help, but you probably didn't, so they are never going to
25
26 get a definitive answer.' (FG2, P9)
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29

30 *Self-disclosure*

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33 Self-disclosure by students regarding family members with dementia occurred, and highlighted again
34
35 how dementia impacts on the wider family:
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38 'My grandfather was diagnosed with dementia but, as soon as he was diagnosed my Mum
39
40 was so cautious and she didn't want him to go out by himself, like walking the dog... I think
41
42 that was quite debilitating for him, he was treated differently from the day he was
43
44 diagnosed, and that wasn't nice for him. He felt like he had lost his independence.' (FG3, P1)
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46

47 ***Lack of social care and pathways for people with dementia***

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49
50 This theme emerged only from 3rd year paramedic students who explored the 'social side' of
51
52 dementia, with an emphasis on the lack of social care and pathways for people with dementia.
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54
55 Students' found their understanding of how to support a person with dementia and their families
56
57 could not be taught in the classroom:
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3 'I think it is the social side of it, the medical side we can fix, that is not really an issue, it is
4
5 the social side of it, how do I communicate this, how do I sort this and I don't really think
6
7 that is something you can teach in a lecture that is something you have to learn through
8
9 experience.' (FG2, P7)
10

11
12 Students reported 'surprise at the lack of social care' and some people were living at home with 'no
13
14 actual social care in place or any NHS services to help them' (FG1, P8). Third year paramedic
15
16 students across focus groups acknowledged that this was a shock to them:
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18
19 'I think the social circumstances were a shock to me, the amount of people with dementia
20
21 that don't have anything in place and are living independently, but not living a good quality
22
23 of life. The fact this person has fallen through the net and no one has noticed they are
24
25 struggling to cope on their own. I think that is the biggest shock.' (FG2, P5)
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27

28
29 The 3rd year paramedic students also discussed the lack of dementia pathways, whilst
30
31 simultaneously acknowledging hospital was not necessarily a good pathway for a person with
32
33 dementia, which demonstrated an insight into the needs of people with dementia:
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36 'I think it is quite frustrating that there is not enough referral pathways, because you can
37
38 either leave them at home, and if they have carers, or are in a care home, then that is fine.,
39
40 but if they live on their own, then that is possibly not the best place for them, and with their
41
42 injuries or illness, hospital is not the best place for them either, and that is generally the only
43
44 two options available to us (paramedics) for patients with dementia.' (FG1, P4)
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47
48 'I think hospital is not the most appropriate place for people with dementia, because when
49
50 they are used to their own environment then they can manage to a certain degree in their
51
52 own environment at home, and when you take them out of it, you always tend to see a rapid
53
54 decline.' (FG6, P2)
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57 Discussion

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3 During the 1st and 3rd year of their programme paramedic students expressed a new understanding
4
5 of the impact of dementia on all concerned, which included not only the person with dementia, but
6
7 their families and healthcare professionals. Furthermore, students highlighted they experienced a
8
9 number of challenges when communicating with people with dementia, which impacted on their
10
11 ability to adequately assess their health needs and gain informed consent for treatment and
12
13 interventions. From this new understanding students expressed negative emotional responses, such
14
15 as sad, scared and helpless when trying to support people with dementia and their families. Only 3rd
16
17 year paramedic students expressed their shock at a lack of social care and support and pathways for
18
19 people with dementia. Two elements occurred across these all of these concepts that of learning
20
21 that occurred in the classroom and learning that could only occur 'on the road', as students reported
22
23 clinical placements as invaluable in supporting the development of their interpersonal skills.
24
25

26 27 *Impact of dementia on all concerned*

28
29
30 Paramedic students discussed the upsetting, stressful and draining nature of dementia for everyone
31
32 involved. This negative image of dementia was developed from their clinical placement experiences,
33
34 which included the support and care of people with dementia and their families during a crisis. A
35
36 number of triggers have been identified which lead to a crisis, but these only contribute to a crisis
37
38 when there is a lack of or inadequate community support (Toot, et al. 2013). Triggers have been
39
40 identified as: falls, other physical hazards around the home, severity of dementia and behaviours of
41
42 the person with dementia such as leaving the house unexpectedly and becoming aggressive (Toot, et
43
44 al. 2013). The elements of a crisis situation may have influenced paramedic students beliefs and
45
46 understanding of the negative impact of dementia, as they are only involved in crisis situations with
47
48 people with dementia and their families.
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53 Therefore, paramedic students' negative beliefs of dementia may differ from other healthcare
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55 professionals. This difference may be extended through the traditional approach of paramedic
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57 programmes with a focus on acute illness and clinical skills within short-term discreet clinical
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3 placements (Banerjee, et al. 2017), which do not support the development of an understanding of
4
5 long term conditions, such as dementia. The development of a therapeutic relationship with a
6
7 person with dementia and their family over time may influence healthcare professionals' beliefs and
8
9 understanding of the impact of dementia. There are limited studies that have included students
10
11 from different healthcare disciplines and those that have do not report differences between
12
13 disciplines (Annear, et al. 2016; Lucas, et al. 2016; Banerjee, et al. 2017).
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16
17 A balanced view and understanding of the impact of dementia on people with a diagnosis and their
18
19 families is required, one approach to support this is 'Time for Dementia' (Banerjee, et al. 2017). This
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21 initiative of regular structured meetings with a person with dementia and their family in their place
22
23 of residence has been embedded in medicine, paramedic science and nursing undergraduate
24
25 programmes. Time for Dementia is a unique approach, which is currently being evaluated (Banerjee,
26
27 et al. 2017). However, a fundamental change to the approach of healthcare professionals'
28
29 undergraduate education is essential to develop the students' knowledge and skills in supporting an
30
31 aging population with an increase in long-term conditions, such as dementia.
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34 35 *Challenges of communicating with people with dementia*

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38 The importance of communication cannot be over emphasised as alongside patient safety and
39
40 compassion was found to be one of the crosscutting themes in all paramedic roles (Tavares, Bowles,
41
42 & Donelon, 2016). However, in this study paramedic students reported challenges in communicating
43
44 with people with dementia and understanding their needs. Communication is essential for all
45
46 healthcare professionals working with people with dementia although difficulties have been
47
48 identified, experienced nurses specialising in dementia reported difficulty in understanding both the
49
50 emotions and needs of people with dementia (Wang, Hsieh, & Wang, 2013).
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54 Difficulties in communication between healthcare professionals and people with dementia may
55
56 occur due to the task focused nature of these interactions. Both nurses and paramedics have a task
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3 to complete when providing care and support for people with dementia, therefore their interactions
4
5 and communications are based on their needs to complete this task rather than adapting to the
6
7 needs of the person with dementia through open listening (Nichols, 1995). The development of open
8
9 listening requires person-centred rather than task-orientated communication strategies with the
10
11 avoidance of directive or instructive communication (Kitwood, 1997; Wang, et al. 2013);
12
13 unfortunately this approach in itself is challenging when trying to understand the needs of people
14
15 with dementia in a crisis situation.
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18
19 Educational interventions have been developed to promote healthcare professionals person-centred
20
21 communication with people with dementia and challenge the negative view of dementia by primary
22
23 care healthcare professionals (Edwards, Voss & Iliffe, 2014). These interventions have been found to
24
25 be successful in primary care environments to foster a person-centred approach to support people
26
27 with dementia and their family members, specifically within GP surgeries (Edwards, Voss & Iliffe,
28
29 2015). However, to date these interventions have not been developed with paramedics, and
30
31 therefore how these could be developed to support paramedics and embedded in paramedic
32
33 undergraduate education is unknown.
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36
37 Paramedic students in the current study acknowledged the uniqueness of each person with
38
39 dementia, their family and situation, but struggled to respond and adapt to this uniqueness.
40
41 Guidelines and protocols were deemed inappropriate by the paramedic students as these could not
42
43 address the uniqueness of the impact of dementia, instead their clinical learning occurred from
44
45 observing experienced colleagues.
46
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48
49 The 'uniqueness' of people with dementia has been acknowledged by healthcare professionals and
50
51 the need to tailor community support (Ducharme, Kergoat, Antoine, Pasquier, & Coulombe, 2014;
52
53 Stephan, Mohler, Renom-Guiteras, & Meyer, 2015; Waugh, 2009). Tailored interventions care and
54
55 services are also important to support and address the uniqueness of family members, especially
56
57 with reference to respite care (Ducharme, et al. 2014). The ability for healthcare professionals to
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3 tailor services is restricted as services are perceived as inflexible or even lacking (Stephan, et al.
4
5 2015; Ducharme, et al. 2014). This may explain why paramedic students working within systems and
6
7 care services viewed as inflexible struggle to adapt to the 'uniqueness' of dementia.
8

9
10 Recommendations from this study go beyond the development of healthcare undergraduate
11
12 programmes to the development of flexible and supportive community services.
13

14 *Negative emotional responses to dementia*

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16
17 In the present study, paramedic students discussed negative emotional responses to caring and
18
19 supporting a person with dementia and their family, such as feeling sad, scared and helpless. This is
20
21 similar to other healthcare professionals' experiences, as healthcare professionals working in
22
23 dementia services highlighted their distress when identifying with family carers, particularly when
24
25 there were similar elements to their own personal lives (Ducharme, et al. 2014). Healthcare
26
27 professionals have also discussed their distress and emotional struggle alongside their ethical duty to
28
29 support people with dementia to live in a safe environment, and the need to internalise their actions
30
31 with the belief they 'did the right thing' (de Witt, & Ploeg, 2016).
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33

34
35 In the current study students expressed their feelings of helplessness as they believed they were
36
37 treating the symptoms of dementia, such as a fall, rather than addressing the underlying cause of
38
39 dementia. This sense of helplessness may be reinforced as they cannot meet the expectations of
40
41 family members during a crisis with a relative with dementia, as their expectations can be high,
42
43 when the resources available in a timely manner may be restricted (Stephan, et al. 2015). The
44
45 emphasis of services to support families to prevent crisis situations is paramount.
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48
49 The development of new paramedic roles to specifically respond to the needs and challenges
50
51 associated with the impact of dementia may reduce paramedic students' sense of helplessness. A
52
53 recent review of the literature to explore the role of emergency medical services (EMS) to support
54
55 people with dementia recommended new paramedic roles to respond to crises, urgent care needs,
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1
2
3 but also transitions between appropriate care facilities (Buswell, et al. 2014). A critique of the
4
5 review was a lack of validated tools in EMS to assess and manage the needs of people with dementia
6
7 (Buswell, et al. 2014). The emphasis on validated tools, although necessary, reinforces the focus on
8
9 clinical skills rather than communication and interpersonal skills (Jackson, 2009, Ross, et al. 2015).
10
11 However, the implementation of these roles would support the development of skilled placement
12
13 educators knowledgeable in dementia.
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16 17 *Lack of social care and pathways for people with dementia*

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19 The lack of social care and clear pathways for people with dementia has been acknowledged
20
21 previously. British family members supporting and caring for a person with dementia described
22
23 social and health care systems as a maze, which was difficult to navigate, access, and were limited,
24
25 with the added pressure of having to 'fight' for any provision of health and social care (Peel, &
26
27 Harding, 2014).
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30
31 The need for clear social and healthcare pathways for people with dementia and their families is a
32
33 global concern, as is evident from national dementia strategies (Department of Health, 2015; The
34
35 Scottish Government, 2010; Welsh Assembly Government, 2011). However, Samsi and Manthorpe
36
37 (2014) have explored the term 'dementia care pathway' and found different interpretations and
38
39 constructions. Interpretations ranged from management of the disease, manual of care activities,
40
41 and how to 'walk with' the person with dementia (Samsi, & Manthorpe, 2014). The interpretation of
42
43 care pathways of the paramedic students within this study was not explored and may be different
44
45 from that of British carers, although this would also support the recommendations of Samsi and
46
47 Manthorpe (2014) of a wider system approach to support people with dementia as they may be frail
48
49 and have multiple co-morbidities.
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53 The development of a wider system approach may include the development of paramedics' skills to
54
55 assess, treat and support people with dementia in the primary care setting. The development of
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3 skills and roles of paramedics beyond emergency medicine to include both prevention and
4
5 education, and a person-centred approach has begun in Canada (Travares, Bowles, & Donelon,
6
7 2016). The role of the paramedic has been conceptualised to include six elements: clinician, team
8
9 member, health and social care advocate, educator, reflective practitioner and professional
10
11 (Travares, et al. 2016). The development of paramedics to provide information and education for
12
13 family members of people with dementia alongside the provision of respite care may reduce the
14
15 number of emergency calls (Stolp, Brown, Toevs, & Berlin, 2016). Paramedic students in the current
16
17 study were beginning to develop a number of these roles, such as becoming advocates for people
18
19 with dementia and completing referrals for them to access social care, whilst simultaneously
20
21 reflecting on their practice and the realisation that sometimes there is not enough support for
22
23 people with dementia to remain living well and independently at home.
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26

27
28 However, this is not a unique issue to the UK, paramedics and social workers who were first
29
30 responders to an emergency call regarding a patient with dementia in the State of Idaho, discussed a
31
32 lack of social care and support for these families, with paramedics requesting further training and
33
34 education in dementia, but also in de-escalation strategies (Stolp, et al. 2016). These elements were
35
36 also highlighted in the current study as paramedic students discussed being called to specialist care
37
38 homes for people with dementia, when staff could no longer support a resident. Students felt that
39
40 the staff were more knowledgeable and trained than themselves to deal with the situation, and they
41
42 had been called in as the last resort.
43
44

45 46 *Learning in the classroom and learning on the road*

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48
49 The current study focused on the development of skills to support people with dementia and their
50
51 families, which might be considered to be more soft skills, such as interpersonal skills, the students
52
53 reported clinical placements as invaluable in supporting the development of these skills. However,
54
55 this is in contrast with Ross et al. (2015) who found students reported clinical placements supported
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1
2
3 the development of their clinical skills such as cannulation, ventilation and airway management in
4
5 resuscitation allowing the consolidation of theory in real life practice.
6
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8 Limitations

9
10 A limitation of the current study was the involvement of students from only one university, although
11
12 their clinical placements were across two different ambulance service providers.
13
14

15
16 A major consideration that impacts on the discussion of this paper, is that the majority of studies
17
18 that have explored the views of people with dementia, their family members and healthcare
19
20 professionals in community settings have not included paramedics (Edwards, et al. 2014; Stephan, et
21
22 al. 2015; Ducharme, et al. 2014; de Witt, & Ploeg, 2016).
23
24

25 Conclusion

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28 Novel and new models of undergraduate paramedic programmes are beginning to be developed to
29
30 support students understanding of aged-care and the needs of people with dementia and their
31
32 families, although many of these are still currently being evaluated.
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36 The development of paramedic specialist roles in dementia are being implemented, however this is
37
38 only one aspect of supporting paramedics to understand and address the changing needs of the
39
40 population they are supporting.
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44 The importance of skilled placement educators knowledgeable in dementia is essential to enable the
45
46 development of interpersonal and communication skills of paramedic students and to empower
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48 them to support and care for people with dementia and their families.
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50
51 Finally, there is currently a lack of research involving paramedics, which impacts on the robust
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53 development of education and training to support the development of the knowledge, clinical and
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55 interpersonal skills to support and care for people with dementia and their families.
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Table 1: Overview of focus groups

Focus Group	Students' Year of study	Participants	Male (Female) participants	Self-disclosed family members with dementia
1	3	10	4(6)	3
2	3	11	6(5)	3
3	1	8	6(2)	3
4	1	9	3(6)	4
5	1	7	4(3)	2
6	3	12	6(6)	3

Total number of participants (n=57)

For Peer Review

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Table 2: Emergence of sub-themes from each focus group

Focus Group	Impact of dementia on all concerned			Challenges of communicating with people with dementia			Negative emotional response to dementia		Lack of social care and pathways for people with dementia	
	People with dementia	Family members	Progressive, untreatable	Communication with people with dementia	Obtaining consent	Each person with dementia and call is unique	Sad, scared and helpless	Self-disclosure	Social Care	Pathways
1 3 rd year students	X	X	X	X		X	X	X	X	X
2 3 rd year students	X	X	X	X	X	X	X	X	X	
6 3 rd year students	X	X	X	X	X	X	X	X		X
3 1 st year students		X	X	X	X	X		X		
4 1 st year students	X	X	X	X		X	X	X		
5 1 st year students			X	X		X	X	X		

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Cross cutting themes

Main themes

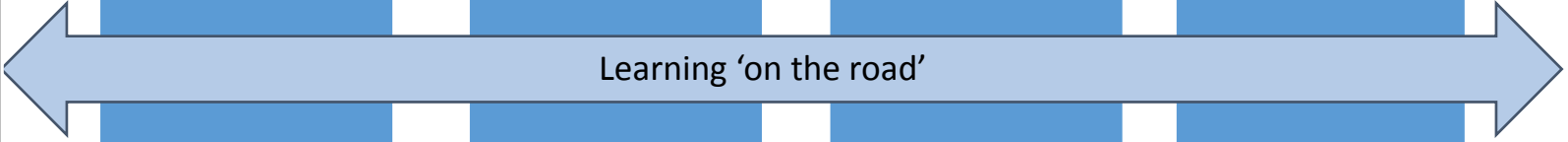
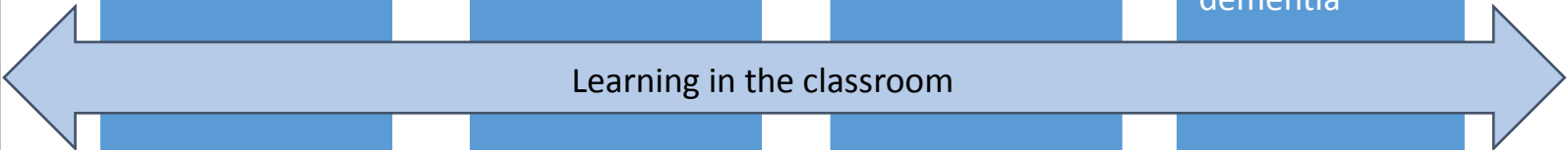
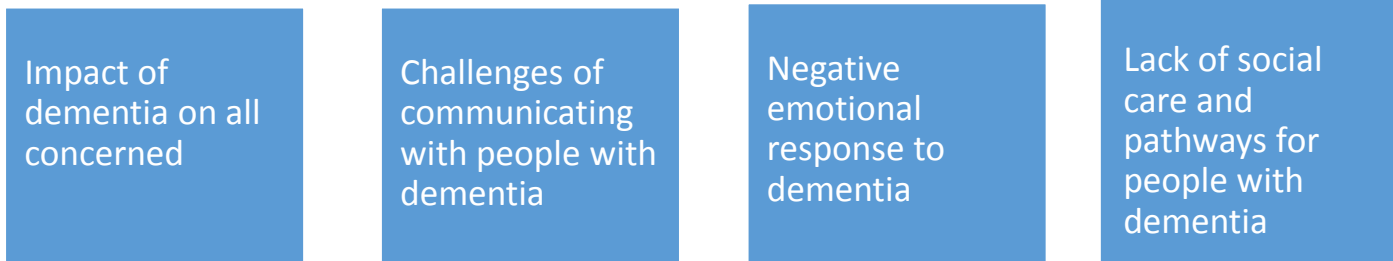


Diagram 1: Model of paramedic students' beliefs and development of clinical and interpersonal skills to support people with dementia and their family