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Palliative Medicine

Barriers and Facilitators to the Receipt of Palliative Care for People with Dementia: The views of medical and nursing staff

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Keywords:	Dementia, Palliative Care, Qualitative Research, Mental Competency, Alzheimer's Disease, Health Care Team
Abstract:	<p>Background The global prevalence of dementia is set to rise to almost 65 million people by 2030, providing policy makers and practitioners with significant challenges not least within the realms of end of life care. The international literature would suggest that people with dementia may benefit from palliative forms of care, but evidence indicates that many fail to access such provision at the end of life. The role of the health care team is pivotal if people with dementia are to benefit from the transition to palliative care.</p> <p>Aim This paper reports on qualitative research conducted in the UK which sought to explore the experiences of health care practitioners working in palliative care and sought to establish the issues relating to end of life care for people with dementia.</p> <p>Design Eight focus groups and four individual interviews were held (N=58). Data were analysed using a thematic approach.</p> <p>Results Four themes were identified: Making the transition; Competence</p>

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	Challenged; 'The long view' and Working together. Whilst there exists good practice in this area, the barriers to timely and appropriate transitions to palliative care for people with dementia and their families continue to exist. The paper concludes with recommendations for policy and practice development.

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Introduction

It is estimated that the global prevalence of dementia is almost 36 million people.

With numbers expected to double every twenty years, resulting in a predicted prevalence of 65 million people with the disease by 2030, the challenges facing policymakers, practitioners and researchers over the coming decades are clear.^{1,2}

Governments in the developed world have sought to address this growing challenge through the delivery of policies which seek to raise awareness, expedite diagnosis, improve support for family carers and enhance workforce competence within a context of supportive care from diagnosis to death.³⁻⁶ The evidence would, however,

suggest that many nation states have a long way to go in providing high quality end of life or palliative care to people with dementia. A recent survey of European countries highlighted that most people with the disease die in institutional forms of care with little support provided in the community⁷. Others suggest that people with dementia in Europe do not gain access to palliative or supportive care,⁸ contrary to the evidence of the efficacy of such an approach for people with dementia.⁹ If

positive transitions to palliative approaches are likely to occur clarity about when the end of life is near is required.¹⁰ In the case of the person with dementia there

remains uncertainty about this. End of life experiences for people with dementia are described as lengthy and typified by slow degeneration and decline, unlike the typical cancer trajectory and death is often precipitated by other acute health events such as pneumonia or fractured neck of femur.¹¹ Several authors have attempted to

identify key indicators of imminent death, noting the significance of weight loss, motor disability and deterioration in physical health.¹²⁻¹⁴ It has been argued that

failure to recognise timely transitions to palliative care can result in prolonged

1
2
3 exposure to aggressive forms of treatment. Paradoxically, it is claimed that
4
5 throughout their illness people with dementia often receive 'too little' care, whereas
6
7 end of life care is often characterized by 'too much'.¹⁵ Evidence indicates that
8
9 interventions such as feeding tubes and systemic antibiotics are used as a result of
10
11 'custom and practice' amongst clinical teams rather than formal guidance¹⁶ and that
12
13 such practice persists despite the ambiguity surrounding effectiveness.¹⁷⁻¹⁹
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20 A growing international literature suggests that palliative approaches at the end of
21
22 life for people with dementia are effective. Several reviews point unequivocally to the
23
24 importance of adopting palliative approaches in non-malignant diseases, such as
25
26 dementia, particularly in acute settings.²⁰⁻²² Many patients, regardless of their
27
28 condition, stand to benefit from a change in approach to care from curative (with a
29
30 focus on disease management) to palliative (with a focus on maximising quality of
31
32 remaining life).²³ Data does, however, suggest that clinical teams are often reluctant
33
34 to enable the transition to take place and that tensions arising from differing views
35
36 about extending life may exist between family members of people with dementia and
37
38 physicians.²⁴⁻²⁶ The role played by clinical teams in promoting and facilitating
39
40 appropriate transitions to palliative care for people with dementia is pivotal. This
41
42 paper reports on focus groups and individual interviews undertaken with health care
43
44 practitioners in the UK. The research was an important part of a wider study looking
45
46 at transitions to palliative care for older people in acute hospital settings²⁷ with the
47
48 specific aim of exploring the experiences of health care practitioners working in
49
50 palliative care in order to establish the issues relating to end of life care for people
51
52 with dementia. Data were gathered within the focus groups and interviews to
53
54 address the issues of cognitive impairment as a factor in such transitions.
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Method

Given the innovative nature of the enquiry and the limited existing evidence base a qualitative study design was adopted. Focus groups were held in two UK cities: one with an ethnically and economically diverse population of around 550,000; the other a smaller more homogeneous city of around 85,000 people. Senior medical staff and nurses assisted in the identification of hospital based participants. GP and community participants were identified and approached via primary care research networks. Groups were comprised of participants from a range of disciplinary backgrounds (see Table 1), purposively sampled in order to achieve the maximum variation of experience and opinion. The focus group and interview guide was developed following a review of the international literature and relevant policy and addressed the key aims of the study. Specifically three key questions were addressed: does a patient's diagnosis influence end of life care; are there any specific issues relating to people with dementia and the end of life care they receive and is it more difficult to achieve palliative care for people with dementia? The focus groups and individual interviews lasted for approximately 40 minutes. The study received ethical approval from a UK NHS Research Ethics Committee and study methods and practices were consistent with UK NHS ethical guidance. All participants gave written informed consent. None of those approached to take part in the study refused to take part.

TABLE 1 HERE

Analysis

Focus group and interview transcripts were recorded and transcribed verbatim. To address issues of rigour and trustworthiness transcripts were read by three of the authors (CG, CI, TR) and core themes were identified. NViVO 8 computer software was used to facilitate analysis. A coding framework was developed by consensus and was grounded in the data rather than decided a priori. Sub-themes were then identified. The themes and subthemes discussed in this article were then further analysed by TR. Direct quotations have been selected to illustrate the issues raised by participants and they are indicative both of typical responses and of the diversity of views obtained.

Results

Four themes were identified as a result of this analysis: Making the transition; Challenging competence; 'The long view' and Working together.

Making the Transition

An important theme identified within these data related to the likelihood that people with dementia make a transition to palliative care at an appropriate point in the care pathway. The theme addresses those factors identified by health care practitioner participants that hinder or facilitate appropriate transitions. The data suggests that there remain considerable difficulties in the achievement of good quality end of life

1
2
3 care in the form of palliative services for people with dementia. There are two
4
5 notable **sub-themes**: candidature; rising tide and resources.
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9
10 The notion of candidature refers to the ways in which people with dementia were
11
12 seen, or not **seen by health care practitioners**, to be the potential recipients of
13
14 palliative care provision. To some **participants in the study**, the idea that dementia
15
16 constituted a condition that might on its own be a cause of death was questionable.
17
18 A failure to acknowledge this provided a barrier to services of a palliative nature.
19
20 Below, the notion that dementia is a cause of death is questioned by health care
21
22 professionals, and participants report how it is often viewed as a normal pathological
23
24 aspect of ageing rather than a specific disorder in its own right.
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31
32 *Dementia isn't a disease it's just something that happens to people.* (Specialist
33
34 Palliative Care Team Focus Group (FG))
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38 *Dementia is not terminal.* (GP Practice FG)
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41
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43 *I think people with dementia are not considered often in the same league as*
44
45 *somebody with heart failure, COPD or cancer. That is what happens to elderly*
46
47 *people isn't it? They get confused.* (GP Practice FG)
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52
53 The final extract suggests that other 'conditions' are considered worthy of specialist
54
55 palliative care whilst dementia is not. Considerable discussion relating to criteria for
56
57 referral to specialist palliative services was evident and in particular the idea that
58
59 conditions other than dementia might warrant such care. These data would suggest
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1
2
3 that some professionals continue to fail to recognise the legitimacy of non-malignant
4 diseases when it comes to the provision of palliative care. Participants in this study
5
6 reflected upon their own experiences of how services inhibit the transition to
7
8 palliative care for older people, particularly those who have dementia. This is
9
10 exemplified in the quotes given below.
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17 *Elderly with dementia don't really get the care. They don't get the active palliative*
18 *care, you know what I'm talking about, active treatments, active palliative care.*(GP
19 Practice FG)
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27 *And it's always been ... again there's been this idea that it's almost like a culture that*
28 *demented elderly patients belong in, and I hate to use the term, but geriatric units.*
29
30 *That's where they go, they don't come to hospices or anywhere for palliative care*
31 *even though they're just as deserving as anyone else.* (Hospice FG)
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38 The notion that '*cancer is the key*' (Specialist Palliative Care Team FG) to accessing
39 services was noted by participants. In addition questions about the resources
40 available to teams to enable them to provide palliative care to a wider population
41 (including people with dementia) were raised. The ideas expressed below, by
42 members of a specialist palliative care team in the community, suggest that existing
43 pressures and already stretched capacity to deliver to its current client group has
44 created tensions in being able to deliver to people with dementia.
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We just couldn't do that [provide palliative care to people with dementia]. We don't have the resources but people with dementia are just allowed to die in nursing home or rest home beds. (GP Practice FG)

[increasing dementia referrals] But is that just reducing the palliative care service available to perhaps other people, I don't know? (Hospice FG)

I would think in terms of beds, we're struggling as it is for palliative care cancer, if they take that [dementia]in it's going to be absolutely chaotic.(GP Practice FG)

Discussion about a 'rising tide' scenario prompted alternative proposals about the function, nature and possible model of palliative care for people with dementia.

Participants articulated a reluctance to offer people with dementia as candidates for specialist palliative care because their difficulties may not be the same as cancer patients, particularly in the realm of pain management. This amounted to a very different approach to palliation in dementia relying upon basic nursing skills and activities such as mouth care, pressure care and maintenance of dignity which it was felt could be provided adequately by non-specialist teams:

Good symptom management, good emotional support, good support for the family, psychological and spiritual, social support, should be part and parcel of what everybody does and it should be offered to absolutely everybody I think (Acute Hospital FG).

Competence Challenged

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6 Participants described a range of experiences and pointed to observations from
7
8 clinical practice about limited competence, skills and capability in working with
9
10 people with dementia. This notion of challenged competence was apparent in
11
12 relation to the assessment and management of care of people with dementia,
13
14 particularly in advanced states. Assessment practices were identified as problematic
15
16 by participants, reflecting the difficulties in working with a group of people who find it
17
18 difficult to communicate their needs. There was recognition by participants that
19
20 current skills and competences within healthcare teams were not sufficient to meet
21
22 the demands of assessment and challenging behaviour. For example, in assessing
23
24 symptoms amongst people with dementia a broader range of 'different indicators and
25
26 different signs' (Hospice FG) need to be considered and clinicians reported that they
27
28 did not always feel confident in doing this. As exemplified below many health care
29
30 professionals in this study felt under-confident about assessing the needs of people
31
32 with dementia, with pain assessment considered especially challenging:
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41 *I think as well it's sometimes the assessment with people with dementia or cognitive*
42 *impairment needs to be very specific, very specialised, you need people that*
43 *approach it in perhaps different ways and I'm not sure that we're great at that in*
44 *palliative care. (Hospice FG)*
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53 *How do you assess their pain if they've got very advanced dementia? It's difficult to*
54 *know how much pain they're in. (Consultant Geriatrician, Individual Interview)*
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4 Similar difficulties were expressed in terms of the care management of people with
5 dementia who might have palliative care needs. Typically, behavioural challenges
6 were identified by teams who reported finding it difficult to accomplish high quality
7 care for those people with dementia experiencing confusion. The respondent below
8 describes the perceived need to recourse to pharmaceutical, rather than behavioural
9 interventions in an uncertain context:
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20 *The ones I've had have been quite aggressive towards the end of their life so it's*
21 *quite difficult because you end up giving them lots of chemicals that you're not sure*
22 *is a good idea or not but they're so upset.(GP Practice FG)*
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29 The perception that people with dementia might display aggression was noted by
30 other participants. Furthermore this was viewed as a factor which might provide
31 significant challenges to teams and inhibit the likelihood that people with dementia
32 might make the transition to a palliative care approach. As with practices associated
33 with assessment, the uncertainty expressed by participants about how to work
34 effectively with confused patients questions the capability of some teams to be able
35 to provide high quality palliative care for people with dementia. Additional training
36 was identified as a strategy to overcome these difficulties, particularly given the view
37 that people with dementia had the right to receive palliative services.
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53 **'The Long View'**

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57 Enhancing decision making for those whose capacity to communicate or consent to
58 treatment is limited has been a central theme within the realm of end of life care for
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3 some time. Participants in this study advocated for greater emphasis being placed
4 upon 'planning ahead' and developing relationships with key people over a long time
5 period to assist in facilitating decision making around palliative care. This theme has
6 been labelled 'The long view' in recognition of these data. Participants pointed to the
7 need for engagement with the wider team and family members when palliative
8 approaches are recognised as being appropriate. For example, this participant
9 recognised that very difficult decisions need to be made in the context of trusting
10 relationships between a group of people.
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24 *I think for patients with Alzheimer's where to exactly draw a line between say*
25 *particularly...feeding aspects or no feeding, those areas are very, very difficult. I think*
26 *when they reach that stage where palliation is required I think there needs to be*
27 *extensive dialogue between the various professionals and the carers and the*
28 *family.(Consultant Geriatrician- Individual Interview)*
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39 This approach is consistent with the sentiment inherent within the UK Mental
40 Capacity Act²⁸ and a best interest approach to decision making. A best interest
41 approach was identified by participants as both a logical and a practical response in
42 the context of decision making for people with cognitive and communicative
43 difficulties and the impact of the UK Mental Capacity Act was noted by participants.
44 For some the Act had merely formalised already existing 'best interest' practices.
45 This was particularly the case within a specialised palliative care team context,
46 where collaborative practices have been well established:
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I agree that in palliative care we've always had, or in most, we've always had that best practice approach involving ... not making unilateral decisions, involving family, involving patients. I think what the Mental Capacity Act certainly in palliative care has done is put things more legally and also it's just given a little bit more structure to it so that people are more aware and doing it in a structured way.(Registrar, Individual Interview)

Another participant, who also had a specialist palliative care background, suggested that the UK Mental Capacity Act confirmed existing practices for people who might lack capacity:

Largely it hasn't changed the way we manage palliative care. In a way I think we clearly go by clinical and social and psychological aspects rather than just a piece of paper in front of you – the mental capacity act. (Hospice Focus Group)

Furthermore, participants pointed to the UK Mental Capacity Act as prompting the kind of capacity assessment and partnership work necessary for good decision making, stating that they felt it had made a '*big change*' (Hospice FG) to practice.

This transformation was not limited to the practice of teams but also to the ways in which they now perceived people with dementia as active participants within the decision making process. The UK Mental Capacity Act in this context had '*made people think*' and this, according to some participants, had helped professionals to re-evaluate the role that people with dementia might play in the decision making process.

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2
3 *I think often people were just written off and just put in a home whereas now at least*
4
5 *we're thinking ok they've got dementia but can they make a decision for themselves?*

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8 (Acute Hospital FG)
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12 The changes prompted by the UK Mental Capacity Act in this context suggest
13
14 positive repercussions for patients and families. In the first case below a member of
15
16 a specialist palliative stresses the importance of using the knowledge of those who
17
18 have known the person with dementia for a long period of time in order to make
19
20 decisions about their care.
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27 *I think one of the great, one of the greatest or more useful tools in looking after*
28
29 *people with dementia is actually having a long view, and actually when you're inviting*
30
31 *specialist services in who get a snapshot it's actually very difficult to base really*
32
33 *complex treatments on a snapshot without that long view component. So you rely on*
34
35 *a GP, a family member, a district nurse, a carer who has the long view to help you*
36
37 *and say that this isn't how they are if you see what I mean, as a guide, and if you*
38
39 *don't have that or the person who you expect to provide you with the long view can't*
40
41 *give you that consistent opinion then it makes assessment more challenging.*
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46 (Hospice FG)
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51 In the excerpt below a specialist palliative care team member recognises that
52
53 relationships between patient, family and health care professional are central to the
54
55 decision making process, but comments that, in her experience, these relationships
56
57 are rarely capitalised upon within this context. rarely in her experience are they
58
59 exploited to these ends.
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6 *It's having some sort of relationship, some sort of a background, a shared history*
7
8 *with that patient so then say look you've been coming to this clinic for however long*
9
10 *and how do you think things are panning out for you? So again I don't think it is*
11
12 *something that we do and probably something that we should.*(General Practice FG)
13
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18 Others pointed to important work which can be undertaken between secondary,
19
20 primary and nursing home care settings to plan for future palliative care needs,
21
22 involving 'liaising' with other professionals, identifying 'opportunities' and going
23
24 further to embed 'systems' to enable this to happen on a more comprehensive
25
26 footing.
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32 **Working Together**

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36 A significant theme that was identified related to how teams from a variety of
37
38 settings, organisations and disciplinary backgrounds can collaborate in seeking to
39
40 achieve high quality palliative care. One team noted how their experiences led them
41
42 to believe that sound collaborative working between professions and consulting other
43
44 'specialists' in the field of dementia care had helped to facilitate transitions to
45
46 palliative care:
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53 *I've got three people on the caseload at the moment that I think really are dying and*
54
55 *it's purely as a result of dementia.... The doctors have wrestled quite a lot with that*
56
57 *and they're really experienced geriatricians we've got on our team and each of those*
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3 cases we sought a second opinion from a psychiatrist but also from another
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5
6 geriatrician as well to say "what do you think?".(Acute Hospital FG)
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10 Participants suggested that failure to gain access to 'specialist' dementia advice and
11
12 guidance hindered transition for the patient. In such cases the compartmentalisation
13
14 of needs is apparent with teams appearing to address only those patient problems
15
16 that they felt were within their perceived remit. Without investment from other
17
18 professionals the following primary care based team participant felt unable to make
19
20 progress:
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27 *It's difficult because we're not mental health trained so although we see the*
28
29 *dementia, the mental health part, we're not trained as much as [mental health team]*
30
31 *it's very difficult getting their services in and working with them.....We don't work*
32
33 *together very well.*(GP Practice FG)
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39 Further discontinuity was highlighted by other participants, particularly in relation to
40
41 PEG feeding. The suggestion below is that clinical staff in hospital will do what they
42
43 can in the short term to solve problems for people with dementia who are dying.
44
45 There is, however, little consideration of how feeding can take place in the longer
46
47 term in primary care, and there is limited collaboration with primary care services:
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53 *A typical example is dementia. They may have put in a peg and a lot of discussion*
54
55 *around that peg is going to be done but if this person goes home or goes to a*
56
57 *nursing home there's absolutely no kind of supporting the other team about what*
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3 should happen to this peg feeding if this person deteriorates.(Consultant Geriatrician,
4 Individual Interview)
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10 These data highlight very difficult issues in collaborative working and suggest that
11 the quality of end of life care may be compromised as a result of ineffective working
12 relationships.
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18 Discussion

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24 The need to provide palliative forms of care to those dying with non-malignant
25 chronic diseases is well established.²⁹ Evidence can also be found to suggest that
26 national policies are being aimed at ensuring access to palliative care for all,
27 including people with dementia.^{30,31} More recent pan-European recommendations
28 aimed at promoting high quality end of life care for people with dementia have also
29 been made.⁸ Recommendations include the adoption of palliative care approaches
30 for advanced dementia, respect of wishes in relation to place of care and
31 involvement of family carers in decision making. More specifically Gove *et*
32 *al*⁸ recommend that healthcare professionals should be provided with dementia care,
33 communication and pain assessment training, demonstrating the pivotal role played
34 by the health care team in enabling people with dementia to achieve high quality
35 palliative provision.
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55 This study has provided some insight into the experiences, ideas and attitudes about
56 approaches to palliative care provision for people with dementia, drawing on a
57 number of clinical teams from two sites in England. Findings suggest that there are
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1
2
3 significant barriers to people with dementia making the transition to a palliative care
4 approach. This failure can, in part, be attributed to cultural (ideas, values and
5
6 practices) and systemic aspects of the service infrastructure (organisational
7
8 boundaries and funding). Clinicians, for instance, alluded to the notion that dementia
9
10 is not recognised as a cause of death and that candidature for palliative services is
11
12 therefore questioned. Mitchell *et al* have demonstrated practitioners hugely
13
14 underestimate mortality rates of people with dementia.³² Poor knowledge amongst
15
16 some teams is apparent here, but uncertainty about prognostication may account for
17
18 some of these shortcomings.²² Indeed Murray *et al*¹¹ suggest that the trajectory
19
20 associated with dementia is protracted and complex, involving 'entry, re-entry'
21
22 scenario³³, resulting in poor acknowledgement of end of life status.³⁴ Inadequacies of
23
24 a systemic nature may also be as a result of the traditional role of hospices (as
25
26 providers of palliative care to people with cancer) and reliance on cancer charities as
27
28 a source of funding. Certainly there appear to be concerns about the resources
29
30 available to provide palliative services to an ageing population, but little critical
31
32 debate about how these challenges might be overcome using different models of
33
34 provision. These data also point to limited confidence amongst some health care
35
36 teams in the assessment and management of dementia at the end of life.³⁵ The pain
37
38 assessment of people with dementia has for some time been highlighted as
39
40 problematic and has prompted a plethora of tools aimed at objective measurement.³⁶
41
42 Limited exposure to such methods of assessment and their usage are a feature of
43
44 these data. To some extent the same can be said of perceived behavioural
45
46 challenges sometimes demonstrated by people with dementia. It has long been
47
48 noted that generalist teams often find difficulty in preventing and managing
49
50 behaviours which manifest as a result of confusion, frustration and communication
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3 difficulties.³⁷ These forms of behaviour have been viewed as a barrier to achieving
4 transition to palliative care.³⁴ These data suggest that little knowledge of the causes
5 of behaviour and how these might be prevented, suggesting that work in this area is
6 important if progress is to be made. Hughes *et al* have highlighted these
7 deficiencies, whilst at the same time recommending the growth of specialist teams
8 as a source of advice and practice development.²⁰ It would appear here, however,
9 that the development of such specialism contributes, to some extent, to the
10 compartmentalisation of skills and resources. Whilst it was noted by participants that
11 collaborative practice is desirable, it was not always possible and where specialist
12 advice was sought it was not always forthcoming. Of particular importance is the
13 collaboration that occurs in order to promote continuity. Ryan has suggested that the
14 development of close working relationships between practitioners and families is
15 fundamental if decision making is to be shared.³⁸ This development of close working
16 relationships between practitioners and the families of people with dementia at the
17 end of life has also recently been echoed in a large scale survey of palliative care
18 Programme Directors in the United States.³⁹ There are data here to suggest that a
19 commitment to 'the long view' helps to promote good practice. The notion of long
20 term investment in planning and building trusting relationships is evocative of the
21 advanced care planning movement and such a framework should be considered as
22 a potential way forward in the context of dementia care at the end of life, particularly
23 given the supporting evidence.⁴⁰ It has also been suggested that the UK Mental
24 Capacity Act (UK MCA)²⁸ is in part responsible for facilitating shared decision
25 making. The findings would suggest that for the participants at least the UK MCA
26 was positively received. Evidence concerning the use of the UK MCA in practice is
27 limited and this paper will contribute to the ongoing evaluation of its impact.
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Conclusion

This exploration of the experiences of health care practitioners in the provision of palliative care for people with dementia has drawn attention to a number of ongoing problems and challenges in clinical practice. Data would support the notion that transition to good quality palliative care continues to be the exception and that collaborative working relationships between acute and primary care as well as among mental health specialists and others are not always apparent. The paper does, however, point to examples of good practice. The data suggest that considerable development is required to help teams to build the internal resources available to them in order for them to be in a position to recognise the needs of people with dementia and meet the challenge they present. This would point to, for example, enhanced training around dementia care and communication. The paper also demonstrates evidence that the UK MCA is being used as a tool to help facilitate best interests decision making. The use of these mechanisms, and others such as advanced care planning, should provide the focus for the establishment of continuity, sound decision making and trusting relationships between family carers and health care professionals.

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Job Title:	N=
Consultant	4
Junior doctor	9
General practitioner	6
Practice nurse	4
Clinical nurse specialist	11
Other nurse	19
Allied health professional	5
Place of work:	
Acute hospital	10
General practice	28
Hospice	15
Specialist palliative care unit	5

Table 1: Breakdown of participants by profession and setting