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Palliative care services for people with dementia: A synthesis of the literature reporting the views and experiences of professionals and family carers

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Abstract

The experience of being a carer of a person with dementia at the end of life is expressed in these 12 accounts. This is a synthesis of the concerns and challenges for carers at the end of life. These accounts are often insightful and provide several views of carers' and professionals' experience. Having a close relationship as a carer gives a unique and poignant view. What emerges from this review is a range of perspectives that provide contrasting views of the heterogeneity of carers and professionals. This may be helpful for professionals and policy makers to consider when planning end-of-life care strategies for people with dementia and insights drawn from hearing directly from carers may be powerful learning tools.

Keywords

carer, caring, palliative care, dementia, Alzheimer's, narrative, review

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Introduction

Dementia is a progressive neurodegenerative disease and currently there are no effective treatments although there is much room for providing care and support and to reduce the excess disability of the impairment. Survival time in the United Kingdom is on average 4.5–5 years from symptom onset and survival from diagnosis is 3.5 years (Rait et al., 2010). Since these are averages, some people with dementia live for a long time with the condition, while others do not. In many families, caring for a person with dementia is complicated by the unpredictable course of the disease and lack of certainty about when the person might be approaching the end of life. How professionals support people with dementia and their carers at the end of life is of increasing importance as the incidence of dementia is set to rise in the next 30 years and because there is great concern that existing systems fail to offer good support or to reduce distress (Department of Health, 2008; Goodman et al., 2010). People dying with dementia may need more help at home compared with people who have cancer. However, many researchers have argued that the needs of people with dementia at the end of life are not met (McCarthy, Addington-Hall & Altmann, 1997) and that carers require more support at this time as they may feel exhausted and alone (Shanley et al., 2011). Sampson, Gould, Lee, and Blanchard (2006) found that older people who died as patients in acute hospital wards and who were recorded as having dementia had received significantly fewer palliative medications or referrals to palliative care teams prior to death in hospital. The management of the end-stages of the disease is complicated by a diminished ability to communicate, difficult-to-manage behavioural and psychological symptoms, and the educational, psychological and support needs of carers. Thuné-Boyle and colleagues' (2010) interviews with relatives of people with dementia at the end of life found that the carers' understanding of dementia and its likely progress had received insufficient attention from professionals. Being a carer at this time may entail bearing major responsibilities for the wellbeing of another person which may not be acknowledged by professionals. It is important for carers to have access to timely care and support to enable them to remain involved, to fulfil both their own and their family members' wishes (Andersson, Ekwall, Hallberg, & Edberg, 2010).

This paper is an interpretive synthesis (Dixon-Woods et al., 2006) of opinions and experiences of a range of professionals and carers (care-givers), including medical practitioners, nurses, social care staff, family members and volunteers, of providing or observing palliative care (or its absence) for a person with dementia. The justification for including such a broad span of observations and experiences is this avoids over-privileging one perspective and underlines, potentially, the potential for all such groups to act as witnesses and to testify about what they have observed (Manthorpe, 2000). Baldwin and Bradford Dementia Group (2008) suggest that such narratives may be powerful influences on policy. Considering the narratives involved, be they personal in terms of writing about a longstanding intimate relationship or offered through a professional lens, they may help in thinking about palliative care in a practical, empathic as well as holistic way.

Methods

A search of electronic databases of papers in English language peer-reviewed journals using broad terms related to palliative care and dementia was conducted in May 2011 as part of a

review of the background literature for the IMPACT (IMplementation of quality indicators in Palliative Care) sTudy. The search terms were: palliative care, terminal care, attitude to death, or dying, end-of-life care, comfort care, symptom control, end stage disease, living will, advance directive, palliate, palliative, and Alzheimer's disease, dementia, neurodegenerative diseases, Parkinson's disease, aphasia. Databases searched were AMED, ASSIA, BNI, CINAHL, EBMR, EMBASE, HMIC, IBSS, Medline, PsychINFO and Social Science Citation Index. The journal *Dementia* was hand-searched from 2002 to present.

A total of 6167 papers was identified covering the time span of January 2000–May 2011 (see Figure 1). Titles and abstracts were reviewed by two reviewers (MR and AW). Papers were included only if they included professionals' or carers' perspectives (indirect as well as direct) on one or more aspects of palliative care concerning a patient or person with

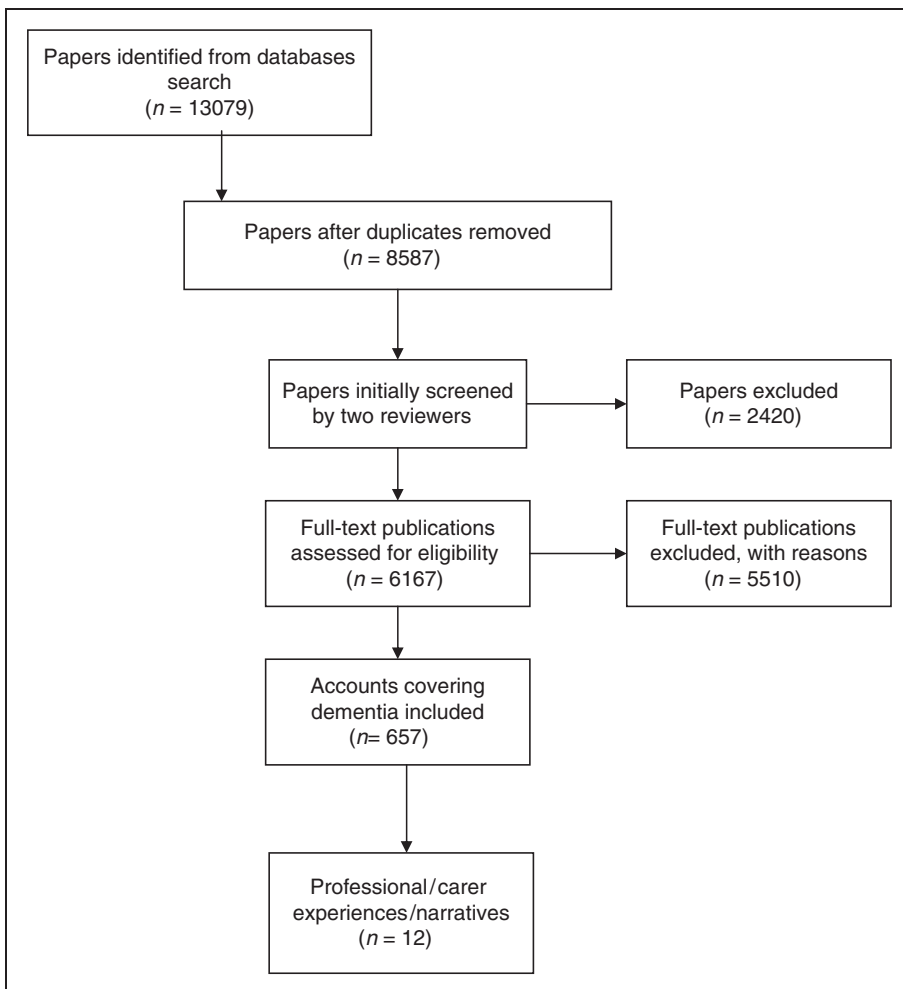


Figure 1. PRISMA flowchart: selection of papers.

dementia/Parkinson's disease/Lewy body dementia/cognitive impairment/Alzheimer's disease or any other type of cognitive impairment. Where the substance of the paper was not clear from the title and abstract, the full paper was read. A broad selection of papers was scanned at first and a third reviewer (SI) reviewed papers if there were doubts over inclusion.

Papers excluded were those about palliative care focusing on other conditions (for example, cancer), published before 2000, covering aspects of care and treatment not related to palliative care (for example, non-palliative interventions) or diagnosis of dementia.

The 12 papers included for detailed review took several formats. They included comments, opinion pieces, letters to the editor and other communications by carers and professionals caring for a person with dementia at the end of life (see Table 1).

The reviewers grouped statements covering pertinent themes together and then wrote summaries under headings such as spirituality, carers, advanced planning.

Findings

Wishes and rights

Some accounts by family carers expressed frustration that they were not prepared for the end-stages of the dementia. Advanced planning for end of life, after speaking with the person with dementia, helped some carers to manage those stages. From the United States (US), DiBartolo (2002) described the deterioration in her aunt's health and her aunt expressing her wish to 'stay in her own home'. In DiBartolo's opinion, it was important that this wish be respected. She called for better public awareness of 'advance directives' (the term used by DiBartolo). In addition, she felt that the family doctor needed to understand and 'revere' her aunt's advance wishes.

Writing about the care of an older woman (Ellie) dying in hospital, Feinstein (2005), a US hospital intern (doctor), perceived a lack of awareness of the person with dementia's wishes among the health professionals involved, despite there being evidence of her wishes. The intern had located 'a hand-typed statement making known her wish for a peaceful ending'. However, in his view, the clinicians seemed to manage Ellie's end-stage mesothelioma too invasively. He portrayed a picture of lack of respect for these wishes, describing witnessing family members' consent being elicited over the phone for invasive and often painful procedures such as chest tube insertions. 'In this case there was evidently no time for a family conference to discuss Ellie's wishes.' He asked 'Where was Ellie's voice in all of this?' and articulated his own sense of powerlessness in voicing his concerns to the senior team members.

Other accounts from friends and family close to the person with dementia make the point that they feel that they alone know the person with dementia's wishes:

The Professor had expressed wishes that he would not like the idea of a nursing home, I promised him that I would take care of him at home. (McFarland, 2010; family carer)

Markowitz and Rabow (2002) interviewed Ms P, the daughter of a woman with Alzheimer's disease. Ms P said that family carers of a person with dementia should think about what the person would want without being selfish or 'focusing on what we want, but rather on what

Table 1. Papers describing carer experiences of palliative care for dementia

Paper	Country of publication	From the perspective of:
Feinstein, J. A. (2005). Her voice alone. <i>Journal of the American Geriatrics Society</i> , 53(11), 2033.	US	Doctor (direct)
Hensel, W. A. (2000). The old man's friend. <i>JAMA</i> , 283(14), 1793–1794.	US	Doctor (direct)
Condon, N. (2005). Meeting Mrs. A. <i>American Journal of Hospice and Palliative Medicine</i> , 22(3), 237–238.	US	Hospice volunteer (direct)
Dartington, T. (2008). Dying from dementia – a patient's journey. <i>British Medical Journal</i> , 337(7675), 931–933.	UK	Husband (direct)
Dartington, T. (2009). Two days in December. <i>Dementia</i> , 6(3), 327–341.		
DiBartolo, M. C. (2002). On her own terms. <i>Journal of Gerontological Nursing</i> , 28(10), 55–56.	US	Niece (nurse) (direct)
McFarland, D. (2010). A journey through Pick's Disease with a loved one: A personal account. <i>International Nursing Review</i> , 57(1), 142–144.	Botswana	Family member (direct)
Lombardo, S. (2003) Caregiver role satisfaction: My mother's final gift. <i>Home Healthcare Nurse</i> , 21(1), 68.	US	Daughter, nurse (direct)
Cohen, J. R. (2001). Journey of a lamb. Walking through dementia together. <i>Journal of Christian Nursing</i> , 18(2), 9–14.	US	Parish (church) Nurse (direct)
Hellwig, K. (2005). Pearl's wisdom. <i>Journal of Gerontological Nursing</i> , 31(7), 55–56.	US	Family member (indirect)
Lella, J. V. (2000). Johnny Colucci's passing: A death in two hospitals. <i>Illness, Crisis, & Loss</i> , 8(4), 405–425.	Canada	Sons, daughter and wife (indirect)
Anonymous (2009). Waiting for death from dementia. <i>End of Life Care</i> , 3(4).	UK	Niece/nephew (direct)
Markowitz, A., & Rabow, M. (2002). 'It's okay, mama, if you want to go, it's okay.' <i>JAMA: Journal of the American Medical Association</i> , 288(18), 2324–2331.	US	Daughter (indirect)

she would have wanted for herself.' She suggested that options and preferences should be discussed with the person and their carers while the person with dementia is able:

You don't have some of the heartaches that my family went through before we finally decided to place my mom into the hospice program. I'm so sad that we didn't have the conversation about life and death and funeral arrangements, just to prepare.

However, not all family carers feel this approach is realistic. The author (Anonymous, 2009) of the paper 'Waiting for death from dementia' expressed frustration that UK government policy emphasises discussions about end-of-life care because, in the case of their relative, it was difficult to accurately anticipate the end of life for a person with dementia:

How do you do that when someone has dementia? I thought aunty Josie could deteriorate and die any time over the years, so my guess three years ago that she might be dead within a year was wrong.

One further account of care at the end of life from the US is from Hensel (2000), a hospital physician, who recalled discussing treatment decisions with the wife of a person with dementia, who was additionally experiencing an exacerbation of chronic obstructive pulmonary disease. Hensel emphasised the importance of having sufficient time for this discussion, and of involving the whole family, who may have differing opinions about withdrawing treatment.

In 'Johnny Colucci's passing' (Lella, 2000), the family found it difficult to discuss the care of their father and husband. In this case, Johnny had clearly made his wishes known in advance in a living will (advance directive). 'They wanted no life-prolonging measures...but now their dad was in hospital seriously deteriorated and deteriorating further, decisions were not so easy...'. The family described spending a long time debating whether to seek for someone to 'actively treat' their dying father or not. In this case the hospital staff provided the family with the time they needed, but the option of a hospice was not on offer. Curiously, from the family's perspective, the doctor suddenly suggested rehabilitation when news arrived that there was no hospice available.

In the same paper the narrator discussed the reasons why at the end of life, decision-making may be seemingly chaotic. 'Family members live too far away, with lives too highly organised to allow them to come and help. The partner is afraid to try and go it alone or even with the help of a stranger, a home care-giver.'

Medical management and symptom control

Pain in the terminal stages of dementia may be very difficult to assess. 'His last days were characterised by marked extreme body stiffness and later, immobility, which left us puzzled because of our lack of knowledge about the disease' (McFarland, 2010). In a commentary entitled 'Waiting for death from dementia' the author(s) (Anonymous, 2009) recalled finding it distressing on hearing their aunt say she had neck pain:

I do not know if the pain is linked to the cancer... I hope not – cancer makes me think of death.
(Anonymous, 2009)

This author(s) made a link between pain and death. They also conveyed the ambiguous nature of the message of pain from the patient, illustrating the frequent difficulties in assessing pain in a person with limited communication such as is symptomatic of some dementias.

In Hellwig's (2005) narrative, the person with dementia had recurrent urinary infections which were difficult to assess. Monthly urine specimens helped alert the nursing home staff and physician to the possible need for treatment.

Lella (2000) described the restraints used to prevent Johnny from having a fall in hospital when agitated and confused but noted 'The family never discussed the issue of restraints and their pros and cons with a member of ward staff clearly designated as responsible for directing his care.' It is not clear what might be the reason for this.

Place of care

Moving from one place of care to the other when a person with dementia was dying was commonly described in the narratives included in this review. Some accounts described stressful and frequent moves from one place to another. In 'Waiting for death from

dementia', Anonymous (2009) described her aunt's move to a long term hospital when her son was unable to cope with looking after his mother. The new environment was presented as confusing for the aunt and a year later the aunt moved to a residential care home:

I was with her when she first arrived and witnessed my aunt's confusion as to why she was there. At times she understood, at others she could not quite remember.

Repeated moves from one family member's home to another's, and then on to a residential home, may be made worse by the person with dementia's and the carer's fears and expectations:

Her grip was like a vice. She was unexpectedly strong and quite unwilling to let go. I had to literally pry her fingers off. That was my first clue that she was not ready to let go, not ready to be taken out. (Condon, 2005)

Some family members express a wish for alternatives to moves between hospitals and care homes but even staying at home is not always reported entirely positively:

She was alone in the apartment. Although this is not a normal situation for a person with dementia, her children were determined that she remain in her home, as she had wished. She had caretakers 24 hours a day, but they came and went. The bedclothes were clean, her nightgown fresh, the hospital rails up, the TV on. But she was alone – totally alone, unmoving, silently playing with the sheet, waiting on an interior timetable. (Condon, 2005)

In 'Johnny Colucci's passing' (Lella, 2000), Johnny's wife is afraid of not being able to look after her husband at the end: 'I just pray every night that I can take care of Daddy so that he doesn't have to go into a home.' Later Johnny is hospitalised. 'Hospitalising Johnny... allowed everyone... to ignore the possible impact of changing his routine and the possible impact of the various therapies on his spirits... And then Johnny fell... he was tied by staff to his chair and bed...'

The account later portrays the decline of Johnny in hospital, the medical complications that arose in hospital and the negative care experience of the person and their family. One of the difficulties highlighted is poor communication with senior staff members:

It was... difficult to know when and how often he (the doctor) was in touch with the ward and how long it took for his orders to filter down... the cast of characters often changed.

In contrast, Markowitz and Rabow (2002) interviewed a daughter who spoke of her mother's positive move to hospice care:

Surroundings were very soothing and calming. I still remember it as being something pleasant, rather than her being in a hospital, dying there, and being real sick.

Both good and bad experiences are reported in the papers reviewed. For instance, Cohen (2001) provided a bleak description of a US nursing home, where the person with dementia was 'belted by a posey' (a restraint) into a chair, the posey leaving marks on her breasts, the forced seated position being uncomfortable due to her kyphosis. However, on moving to a different home where 'light restraints' were used, she could lean across a table when seated and became more calm and pleasant.

Dartington (2008, 2009), an academic, described encounters with the UK health and care system while his wife's condition deteriorated. Care was provided following an assessment of needs to accommodate the change in her circumstances. He found it useful to have frequent

review meetings to change the care plan in response to her developing symptoms of dementia. A palliative care consultant became involved and talked to him about his wife's wishes:

She questioned me about my understanding of Anna's wishes at this time and sought the agreement of the other professionals, including Anna's general practitioner, to the implementation of this advance care plan. (Dartington, 2008)

Dartington (2009) reported feeling under little pressure to immediately move his wife to a care home, something he wanted to avoid, until it was considered necessary – perhaps in the final stages of her illness. He struggled to get support from the social care system at first, but eventually received some support:

The social care was increased according to Anna's increased dependency until there were four visits a day from the home care team, supported by up to four hours of informal carer visits, which I arranged. (Dartington, 2008)

His wife became eligible for National Health Service (NHS) 'continuing healthcare' (free care from public funds). This is a rare account by a carer of the operation and interaction of health and social care systems at end of life.

Some narratives have also presented experiences of hospital care at the end stages of life. Dartington (2008) described how, once, his wife entered hospital she became further unwell. Through the experience of seeing how many inappropriate and invasive tests were done in the hospital, he decided that it would be in her best interests that she would not go to hospital again:

When he (the doctor) proposed inserting a catheter I was able to question the need for invasive treatment at this time, arguing successfully that continuing care at home was more appropriate. Otherwise she might well have died then in hospital or lingered on as a 'delayed discharge' statistic. On the second occasion I was able to argue at once against the emergency transfer to hospital, signing a disclaimer form for the paramedical services.

In contrast, Hellwig's (2005) account of Pearl's death presented a more hopeless experience in hospital:

We watched with feelings of impotence as she struggled to gain comfort in the foreign environment of the acute hospital setting. The tubes, unfamiliar surroundings and people, and the intrusion into her body with invasive procedures created stress for Pearl and for us. She could not comprehend what was happening to her.

In hospital, Hellwig reported: 'her soul and comfort were not addressed or nurtured. The night she returned to her nursing home bed, with its attendant feel and smells, she immediately relaxed, became more responsive, and her grimace transmuted into a smile.'

Lella (2000) described the physical and psychological effects of hospital admission on an already vulnerable older person, the difficulties faced by families such as his in communicating with hospital staff who change frequently; the problems involved in deciding on care after discharge from acute care; and the difficulty, which she acknowledged affects families and professionals alike, of deciding between 'heroic' and palliative care. In the same account, it is maintained that the decisions made were dependent on the finances of the Medicare system. 'He was on a costly staff-intensive, acute care ward and Medicare/insurance rules would no longer allow payment...'

Food and drink

One family member narrative (Hellwig, 2005) described the decision making process to insert a Percutaneous Endoscopic Gastronomy (PEG), a procedure to support nutritional feeding. Pearl had dysphagia and her family were consulted about a decision to insert a PEG. The narrator debates the ethical dilemma regarding feeding, nutrition and risk of aspiration pneumonia, and finally a decision is made:

The vision of Pearl choking on food outweighed allowing her to die without medical intervention.

The clinical team decided to insert a PEG, but the carer wondered later if this may not have been in the person with dementia's best interests, but had made the family feel better. In this case those looking after the person with dementia were not aware of any statement of advance wishes so the family were consulted.

Lella's (2000) account described their father's worsening appetite: 'Leonora wept over the phone to her daughter... "He's starving himself to death."' Later the family needed to decide on whether Johnny, who was said to be dying, should have a PEG inserted. The staff expressed their concerns 'if he gets some food into him, he'll feel stronger' so a nasogastric tube was put in place. The surgeon suggested a gastrostomy saying to the family that 'you'd be surprised at what a little food will do to his spirits, and it isn't uncomfortable.' The family considered this for a while, and even though their father's living will stated that extra measures shouldn't be tried they wanted their father 'to have every benefit of the doubt, every fighting chance to get back to his clearly limited but still satisfactory prehospital life.' As in the section on wishes and rights above, this example also illustrates that people cannot be assured that their wishes will be respected if they make them formally or express them in advance.

Elder abuse and neglect

Cohen (2001) provided a rare account of poor quality care or abuse of a person with dementia at end of life. An older woman with Alzheimer's disease who was being 'looked after' by a family member was discovered in a fragile and neglected state by another relative:

They found Crystalline locked in her bedroom upstairs, where, dressed in a tattered nightgown, she was seated next to her bed on a straight back chair. The near-empty room was illuminated by a twenty-five watt bulb in a lamp on the floor. A stinking commode stood across the room, next to which lay badly soiled and worn sneakers without laces. A small pile of Crystalline's dirty laundry lay beneath two dirty dresses and several pairs of stained slacks and blouses that hung from nails near the door.

The importance of this account is that it presents a different view of family carers and alerts professionals to the need for vigilance generally and interventions in some circumstances.

Spirituality

Some accounts by family carers emphasise spirituality at the end of life. DiBartolo (2002) described calling a priest to conduct the last rites when her aunt was dying at home: 'It was as if she waited for that specific encounter before she departed the earth.' Cohen's article,

published in the *Journal of Christian Nursing*, highlighted the importance of religion for some people with dementia and for some carers who drew emotional strength from religious faith when witnessing the terminal stages. When Johnny is dying in Lella's (2000) account, her son 'read some psalms to himself, and prayed for God to watch over his father.'

Traditions and culture

The culture of both carer and person with dementia may influence the type of care that is accessed and experienced. One paper, 'A journey through Pick's Disease with a loved one: A personal account', expresses the views of a carer originally from Botswana:

The concept of placing a family member in a nursing home was foreign to me. I am from Botswana, and the Setswana tradition is that a sick person is taken care of at home by other family members. Being born and raised in that culture, placing a loved one in a nursing home was difficult to consider. (McFarland, 2010)

Another dimension of culture is reflected by Anonymous (2009) in an account of nursing home care where a family member described her frustration with poor communication between staff members and family members. This is described as arising from lack of cultural competency:

Communication with the staff members at the care home is not good. They are reluctant to offer any information about my Aunty and often seem unclear as to the nature of her problems and needs. Many have not been working in the home for long and the majority do not speak English as a first language, which consequently causes difficulties in understanding.

Lella (2000) describes a similar frustration: 'Some physicians were foreign medical graduates whose command of English – both understood and spoken – did not make for easy communication, especially with elderly patients.'

Being a family member or carer

Carers' emotions near the end of life of the person with dementia ranged from exhaustion and desperation to exultation and relief. Cohen (2001) described the effect of their mother's sudden deterioration on family members' mental health, particularly one young child:

School counsellors believed the problems were related to his initial ambivalence and ultimate anger about his grandmother living in his home. He was often the person responsible to watch her on return from school.

Lombardo (2003) and McFarland (2010) both presented accounts of carer exhaustion. However, some narratives are more positive, for example Lombardo described in 'Caregiver role satisfaction: My mother's final gift' the closeness she experienced with her mother during the time when she looked after her. She felt she had an increasingly important role as caregiver during that time, making it easier for her emotionally after her mother's death:

It seems incredible that caregiving can be so satisfying. I look into her bedroom now and I can feel her presence... and I am thankful for the final gift she gave me... I remembered when she

was in control, and when I needed her – and she was always there for me. As her memory worsened, I began to appreciate my mother in a way I never knew possible.

However, some carers described their frustration with the difficulties presented by changes in personality or behaviour in the person with dementia (Dartington, 2008; DiBartolo, 2002).

I became temporarily disorientated and angry whenever there was a significant further loss of capacity for us to cope with. At first it was losing keys or puzzling over a diary entry; later it was physical aggression or double incontinence. (Dartington, 2008)

For close family members this change in personality and change in awareness of safety, environment and people, not surprisingly, may be distressing and shocking:

It reminded me of someone whose world has gone completely askew, tilting out of control. They are so off kilter they think they are falling off the world, so they hold on to anything with an almost superhuman strength that belies the frailty of their physical bodies . . . It was obvious to me she was looking intently at something beyond my grasp of understanding. It took me weeks to get her to relax in my presence and let her eyes show me her true feelings of relief, interest, pain, tenderness, and plain old tiredness of living. (Condon, 2005)

Grief

DiBartolo (2002) described a sense of relief when her aunt died. McFarland (2010) reported similar feelings:

Even though it was expected, Professor's death was a painful blow to all of us in the family as well as to others who knew him closely. But we took comfort in knowing that he was at peace and resting and that his suffering was over. What was left was our suffering and how to deal with it. At the same time, this was the most rewarding thing that I have ever done; his appreciation was conveyed by his last words to me, 'I do not know what I did to deserve you.' It gave me peace of mind to know that I did the best I could for him and that even in his decline he appreciated what I, together with friends and family, had done for him.

In Markowitz and Rabow's (2002) interview, Ms P suggested that grieving starts early, well before death:

Our mother was sick for 5 to 6 years, and we had lost her back then, actually, so we grieved for 5 or 6 years, but I truly believe that this was a blessing, that God gave it to us this way so that it wouldn't be as hard on us.

Grief started before death in Lella's (2000) account:

The decision to let go, to do nothing, to let nature take its course, is not easy among people like us who celebrate doing, activity, competition . . . even when the road was obviously coming to an end, it was still difficult to abandon it.

Limitations of this study

This search was confined to electronic databases and focused on papers in peer-reviewed journals. The concentration on journals excludes some longer accounts, such as books by

carers (see Smith, 2004) and by social scientists (Gass, 2004; Savishinsky, 1991). Other narratives, such as those in self-help or support materials, were not included but they are acknowledged to be very valuable presentations of carers' perspectives and experiences.

Discussion

Few published accounts of carers' experiences of the management of dementia at the end of life are available from the published research literature in journals. A small number of different perspectives were identified from this search which may be investigated further.

Personal experiences are often insightful and provide several views of carers' and professionals' experience of dementia at the end of life. Having a close relationship with the person with dementia as a carer gives a unique and poignant view of the person with dementia. As is frequently observed by carers (Shanely et al., 2011), professionals need to acknowledge the carer's perspectives when supporting a person with dementia and should consider the wishes of family members. This may improve outcomes for both the person with dementia and their family carers.

One key finding of this synthesis is that when considering palliative care and people with dementia the suggestions relating to good practice resonate with those applicable to good practice with all carers. In this context, the following observations may be practice relevant.

Health and social care professionals should ascertain carers' perspectives on a person with dementia's situation and their (carer's) wishes. This should respect the provisions of the Mental Capacity Act 2005 in the context of England and Wales. Familiarity with legal frameworks is essential but so too is a sense of confidence among professionals that they can also work within possible disputes and differences of opinions. A lack of communication between people with dementia, carers and family, and professionals may lead to poor experiences at the end of life but communication is not uni-directional.

People with dementia's and carers' cultural backgrounds, beliefs and experiences of professionals may influence choices over what kind of support and care is desired. There is great heterogeneity among them.

Advance care planning may be helpful to all parties but is not universally desired. Prognosis could be discussed, as well as decisions over management of the risks of nutrition, complications and preferences over place of care. However, there are circumstances when it will not be possible for professionals to draw on these discussions.

Health and care professionals need to be aware of the possibility of elder abuse or poor quality care when supporting people with dementia and should know their legal and professional responsibilities in such situations. These may relate to carers but also to professional care. Difficult situations may place great stress on paid and unpaid care providers.

However, there may be areas where practice could be improved that are relevant to end-of-life care or palliative care more specifically. Health and care professionals in both hospital and community settings may benefit from skills development and access to resources in seeking to implement a holistic approach to end-of-life care for people with dementia. The involvement of carers in such education may be useful as a testimony to current practice and its deficits (Manthorpe, 2000). Opportunities for reflection on end-of-life care practice may support staff. Health and care professionals, carers and other family members may need to be ready to address changes as people move to end of life. There could be offers of timely

discussions about the wishes of the patient and the family to see if these can be followed and their rights respected.

While there are growing numbers of accounts of the experience of being a carer and from professionals working in dementia services in general (see Gass, 2004; Savishinsky 1991), few articles have focused on experiences at the end of life. What emerges from this review is a range of perspectives that provides contrasting views of the heterogeneity of carers and professionals. This may be helpful for professionals and policy makers to consider when planning end-of-life care strategies for people with dementia. However, the research literature contains few such accounts or narratives and readers are advised to consult the broader literature, including internet sites, and to elicit personal experiences from support and campaigning groups, such as Carers' Groups and Alzheimer's support groups. The insights drawn from hearing directly from carers may be powerful learning tools.

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Conflict of interest statement

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Disclaimer

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