

# Approaching the end of life and dying with dementia in care homes: the accounts of family carers

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## Summary

Research into end of life and dying with dementia in care homes from the family carer's perspective is limited. From the available evidence, it appears that family carers find themselves in an unfamiliar situation about which they lack knowledge and experience. Whilst dementia tends not to be acknowledged as a terminal illness by many family carers, they are expected to make end of life decisions on behalf of their relatives. Family carer decision-making is underpinned by values of quality of life, previously expressed wishes, comfort provision and dignity preservation. This is often approached when family carers are grieving for the anticipated loss of their relative and have their own personal needs that require to be addressed. Within a care home setting, a curative care–palliative care split is unhelpful in resolving these tensions and a model of comprehensive care appears a more appropriate approach. This requires ongoing communication between the person with dementia, family members and professionals from the early stages of the condition.

*Keywords:* care homes, nursing homes, dementia, family carer, end of life, dying.

## Background

It is estimated that 24 million people are living with dementia worldwide and that this number will increase to 81 million by 2040.<sup>1</sup> In developed countries, as life expectancy increases and mortality rates for other diseases reduce, dementia is becoming a major cause of death.<sup>2</sup>

The course and trajectory of dementia can be protracted and unpredictable.<sup>3,4</sup> People with dementia often experience 'gradual death' (<sup>4</sup>; p8),

with progressive physical and cognitive losses that result in increased dependency. As a result, a person with dementia requires escalating levels of care,<sup>5</sup> making admission into a long-term care setting such as a nursing home or care home common,<sup>6</sup> particularly in the last year of life.<sup>7</sup>

In this paper we use the term 'care home' to refer to a long-term care facility for elderly people, offering personal care alone, or nursing and personal care. It is difficult to estimate the number of people with dementia who die in care homes, and figures can be misleading. Cox and Cook<sup>8</sup> describe three ways of 'dying with dementia': those who reach the end of their lives with dementia but die as a result of another identified condition, e.g. cancer; secondly, those who reach the end of life with a mixture of physical and mental conditions, but cognitive impairment is not advanced; and thirdly, those who die as a result of the complications of dementia. This review is largely concerned with this third category.

People with dementia are frequently not recognized to be dying, and are admitted to acute hospitals in the final few days or weeks of life for the treatment of conditions such as pneumonia or urinary tract infection.<sup>9</sup> This is despite evidence to suggest that acute hospital admission can be detrimental to people with dementia and stressful for their carers.<sup>10</sup> Estimates of death rates are further impeded by under-diagnosis of dementia.<sup>9</sup> However, the proportion of people with dementia who die in nursing or residential care homes is estimated to be 70% in the USA.<sup>11</sup> In the United Kingdom (UK) it is estimated that 40% of older people with dementia die at home or in a care home without on-site nursing care.<sup>12,13</sup>

The specific nature of dementia and, following a medical model, its degenerative trajectory, makes the context of care-giving specific and constantly evolving. Family carers have to cope

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with multiple losses over a long period, resulting in high levels of anxiety and 'pre-death grief'.<sup>14</sup> With the progressive loss of cognitive function experienced by people with dementia, family carers are called upon to contribute to decision-making on behalf of their relatives. Currently, the literature on family carers of people with dementia overwhelmingly focuses on their needs in the home care setting,<sup>15,16</sup> with coping,<sup>17,18</sup> stress,<sup>19</sup> quality of life<sup>16,20</sup> and interventions to ease care-giver burden and pre-death grief<sup>14,17,21,22</sup> to the fore. Care-giver resilience and predictors of care-giving transition from home to care home are also areas receiving significant attention.<sup>15,23,24</sup> The specific literature on family carers of people with dementia living in care homes mirrors the interest in transitions of care<sup>25,26</sup> and extends to explore relationships between family carers and professional care staff.<sup>27-29</sup>

Within dementia care and care homes, end of life issues are increasingly recognized and are highlighted in the policy debate.<sup>30,31</sup> Research on palliative care in care homes is centred on the provision and quality of care,<sup>32-35</sup> the experiences and attitudes of professionals<sup>36-38</sup> and their educational needs.<sup>39-41</sup> Where the views and experiences of family carers have been sought, it is usually to evaluate quality of life, quality of death and proxy views regarding a good death, on behalf of their relative, post-bereavement.<sup>20,42-45</sup> Rarely have the views and experiences of family caregivers in their own right been elicited.

This literature review aims to identify, synthesize and evaluate current knowledge about family carers' experiences and needs regarding end of life and dying in care homes for people with dementia. Recommendations for future research will be made in the areas of practice, education and policy.

### Search strategy and selection criteria

A systematic literature review was conducted.<sup>46</sup> The search strategy included the search of thirteen electronic databases, eighteen web sites, a hand search of five key journals, examination of papers recommended by experts working in the field and a hand search of reference lists from relevant papers. A range of subject headings, key words and phrases were used to maximize the number of relevant papers. The search was carried out between May and October 2009 and revealed a total of 544 references. Empirical research papers

that employed qualitative and/or quantitative research methods, 'grey' literature and case studies were identified and selected for this review. Following a meta-ethnographic approach,<sup>47</sup> lists summarizing the original authors' findings, using their terms and concepts, were drawn up for each of the papers and the information was added to the research summary sheet (Table 1). Themes and findings were compared across studies to indicate relationships. Concepts that encompassed the papers being synthesized were derived, resembling second-order constructs in the analysis of primary qualitative research data. The results of the synthesis were shared and discussed by the authors to develop the final integrative review of the literature. Further details of the search methods and selection criteria are available from the corresponding author.

### Results

Twelve papers, reporting ten research studies, were identified and met the inclusion criteria. One study was conducted in Australia, one in England and one paper reports a cross-national comparison of data collected in The Netherlands and USA; the remaining seven studies were North American (Canada  $n = 1$ ; USA  $n = 6$ ). One paper reports survey data that used End of Life in Dementia Scales, but this review only includes findings from the 'Satisfaction with Care Tool' used to elicit family perspectives within the study.<sup>48</sup> Three of the studies were longitudinal, two of which collected qualitative data. One study used a concurrent mixed methods design<sup>49</sup> and one used a prospective cohort study design.<sup>2</sup> The remaining nine papers report exploratory studies using individual interviews or focus groups with family carers. Eleven of the papers describe the setting as either 'nursing homes' or 'long-term care facilities'. Whilst the twelfth was conducted in a 'hospice unit', the majority of research participants were care-givers of people with dementia living in a long-term care facility and receiving care/support from a hospice service.

Clearly, each of the studies was conducted within the context of its own policies, and legal and health care system, all of which have an impact on decision-making processes; but despite obvious differences, the care of family members of people with dementia at an individual level appears to be an issue of concern in the developed world.

Table 1. *Summary of papers included in review*

Authors	Caron, Griffith, Arcand 2005a, 2005b <sup>50,51</sup>	Clarence-Smith 2009 <sup>56</sup>	Elliot, Gessert, Peden-McAlpine 2007 <sup>57</sup>	Forbes, Bern-Klug, Gessert 2000, 2000–01 <sup>54,55</sup>	Lopez 2009 <sup>52</sup>
<b>Aim</b>	To explore the experience, concerns and treatment decision making of carers re end of life in late stage dementia	To explore the provision of healthcare to people with dementia living in a care home through the experiences of their relatives	To improve understanding of values and beliefs that families use to guide end of life decision making for older adults with advanced cognitive impairment	To describe family decision making re end of life for nursing home residents with moderate–severe dementia. To identify areas where better communication may be beneficial to end of life decision making	To explore family decision making of nursing home residents with moderate–severe dementia
<b>Research design</b>	Grounded theory	Qualitative design	Qualitative design	Naturalistic inquiry	Grounded theory
<b>Setting</b>	2 Long-term care facilities, Canada	2 Care homes, England	Nursing homes, USA	4 Nursing homes, USA	4 Nursing homes, USA
<b>Sample</b>	24 Carers of 20 people with dementia (of which 16 were post-bereavement interviews)	16 Carers of people with dementia	39 Family members	28 Carers of 26 people with dementia	12 Family carers
<b>Methods and concepts</b>	One in-depth interview (some dyads)	One in-depth semi-structured interview	8 Focus groups, Interview guide	4 Focus groups	Purposive sample, 1 semi-structured interview each
<b>Data analysis</b>	Constant comparative method and line by line dimensional analysis	Thematic analysis	Thematic analysis	Content analysis	Iterative, 3 levels of coding
<b>Validity</b>	Data analysis by 2 team members independently; cross-validation	Data analysed by independent researcher	Independent data analysis by 3 researchers; field notes	Peer de-briefing; multidisciplinary team; 6 meetings; exploration of rival explanations	Member checking; final theory presented to 2 participants. Data collection, analysis and write-up by the author. Researcher notes during and after interviews
<b>Reliability</b>					
<b>Reflexivity</b>					
<b>Ethics</b>	University Research Ethics Committee approval, written and ongoing verbal consent	Not discussed	Institutional approval; written consent	University Research Ethics Committee	Institutional approval

Table 1. (continued)

Authors	Caron, Griffith, Arcand 2005a, 2005b <sup>50,51</sup>	Clarence-Smith 2009 <sup>56</sup>	Elliot, Gessert, Peden-McAlpine 2007 <sup>57</sup>	Forbes, Bern-Klug, Gessert 2000, 2000–01 <sup>54,55</sup>	Lopez 2009 <sup>52</sup>
<b>Findings</b>	Caregiver role as decision maker. Quality of life. Phases of end of life decision-making. Context of interactions with health care providers. Quality of relationship, frequency of contact, values and beliefs, level of trust	Main findings re end of life: frustration and uncertainty with primary health care. Confusion about responsibility re end of life wishes and who makes decisions on behalf of person with dementia. Positive effect of respect, kindness and sensitivity shown towards carers	Managing stress; decision maker (choosing to remain involved); using prayer and faith in decision making	Emotional effect. Insult to life story. Two faces of death. Values and goals re end of life treatments. Unrecognized dying trajectory. Stress/guilt. Making decisions with limited information. Goal setting. Health professional's role	Wanting to do the best in the face of uncertainty. Sources of uncertainty; lacked knowledge re treatment options and illness trajectory, didn't recognize dementia as a terminal illness. Themes; protecting life; creating comfort; relying on religion; honouring wishes; seeking guidance
<b>Conclusions</b>	Care-giver role unclear, some saw the role of medics to be decision maker, others wanted involvement. Carers based decisions on quality of life for person with dementia, using preferences and personal history of the person as a guide. Carers felt uncomfortable making decisions at times of uncertainty, needing professionals to explain disease progression/ treatments. Grieving carer/decision maker problematic when entering palliative phase. Palliative care approach (to predict	Confusing haphazard healthcare interventions. Written information would be helpful. Staff from all disciplines lacked specialist knowledge. Lack of care planning. Need for staff training and improved communication skills	Values and belief systems used to inform decision making in difficult situations. Used as a way of finding hope and meaning and a way of coping with the stress. For some faith added to the stress	Decision making seen as a long difficult journey – 'rocky road'. Prominent markers not recognized, lack of a guide, limited horizon. Advanced care planning (ACP) would help carers to be actively involved in decision making, without which they over- or under-treat and reduce their own peace of mind. ACP would improve care, normalize discussions and develop communication with health care professionals. Carers had own significant needs. Family see	Professionals need to recognize uncertainty, support the family by open discussion and explanation. Honour wishes and religious beliefs of person with dementia to give individualized care

death) and quality of life evaluation (with carer) allows communication with family and lightens decision making. Carers sought understanding and empathy from staff by trying to personalize relationships. Wanted frequent contact with staff and to be involved in care planning. Some carers had 'blind trust' in professionals, for others trust developed over time. Carers lacked knowledge to make informed decisions, but were passive; waited to be offered information. Carers felt validated when values and beliefs were shared with professionals and fear, anger, guilt when they were not

themselves as responsible/guilty. Death not seen as timely/appropriate

<b>Authors</b>	Mitchell <i>et al.</i> 2009 <sup>2</sup>	Moyle, Edwards, Clinton 2002 <sup>58</sup>	Powers, Watson 2008 <sup>49</sup>	Sanders, Butcher, Swails, Power 2009 <sup>53</sup>	Van der Steen <i>et al.</i> 2009 <sup>48</sup>
<b>Aim</b>	Better understanding of the clinical trajectory of end stage dementia	To investigate family caregiver's perceptions of having a relative with dementia in an institution	To describe the meaning and practice of palliative care for nursing home residents with dementia at the end of life	To explore the experiences of caregivers for patients with end stage dementia enrolled into hospice care	Cross-national comparison of data collected using End of Life in Dementia Scales
<b>Research design</b>	Prospective cohort study	Qualitative exploratory framework	Concurrent mixed methods (prospective and retrospective)	Ethnomethodology	Mortality follow-back methodology

Table 1. (continued)

Authors	Mitchell <i>et al.</i> 2009 <sup>2</sup>	Moyle, Edwards, Clinton 2002 <sup>58</sup>	Powers, Watson 2008 <sup>49</sup>	Sanders, Butcher, Swails, Power 2009 <sup>53</sup>	Van der Steen <i>et al.</i> 2009 <sup>48</sup>
<b>Setting</b>	22 Nursing homes, USA, 2003–2007	Long term dementia unit, Australia	3 Nursing homes, USA	Two × 100-bedded ‘hospice units’, USA	Nursing homes, USA 1999 and Netherlands 2005–2007
<b>Sample</b>	323 Nursing homes residents with advanced dementia and their health care proxies (families)	15 Family care-givers (9 wives, 5 daughters, 1 son-in-law)	30 Cases (nursing home residents, their family members and staff)	27 Caregivers (of 25 people with dementia living in long-term care facility and 2 receiving home care)	Caregivers of people with dementia who died 2–12 months previously. 54 Dutch/76 US care-givers
<b>Methods and concepts</b>	Chart review, documentation of clinical complications in person with dementia. Health care proxy data (age, sex, relationship to person with dementia, understanding of clinical complications expected with end stage dementia and whether informed of prognosis or clinical complications by physician. 18 months follow-up and quarterly assessment	2 Focus groups	Quantitative retrospective chart review and ethnographic field study	Semi-structured interviews (2–4 with each carer) and chart review	Retrospective postal questionnaire
<b>Data analysis</b>		Content analysis	Content analysis (of the qualitative data)	Line by line open coding producing meaning units	
<b>Validity Reliability Reflexivity</b>		Two researchers at each group	Not discussed	Independent coding by 2 researchers. Data presented to independent consultant and social workers at hospice. Prolonged	

<b>Ethics</b>	Institutional approval. Written informed consent from health care proxy	University Research Ethics Committee	Not mentioned	engagement. Field notes and journals. Debriefing. Search for researcher bias Not discussed. Written and verbal consent	University Medical Centre Approval
<b>Findings</b>	96% believed comfort to be the primary goal of care. At the last assessment before death 20% health care proxies believed the resident had less than 6 months to live. 18% said that they had received prognosis from physician. 81.4% said they understood the clinical complications to expect in end stage dementia. 32.5% said that they had been counselled about this by the physician	Major theme: living with loss. Sub-themes; relief <i>v.</i> burden of loss; loss from observation of cognitive decline; loss of companionship; loss of creating fear and frustration; loss of personhood; anticipation of death	Themes: gauging the decline and intervening appropriately; maintaining normality and upholding dignity	Four caregiver portraits: Disengaged (minimal involvement, self-focused, busy); Questioning (struggled to understand the disease and progression, in denial, guilt re: using hospice resources); All consumed (highly involved with care, expressed grief ++); Reconciled (still engaged, but ready for, and see death as a relief, realistic re: disease process)	Findings re Satisfaction with Care Tool: item re knowing the Dr/Nurse in charge of care rated the lowest in each country. Dutch have a shared decision-making model – item re lack of information and decision making frequently rated N/A. Satisfaction dependent on expectations and country specific standards. Reluctance to be critical of care – recognition of nurses’ hard work, guilt re ‘abandoning’ hands-on care, admiration of staff dealing with difficult behaviour

Table 1. (continued)

Authors	Mitchell <i>et al.</i> 2009 <sup>2</sup>	Moyle, Edwards, Clinton 2002 <sup>58</sup>	Powers, Watson 2008 <sup>49</sup>	Sanders, Butcher, Swails, Power 2009 <sup>53</sup>	Van der Steen <i>et al.</i> 2009 <sup>48</sup>
<b>Conclusions</b>	Patients with proxies who understood the prognosis and clinical course were less likely to receive aggressive treatment near end of life than those who did not	Craved support and distraction from grief. Focus of care by professionals was the person with dementia. Carers wanted to be involved with decision making, relationships and communication with staff. Death was anticipated as a blessing; a way of relieving stress, but was dreaded. Education re disease process necessary as a means of relieving carer's guilt. Involvement of carers in caring as a means of developing trust with professionals and in delivery of personalized care	Difficulty predicting the course of the disease and symptom management affected communications. Professional caregivers and family were afraid of addressing end of life issues prematurely, giving rise to family member's fears and doubts. However, what was not discussed was enacted ritually ('dying' people excluded from activities, upsetting relatives). Need for early, open communication. Family members tend to resist 'palliative care' suggesting loss and 'giving up'. A different approach is needed – combining palliative and curative care – 'comprehensive care'; promoting quality of life and comfort	Research participants tended to remain within their portrait groups – ? due to lack of support from professionals. Hospice work not focused on dementia, professionals need more education/ preparation, nursing home staff tend not to offer grief/bereavement support to families. Permission for carers to withdraw (finding comfort and the ability to go on by distancing from the reality of disease). Giving to others	More work needed on the 'Satisfaction with Care' scale. Recommend the use of item scores and adjustment for potential confounders



The concepts derived from the synthesis of the findings are presented under three main themes: unfamiliar territory, making decisions and the grieving carer.

### *Unfamiliar territory*

Under the theme of unfamiliar territory three categories of experience are described: lack of knowledge and experience; poor or lack of communication with professionals; and opting for active interventions in an effort to 'do the best' for the dying relative. Family carers felt that they lacked knowledge of the dying process and wanted to understand what was happening;<sup>50</sup> they needed professionals to explain the disease progression and treatment options.<sup>51–53</sup> Family carers tended not to regard dementia as a terminal illness,<sup>52</sup> and the process of dying was not recognized.<sup>49,52,54,55</sup> Forbes *et al.* used the analogy of 'travelling on a journey' and caring for the person with dementia being likened to a 'rocky road' (55; p. 256). The horizon on the journey tended to be limited, with family care-givers focusing on small, day-to-day changes in the person's condition, rather than seeing the 'bigger picture' and the general decline, indicating that their relative would die.

Family carers described worries about discussing end of life care prematurely, which affected their communication with professionals.<sup>49</sup> From the family carer perspective, there was often a lack of verbal communication between professionals and themselves about end of life issues. However, the family carers described the implicit ways in which they learnt that the condition of their relative with dementia was worsening. For example, people with dementia who were thought to be dying were excluded from the usual social activities, leaving relatives feeling anxious and confused about their lack of inclusion in daily activities.<sup>2,49,56</sup>

The studies revealed that poor, or non-existent, staff–family carer communication combined with a lack of knowledge or understanding about the end of life process in dementia, resulted in family carers constructing palliative care as being 'sub-optimal' and as 'giving up'. As a result, there was a tendency to opt for active interventions such as hospital admission, antibiotic therapy for pneumonia and tube feeding, which have little proven benefit.<sup>2,49,52</sup> When communication did occur, it tended to be during times of

crisis, resulting in rushed decision-making,<sup>2,56</sup> over- or under-treatment,<sup>55</sup> unnecessary hospital admissions and further distress for relatives.<sup>2,56</sup> Conversely, there is evidence that if family carers understand the prognosis, then their relatives with dementia are less likely to undergo interventions of dubious benefit and are more likely to receive care aimed at offering comfort.<sup>2</sup>

### *Making decisions*

The role of the family carer in decision-making for the person with dementia living in care homes is currently ill-defined and unclear.<sup>51,56</sup> Family carers in the studies reviewed generally wished to remain involved in the decision-making process.<sup>50,51,53,57,58</sup> Those who did not wish to be involved in decision-making still wanted their values to be reflected in decisions made by professionals on their behalf.<sup>51</sup> At times of uncertainty, family care-givers felt uncomfortable in their decision-making role<sup>51</sup> and expressed feelings of stress, guilt,<sup>54,55</sup> fear, doubt<sup>49</sup> and anxiety.<sup>53</sup> They felt uncomfortable making decisions that might be seen to hasten death.<sup>54</sup>

Family care-givers used a range of values to underpin the decision-making process, including quality of life,<sup>51,55</sup> honouring previously expressed wishes,<sup>51,52</sup> the personal history of the person with dementia,<sup>51</sup> the preservation of dignity and the provision of comfort.<sup>2,49,55</sup> Religious faith was also used as a guiding force for some,<sup>52,57</sup> being used to make and confirm a wide range of decisions including the withholding, continuance or withdrawal of treatment.<sup>57</sup> The religious faith of the person with dementia was also used as a guide when planning individualized care.<sup>52</sup>

Where active communication between people with dementia, their families and professionals is ongoing, and models of shared decision-making are employed, decision-making appears to be less problematic for family members. Family carers frequently rated an item on information and decision-making as not applicable in a study from the Netherlands where a model of shared decision-making is in place.<sup>48</sup> Family carers' responses indicated that they were well informed regarding the condition of their relative and that decisions were shared between family carers and professionals. This shared decision-making model is characterized by family involvement from the

moment of admission of the person to the nursing home and open ongoing dialogue between family members and professionals.<sup>59</sup>

### *The grieving carer*

Family carers often find themselves in the unenviable situation of both grieving for their relative and being required to make decisions on their behalf regarding care and treatment towards the end of life. The dual role of grieving carer and decision maker has been described as being problematic when entering the palliative phase, due to unresolved grief.<sup>51</sup>

Family carers had strong personal needs during this period: they wanted frequent contact with staff,<sup>50</sup> they sought empathy, reassurance,<sup>55</sup> understanding, guidance<sup>52</sup> and communication.<sup>58</sup> They attempted to meet their own needs by trying to personalize relationships with professionals.<sup>51</sup> As mentioned above, family carers described themselves as travelling in unfamiliar territory 'filled with unrecognisable landmarks' (<sup>55</sup>; p. 256); they expressed a desire for a companion on the journey, someone who had experience of travelling over similar terrain, who was able to support the traveller on the road.

Carers felt validated when values and beliefs were shared by professionals<sup>51,58</sup> and fear, anger and guilt when they were not.<sup>50</sup> They wanted 'peace of mind'; knowing that 'I did everything I could' (<sup>55</sup>; p. 255), and did not want to be regarded as 'giving up' on their relative (<sup>49</sup>; p. 324); they also had a desire to 'do what's best' (<sup>52</sup>; p. 619). Family carers feared that they would judge themselves as guilty or responsible if death occurred following withdrawal of a treatment, rather than seeing the death as timely and appropriate.<sup>54</sup> The death of the person with dementia was seen both as a blessing and a tragedy.<sup>52,55,58</sup> Religion was used as a source of meaning and hope;<sup>57</sup> some found their faith to be a source of comfort, whilst others found that it provoked anxiety.<sup>57</sup>

There is evidence that family care-givers were often disappointed by the lack of contact with professionals caring for their relative.<sup>53,58</sup> This is despite data suggesting great need and efforts on the part of carers to meet those needs. In survey data, family care-givers rated the lowest an item regarding knowing the doctor or nurse in charge of the care of their relative<sup>48</sup> and as few as 18% of

relatives said that they had been given the prognosis by a physician,<sup>2</sup> suggesting lack of communication with professionals.

The encouragement of 'hands on caring' by family members is suggested as a means of developing relationships and trust with professionals.<sup>58</sup> A hands-on caring strategy was used by some family care-givers, and in addition to assisting in the development of relationships with professionals, it was reported to reduce their feelings of loss and levels of stress.<sup>53</sup>

In their conclusions, authors suggest that the palliative care/curative care dichotomy is an unhelpful approach in this setting. A model of 'comprehensive care' with an emphasis on ensuring a good quality of life with comfort care is proposed.<sup>49,51</sup> Quality of life for the person with dementia can only be achieved by early and open discussion between professionals, the person with dementia and their family members. However, hospice staff lacked skills and knowledge in dementia care.<sup>53,56</sup> Whilst care home staff tend to have experience and skills in dementia care, they lack counselling and communication skills.<sup>49,53</sup> Through improved communication, wishes can be ascertained, individualized care delivered and decision-making lightened for family members towards the end of the life of their relative.<sup>49,51,52</sup>

Forbes<sup>55</sup> and Gessert<sup>54</sup> propose the continued use of the advance care planning model with the appointed proxy as a way of normalizing discussions and developing communication with family members.

This literature review highlighted a group of family members who were only described by one group of authors. Sanders *et al.*<sup>53</sup> describe four care-giver portraits: questioning, all-consumed, reconciled and disengaged. Whilst three of the portraits are described in the findings of other researchers, the disengaged care-givers are not. The disengaged care-givers were 'emotionally disconnected' (<sup>53</sup>; p. 537) from their family member with dementia, and were engaged with their own lives, families and work. Characteristic themes within the portrait of the disengaged care-giver were: conflict between person with dementia and the family care-giver, focus on self and career, minimal involvement in care and being prepared for the death of their relative. They were a group who were exclusively adult children of the person with dementia of either gender, with a mean age of 50 years.

## Discussion

This literature review has highlighted the fact that there is limited research in the area, but it is clear that there are high levels of unmet need,<sup>53,56,58</sup> a finding that is supported by Scott and Pace.<sup>32</sup> The issues raised by this review of the literature are multifaceted and therefore need to be addressed at various levels, through research, policy, education and practice.

From a research perspective there is limited research in the area, a lack of longitudinal studies and a lack of studies involving interventions or clinical trials. The 'disengaged carer' is identified and described in only one study,<sup>53</sup> raising the question: 'Is this a unique finding or have other studies failed to recognize this group, due to the methods of recruitment or to the research approach?'

For individual family members the review of the literature shows that families wanted communication, information and support in their decision-making. It is encouraging that there are many examples of good practice that are currently being evaluated.<sup>32,60</sup> There are also models of practice where memory clinics are involved in giving the diagnosis to the person with dementia and their families. In this setting, open communication is developed and care is tailored to individual needs.<sup>10</sup> It is at this early stage in the disease process that proxy decision makers may be appointed<sup>2</sup> and the values and wishes of the person with dementia can be elicited and shared. This may be done as part of post-diagnostic work, in clinics or in the home, by members of the community palliative care team or general practitioner.<sup>10,61</sup> Admiral Nurses may also take on this role. They are specialist dementia care nurses in the UK, who have a registered mental health nursing qualification and who practice in the community. The casework of the Admiral Nurse focuses primarily on the needs of the family and its wider network in the support, care and empowerment of the person with dementia. Whilst Advanced Care Planning is recommended by some authors,<sup>55</sup> others have found that doctor's decisions were influenced more by the patient's condition, assumptions about the quality of life of the individual as indicated by information gleaned from a wide range of sources and involving the family, and less on advanced care planning directives.<sup>59</sup>

From an educational perspective, the review has highlighted that family members perceived

professionals as lacking preparation and education for their role in guiding and supporting family caregivers in their decision making.<sup>51,55,56</sup> Professional carers were also perceived to lack communication and counselling skills.<sup>49,53</sup> Inconsistency of care provider and lack of care planning resulted in rushed, poor decision making at times of crisis.<sup>2,10,56</sup> In keeping with these findings, hospital staff in acute settings have reported themselves to be ill-equipped to cope and respond to the needs of people with dementia, tending to rely on family members to provide nursing care.<sup>10</sup> In the UK, national minimum standards have been set for the inclusion of dementia-specific training of staff in both health and social care settings.<sup>62</sup>

At a policy level, it is important that the general public are encouraged to think and speak about their values and wishes regarding end of life care, during the course of 'normal conversations'. This will have the dual effect of informing others regarding their wishes and views, but will also normalize such discussions and remove the associated stigma. Recently published policy documents have encouraged public awareness of dementia and end of life issues.<sup>30,31</sup> In the UK the National Council on Bioethics have issued a Consultation paper to stimulate discussion, collect views and develop policies.<sup>63</sup> The National Council for Palliative Care have also been working to develop collaborations between the disciplines of palliative care and dementia care.<sup>64</sup> Also on a more individual level, several public figures have openly discussed their own diagnosis of dementia and their future care wishes,<sup>65</sup> or their role in caring for a family member with dementia.<sup>66</sup> Whilst there is a long way to go, this has helped open the public policy debate and has started to bring the 'unfamiliar territory' into the public domain.

## Conclusion

This literature review has identified little literature, but indicates high levels of unmet need. Family members find themselves in an unfamiliar situation about which they lack knowledge and experience. They find end of life decision making in the face of uncertainty stressful. They also have personal needs, as they are simultaneously grieving and caring. There is evidence that family care-givers seek communication, guidance and companionship from professionals, but are

frequently disappointed. There is a need for more research, especially longitudinal studies, in order that the needs and experiences of this group of care-givers might be better understood.

### Acknowledgements

JH was funded to write this literature review by a scholarship from the Cancer Experiences Collaborative, a palliative and supportive care research funded collaborative funded by the UK National Cancer Research Institute (NCRI).

### Conflicts of interest

The authors declared no conflicts of interest.

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