



Article

# End of life care: The experiences of advance care planning amongst family caregivers of people with advanced dementia – A qualitative study

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## Abstract

**Background:** End of life decisions for people with advanced dementia are reported as often being difficult for families as they attempt to make appropriate and justified decisions.

**Aim:** To explore the experiences of advance care planning amongst family caregivers of people with advanced dementia.

**Design:** Qualitative research including a series of single cases (close family relatives).

**Methods:** A purposive sample of 12 family caregivers within a specialist dementia unit was interviewed about their experiences of advance care planning between August 2009 and February 2010.

**Results/Findings:** Family caregivers need encouragement to ask the right questions during advance care planning to discuss the appropriateness of nursing and medical interventions at the end of life.

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**Conclusions:** Advance care planning can be facilitated with the family caregiver in the context of everyday practice within the nursing home environment for older people with dementia.

### Keywords

dementia, family caregivers, nursing home, advance care planning, end of life care

## Introduction

There has been increasing international attention of governments and policy makers to the experience of dementia over the last decade. This is in part due to the anticipated rise in the numbers of people who will be diagnosed with the condition (International Association of Gerontology and Geriatrics (IAGG), 2011). Alzheimer's Disease International (2012) estimated that 36 million people were living with dementia worldwide in 2010 and this is expected to increase to 66 million by 2030. The World Health Organisation (2012) describes this as a global public health priority and argues that there is an urgent need to improve the awareness and understanding of dementia across all sections of the global community. Despite recent national and international government and nongovernmental policy initiatives, the World Health Organisation (2012) acknowledges that globally, people with dementia have been repeatedly failed by governments and communities and the key role of family caregivers is often neither supported nor properly acknowledged.

Dementia is a multifactorial disorder, characterised by deficits in memory, language and personality change resulting in difficulties with self care management, self neglect and psychiatric syndromes (Harris, 2006; IAGG, 2011). Dementia has been shown to have an unpredictable disease trajectory (Department of Health (DH), 2009; Mitchell, Kiely, & Hamel, 2004; Mitchell, Kiely, Hamel, Park, et al., 2004), it often starts gradually and a typical trajectory can last over several years (Phillips, Ajrouch, & Hillcoat-Nalletamby, 2010). Survival rates for people with dementia are dependent on the age at which the disease is first diagnosed and can range from 2 years to 10 years (Rait, Walters, Bottomley, Peterson, & Illiffe, 2010; van der Steen et al., 2013). Most people with dementia also have at least one other co-morbidity (National Audit Office, 2007) and often present with complex physical and psychological needs particularly in the advanced stage of the disease (Sampson et al., 2008).

One of the major themes within the international literature is the agreement that dementia is a terminal condition, but there is a distinct lack of a coordinated palliative care philosophy (Gott, Ibrahim, & Binstock, 2011; Houttekier et al., 2010; Mitchell et al., 2009; Mitchell, Teno, Intrator, Feng, & Mor, 2007; Ryan, Gardiner, Bellamy, et al., 2011; van der Steen et al., 2013) and the difficulties associated with the diagnosis of the terminal stage (Lloyd-Williams & Payne, 2002; Mitchell, Kiely, et al., 2007; Mitchell, Kiely, et al., 2004). However, there is an emerging consensus that palliative care is applicable to all stages of dementia, which is especially relevant as the disease progresses to the advanced stage (van der Steen et al., 2013).

Within the United Kingdom the Department of Health (DH) End of Life Care (EoLC) Strategy attempted to apply the hospice model of care to general care within primary and

community care services including care homes (DH, 2008). It emphasised the need to provide high quality care for all those approaching the end of their lives whatever their condition and whatever the setting in which they may reside (DH, 2008). The programme promoted three possible models to deliver palliative care in a variety of 'non hospice' care settings (DH, 2008): The Gold Standards Framework (GSF) (DH, 2008), End of Life Care tools and the Preferred Priorities of Care (DH, 2008) which includes Advance Care Planning (ACP). The Leadership Alliance for the Care of Dying People (2014) has produced a report and recommendations following a review into how end of life care was being interpreted and delivered by health care professionals. Variations in care for dying people were found by the review which could and sometimes did result in poor standards of care. The report emphasises the priorities of care that are required when it is thought a person is dying.

The World Health Organisation (WHO, 2011) described ACP as a discussion about preferences of future care between an individual and a care provider in anticipation of future deterioration. The benefits of ACP are viewed as providing an opportunity to anticipate future decisions relating to health and care needs, allowing the person to feel in control, make choices and provide an opportunity to initiate timely palliative care in life limiting conditions (DH, 2010; Hertogh, 2006). Ideally ACP should be undertaken with the person who has dementia early in the disease to ensure their wishes are represented and responded to appropriately. However, discussions such as these can be distressing to some people, especially if the health and or social care professionals do not have the appropriate training or interpersonal skills (DH, 2010). The Leadership Alliance for the Care of Dying People (2014) suggests that education and training programmes should extend beyond the immediate end of the training course and should include how to apply learning to practice and evaluation methods.

In the UK, ACP is a relatively new concept and has limited impact to date on end of life care in life limiting disease (Preston, Cohen Fineberg, Callagher, & Mitchell, 2011). The consequence of inadequate preparation for the deterioration of people with advanced dementia has the potential for adding to the suffering of the dying (Di Giulio et al., 2008). However, recent UK local and national initiatives for end of life care which relate to the GSF, and include ACP (DH, 2008, 2010) have been suggested to have the potential to improve end of life care (Shaw, Clifford, Thomas, & Meehan, 2010) for all life limiting conditions. Van der Steen et al. (2013: 10) suggests that 'palliative care in dementia across dementia stages needs further study, especially given the increasing possibility of early diagnosis.'

There is some suggestion from the international literature that ACP can reduce some of the burden of decisions regarding end of life interventions and care (Engel, Kiely, & Mitchell, 2006; Lacy, 2006; Yeun-Sim Jeong, Higgins, & McMillan, 2011). Concerns over the legal standing of such plans and the complexity and range of different forms can contribute to the lack of implementation in care settings (Dobalian, 2006; Rurup, Onwuteaka-Philipsen, Pasman, Ribbe, & van der Wal, 2006).

For people with dementia, ACP provides an opportunity to anticipate future decisions relating to health and care needs as eventually the person loses capacity and will be unable to make their choices known. Studies also suggest that families struggle to represent the wishes of their relative and where previous discussions have taken place this can be beneficial (Black et al., 2009; Elliott, Gessert, & Peden-McAlpine, 2009).

## Background

End of life care decisions for people with advanced dementia are reported as often being difficult for families as they appear to attempt to make appropriate and justified decisions within the context of the person's life story (person centred) (Baldwin, 2004; Black et al., 2009; Goodwin & Waters, 2009; Moorman & Carr, 2008). Family caregivers anticipatory grief and isolation have been acknowledged as it becomes difficult to maintain and sustain relationships (Lawton, 2000) with the person with dementia due to deteriorating communication and memory loss (Lindstrom et al., 2011). These existential issues include experiences and feelings, which are not often addressed and managed by nursing and care staff (Papastavrou, Kalokerinov, Papacostas, Tsangari, & Sourtzi, 2007) and may impact upon appropriate end of life decision making.

In the North West of England, the National Health Service commissioned a study in 2007–2008 which involved an evaluation of the implementation of the GSF (DH, 2008), which included ACP, for people with dementia in five pilot care settings across Greater Manchester (McClelland, Ashton, Roe, Mazhindu, & Gandy, 2008).

Limitations of the evaluation were on the design as it was restricted to the perspectives and experiences of health professionals about ACP and those of family caregivers or the older people with dementia were not explored. These findings and gaps in knowledge were the basis that led to and has informed a follow on study (and PhD), which has addressed the question of investigating ACP from the perspectives of family caregivers and is the focus of this paper. This study advances our understanding of the experience of undertaking ACP with family caregivers, who often attempt to represent the person with dementia at the end of life and contributes to the evidence base.

## Method

### *Aim*

To explore the experiences of ACP amongst family caregivers of people with advanced dementia.

### *Design*

This study is identified as a descriptive qualitative study based on the principles of naturalistic inquiry (Polit & Beck, 2010). 'Qualitative research is an experience of discovery and understanding' (Thomas & Magilvy, 2011: 154), it involves 'a set of interpretive activities that seeks to understand the situated meaning behind actions and behaviours' (Sinkovics & Alfoldi, 2012: 818). Naturalistic inquiry emphasises the human experience in the context of the participants' own social world. It therefore usually takes place in the field and so the findings from in-depth qualitative research are frequently caught up in the real life experience of people with first hand experiences of the phenomena (Polit & Beck, 2010). Semi structured interviews with family caregivers provided an opportunity to share their experience and views of ACP. Interviews provide insight from the family caregivers' perspective and provide opportunities to share their experiences to enhance the understanding of ACP and its potential for use in nursing homes for people with advanced dementia.

## *Sample*

The chosen care setting was a specialist dementia unit within an independent nursing home provider in a large urban town within the North West of England. This specialist dementia unit had been involved in a previous evaluation to study the impact of implementing the GSF within five nursing home settings (Ashton, McClelland, Roe, et al., 2009). The study reported that they had fully implemented the end of life care pathways as recommended by the GSF (DH, 2008) which included ACP. Participants were selected through purposeful sampling. Family caregivers were identified by the care home manager as being, the next of kin, were proxy decision makers, had facilitated the place of their relative within long term care, had and continued to manage their financial arrangements, and had been involved in ACP relating to end of life care.

An open invitation was made to all the family caregivers of people with advanced dementia within the specialist dementia unit; whoever responded was accepted unconditionally to participate in the research.

Care planning notes for each resident confirmed the completion of an ACP with the identified next of kin, which usually involved the family caregiver responsible for decision making and with the appropriate power of attorney.

Each identified family caregiver was written to and advised of the purpose of the study and informed how their experience would be valuable to the research in understanding the needs of people with advanced dementia who are at the end of life. Interviews were only initiated once the family member had responded as a result of one of the suggested communication methods and informed consent obtained. Participants were then given the opportunity to discuss the study, their potential participation and choose the location of the interview.

Research suggests that recruiting participants for interview on sensitive life events, including those recently bereaved, can be challenging and therefore samples are often small (Dyregrov, 2004; McPherson & Addington-Hall, 2004; Parkes, 1995). Only family caregivers who wished to be involved were interviewed. Participants were able to choose the location of their interview to minimise any disruption to their usual routine and they were also informed that they could withdraw at any time and were under no compulsion to take part.

## *Data collection*

Twelve semi structured interviews were conducted between August 2009 and February 2010 by one of the research team. The data collection method chosen for this study was semi structured, in-depth interviewing and was undertaken during one episode of fieldwork, within one care setting using a digital recording device. Interviews were conducted individually and were focused on the experience of the ACP with care setting staff. The interview schedule asked the family caregiver to describe their experience of ACP that they had had with the care staff. Prompts included: Did the care staff discuss 'life sustaining treatment' and the role of the doctor; To what extent did the care staff try to find out what the view of your relative would have been; Do you feel that an ACP is necessary?; Is it possible to review the document?; What suggestions do you have to improve the process? Although all family caregivers were asked the same questions, any new topics introduced by the interviewee were explored as they arose.

### *Ethical consideration*

ACP, in relation to end of life care, is a sensitive issue and this exposed the family caregivers to potentially distressing memories and emotions. Care was taken in this research to support the interviewees, particularly the family caregivers to avoid any undue distress when reporting their experiences on behalf of the person with dementia. Interviews were conducted once informed consent had been given. Approval to conduct the study was obtained from the university research ethics committee and guidance was also sought from the then Central Office for Research Ethics Committee (now known as the National Research Ethics Service).

### *Data analysis*

Data were analysed by content analysis. Content analysis was chosen for this study in an attempt to increase understanding of the experiences of family caregivers of undertaking ACP. Content analysis assumes there are no preconceived ideas or assumptions but that the data is 'heard' and examined for explicit and covert meanings (Bernard & Ryan, 2010). Content analysis can be inductive, describing what is found in the data, making valid inferences which should be made objectively and systematically (Joffe & Yardley, 2004).

Segments of each interview transcript were analysed by the researcher for their consistency of emerging categories and sub-categories and also for the coherence of the sub-categories to identify any contradictions or the reporting of a different version of events by any of the study participants, and identified as a deviant case (Silverman, 2010). A sample was then analysed independently by a member of the research team and an agreement was made on the accuracy of categories and sub-categories. The purpose was to demonstrate that core concepts were consistent in each interview transcript within the care setting. Any inconsistencies were identified and examined, not to eliminate them, but to understand why they occurred. Quotes from the participants were selected to provide detail and evidence from the interview transcripts.

### *Rigour*

Strategies used to establish credibility included peer debriefing and examination of the data and audit trail of the chain of evidence (Yin, 2003). Coding consistency across the interviews by researchers with expertise in the field enhanced the credibility of the results. Discussion and agreement between the research team confirmed the categories and sub-categories identified (Cresswell, 2009; Lincoln & Guba, 2000; Sinkovics & Alfoldi, 2012). This challenging academic exercise allowed for alternative explanations to be discussed and explained and to find strong supporting evidence to increase confidence in the findings (Patton, 2002).

### *Findings*

Eighteen family caregivers were contacted who had been identified in the care plan as participating in an advance care plan meeting. Twelve family caregivers responded to the request to participate in the research and be interviewed. Four family members did not respond. Two family caregivers responded but preferred not to be involved at this time,



stating they were not ready to discuss the subject matter due to the recent death of their relative.

The age range of the 12 family caregiver participants was between 35 years and 82 years. Their relationship to the resident was confirmed as: spouse ( $n = 4$ ), child ( $n = 4$ ), niece ( $n = 2$ ), granddaughter ( $n = 1$ ) and sibling ( $n = 1$ ). Eleven participants confirmed that an ACP had been discussed and completed. One participant was identified as a 'deviant case' and provided a differing interpretation from the respondent and added variability from the sample population. The reason why this case contrasts from the others is that during the interview her viewpoints and responses differed with the majority of the study participants. Rather than set aside her view as different, it was important for the purpose of relevance and validity, that this study participant's understanding and experience was reported (Silverman, 2006, 2010).

ACP was reported by the majority of family caregivers to be a planned discussion between these caregivers and the senior nurse on the unit. There did not appear to be any fixed time frame in which the discussion took place nor did there appear to be any 'set' model of how this took place. The study demonstrated that ACP is complex with many influencing factors which may contribute to the completion of the document. Direct quotes are used to provide the best exemplars from the categories and sub-categories. This includes: the experience of ACP; the relevance of ACP for people with advanced dementia; and the content of the ACP interviews.

### *The experience of ACP*

Study participants were invited to describe their experiences and understanding of ACP. The ACP document used in the care setting was from the GSF ACP document 'Thinking Ahead' (GSF, 2012), and also included an 'additional information sheet' from nursing home documentation which indicated any personal information about the resident and review dates and any follow up ACP interviews with family caregivers.

Study participants reported ACP to be a planned, yet occasionally informal discussion with the senior nurse, particularly in the initial conversations. It appeared that for some study participants there was some uncertainty about what ACP was. The most recurrent account suggested that it was an uncomfortable experience.

"I wasn't sure what she meant at first and thought it was some sort of agreement to stop any treatment. But Xxxxx explained it to me that it was to find out what XXX would have preferred at the end of his life. I must say I was a bit upset at first to be talking about this. I did not want XXX to think I wanted him to die but he didn't know anyway. It did feel a bit uncomfortable."  
(Wife 3)

"It was to try and decide what would be the best course of action if she became very ill and was going to die. There is no point in pretending that is what they did not mean, although I can see why some people would find this very difficult. I just found that I wanted to get on with it. We talked about hospital; well you know what I think about that."  
(Niece 1)

### *The relevance of ACP for people with advanced dementia*

There was general agreement from all study participants that ACP was appropriate for people with advanced dementia. Despite their obvious distress during their recollections of the ACP discussion the study participants welcomed the opportunity to be involved in

end of life care decisions as they felt it was their responsibility as the person was very vulnerable and in need of protection.

“I think the advance plan or care plan is good for people with dementia otherwise everybody just guesses what the person wants as they often cannot speak. My XXX could not talk or communicate towards the end he just smiled sometimes and looked lost.” (Wife 3)

“I would say, it removed a lot of the uncertainty, that perhaps hadn’t the advance planning been done, all of a sudden you’ll be faced with a decision, it would be at a time perhaps when you’re not emotionally prepared for it, and it would be a bit too much at that stage. At least if you’ve planned it, I thought it helped, in my case, I discussed what was going to happen, how best end of life can be dealt with in terms of making her life as easy as possible really.” (Son 2)

Several participants expressed a view that ACP discussions were an opportunity rather than something negative. Participants suggested that it allowed them to confront important and inevitable decisions that had to be made as the resident deteriorated. The following quotations represent this view.

“One thing the advance plan has done is that it has given me the opportunity to really think about my aunt and what she was like. How she would think of how things have turned out and if she wants to be kept alive for as long as possible. I don’t think she would want this but I suppose I can only do the best I can and hope I am doing the right things and making the best decisions, but really no one prepares you for this burden.” (Niece 1)

“I wonder about doing the right thing as I did not have a lot of contact with her up until she became ill so I try and think about what she would have wanted when she was younger or what I would have liked. I also think about how our parents died. I suppose you just have to do the best you can.” (Brother 1)

### *Content of the ACP interviews*

Study participants expressed the benefits of being able to have open and honest discussions with the care staff; in particular, the senior nurse with whom the ACP discussions had taken place. Similar responses referred to the care at the end of life and what would or should happen if the person deteriorated and was now considered to be dying. Participants also expressed that when treatment is futile the resident should not be distressed by active interventions. Active interventions were cited as tube feeding, emergency procedures and hospitalisation. There was some suggestion that advanced dementia was viewed as a terminal condition and worthy of end of life discussions during the ACP process, but this was not always identified specifically by study participants, during the interview.

“We talked about drips and tubes and pain relief. XXXXX was as blunt as she could be without making it sound as though she was trying to influence our decisions. We talked about if withholding treatment would make her suffer.” (Niece 1)

“I think there was a reasonable discussion about the physical side effects, when it got to the stage where she (Mum) refused food or fluids, what would happen and such from a physical point of view. And then what can be done from a medical point of view without obviously horrendous intervention. How pain relief can be used, other drugs were mentioned, calming and all this sort of stuff. It was a bit heavy towards the end and more discussion about that side of things.” (Son 2)

Study participants referred to the loss of the person with advanced dementia. It was important to remember them as a person and not just someone with dementia. This was



expressed as what was meaningful to the resident even though they were unable to communicate. Participants accepted that death was to be soon and expressed a desire for it to come sooner rather than later, but also expressed a need to make sure the personal history and personality of the person is kept alive to the end. Although none of the participants initiated a spontaneous discussion about the meaning of religion in end of life care, some included the personal preferences in respect to this and religious practices.

“We have been saying goodbye to grandma for over 10 years because my grandma’s gone! You get little glimpses of her but she’s not there anymore. You know? She doesn’t play her music anymore she doesn’t play her Black Sabbath at full volume and dance round the kitchen like she use to . . . and that’s at 80 . . . She can’t get on the back of the boys bikes anymore . . . “She’s not there”. Which is sad?” (Granddaughter 1)

The maintenance of the image of the whole person, to keep alive their personal history, was expressed as being very important by study participants and was an important feature of ACP discussions. The relationship that family caregivers and the resident had developed with the care staff in the nursing home was also very important.

### *Deviant case*

Documentary evidence within the nursing notes suggested an ACP had been commenced with this study respondent. However during the interview she did not appear to embrace or accept the purpose of an ACP and the relevance of this to her husband’s advanced stage of dementia. Her husband had been a resident in the nursing home for several months, but the ACP discussion had only been commenced three weeks prior to the interview for this study.

“Oh that (ACP), she tried to say it was some scheme they were involved in and that I needed to talk about what XXXX would want if he became very ill. He is going to get very ill if he stays like this. I don’t know what she was talking about. I think XXXX is getting depressed in there. I don’t want to talk about it, that would be like giving up and I haven’t given up.” (Wife 4)

Despite her husband’s deteriorating condition due to dementia, she was in denial about his diagnosis and his impending deterioration. She was therefore not ready to discuss ACP during the interview. Despite several attempts to discuss the ACP the study participant was not receptive and therefore there was no ethical and justifiable reason to continue with this level of questioning.

## **Discussion**

There has been increasing attention to the experience of dementia over the last decade. This is in part due to the anticipated rise in the numbers of people who will be diagnosed with the condition. There is also growing recognition that people with dementia are entitled to palliative care. The European Association of Palliative Care (EAPC) published a White Paper on Dementia, which recognises that palliative care for people with dementia is distinct from those of other groups (van der Steen et al., 2013). Intervention strategies require resources and it has already been established that people with dementia have historically been a marginalised and disadvantaged group (WHO, 2012). Brinkman-Stoppelenburg, Rietjens, and van der Heide (2014) conducted a systematic review of the literature and suggested that although there is evidence that ACP positively impacts upon

the quality of end of life care, more studies are needed to explore how complex interventions can be more effective in meeting the different needs of different people in a variety of settings.

In the later stage of the disease most people are not able to communicate their preferences which may leave them at an increased risk of symptom burden and prolonged suffering (Di Giulio et al., 2008). There is currently insufficient evidence to identify a 'best' approach to ACP for people with dementia. ACP with family caregivers is difficult but can provide an insight into what people with advanced dementia, who may be incapable of making informed decisions, have about what choices they may wish to make at the end of their life (Baldwin, 2004; Black et al., 2009; Goodwin & Waters, 2009; Moorman & Carr, 2008). This could include balancing competing demands including their relatives 'historical identity' and decisions which are consistent with the preferences and lifestyle of their family member. This was typical of the family caregivers in this study as they attempted to balance their knowledge of their family member and what would be in their best interests. However, discussing this informally and then formally writing it down in a care plan is a responsibility that most family caregivers found relevant but burdensome. Some studies have found that family caregivers are reluctant to engage in ACP and are unprepared for this responsibility (Ayalon, Bachner, Dwolatzky, et al., 2012). A limited understanding about the disease trajectory could also make it difficult to anticipate the role of an ACP for family caregivers (Caron, Griffiths, & Arcand, 2005; Dickinson et al., 2013). Family caregivers with limited knowledge of their family members previously expressed preferences could struggle to make appropriate decisions and would perhaps justify decisions based on what is the best thing to do in the circumstances which may or may not reflect the wishes of the person with dementia. Health professional's cannot assume that the family caregiver has a depth of understanding of their relatives life story and therefore additional informal discussions may be required.

This study demonstrates that ACP can be facilitated with the family caregiver in the context of everyday practice. This study advances knowledge to assist nurses in care homes and other countries to develop and apply ACP for the benefit of residents and their families and to inform the development of services, care and further research. However, ACP is a complex activity with many influencing factors which includes the family caregiver's readiness to participate in end of life care discussions. Samsi and Manthorpe (2011) suggest that ACP is driven by individual disposition and so there is a need to identify the rationale, the benefits and support available to family caregivers to complete an ACP. In this study, the family caregivers had been supporting the person with dementia for several years and would naturally feel protective towards the wellbeing. Recognising and maintaining the importance of promoting a person centred care approach to decision making, which maintains the integrity of people with dementia, and also acknowledging the importance of the relationship of trust and honesty between family caregivers and health professionals is an essential consideration. Family caregivers also need encouragement to ask the right questions during ACP to discuss the appropriateness of nursing and medical interventions at the end of life.

The WHO (2012) suggest a supported decision making model should be introduced soon after the diagnosis of dementia. The model supports the involvement of the person with dementia as much as possible at every stage of the disease, so when capacity is eventually impaired those supporting the person, including family caregivers, have a good understanding of their care preferences and wishes as they approach the end of their life and are in a better position to determine what the person would have wanted. The Royal College of Physicians (2009) support the view that ACP discussions should be offered early

in the disease. However the timing of such discussions is a contentious issue. It is generally accepted that ACP discussions would be beneficial before capacity is lost, so that the person still has an opportunity to plan for their future care needs and preferences but also to identify personal goals they may still want to achieve (Robinson et al., 2012). ACP discussions at the point of diagnosis might be considered too early and stressful. Although Poppe, Burleigh, and Banerjee (2014) found that ACP discussions soon after diagnosis were enabling for the person with dementia to make their wishes known once they had had an opportunity to reflect about their diagnosis.

In this study dying with dignity was an important feature of the ACP discussions for family caregivers and included the discussion of complex nursing and medical interventions to relieve suffering or prevent undue distress in the dying resident, some of which were not familiar to the family caregiver. The participants in this study welcomed the opportunity to be involved in end of life care decisions and suggested that ACP allowed them to confront important and inevitable decisions that had to be made as the resident deteriorated. The involvement in ACP allowed the family caregivers to have some control over the caring process and remove the disempowerment of their caring role following admission to the nursing home (Molyneaux, Butchard, Simpson, & Murray, 2011).

Positive engagement and creating a person-centred approach by the nursing home promoted insights into the appreciation of how to work with family caregivers (Kellet, Moyle, McAllister, King, & Gallagher, 2010; Lindstrom et al., 2011; Moorman & Carr, 2008). In this study, there appeared to be an assumption by care staff in the way ACP was approached and that family caregivers wanted to be involved in these decisions and would welcome a role in determining a person's best interest at the end of life. However in other studies nursing staff have avoided or been reluctant to discuss ACP (Sampson et al., 2008; Yeun-Sim Jeong et al., 2011).

The deviant case identified the important issue of 'readiness'. Separation distress has been highlighted by Kiely, Prigerson, and Mitchell (2008) as a common death grief symptom for family caregivers of people with dementia before the actual death and sensitivity and support is needed to reduce distress. The deviant case highlights the severe emotional strain that some family caregivers have and continue to experience even when the person has been admitted to a long term care environment (Dempsey, 2013). Poor knowledge and understanding about the disease trajectory can impact upon the family caregivers relationship with health professionals and so bridging this gap in knowledge must be a priority before ACP discussions are attempted, otherwise it may be difficult for the family caregiver to accept why these discussions are needed.

Attitudes to ACP require further investigation, as failure to implement this early in the disease trajectory of dementia can have an impact on how the person is cared for at the end of life (Addicot, 2010). ACP as interpreted by family caregivers needs a more wide reaching research to explore the issues identified in this study to examine if ACP can, and does, impact upon end of life care decisions, actual care delivery provided and the choices people make about their preferred place of dying.

ACP has a role in the care of people with dementia. Discussing decisions in advance has the advantage of alerting the family caregiver to the potential difficulties experienced during the advanced stage of the disease. The EAPC suggests that care of the family is very important especially in their role of proxy decision maker in the more advanced stage of the disease (van der Steen et al., 2013). To do this the ACP facilitator needs to assess the current level of knowledge of the disease trajectory that the family caregiver has. A lack of

understanding of the disease trajectory and a lack of a palliative care approach are cited in the literature as being one of the main barriers to effective end of life care for people with dementia (Di Giulio et al., 2008; van der Steen, Gijsberts, Knol, Deliens, & Muller, 2009; WHO, 2012).

Deciding when and if to withdraw active treatment and interventions and opt for comfort care has ethical implications. The difficulties associated with when and if the person with dementia has entered the dying phase is problematic for clinicians. In the advanced stage of dementia, ethical issues often include decisions relating to artificial hydration and nutrition (AHN), discontinuation of medication and pain management. Kumar and Kuriakose (2013) suggest that in relation to AHN, procedures should be judged on the amount of discomfort associated with it and consider what the person would have wanted. Parsons, Hughes, Passmore, and Lapane (2010) suggest there is limited evidence to guide clinicians on the discontinuation of medication for patients with dementia who are at the end of life. Ethical care is about not subjecting individuals to unnecessary and sometimes painful and distressing investigations and treatment because of uncertainty about the diagnosis of dying. The Leadership Alliance for Care of Dying People (2014: 24) identify the importance of 'an individual plan of care which includes food and drink, symptom control and psychological, social and spiritual support is agreed, co-ordinated and delivered with compassion.' People with dementia should have access to specialist palliative care services and family caregivers should be fully involved in all discussions on care interventions. ACP needs to be flexible enough to provide guidance but not diminish the clinical judgements of suitably qualified and trained professionals in dementia care. It should also be acknowledged that there is more to ACP than planning medical interventions and that comfort care needs to be explored and emphasised within discussions (Detering, Hancock, Reade, & Silvester, 2010).

### **Limitations of the study**

There are limitations in conducting research within the context of one specialist dementia unit and with a small sample population. According to Evans and Goodman (2009) the intrinsic heterogeneity of nursing homes makes identifying representative care homes problematic.

The extent to which 12 respondents can be sufficient to represent other family caregivers in the UK who may experience similar circumstances is a limitation although the findings may be transferable to similar care settings. The sample population where all white British and therefore did not represent the diversity of the current UK population. Cultural and religious diversity was not represented in the sample. Further studies would need to address this ethnic bias and include a more representative sample.

### **Conclusions/Recommendations for practice**

In dementia, ACP can provide an opportunity to anticipate future decisions relating to health and care needs as eventually the person loses capacity and will be unable to make their choices known. The findings from this study suggested that ACP provided a platform for family caregivers to confront their understanding of the end of life care that may be required for their relative before any crisis event. This advances knowledge related to practice and has the potential for nurses in care homes and in other countries to develop

and apply ACP to the benefit of residents and their families. ACP should always reflect the person's personal choices and preferences or if they lack capacity should indicate their best interests. All people must be given an opportunity to consider their best options for future care provision, regardless of the disease. Health professionals need to ensure, where possible, the individual preferences of people with dementia are known and recorded before capacity is lost.

The anxieties of family caregivers when acting as proxy decision making suggest there is a need to prepare adequately for ACP discussions. To do this the ACP facilitator needs to assess the current level of knowledge of the disease trajectory that the family caregiver has.

This will enhance the empowerment of individuals or family caregivers towards shared decision making and develop trusting relationships. ACP must be sensitive to the cultural and religious differences that reflect the demographics of a country and it should be a flexible document as people's priorities and preferences change over time.

Health and social care professionals need to acknowledge and develop their own skills in relation to communication and knowledge of specific disease trajectories. Family caregiver's role in ACP should be acknowledged and supported and be given due consideration to their own needs influenced by grief and anxiety. Continuous education and training in ACP should be available to all health and social care professionals and be included in undergraduate medical and nursing programmes.

The study demonstrates that ACP can be facilitated with the family caregiver in the context of everyday practice within the nursing home environment for older people with dementia. Family caregivers need encouragement to ask the right questions during ACP to discuss the appropriateness of nursing and medical interventions at the end of life.

The EAPC, together with other recent UK campaigns may offer future directions of policy, practice and research into palliative care in dementia across Europe as a result of widespread consultation and the identification of best practice initiatives, which should include ACP.

## Declaration of conflicting interest

None declared.

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