**Identifying Palliative Care Needs in People with Dementia**

**Professor Mari Lloyd-Williams M.D., F.R.C.P., F.R.C.G.P.,M.Med.Sci., J.P., FLSW.,**

**Professor and Honorary Consultant in Palliative Medicine**

**Academic Palliative and Supportive Care Studies Group (APSCSG)**

**IPHS**

**University of Liverpool**

**Waterhouse Building**

**Block B 1st Floor**

**1-5 Brownlow Street**

**Liverpool**

**L69 3GL**

**Email mlw@liv.ac.uk**

**Caroline Mogan**

**NWDTC ESRC PhD Student**

**Academic Palliative and Supportive Care Studies Group (APSCSG)**

**IPHS**

**University of Liverpool**

**Waterhouse Building**

**Block B 1st Floor**

**1-5 Brownlow Street**

**Liverpool**

**L69 3GL**

**Karen Harrison Dening RMN, RNLD, RGN, MA, PhD,**

**Head of Research Dementia UK /**

**Honorary Research Fellow**

**Academic Palliative and Supportive Care Studies Group (APSCSG)**

**IPHS**

**University of Liverpool**

**Waterhouse Building**

**Block B 1st Floor**

**1-5 Brownlow Street**

**Liverpool**

**L69 3GL**

**Abstract**

**Purpose of the Review**

Dementia is now recognized as a progressive life limiting illness where many patients can benefit from access to palliative care

**Recent Findings**

This review has focused on three areas namely, advanced care planning in supporting palliative care for dementia;hospice provision for people with dementia and provision of care within family home. In advanced care planning, there is little research on systematically developed and implemented advance care planning interventions or whether they achieve desired outcomes for end-of-life care. There is limited research on hospice based care for dementia patients and most studies are USA based. Equally studies exploring how family carers can be supported and facilitated to care at home for the person with dementia to the end of life are exploratory rather than determining what factors may be importan.

**Summary**

There are relatively few studies, especially quantitative studies or intervention studies being carried out to determine most effective means of providing palliative care for people with dementia, particularly with respect to advanced care planning, the provision of hospice based care and support at home. Despite increased public awareness of dementia as a terminal illness, more research is required to support patients with dementia and their families at the end of life.

**Key words ; Palliative Care, Dementia, Advanced Care Planning, Hospice, Community**

**Introduction**

People living and dying with a non-cancer diagnosis, including people with dementia, have poorer access to palliative care and hospice services and experience worse outcomes in terms of pain and other symptom control. Clinicians often express concern that it is difficult to know when a patient with dementia requires or would benefit from palliative care and interest in defining and delivering appropriate and compassionate palliative and end of life care for people with dementia is increasing (1-5). Policy documents have all called for improvement in care for people with dementia towards the end of life by promoting the use of ‘advance care planning’ (6-8). Advance care planning is becoming a ubiquitous term used to describe many different elements of decision making in dementia and research on advance care planning has peaked and troughed over the last two decades with varying attention given to elements such as, the numbers of people with dementia who have advance care plans; who is the best placed professional to facilitate and exploring the various barriers to their implementation (9). Access to hospice care varies from country to country, often dependent upon the payment structures to receiving health and social care. In countries, such as the USA, dominated by medical insurance processes and payments, there may be higher access for this group of patients to hospice. For this review we have focused on research relating to advanced care planning, access to hospice support for people with dementia and research enabling people with dementia to die at home. As the number of papers are small, we have included papers from 2015 onwards.

**Advance Care Planning in Dementia**

Several studies aimed to understand the perspectives of health and social care professionals in relation to advanced care planning . In a qualitative study Hirakawa et al (10) analysed data from three focus groups (n=13 participants in total) of Korean health and social care professionals’ views on barriers to achieving high-quality community based dementia. Whilst not a study designed specifically to explore the barriers to advance care planning in dementia, one of the nine themes found from the data was that a significant barrier to achieving high-quality care was in the absence of attention to patient wishes and preferences and that systematically implementing advance care planning might be a way to articulate and so honour the decisions made by people with dementia.

Lopez et al (11) used semi-structured interviews with a purposive sample of healthcare providers (n=20) from nine nursing homes in the USA. Of particular focus was the hospital transfer of the nursing home residents and the context for this occurring; care staff ability and confidence to care; comfort with holding end-of-life conversations and the surrogate decision-makers preferences. Whilst they acknowledge that advance care planning as a baseline for establishing a person’s wishes and preferences is a first step in the process of decision-making effective attention is required to support decision making at the time of each acute event to ensure goals of care are met.

When a person with dementia has lost the ability to make treatment decisions, clinicians often rely on family carers to know and articulate these preferences with assumed accuracy. Harrison Dening et al (12) used a modified Life Support Preferences Questionnaire (LSPQ) in cross-sectional interviews of 60 dyads (a person with early dementia and preserved capacity and their family carer) to explore whether family carers’ choices show agreement with the end of life care preferences of the person with dementia for whom they care and what factors influence this. In interviews people with dementia were able to indicate their treatment preferences across LSPQ scenarios. Overall, family carers had a low to moderate agreement with the person with dementia on preferences for end of life treatment. Relationship quality, carer distress and burden had no influence on agreement.

In a second study using semi-structured interviews with a purposive sample of their original cohort (n=6 dyads) Harrison Dening et al (13) explored the ‘lived’ context to health care decision-making of the dyads in respect of past, present and future healthcare decision-making. Although dyads described a history of making decisions together this had not usually involved healthcare decisions and they described how decision-making changed after the diagnosis of dementia. Family carers recognised their increasing responsibility for decision-making after the diagnosis of dementia but that the ‘day to day’ decisions were burdensome so much so that it distracted their attention from the more important, long term planning. However, both people with dementia and family carers show uncertainty about their preferences for end of life treatment choices.

A study by Shanley and colleagues (14) sought to understand the views of a purposive sample of 34 surrogate decision-makers of people with dementia on what would better facilitate care. They employed a qualitative methodology of semi-structured face-to-face and telephone interviews. Using a thematic approach to analyse transcripts they identified four main themes; need for a greater public awareness of dementia and its impact, early intervention, ongoing health and social care support and a person centred approach. With these themes, supported by their literature review, the authors proposed a set of principles to support surrogate decision-makers involving a ‘key worker’ to support advance care planning with the person with dementia and their carer to drive up personalised dementia care but also to increase public understanding of dementia and its effect upon decision making.

Researchers have developed tools and frameworks to better support advance care planning in dementia; one such tool is we DECide for care home residents Ampe et al, (15,16) followed up this original work undertaking a pre-test-post-test study of 18 Belgian nursing homes and found that whilst the we DECide tool had had a positive influence on policy it still failed to impact on daily practice.

Much of the advance care planning in dementia literature is still focusing on the barriers to their implementation and concluding that families affected by dementia may benefit from early and ongoing practical and emotional support to prepare for potential changes brought about by a diagnosis of dementia. Many papers also suggest interventions and transition points in the dementia trajectory that may aid decision making in the context of the realities of care towards the end of life. However, there is still a lack of research that has systematically developed and implemented an advance care planning intervention; determined which professional is best placed to facilitate these discussions and, indeed, whether they achieve their desired and stated outcomes for end-of-life care.

Amador et al (17) repeated a national survey of services (n=16) developed to deliver end-of-life care for people with dementia that was undertaken by the National Council for Palliative Care in 2008. Fifteen services responded to the repeat survey by Amador at al (2016) of which demonstrated a range of activities; 80% provided direct care and 87% provided workforce development and advice to generalist practitioners. Results indicated that such services as being patchy but their success in sustainability was often due to being driven by the charity or hospice sector, had strong clinical leadership and wider system support through funding mechanisms and a minimum level of integration with normal service provision.

**Hospice Care**

Referral to hospice of people with advanced dementia following an admission to an acute hospital from care home is increasing Ankuda et al, (18). An American study that examined retrospective referral activity of a range of physician specialties using the minimum dataset of the healthcare ‘billing process’. They found and increase from 2.8% in 2000 to 11.2% in 2010. However, the referrals were higher in those physicians that were hospital based, possibly indicative of seeking alternative places of care to free hospital beds rather than based upon need?

In a qualitative study Wladkowski (19) explored the experiences of family caregivers (n=24) of those discharged from hospice care; usually termed as a ‘live discharge’, given that most people admitted to hospice may die in place of care. These individuals were reported to have a slower decline in health than expected and often include people with dementia. The study reported that family caregivers and the person with dementia experienced greater distress and a need to receive support in readjustment to the protracted and often unpredictable trajectory when dying with dementia. However, this was again an American study and negative outcomes of a ‘live discharge’ was also reported to have implications for Medicare insurance payments. . Oud (20) examined retrospective admission data of nearly 900, 000 hospital admissions of people with dementia and report that over 40,000 of these were discharged to hospice; this showed an increase from 1.5% (n=908) in 2001 to 6.3% (n= 7,398) in 2010. However, results indicate that a significant number of these referrals to hospice (45.2%) involved a prior admission to an intensive care unit, likely that goals of care often only took place following a period in critical care. They suggest that discussions about future care and the cost benefits of certain interventions need to be undertaken much earlier to avoid unnecessary and/or overly aggressive or futile interventions and to facilitate a more timely and consistent use of hospice. However, to avoid any added distress caused by the effects of a ‘live discharge’ from hospice (19), of key importance is to hold frequent and honest discussions with families about the nature, trajectory and prognosis of dementia.

**Community Care and Barriers and Facilitators to Dying at home with Dementia**

Place of death has been identified as an important component of high-quality end of life care and it is reported that given the right support, most people would choose to die in their own homes (21). A review of qualitative literature on place of death for people with dementia, concluded that a preference to die at home was motivated by a lack of access to palliative care services, as well as caregivers’ reluctance to send their relative to a care home for normative and emotional reasons, and by a wish to avoid acute care settings (22).

In recent years, there has been increased commitment to provide care in community settings and policies have been developed to support people to die in their place of choice (21). However, research indicates that people with dementia who want to die at home are still more likely to die elsewhere (23).

Care in the community is often provided by family or friends who fulfil a vital caregiver role which enables the patient to remain at home (24). However, as a person moves into the end-stages of dementia they typically need a more extensive level of support.

Palliative care delivered in community-based settings to individuals with a variety of progressive, life-limiting diseases concurrently with disease-focused care is becoming more common. This is partly due to an increased understanding of the needs and preferences of these individuals and their families and because of pressures to reduce hospital stays and increase community support on the grounds of reducing hospital acquired infection, health care costs and inappropriate lengthy hospital admission.

A study from the USA by Cassel, et al., (25) found that a home and clinic based palliative care program which engaged participants from four disease groups (cancer, chronic obstructive pulmonary disease, heart failure, and dementia) several months before death, resulted in a significantly lower hospital usage and lower healthcare expenditures when compared with controls. They also found that the percentage of people dying in hospital was lower in the intervention group than in controls. Similar results were also reported in an Australian study by Rosenwax, et al., (26) who found that out of a dementia cohort comprising of 5261 decedents, those who received community based palliative care were significantly less likely to attend hospital emergency departments in the last year of life when compared with those who did not. Furthermore, only 6 percent of the dementia cohort utilised palliative care services, compared to 26 percent of a non-dementia comparative cohort.

While there are a growing number of studies that report on community based palliative care for dementia, it must be acknowledged that there is a wide configuration of services and so the mechanisms which support end of life care at home for people with dementia, along with ways in which these services can identify eligible patients, needs to be explored further.

A systematic review (27) that examined the challenges and facilitators of delivering end of life care at home for people with dementia found that while this population may not always require specialist care at the end of life, they will often have a range of needs in relation to practical, medical and emotional support and so are likely to be simultaneously engaged with using health services, as well as a range of other community based care services and informal supports. They concluded that services which help to sustain and support people with dementia to die in their own homes do not operate in isolation and further research is required to establish how clinicians, statutory services, voluntary agencies, and volunteers can combine their skills to allow a greater number of people with dementia to die at home and to determine what services are required.

Indeed, when considering the growing number of people with dementia, coupled with the economic limitations within health and social care sectors, services will have to reassess how palliative care can be extended and delivered to those who wish to die in their own homes. A recent, interesting example of this has been proposed (28) who describe the role of a trained lay person delivering palliative care to people with heart disease, cancer, and dementia. The intervention is an in-home approach that is structured on the domains and recommended practices of palliative care. It is delivered primarily by trained lay persons (care guides) who are supported by a clinical team. It is directed at people who are living at home and may be in the last three years of life. Currently around 1200 individuals, including participants, family members, and comparison patients and families, are enrolled in the programme and are being surveyed quarterly. However, results on the effectiveness of this model are not yet available.

**Conclusions**

Palliative care for dementia and identifying palliative care needs is a complex issue. This review suggests that there are many research studies which are being carried out with the direct aims of improving both the provision and access to palliative care for patients with dementia. However in each of the three key areas of advanced care planning, access and support from palliative care by Hospice services and supporting families and communities to allow more people with dementia to die within their own home, there is still much to be done. We need to develop and trial effective interventions , but also to ensure that such interventions can impact and be fully embedded in future health and social care policy and it is only then that palliative care for people with dementia can be said to have truly improved.

**Key Points**

* Researching Advance Care Plans in dementia is still preoccupied with the barriers to the process rather than its implementation.
* Hospice facilitated care for people with dementia is limited
* There is very little research on trialing interventions to improve end of life care for people with dementia
* There continues to be a paucity of research on how best to support people with dementia who wish to die in their own homes
* Healthcare providers need to reassess how palliative care can be extended and delivered to those who wish to die in their own homes

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This qualitative study aimed to understand the perspectives of health and social care professionals. Data was analysed from three focus groups of health and social care professionals’ views on barriers to achieving high-quality community based dementia. One of the nine themes found from the data was that a significant barrier to achieving high-quality care was in the absence of attention to patient wishes and preferences and that systematically implementing advance care planning might be a way to articulate and so honour the decisions made by people with dementia.

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A qualitative, descriptive study using semi-structured interviews with a purposive sample of healthcare providers (n=20) from nine nursing homes in the USA. Researchers acknowledged that advance care planning was a first step in the process of decision-making and that effective attention is required to support decision making at the time of each acute event to ensure goals of care are met.

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Authors used a modified Life Support Preferences Questionnaire (LSPQ) in cross-sectional interviews of 60 dyads to explore whether family carers’ choices show agreement with the end of life care preferences of the person with dementia for whom they care and what factors influence this. Overall, family carers showed low to moderate agreement with the person with dementia on preferences for end of life treatment. Relationship quality, carer distress and burden had no influence on agreement.

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Using semi-structured interviews with a purposive sample of an original cohort (n=6 dyads) researchers explored the ‘lived’ context to health care decision-making of the dyads in respect of past, present and future healthcare decision-making. Although dyads described a history of making decisions together this had not usually involved healthcare decisions and they described how decision-making changed after the diagnosis of dementia. Both people with dementia and family carers showed marked uncertainty about their preferences for end of life treatment choices.

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A qualitative methodology of semi-structured face-to-face and telephone interviews of a purposive sample of 34 surrogate decision-makers of people with dementia on what would better facilitate care. Four main themes were identified; need for a greater public awareness of dementia and its impact, early intervention, ongoing health and social care support and a person centred approach. From this the authors proposed a set of principles to support surrogate decision-makers involving a ‘key worker’ to support advance care planning with the person with dementia and their carer.

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Researchers repeated a national survey of services (n=16) developed to deliver end-of-life care for people with dementia that was undertaken by the National Council for Palliative Care in 2008. Fifteen services responded to the repeat survey who demonstrated a range of activities; 80% provided direct care and 87% provided workforce development and advice to generalist practitioners. Results indicated that such services as being patchy but their success in sustainability was often due to being driven by the charity or hospice sector, had strong clinical leadership and wider system support through funding mechanisms and a minimum level of integration with normal service provision.

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An American study that examined retrospective referral activity of a range of physician specialties using the minimum dataset of the healthcare ‘billing processes. They found and increase from 2.8% in 2000 to 11.2% in 2010. Referrals were higher in those physicians that were hospital based.

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This qualitative study explored the experiences of family caregivers (n=24) of those discharged from hospice care; usually termed as a ‘live discharge’, given that most people admitted to hospice may die in place of care. These individuals were reported to have a slower decline in health than expected and often include people with dementia. The study reported that family caregivers and the person with dementia experienced greater distress and a need to receive support in readjustment to the protracted and often unpredictable trajectory when dying with dementia.

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Data of nearly 900, 000 retrospective hospital admissions of people with dementia were examined: over 40,000 of these were discharged to hospice. This showed an increase from 1.5% (n=908) in 2001 to 6.3% (n= 7,398) in 2010. However, results indicate that a significant number of these referrals to hospice (45.2%) involved a prior admission to an intensive care unit, likely that goals of care often only took place following a period in critical care.

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This systematic review of qualitative literature on the preferences about, and the factors influencing, place of care and death in people with advanced dementia identified fourteen studies for inclusion. They found that access to hospice care was problematic and these services were often unable to accommodate for people with dementia. Hospitals were also unable to provide necessary end of life care as there was a lack of staff training and resources. They also found that transitions between care settings at the end of life can be unsettling and even life threatening for people with dementia. They concluded that Advanced Care Planning is crucial in achieving preferred place of death and that there is now more reliance on communities and informal caregivers to look after people with dementia.

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This study was a secondary analysis of the National Quality Improvement Programme for Palliative Care which was undertaken to explore factors relate to ‘dying in the preferred place’. 797 bereaved relatives filled in the CQ-index Palliative Care, a validated and reliable questionnaire. They found that two-thirds of the patients died in their preferred place. A preference for dying at home and having had a stroke decreased the likelihood of dying in the preferred place, while having a partner, dementia, contact with the GP in the last week before death, and continuity of care between professionals increased the likelihood of dying in the preferred place. However, people who wanted to die at home and also had dementia were more likely to die elsewhere than people without dementia who wanted to die at home.

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This study aimed to evaluate the nonclinical outcomes of a community based palliative care program. The 368 individuals who received the intervention and were matched with 1,075 comparison individuals within each of four disease groups: cancer, chronic obstructive pulmonary disease, heart failure, and dementia. Intervention participants in all four disease groups had less hospital use and lower hospital costs than non-intervention participants, which resulted in lower overall healthcare costs. In the final 6 months of life, healthcare costs for the intervention groups stayed largely the same from month to month, whereas costs for comparison participants increased dramatically.

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This systematic review synthesized qualitative and quantitative studies to explore the challenges and facilitators of providing end of life care at home for people with dementia. 7 studies met all eligibility criteria (4 quantitative, 3 qualitative). Six key themes were identified - four facilitators and two challenges. Facilitators included “support from health care professionals”, “informal caregiver resilience”, “medications and symptom management” and “appropriate equipment and home adaptations”. Challenges included “worsening of physical or mental health” and “issues with formal services”

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