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Decision making at end of life for people with dementia by their informal carers: a rapid scoping review

Sue Barker, Mary Lynch and Jane Hopkinson

Abstract

Background: There are an increasing number of people living with dementia and an expectation that care decisions are made collaboratively with those with the disease entering the end stage and their families. This has increased the burden on family carers. **Aim:** To explore the evidence on the decisional support needs of informal carers of people with end-stage dementia. **Design:** A rapid scoping review was undertaken of peer-reviewed publications between 2000 and 2016, which included all healthcare settings and the person's own home. Six databases were searched (CINAHL, MEDLINE, EMBASE, BNI, PSYCHINFO, Web of Science) and all papers meeting the inclusion criteria were read. A thematic analysis was undertaken of the selected papers using a pragmatic approach based on how the papers addressed the research question. **Results:** Sixty papers were individually appraised, with 40 being included in the review. Of these papers, 11 were literature reviews and 29 were primary studies. The themes identified were: influential factors in carer decision making, the scope of carer decision making, conflicts/problems in carer decision making, resources carers need to make decisions, and impact of carer decision making. **Conclusion:** To date, the emphasis in dementia care has been one of living well with dementia, but realistically there is a need to plan for a 'good death' for the person and their carers. There is a need to support people with dementia and their carers to make an Advance Care Plan while the person with dementia can take part in the decision-making process. This proactive intervention is likely to reduce carer decision burden at end of life and facilitate achievement of death in the person's preferred place, which is usually home/care home.

Key words: ● Carers ● Dementia ● Decision making ● Palliative care ● Health economics

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In a recent editorial in this journal, Hassan (2017) called on readers to think about the conditions faced by homeless individuals as they approach the end of life, and to reflect on how palliative care services might provide support. The title of her editorial, 'The homeless deserve a good death too', reminded readers that access to quality end-of-life care is inequitable, particularly for those living at the margins of society. She squarely placed the concept of a good death within a moral frame of analysis, implying that opportunity to experience a good death is a universal right. Hassan's message echoes contemporary discourses about the palliative approach to care.

Such an approach adapts existing palliative care knowledge for use outside of specialist palliative care services (Sawatzky et al. 2016). The idea is that everyone who is facing problems associated with ageing or chronic and life-limiting illness should benefit from the foundational principles of palliative philosophy.

These principles include organising care so that it: responds to personal needs, preferences, and values; focuses on excellent symptom management and advanced care planning; and gives holistic attention to the psychosocial and spiritual determinants of health. Together, these features of care are meant to optimise overall quality of life, increase patients' autonomy and control in care, and improve health outcomes.

The Canadian Hospice Palliative Care Association (2015) is one national organisation that articulates a framework calling for 'equitable access' (2015: 22) to a palliative approach wherever people are living, ageing and dying. By explicitly including shelters as well as correctional facilities as contexts where a palliative approach is needed (2015: 9), this national association deliberately expands—like Hassan's editorial—the vision that palliative care should reach the most marginalised and vulnerable individuals in our society.

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There are over 46 million people living with dementia globally, more than the total population of Spain, according to the World Alzheimer's report 2015 (Alzheimer Disease International (ADI) 2015), a number which they expect to rise to 131.5 million by 2050. This has a huge economic cost worldwide and it is suggested that if dementia care were a country it would be the world's 18th largest economy, and more than the market values of companies such as Apple, Google or Exxon (ADI 2015).

It is estimated that 94% of people living with dementia in low and middle income countries are cared for at home (ADI 2015). Two thirds of the cost of dementia is paid by people with dementia and their families. Alongside this financial burden the carers of people with dementia feel overworked and under-supported (Alzheimer's Society 2014).

When people with dementia reach the end stage of the disease, demands on carers increase and they are at particular risk of experiencing carer burden (Thompson and Roger 2014). There has been some debate in the past related to the need for palliative care for people with end-stage dementia but it is now generally accepted that a palliative approach is required (van der Steen et al. 2014).

Background

End-of-life care for those with dementia has been found to be fragmented and many people die in pain (Jones et al. 2016). The National Institute for Health and Care Excellence (NICE) in the UK have developed guidelines for both dementia (2016) and end-of-life care (2011), which guide healthcare practitioners in the delivery of person-centred, compassionate and patient-centred care.

NICE guidelines (2016) appear to assume that healthcare practitioners have the primary role in providing care for people with dementia and at the end of life. However, the European Association for Palliative Care (EAPC) identifies symptom control, comfort, communication, shared decision making, continuity of care, along with psychological and spiritual support, as necessary (van der Steen et al. 2014). Both NICE and EAPC acknowledge that informal carers have an important role and therefore need support and should be part of the care planning, but their role lacks definition.

Within this ill-defined role, the carer, usually the spouse or another family member, needs not only deal with a deteriorating terminal condition and their own grief, but also the legal and ethical dimensions of caring for a person losing the

capacity to make their own decisions. Legal provision has been enacted in the UK to protect the rights of the person who loses the capacity to make their own decisions in the guise of the Mental Capacity Act 2005 in England and Wales and as part of the reform of the Mental Health Act 2007, the Scottish Adults with Incapacity Act 2000, which is currently under review, and the Mental Capacity Act (Northern Ireland) 2016.

While there are differences in these acts, they all aim to protect the right of the individual to make choices (personal decision making). This can also be seen in US and Canadian law (Buchanan 2004) but the availability of this type of legislation is not worldwide.

This entire legislature seeks to ensure the person's values, beliefs, needs and desires are instrumental in decision making for and about them. They all have a starting point of assuming the person is able to make their own decision, however unwise the decision may seem to others, unless they are assessed to lack capacity. In the UK they also include provision for the person to identify who they would like to make decisions for them when they lose capacity. This is usually a close family member. The laws expect the proxy decision maker to make choices in the person's 'best interest'. The family member may be given the power to make decisions on behalf of the person in all areas of their life including social issues (housing etc.), health and financial decisions.

While Anglo-American law has sought to protect the interests of the person with dementia and national governments and charities to assess the disease-related burden, there is little empirical evidence to date of the economic impact of end-of-life care in advanced dementia. It is, though, assumed to be included in the broad figures highlighted by the Alzheimer Disease International in their report (ADI, 2015).

Economic evaluation of palliative care interventions in advanced cancer patients with complex care needs found that early intervention by palliative teams decreased healthcare spending by nearly a quarter (May et al. 2016). However, the research excluded advanced cancer patients with complex care needs and dementia. It has been noted that investigation of end-of-life care in dementia is limited, has been of poor methodological quality and provides scant economic data (Martin et al. 2016). Further exploration of the available economic evidence on end-of-life care provided for dementia patients is required to ensure resources are used to their best advantage. Also, economic considerations need to include changes in

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population characteristics, differing disease trajectories and statistics globally.

Shared decision making by carers and professionals has been identified by the EACP (van der Steen et al. 2014) as necessary to ensure an optimal care experience; this was also raised as an area that needed exploration in the NIHR EVIDEM study (Illife et al. 2015). Hasselaar and Payne (2016) evidenced barriers and opportunities in the provision of shared decision making (also referred to in the literature as collaborative care or integrated care). Examples include professionals lacking knowledge of how to support carer decision making. There is a need for further exploration of how to support carers to make decisions on behalf of people with dementia approaching the end of life and also to understand the economic impact of these decisions.

Review question/purpose

Our aim is to explore the evidence on the decisional support needs of informal carers of people with end-stage dementia.

Method

A rapid scoping review was undertaken, as described by Arksey and O’Malley (2005). A scoping review is rapid and is used where the research question may be less well defined and

the quality of the studies is less rigorously evaluated than in a systematic review. It provides an overview to facilitate the clarification of research questions and the current breadth of knowledge on a given subject to identify gaps.

The inclusion criteria for this review required the evidence to be peer-reviewed publications between 2000 and 2016, which included all healthcare settings and the person’s own home. Five databases were searched (CINAHL, MEDLINE, EMBASE, BNI, Web of Science) with subject librarian guidance (see Table 1). Methods were informed by guidance for the conduct of a scoping review provided by Arksey and O’Malley (2005). The PRISMA flowchart guided the selection of papers included (Moher et al. 2009) using the categories: identification, screening, eligibility, included.

The titles and abstracts were read of all the papers from the identification stage to undertake the screening for duplication and adherence with the inclusion criteria (Table 2). Barker and Lynch searched the databases with librarian support. After Barker and Lynch had screened the identified papers, along with Hopkinson, they selected those eligible for this review.

The 60 included papers were read and information extracted and charted using the appraisal template in Table 3.

Table 1. Scoping review: searches

Database	Search terms	Number of papers	Papers meeting inclusion criteria (after duplicates removed)
BNI	Dementia AND (Carer or Family) AND (palliative care or end of life) AND (decision making or choice)	22	9
CINAHL complete	(Dementia (Tag/ MeSH)) AND (Caregivers or care givers or carers) AND (Decision making (tag/ MeSH)) AND (Terminal care (tag/MeSH))	51	17
MEDLINE	Exp Dementia + exp caregivers or care giver. mp.+ exp decision making or choice behaviour + end of life or terminal care or palliative care	31	13
EMBASE	Exp Dementia + exp caregivers or care giver. mp.+ exp decision making or choice behaviour + end of life or terminal care or palliative care	105	7
PSCHYINFO	(Exp Dementia) AND (exp caregivers or care giver. mp.) AND (exp decision making or choice behaviour) AND (end of life or terminal care or palliative care)	24	9
Web of Science	Exp Dementia + Cost analysis or Economics.+ Direct costs or Indirect costs+ Care costs + Associated costs + Economics, behavioural (MeSH)+ Costs and Cost Analysis (MeSH)+ Cost comparison+ Cost Minimization Analysis +Cost Measure+ Cost-benefit analysis (MeSH) + Economic evaluation* Cost utility analysis or Choice behavior (MeSH)+ Family decision making (tag)+ Family decision making (tag) + Advance care planning (tag)+ Preferences+“Contingent behavior”+ Consumer behaviour (MeSH) and end of life or terminal care or palliative care	29	7

Table 2. Scoping review: inclusion and exclusion criteria

Inclusion	Exclusion
People diagnosed with a form of dementia	Mild cognitive impairment
People self-identified as caring for people with dementia	Palliative care primarily for another disorder
Carer's decision making	Professional decision making
Primary studies and literature reviews	Opinion, dissertations, conference presentations or discussion papers
Peer reviewed	Not peer reviewed
Published between 2000 and 2016	Published before 2000
All geographical areas but written in English	Language other than English

Table 3: scoping review: information charted

Author/Title of Paper:
Quantitative, qualitative or mixed methods
Aim, hypothesis and/or research questions
Data collection method
Sample
Country and clinical setting
Approaches to data analysis, interpretation & outcome measures
Results/Findings
Main learning from the research

Table 4. Template used to discern whether papers met inclusion criteria

No	Author/date	Title	Carer decision making	Method	Economics	Met criteria

On retrieval of the full text, 20 of the publications were found not, on more detailed appraisal, to meet the inclusion criteria, this decision was made by the team using the template in *Table 4*. No quality assessment was conducted, as is usual of a scoping review where the purpose is to reveal the breath of information on a topic and to identify research gaps (Arksey and O'Malley (2005).

As this was a scoping review the team examined the included papers by asking what knowledge they provided for the understanding of the research question. This led to five primary areas: influential factors in carer decision making, the scope of carer decision making, conflicts/problems in carer decision making, resources carers need to make decisions, and impact of carer decision making.

The reference lists for the extracted publications were also searched to check for any additional

papers. Two were identified, but, on further scrutiny, these did not meet the inclusion criteria. The team of authors met regularly to develop the method used and establish its application. They also discussed the papers reviewed by each other. Decisions were made consensually.

Findings

Through the structured framework five themes were identified in the exploration of decision making in carers for people with end-stage dementia. These were: influential factors in carer decision making, the scope of carer decision making, conflicts/problems in carer decision making, resources carers need to make decisions, and impact of carer decision making.

The inclusion criteria allowed for publications to be included from anywhere in the world but written in English, which may have affected the

geographical spread. Most of the papers originated from the UK, USA and Canada. Most of the UK papers were a form of literature review, whereas most papers from the USA and Canada were primary research. The majority of the health economics publications originated in the USA.

There is a wide spread of papers across the 16-year period but in the UK this peaked in 2010, unlike the USA and Canada where there has been increasing interest over the last few years. Despite the apparent reduction in UK research in this area, globally there appears to be a developing concern leading to increased publications (see *Table 5*).

Thematic analysis

Influential factors in carer decision making

Carers recognised the need to make decisions for their ‘loved one’ due to their perception that the person with end-stage dementia could not make decisions for themselves. This was more frequently the case than with people receiving palliative care for other terminal conditions such as cancer (Chambaere et al. 2015).

Level of education, rural or urban settings and nationality all influence individuals’ responses to decision making about place of care and interventions at the end of life (Caron et al. 2005a; 2005b; Chen et al. 2006; Gessert et al. 2006). Gessert et al. (2006) identified that people who lived in rural areas were more likely to be hospitalised than those in urban residences, but their stays were usually shorter and did not involve intensive care at the end of life. Along with Chen et al. (2006) and Teno et al. (2011), they also found that people from ethnic minority groups were more likely to receive aggressive medical intervention.

Caron et al. (2005b) offer five areas which are considered to be involved in decision making: dimensions of the person, dimensions of the caregiver, context of interaction with the medical team, family context, and the treatment itself. These dimensions or contexts are perceived through the carer’s cultural lens and decision making in general is influenced by their understanding of the disease (Sarabia-Cobo et al. 2016), religious beliefs, professional training, what is understood of palliative care and the perspectives of other patients (Goodman et al. 2010).

Table 5. Publications that met inclusion criteria for scoping review

Country	Number of papers	Number of papers including economics	Dates —decision-making papers	Dates—health economic decision making	Methodologies
United Kingdom	16	1	2000 (x1) 2003 (x1) 2010 (x6) 2012 (x2) 2013 (x1) 2014 (x1) 2015 (x2) 2016 (x1)	2015	Qual (x3), narrative synthesis, systematic review (x3), nominal group study, lit rev (x6), survey (x2), RCT
United States of America	10	4	2001 2009 2011 2012 2014 (x2)	2014, 2004, 2011, 2013	Pilot, quant (x3), mixed, lit rev, contents analysis
Canada	5	1	2005 (x2) 2014, 2015	2016	Qual
Netherlands	1	1	2005		survey
Belgium	2	2	2015, 2014		Quant, survey
Ireland	1	1	2010		Clinical notes study
Norway	1	1	2015		mixed
Australia	1	1	2016		Qual
Japan	1	1	2008		survey
Spain	1	1	2016		qual
Germany	1	1	2012		quant

Many carers wished for active treatment for people with dementia when in life-threatening situations, but their decisions did not strongly link to disease parameters, as identified by health professionals, which affect the quality of life of the individual (Potkins et al. 2000). The carers had limited understanding of the medical interventions, stating a desire for active treatment despite being likely to refuse intravenous antibiotics and accept oral antibiotics.

When families were faced with decision making about treatments, they based these on: pointlessness in prolonging life, little prospect of improvement, poor quality of life (Caron et al. 2005b; Chambaere et al. 2015), prevention of further suffering (Chambaere et al. 2015) and age of the dying person (Jox et al. 2012). These decisions were made intuitively (Jox et al. 2012) with a concern for what the person would have wished (Connolly et al. 2012).

Relatives' opinions of the patient's preferences were mainly based on assumptions; they had seldom talked about this explicitly (Black et al. 2009; Teno et al. 2011; Gjerberg et al. 2015). When conversation did occur the carers had higher satisfaction with care and were more likely to have decided on medical options listed in residents' advance directives (Do Not Resuscitate, Intubate, Hospitalize) over time (Reinhardt et al. 2014).

In a study by Bonner et al. (2014) they found that when advance care treatment (ACT) plans were developed, families had higher satisfaction with care and made decisions based on conversations with the person before they lost capacity. ACT planning led them to give considered reasons for their choices such as effectiveness and impact of the intervention and the person with dementia's preferences (Bonner et al. 2014).

In general, physicians, nurses and relatives agree on many aspects of end-of-life decision making for nursing home residents with dementia (Rurup et al. 2006). However, on some issues the outcomes of the decision making may differ. Relatives attach more importance to advance directives than physicians, and have more permissive attitudes towards hastening death (Rurup et al. 2006). If the carer trusts the physician it will positively influence their treatment decisions: they will be more inclined to agree with medical decisions (Bonner et al. 2014). This relationship between the carer and the professionals involved has a major influence on decision making (Helton et al. 2006; Kaldjian et al. 2010). Joint values and beliefs were important for developing this level of trust (Caron et al. 2005a).

Important decision-making principles have been identified as largely a reflection of expert opinion. These principles may have the potential to be developed into simple heuristics that could be used in practice (Mathew et al. 2016). Decision-specific manualised aids have also been developed. Results for those supporting decisions related to respite and percutaneous endoscopic gastrostomy (PEG) feeding have shown some promise in pilot studies (Lord et al. 2015).

In summary, informal carers' decision making is usually guided by professional healthcare staff, especially when a relationship has been developed between them, creating trust. They are more influenced by advance directives than professionals, but they rarely have conversations with the person with dementia while they still have capacity to ascertain what their preferences are. When informal caregivers make decisions without advance directives they are guided by their intuition and a limited knowledge base. This leads to carer dissatisfaction and discomfort with the care provided. In contrast, carers who had advance directives to guide decision making were more comfortable and satisfied with care provision. ACT plans, professional heuristics and manualised aids have been found useful in supporting decision making.

The scope of carer decision making

The majority of carers wanted to be involved in the decision-making process, but leave the final decisions to the health professionals (Gjerberg et al. 2015), with 95% of one study saying they would authorise antibiotics and IV fluids if the doctor thought it was best (Kaldjian et al. 2010).

The treatments carers gave decisions on, ranged from all active treatments (Coetzee et al. 2003; Potkins et al. 2000), to advance care planning (Sampson et al. 2010), tube feeding (Bonner et al. 2014; Jox et al. 2012; Kaldjian et al. 2010; Nakanishi and Honda 2008) PEG feeding (Lord et al. 2015), pacemaker placement (Jox et al. 2012) and CPR (Bonner et al. 2014; Kaldjian et al. 2010).

Informal carers have been required to make decisions on all treatments and welfare issues in the studies reviewed. It is unclear whether the carers in these studies had lasting power of attorney for personal welfare and, given that the studies were from around the globe, legislation will be different. Regardless of legislation, the carers indicated they wished to be involved but they would prefer the healthcare professionals to make the final decisions.

‘Informal carers’ decision making is usually guided by professional healthcare staff, especially when a relationship has been developed between them, creating trust.’

‘No intervention has yet been shown to significantly reduce decisional conflict or carer burden relating to decision making.’⁹

Conflicts in decision making

Many carers found they were not included in decision making as much as they would have liked to be. Carers of people with dementia were less likely to be involved in decision making at end of life than carers for people with other terminal diseases (Afzal et al. 2010). Caron et al. (2005a) report their greatest dissatisfaction is due to limited contact with professional care providers. The communication between them is limited and decisions are not made in collaboration (Gessert et al. 2001, Vandervoort et al. 2014).

The lack of communication is a significant problem as professionals and family carers have different problem-solving approaches and knowledge bases. Professionals relied on medical and legal authorities’ guidelines and emphasised patient autonomy (Jox et al. 2012).

Clinicians also favoured more active treatment of potentially fatal events in end-stage dementia, whereas carers focused on issues of dying with dignity, best interests and the patient’s wishes (Coetzee et al. 2003). Carers are identified as having a lack of understanding that poor communication does little to ameliorate (Thuné-Boyle et al. 2010).

Carers were unclear about their roles (Coetzee et al. 2003; Caron et al. 2005b), with many feeling unprepared and unsupported (Thompson and Roger 2014). They were unfamiliar with the dying trajectory (Gessert et al. 2001; Peacock 2013), and ambivalent about the death of their family member and the natural progression of dementia (Gessert et al. 2001). This led to families having unresolved emotional needs as they felt unprepared for decision making (Gessert et al. 2001; Sarabia-Cobo et al. 2016), and a lack of information and emotional support (Sarabia-Cobo et al. 2016).

Feelings of burden and guilt by family carers were major issues that led to them finding it difficult to make end-of-life decisions (Gessert et al. 2001; Peacock 2013). They report that proxy decision making is both challenging and distressing (Gessert et al. 2001, Lord et al. 2015). This is especially the case when decisions are made that do not comply with the wishes of the care recipient and there is limited support from professionals (Lord et al. 2015). In an effort to reduce decision-making distress an experimental informational intervention was conducted. As the study progressed the decisional conflict within the carers appeared to increase. The researchers suggested that this may be due to chance or because they were presented with more options and possibilities to consider (Sampson et al. 2010).

Alongside the experience of lack of collaboration, information and support, some carers report being pressured by doctors (Teno et al. 2011). Teno et al. (2011) report that 11.1% of carers in their study said the doctor had pressured them into consenting to a feeding tube being inserted. This was particularly distressing for the carer as 25.9% of those with a feeding tube needed to be restrained physically and 29.2% needed medication to calm them. Teno et al. (2011) also reported that those with feeding tubes were more likely to die in hospital and less likely to be identified as having quality end-of-life care (Teno et al. 2011).

In this milieu and despite the stated focus of carers as being person-centred, such as dying with dignity, best interests and the patient’s wishes (Coetzee et al. 2003), carers’ views tended to override those of the person with dementia (Dening et al. 2012).

Carer decision making about place of death was more influential than the person’s own stated wishes (Badrakalimuthu and Barclay 2014). The patient’s current behaviour (Jox et al. 2012) and the views of professionals and family members had a higher impact on decisions than the patient’s prior statements or life attitudes (Connolly et al. 2012; Jox et al. 2012). This becomes clear in Nakanishi and Honda’s (2008) study related to death in group homes, where they found 90.9% family carers wanted the person to die in an institution, whereas 45.5% of the people with dementia wanted to die at home.

No intervention has yet been shown to significantly reduce decisional conflict or carer burden relating to decision making. A decision aid, which increased knowledge and understanding for advance care planning, actually increased decisional conflict (Lord et al. 2015).

Resources carers need to make decisions

Family carers need access to information (Gjerberg et al. 2015; Livingston et al. 2010; Peacock 2013; Sarabia-Cobo et al. 2016; Thompson and Roger 2014) and emotional support (Livingston et al. 2010; Peacock 2013; Sarabia-Cobo et al. 2016), but counselling has been found unhelpful (Livingston, et al. 2010). Advance care directives have helped carers making difficult decisions (Bekelman et al. 2005; Murray et al. 2016).

Communication and discussing the future with relatives are important for involving carers to gain consensual decisions (Caron et al. 2005b; Potkins et al. 2000; Reinhardt, et al. 2014; Sampson et al. 2010; Teno et al. 2011);

collaborative working is essential (Sampson et al. 2010; Vandervoort et al. 2014), with family carers seeking a personal relationship with the care provider (Caron et al. 2005a). Gold Standards Framework for Care Homes (GSFCH) and Liverpool Care Pathway (LCP) have been identified as improving end-of-life care by influencing end-of-life culture, decision-making and practice involving families/friends, staff and GPs (Watson et al. 2010). The GSFCH and LCP were, however, developed for the end-of-life care for people with cancer and not dementia, which have different trajectories. There has been a lot of debate in the UK about, particularly, the LCP, leading to the NHS removing it from use (Neuberger et al. 2013). Despite concerns about set care pathways, the study from Watson et al. (2010) can still demonstrate a proactive approach to be necessary.

Impact of carer decision making

Empirical evidence from an RCT exploring end-stage dementia (Campbell and Guzman, 2004) suggests that taking a proactive approach in early consultation and palliative service support in end-of-life care improved care provision for patients, as well as reducing non-effective invasive interventions, thus reducing costs.

Systematic reviews of Advance Care Planning (ACP) (Dixon, et al. 2015; Martin et al. 2016) examined the empirical evidence on the economic impact of ACP. Costs, expenditures and savings were measured to evaluate various types of ACP interventions. Investigation of the impact of ACP on nursing home residents using hospitalisation as an outcome measure identified that taking choice and preference into account significantly decreased hospitalisation rates and was not associated with increased mortality.

ACP instigated greater adherence and compliance to patient's medical wishes, thus influencing place of death and use of community palliative care services, as well as a reduction in overall health costs in end-of-life care among dementia patients (Martin et al. 2016). Exploring decision making and care provision for advanced dementia patients, cost effectiveness analysis suggests hospitalisation is not cost effective for acute illnesses among nursing home patients. This was influenced by whether an advance directive was in place and is strongly associated with receiving less aggressive treatment, and reduced hospitalisation and healthcare expenditure (Goldfeld et al. 2013). In addition, research exploring end-of-life care has indicated that patients with severe dementia living in the community with an advance directive in place

was strongly associated with receiving less aggressive treatment, and reduced hospitalisation and healthcare expenditure (Nicholas et al. 2014).

The lack of evidence indicates that cost-effectiveness studies have not been conducted and that cost evaluations have primarily focused on healthcare savings, and reduced overall cost, rather than value for money. Nevertheless, the limited research available suggests that ACP interventions are associated with healthcare savings as well as reduced healthcare costs. The true economic impact of ACP is unclear but some evidence is available that there are cost savings associated with ACP and living with dementia in the community (Dixon et al. 2015).

Conversely, some evidence is available that ACP in the last 6 months of care does not reduce costs when associated with decreased functionality and several complex illnesses. Demographic characteristics, such as ethnic background and family living nearby, are associated with lower expenditures in healthcare provision, but further research is required in the exploration of patient preference for treatment and level of intensity, influencing costs (Kelley et al. 2011).

There is an inconsistency in high-quality methodologies applied to investigate this topic as well as scant economic data (Martin et al. 2016). Further exploration of the available economic evidence on end-of-life care in dementia patients is required considering change in population characteristics and statistics globally. This means it is very difficult to assess the impact of carer decision from an economic perspective, although, as highlighted earlier, carer decision making is based mostly on their own intuitive preferences and guided by professionals they trust unless the person with dementia has an advance directive.

Summary of findings

Informal carers' decision making is usually guided by professional healthcare staff, especially when a relationship has been developed between them creating trust. They are more influenced by advance directives than professionals, but they rarely have conversations with the person with dementia while they still have capacity to ascertain what their preferences are. When informal carers make decisions without advance directives they are guided by their intuition and a limited knowledge base. This lack of understanding leads to carers' lack of confidence, dissatisfaction, and discomfort with the care provided by healthcare professionals. Informal carers have been required to make decisions on

all health-related issues on behalf of the person in a manner the person would if they had capacity. While they wish to be involved they would prefer the healthcare professionals to make the final decisions.

The patient's current behaviour (Jox et al. 2012) and the views of professionals and family members had a higher impact on decisions than the patient's prior statements or life attitudes. No intervention has yet been shown to significantly reduce decisional conflict or carer burden and a decision aid, which increased knowledge and understanding, for advance care planning actually increased decisional conflict (Lord et al. 2015). GSFCH and LCP have been identified as improving end-of-life care by influencing end-of-life culture, decision making and practice involving families/friends, staff and GPs (Watson et al. 2010).

ACT planning and advance directives appear to offer the opportunity for collaborative decision making and may reduce carer burden and increase their satisfaction, but conversations need to be held prior to the person losing capacity. Carers also seem reluctant to undertake these conversations and document an advance treatment plan (Sampson et al. 2010). There appears to be a need for healthcare professionals to be proactive in initiating conversations about death and dying with the person with dementia and their carer prior to the loss of capacity. ACPs may be a useful way forward for those with advancing dementia to support their carers in their decision making and to reduce the economic burden, through reduced hospital admissions and aggressive treatment, but at present the evidence base for these advantages is limited.

Discussion

This literature review has considered the evidence on the context of decision making (what the carers needed to make decisions about), what these carers perceive they need, and the contextual culture in which they were trying to make these decisions (conflicts and influencing factors). While collaboration with people with dementia and their carers is recommended and it is recognised that they need support, there is little guidance on how this can be achieved or the impact of their decision making.

Through this review of the literature it is apparent that carers, whether they have power of attorney or not, are required to make decisions on all elements of the person's care as part of the best interests of the person. To understand how

informal carers could be supported, an understanding of the context of their decision making is required.

The context in which decisions are made by dementia carers has an impact on the decisions made and, in turn, the impact of the decisions. The process of decision making, alongside the grief associated with the dying of a loved one, can create discomfort, distress and ill health in the carer (Thompson and Roger 2014). Where trusting relationships are developed with healthcare professionals, and open conversations are held, carer burden is reduced. Healthcare providers' recognition of the health economic impact of facilitated ACP could be an important driver for action to develop supportive, trusting relationships and open conversations. This is also likely to result in the important benefit of the person with dementia's wishes being addressed, especially if these conversations occur early in the dementia journey.

Limitations

This was not a systematic review using one of the established protocols such as the Cochrane or Joanna Briggs, but a scoping review, and therefore does not include an evaluation of the quality of those approaches. The method used here is established for the conduct of a scoping review. It does offer a structure that is transparent, facilitating critical review and demonstrating rigour, as it provides sufficient information for other researchers to repeat the study process. The paper offers some new insights and a platform for further exploration.

Conclusion and implications

To date, the emphasis in dementia care has been one of living well with dementia, but there is a need to plan for having a 'good death' for the person and their carers. This review reveals that proactive ACP may also lead to reduced care costs.

The palliative care approach, alongside conversations with people with dementia and their carers about death and dying, is essential early in the dementia pathway, if carers are to be relieved of some of their decisional burden as the person with dementia approaches end of life. Research needs to be conducted into how this approach can be incorporated into practice to achieve a 'good death' for the person with dementia and peace or comfort for the bereaved carer. 

Declaration of interests

The authors have no conflict of interest to declare.

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