

# BMJ Open Support needs of carers making proxy healthcare decisions for people with dementia: a systematic review based on the Noblit and Hare meta-ethnographic synthesis of qualitative studies

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**To cite:** Hodges V, Hynes C, Lassa S, *et al.* Support needs of carers making proxy healthcare decisions for people with dementia: a systematic review based on the Noblit and Hare meta-ethnographic synthesis of qualitative studies. *BMJ Open* 2021;**11**:e052608. doi:10.1136/bmjopen-2021-052608

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2021-052608>).

Received 22 April 2021  
Accepted 29 September 2021



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## ABSTRACT

**Background** There are 50 million dementia sufferers worldwide. Decisions about healthcare often need to be made when the person with dementia lacks capacity to do so.

Understanding the support needs of carers acting as proxy healthcare decision-makers will be vital in improving the decision-making process for people with dementia and addressing the holistic needs of carers.

**Objective** The objective of this study was to review the existing literature on the support needs of carers acting as proxy healthcare decision-makers for people with dementia.

**Design** A qualitative systematic review protocol was published on PROSPERO. The Critical Appraisal Skills Programme checklist was used to appraise study quality. A meta-ethnographic synthesis was performed to develop third-order constructs.

**Data sources** A search was conducted using three online databases (MEDLINE, CINAHL and PsycINFO).

**Eligibility criteria** Fifteen studies met the inclusion criteria: primary qualitative research involving carers of people with dementia who had been involved in making proxy healthcare decisions.

**Data extraction and synthesis** Two independent researchers conducted validity assessments for each paper selected for inclusion, and discrepancies were resolved by discussions with a third reviewer. Nvivo software was used and conceptual findings from study papers lead to interpretations of findings by the team.

**Results** From the 15 papers included in the study, three main domains arose from the meta-ethnography; informational, practical and emotional. Informational support needs included information about dementia itself and the anticipated disease trajectory. Practical needs included continuity of care, person-centred care and the use of legal frameworks.

Emotional support included recognising the guilt that healthcare decisions can provoke and the importance of providing guidance in an empathic manner.

**Conclusions** This meta-ethnography highlights opportunities for healthcare professionals and policymakers to improve experiences of carers making proxy healthcare decisions for people with dementia.

**PROSPERO registration number** CRD42020124485.

## Strengths and limitations of this study

- To our knowledge, this is the first systematic review to focus on the experience of proxy healthcare decision-making for carers of people with dementia.
- By translating results of multiple studies, we make the results more readily available to practitioners, policymakers and researchers.
- Although there was a comprehensive search strategy with inclusion of international papers, the study did not include non-English-language publications.
- Studies may also have been missed due to the variety of terminology used in this field.

## INTRODUCTION

Dementia affects an estimated 50 million people worldwide with 850 000 sufferers in the UK. As the UK population ages and deaths from other causes are avoided due to improvements in prevention and treatment, dementia prevalence is likely to rise. The number living with dementia in the UK is expected to almost double to 1.6 million in the next 10 years.<sup>1</sup> Dementia is the leading cause of death in the UK,<sup>2</sup> but the disease often runs a protracted course over many years, and most people affected will have other significant health problems. Over 90% of dementia sufferers have at least one comorbidity.<sup>1</sup> Approximately, 700 000 people in the UK provide informal care for someone with dementia. It is a particular difficult and stressful condition to care for.<sup>3</sup>

Decisions frequently need to be made about the healthcare of people with dementia. These range from decisions to undergo testing to commencing or continuing treatment for dementia or for other conditions. Dementia can be worsened by the disruption to routine and changes to physical health that may result from healthcare decisions.

This must be balanced against the potential gain from accepting care making these decisions complex. Carers are often required to be involved in proxy decision-making about healthcare as an individual's capacity to make decisions declines.

Shared decision-making is a key feature of personalised care, which forms part of the National Health Service (NHS) long-term plan.<sup>4</sup> Shared decision-making ensures that individuals are supported to make decisions that are right for them. It is a collaborative process through which a clinician supports a patient to reach a decision about their treatment. The conversation brings together: the clinician's expertise, such as treatment options, evidence, risks and benefits and what the patient knows best: their preferences, personal circumstances, goals, values and beliefs. Shared decision-making is known to lead to more realistic expectations, a better match between individuals' values and treatment choices and fewer unnecessary interventions.<sup>5</sup> The NHS long-term plan states that personalised care will underpin care for people with dementia.<sup>4</sup> Understanding the support needs of carers acting as proxy decision-makers will be vital if people with dementia who have lost decision-making capacity, and their carers are to benefit from the move towards shared decision-making.

The rationale for this systematic review and meta-ethnography of qualitative studies were to review the existing literature with a view to developing new understanding of the support needs of carers for people with dementia facing healthcare decisions and to inform practitioners who may be in a position to provide support. Most published research on making decisions by proxy for people with dementia has focused on end of life care<sup>6,7</sup> and nursing home placement.<sup>8-10</sup> Decision-making about healthcare for comorbidities earlier in the disease trajectory has been less well studied.

### Research objectives

- ▶ Describe family carer experiences of proxy decision-making about healthcare treatment for a relative with dementia, excluding decisions about end of life care.
- ▶ Identify barriers and facilitators family carers experience when making proxy decisions about healthcare treatment for a relative with dementia.

## METHOD

### Patient and public involvement

Patient and public involvement (PPI) work was conducted with a dementia-specific PPI group based at the University of Sheffield. This shaped an initial scoping literature review and development of the research question.

### Eligibility criteria

Inclusion criteria:

- a. People of any age and gender who have a close relative with dementia (regardless of where they reside).
- b. Proxy decision-making about a healthcare treatment

- c. Any primary, empirical research; qualitative, mixed methods

Exclusion criteria:

- a. Published prior to 1995
- b. Non-English language
- c. Only report proxy decisions not related to healthcare
- d. End of life
- e. Reviews, editorials, dissertations, meeting abstracts and correspondence

### Information sources

We searched MEDLINE, PsycINFO and CINAHL. Searches were limited by date from 1 January 1995 to 1 May 2020. Searches were restricted to English language. Searches were repeated on the 22 June 2021.

### Search strategy and selection criteria

The objective of this study was to review the existing literature on the support needs of carers acting as proxy healthcare decision-makers for people with dementia. The protocol for this systematic review was published in the international prospective register of systematic reviews on 5 June 2020. <https://www.crd.york.ac.uk/PROSPERO>

Qualitative studies that clearly reported qualitative findings were eligible for inclusion if they discussed proxy healthcare decision-making.

Target searches using Boolean operators combined terms and Medical Subject Headings related to

- ▶ carer or caregiver or informal carer or family carer or relative AND
- ▶ Decision making or Proxy or Decide or Surrogate decision mak\* or 3rd party decision mak\* AND
- ▶ dementia or Alzheimer's AND
- ▶ Qualitative

### Study selection

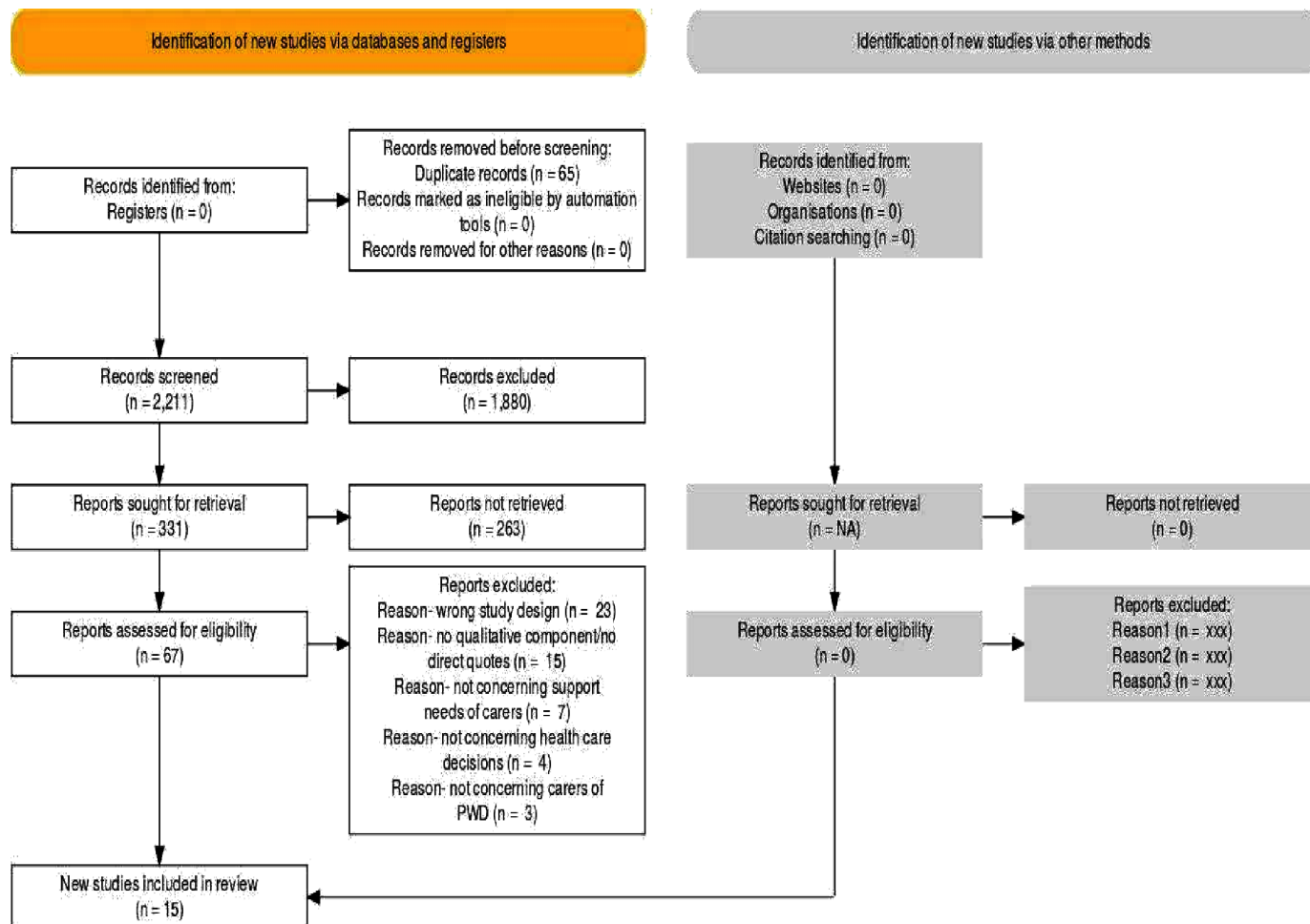
Studies were excluded if they focused entirely on decisions about nursing or home placement, or end of life care and the steps of study selection are represented in the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) diagram (figure 1).

### Quality appraisal

The qualitative version of the Critical Appraisal Skill Programme (CASP) (Critical Appraisal Skills Programme, 2018)<sup>11</sup> was used to assess methodological quality of the included studies by VJH with a sample of papers also being assessed by SL. Discrepancies were resolved by discussion. Quality ratings informed data synthesis and were not used as exclusion criteria. The CASP was also used to reduce the risk of reporting bias, and discussions of the validity of each study were done during data extraction and synthesis.

### Data Extraction

Key features of each study were extracted by VJH and independently checked by SL and CM. For each study, the followings were extracted: author, year of publication, country of origin, stated aim, participant characteristics,



**Figure 1** Preferred Reporting Items for Systematic reviews and Meta-Analysis diagram.

method of data collection, qualitative methodology and analytical approach. The outcomes that were sought in the papers are summarised in [table 1](#), and these features are found in [table 2](#).

We followed Noblit and Hare’s seven steps of meta-ethnography.<sup>12</sup> In a meta-ethnographic analysis, information is classified as a first, second and third-order constructs. First-order constructs are direct quotes within studies, second-order constructs are authors’ interpretations within the primary studies, third-order constructs

are interpretations synthesised by the reviewers from second-order constructs.

VJH and SL read each paper repeatedly to familiarise themselves before performing line-by-line coding of all first and second-order constructs from the results and discussion sections of each paper. The research team met regularly throughout the review process to discuss the first and second-order constructs. These were clustered into candidate third-order constructs. The next stage of the meta-ethnography was to translate the studies into each other. This was done by focusing on each candidate third-order construct in turn and compiling lists of first and second-order constructs that related to it, where candidate’s third-order constructs were not robustly supported by the data they were rejected. A process of constant comparison between papers was conducted, leading to the development of concise statements for each construct (synthesising translations). Both contradictory and directly comparable findings were considered together to develop a line of argument synthesis. An example of how this was applied in this study is seen in [table 3](#).

### Bias assessment

Two independent researchers conducted validity assessments for each paper selected for inclusion and

**Table 1** PICO

	<b>People of any age and gender who have a close relative with dementia (regardless of where they reside)</b>
<b>Sample</b>	
Phenomenon of interest	Proxy decision-making about a healthcare treatment
Design	Any qualitative primary, empirical research
Evaluation (outcomes)	Experiences, support needs, barriers, facilitators of family/informal carers making proxy decisions about healthcare treatment for a relative with dementia

PICO, Population, intervention, comparison, outcome.

Table 2 Features of papers

Author, year and country	Stated aim	Participant characteristics	Method of data collection	Analytical approach	Themes/decisions examined	Setting	Range of capacity of person with dementia
Bloomer <i>et al</i> 2016 Australia <sup>13</sup>	Explore the experiences of family carers of people with dementia who are hospitalised	20 carers age range 34–92 equal gender distribution mixture of spouses, adult children and friends (no details provided)	Individual face to face interviews	Thematic analysis	Experience of transitioning through the hospital system	Hospital	Not mentioned
Carter 2018 UK <sup>14</sup>	Exploring the experiences and preparedness of family carers for best interest decision-making of a relative living with advanced dementia	20 carers 75% female 4 siblings, 2 spouse, 13 children, 1 extended family member	Face to face interviews	Thematic analysis	Experiences and preparedness of family carers for best interest decision-making on healthcare needs	Nursing home	Not mentioned
DeBellis 2017 Australia <sup>15</sup>	To explore relatives' experience, knowledge and perceptions of challenging behavioural and psychological symptoms of dementia and association with antipsychotic use for persons with dementia in residential aged care.	Six participants all F age 45–62, four daughters, one wife, one daughter in law	Face to face interviews	Thematic analysis	Experiences, knowledge and perceptions of antipsychotic medication use for the person with dementia	Residential care home	Not mentioned
Dening 2017 UK <sup>16</sup>	To understand the lived context of healthcare decision-making in the past, present and future for people with dementia and their family carer	Six carers age 49–85 Five spouses, 1 adult child	Face to face interviews	Thematic analysis	Healthcare decision-making in the past, present service and future	Memory clinic	Had capacity to participate in the study
Elliot 2007 USA <sup>17</sup>	Investigating the decision-making of family members of institutionalised older adults with advanced cognitive impairment, with particular focus on spirituality and meaning	39 family members average age 62 4 same generation (spouse/sibling) 35 adult children	Focus groups	Constant comparative method	Healthcare decisions	Nursing home	Not mentioned
Griffiths 2020 UK <sup>18</sup>	Decision-making in cancer care for people living with dementia	22 family relatives Female (64%) Relationship to participant Child 55% Spouse 32% Sibling 9% Grandchild 5%	Face to face interview with relatives	Thematic analysis	Decisions on healthcare needs	Hospital setting	Full capacity
Jamieson 2016 Australia <sup>19</sup>	Investigating the experience of people with dementia and their carers when transitioning from home to hospital	30 carers 87% female	Started with focus groups, but as these were difficult for carers to access, changed to individual telephone interviews	Thematic analysis	Decisions on health and social care needs during transitions home from hospital	Decisions on health and social care needs during transitions home from hospital	Not mentioned

Continued



Table 2 Continued

Author, year and country	Stated aim	Participant characteristics	Method of data collection	Analytical approach	Themes/decisions examined	Setting	Range of capacity of person with dementia
Livingston 2010 UK <sup>20</sup>	Exploring how carers make decisions for people with dementia who lack capacity	Focus groups: 43 participants Individual interviews: 46	Focus groups to generate the list of difficult decisions, Individual interviews to explore in depth	Grounded theory	Decisions on health and social needs	Primary care clinics	Not mentioned
McWilliams 2018 UK <sup>21</sup>	To investigate cancer-related information needs and treatment decision-making experiences of people with cancer dementia, their informal caregivers and oncology health care professionals	Nine carers mean age 73.6 44% female 56% spouse, 44% child	Face to face interviews	Thematic analysis	Decisions on healthcare needs	Hospital setting	People with dementia ranged from having full capacity to no capacity
Shanley 2017 Australia <sup>22</sup>	Providing support to surrogate decision-makers for people living with dementia: healthcare professional, organisational and community responsibilities	34 surrogate decision-makers. 79% female 85% adult children mean age 57.4	Individual face to face or telephone interviews	Thematic analysis	Decisions included residential care, giving up driving, consenting to medical treatment and end setting of life	Community or in a residential care setting	Not mentioned
Sinclair 2018 Australia <sup>23</sup>	Explore how couples with dementia experience healthcare, lifestyle, and everyday decision-making	15 carers Aged 59–82 60% female All spouse partners	Face to face interviews, 6 individuals, 9 couple dyad interviews	Thematic analysis	Decisions on healthcare, lifestyle, and everyday decision-making	Community and residential care settings	Not mentioned
Thompson 2021 Canada <sup>24</sup>	Clarifying the information and support needs of family caregivers of nursing home residents with advancing dementia	17 family caregivers Female (70.6%) Male (29.4%)	Face to face interviews with bereaved family caregivers of persons with dementia	Thematic analysis	Decisions on healthcare needs	Nursing home setting	Not mentioned
Truglio-Londrigan 2018 USA <sup>26</sup>	To identify Alzheimers disease-specific decisions that past and present caregivers faced over the disease trajectory	13 carers 85% female Nine adult children, Three spouses	Focus groups	Thematic analysis	Decisions on health and social care needs	Community setting	Not mentioned
Walker 2001 UK <sup>26</sup>	Investigating how we facilitate carer's involvement in decision-making?	20 carers of people with dementia No further details on participants provided	Face to face individual interviews	Constant comparative method	Decisions on healthcare needs	Hospital setting	Not mentioned
Wolfs 2012 The Netherlands <sup>27</sup>	Gaining carer's insights into the decision-making process about treatment and care in dementia patients	26 carers 50% female 11 spouses, 12 adult children, 3 other	Brief individual interviews inform interview schedule, then focus groups	Grounded theory	Decisions on healthcare needs	Community setting	Not mentioned

**Table 3** Constructs

Construct	Explanation	Example
First-order constructs	Carers accounts of their experiences	<i>'it's a lot of negotiation... sometimes...it's a case of having a familiar face'</i> <i>I think, you know, when he was initially diagnosed, it would have been great to have somebody from that point onwards that you could have dealt with like one single person or one single number that you could call and say, "This is happening now. What typically happens here?"</i> <i>You know, what, what is a good decision to make here?" ... So yeah it just would have been good to, to, I suppose just to have some sort of advocacy [Right] for the families just so that you can make informed decisions.</i>
Second-order constructs	Author's views and interpretations expressed as themes in the primary papers	Similarly, healthcare professionals unfamiliar with the family and the resident's individual wishes were also noted to cause unnecessary anxiety, again resulting in reluctance of further contact. The experience of an uncoordinated discharge process was for family and friends compounded by their own exhaustion after their hospital vigil. The tiredness was further complicated by delays in restarting community services that were accessed previously. This health professional was often their general practitioner (GP). Having this consistent, ongoing support helped the surrogate decision-maker become aware of issues and find their way through the complex maze of service provision. It meant that surrogate decision-makers did not have to keep repeating their story and building trust with new professionals.
Third-order constructs	The views and interpretations of the synthesis team	Continuity of care Having a trusted health or social care professional who understood both the patient and the healthcare system was hugely valued by carers.

discrepancies were resolved by discussions with a third reviewer. Nvivo software was used and conceptual findings from study papers lead to interpretations of findings by the team. A thorough CASP for qualitative studies was done to reduce for other biases (see [table 4](#)).

## RESULTS

### Literature search results

The initial and updated searches combined identified 2276 records from the original database searches. After removing duplicates, initial screening of abstracts and titles, and 67 full texts were further assessed for inclusion. At this stage, 52 full texts were excluded, leaving 15 papers for inclusion in the review.<sup>13-27</sup>

Out of 15 studies, 5 were conducted in Australia, 6 in the UK, 2 in the USA, 1 in Canada and 1 in the Netherlands. Nine collected data through interviews only, two used focus groups only, two used a combination of focus groups and individual interviews. One of the studies that used interviews had intended to use focus groups but changed data collection methodology due to difficulty recruiting to focus groups. In total, the included participants across all studies were 366. There was marked variation between the levels of information presented about participants. For studies where the information was available, 69% of participants were women and the majority were either spouses/partners or adult children of the person with dementia. Only three studies (Griffiths, Livingston and Thompson) provided data on ethnicity or deprivation. The lack of discussion of diversity in the other studies may indicate that this had either not been sufficiently considered or achieved.

### Quality of reporting

CASP ratings ranged from 6 to 10 out of 10, indicating general moderate to high levels of quality in reporting qualitative research. The median of the ratings was 9, with most studies omitting to report reflection on the relationship between the researcher and the participant.

### Synthesis

An illustration of how constructs were developed is provided in [table 2](#). Support needs of carers making proxy healthcare decisions for people with dementia fell into three main domains; informational support, practical support and emotional support. Third-order constructs within this synthesis are illustrated using example of first-order constructs from the original papers.

#### Domain 1

##### Informational support needs

Carers needed a number of pieces of information to be able to make proxy decisions. This domain captures support needs regarding information on dementia itself as well as details of the healthcare decision being faced.

##### Awareness of dementia and disease trajectory

In order to be able to make confident and informed decisions for their loved ones, carers require a sound understanding of dementia, especially with regards to the disease trajectory. An absence of this understanding was a recurring theme in many of the included studies. The reality of inevitable cognitive decline and loss of capacity only became apparent to many participants as they lived through it.

**Table 4** CASP ratings

Study	Bloomer	Carter	DeBellis	Dening	Elliott	Griffiths	Jamieson	Livingston	McWilliams	Shanley	Sinclair	Thompson	Truglio-Londrignon	Walker	Wolfs
Was there a clear statement of aims of the research?	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was the research design appropriate to address the aims of the research?	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was the recruitment strategy appropriate to the aims of the research?	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was the data collected in a way that addressed the research issue?	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Has the relationship between researcher and participants been adequately considered?	No	No	No	No	No	Yes	No	No	No	No	No	No	No	No	Yes
Have ethical issues been taken into consideration?	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was the data analysis sufficiently rigorous?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is there a clear statement of findings?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
How valuable is the research?	High	High	Medium	Medium	Low	High	High	High	High	High	High	High	High	Medium	High
CASP rating	9	9	8	8	6	10	9	9	9	9	9	9	9	8	10

CASP, Critical Appraisal Skills Programme.

We didn't realise what dementia meant, the implications... I think that people who are carers should receive some training... told what to expect and what to do, before it happens, not when it happens—Livingston.

### Information about the individual decision to be made

#### Information content

Shared decision-making requires individuals to have sufficient information about the options available and the evidence, risks, benefits for these. In reality, carers described making decisions with incomplete information.

They didn't say it like it were...we thought there would be one or two [side effects], but I didn't think they'd be as severe as they were—McWilliams

It's also hard to know at each step, is it happening because of the disease or is she medicated? I don't know—Debellis

#### Information delivery

Carers were usually keen to involve the person with dementia as much as possible in decision-making. In order to achieve that, information needed to be delivered at a slower than normal pace, and carers often went to efforts to translate the information into a more understandable form.

It's really fast for me...all I could think was well if I wasn't there and you [patient] wouldn't have remembered...for somebody with dementia it needs to be slowed down—McWilliams

In reality, the person with dementia was not usually able to make healthcare decisions due to their complex nature, but the intention to involve them remained important.

We start off as a joint thing to talk about what needs deciding but normally [it] ends up with me making the final [decision]—Sinclair

#### Signposting

Carers often sought informational support from sources other than the healthcare professional. Other carers with experience of making similar decisions were particularly useful.

I've got an online specialist frontotemporal dementia support forum which is an international forum which consists entirely of other carers and other patients and it's a very knowledgeable forum very well organised very well moderated. And I wish I'd found it 2 years earlier—Shanley

Appropriate signposting to these services can help carers to feel supported with healthcare decisions.

### Practical support needs

This domain focuses on the practicalities surrounding healthcare decisions. It deals with how services can be

organised to provide better support for carers. It also considers legal support structures.

### Continuity of care

Having a trusted health or social care professional who understood both the patient and the healthcare system was hugely valued by carers.

'We have a lot of faith in our case manager. He knows the entire dementia network and whatever question or needs we have, he takes care of it—Wolfs

Many carers had not experienced continuity of care but recognised how valuable it could have been when faced with healthcare decisions.

when he was initially diagnosed, it would have been great to have somebody from that point onwards that you could have dealt with like one single person or one single number that you could call and say, "This is happening now. What typically happens here? You know, what, what is a good decision to make here?" ... So yeah it just would have been good to, to, I suppose just to have some sort of advocacy for the families just so that you can make informed decisions—Shanley

### Person-centred care

Carers become experts in the person with dementia as an individual. They act as advocates and their input into healthcare decisions is essential to achieve true person centred care.

Carers' expertise in their loved one's condition and knowledge of their preferences was routinely overlooked or dismissed by healthcare staff. This left carers feeling disempowered and frustrated.

there was never any communication with me, when I did try to say something they just ignored me and listened to him—Jamieson

### Early planning and legal context

Proxy healthcare decisions are easier to make when carers have a clear knowledge of the person with dementia's wishes. Encouraging families to have these discussions early in the disease trajectory while the person with dementia has capacity to do so facilitates future healthcare decision-making.

*Yes, it was very, very difficult. And in hindsight, it would have been a wonderful thing to have had them [conversations] but we didn't—Shanley*

These conversations are difficult and some individuals and families need a lot of support with them. Explanation of the potential benefits for carers when they are faced with healthcare decisions in the future may help some individuals to address this.

we tried to talk to mummy about what care she would like further down the line, but she never discuss it... she just wouldn't get into that conversation... and I



suppose just when we had to start making those decisions mummy was beyond having any input really in it—Carter

The studies were conducted in a range of countries. Each of the included countries have legal provisions, which allow individuals to formally nominate one or more individuals to act on their behalf should they lack capacity in the future. In the UK, this is known as lasting power of attorney (LPA). The studies in this review showed that some participants were aware of the existence of these legal frameworks. A minority had put them in place. Commonly, carers and people with dementia were resistant to making LPAs.

...I didn't say not at all... I wouldn't do it until much later on I think... I see it as something you hand over when its necessary, not before...—Dening

The mistaken belief that there would be opportunity to set up LPAs once dementia was more advanced led to many reaching a situation where the opportunity was lost.

The only thing that could happen now is Court of Protection... because my wife can't sign—Livingston

One technique that some families used to encourage the person with dementia to make an LPA was to make them for other family members at the same time. This allowed it to be framed as a generic safeguard in case of future eventualities rather than an individual decision necessitated by their inevitable loss of capacity.

if we did [lasting power of attorney] for both of them [parents], it wouldn't feel like it was just for my mum because she's dementing—Livingston

### Emotional support

This domain focuses on the emotional impact of making healthcare decisions by proxy and how carers can be supported with this.

#### Guilt

Making proxy healthcare decisions can be an emotionally fraught process. Healthcare professionals need to be mindful of the impact that decision-making can have on carers. Checking in with carers about the emotional burden and where necessary signposting to services is important.

*But for a time there, I did feel like I was in charge of ending my mother's life. And I think, if I hadn't had the psychologist to talk that through, I would have found that really difficult, really difficult—Shanley*

The burden of guilt was particularly difficult to manage when carers had to make decisions alone or in conflict with family members.

*My brother and sister... wanted the drip, antibiotics and the oxygen reinstated... and the doctor said 'it will flood*

*her heart' and she died a horrific death... but my brother always said, 'oh where there's hope'... There was no hope—Livingston*

Where decisions were shared, it significantly alleviated the guilt.

*My case manager explains what options there are and what they mean, and I make the decision together with my mother and my sisters. If you work as a team, you make the best choices—Wolfs*

### Empathic guidance

When facing proxy decisions, carers appreciated guidance from healthcare professionals. It was important, however, that those decisions were not made unilaterally by professionals.

Recognition and consideration of the needs and concerns of the person with dementia and the carer were key. This approach is described variously in the included papers, but one paper (Shanley) uses the elegant-term empathic guidance.

*And, and I think that was, it was very, it was really helpful to have the medical staff kind of put it in, you know, they didn't beat around the bush ... I really felt like they were very supportive and they were looking out for her, and they were looking out for me as well. And so I kind of, I did put a lot of trust in what they said ... And they were actually considering her needs at the time and, and so they helped me make that decision—Shanley*

Where healthcare professionals did not act as empathic guides and failed to demonstrate consideration of the needs of all parties, attempts to engage carers in decision-making were often superficial and unsatisfactory.

*The hospital was no help, and I got aggravated with all of them and finally I had to call a meeting between all the doctors because I could not get anyone to give me any answers—Truglio Londrigo*

## DISCUSSION

### Summary of main findings

In order to make healthcare decisions for people with dementia, carers require an understanding of the dementia itself and the likely disease trajectory. They also need information about the decision to be made, presented in a form that can be understood and that can be shared with the person with dementia wherever possible.

Carers may be facilitated in decision-making by access to support groups, especially with carers who have faced similar decisions.

Preparation for future healthcare decision-making should be facilitated early in the dementia trajectory, so that carers feel more confident about the person with dementia's wishes and so that decisions truly are made

in their best interests. Healthcare professionals should encourage families to formalise arrangements for future decision-making using the relevant legal structures such as LPAs.

Professionals who recognise the emotional burden of decision-making and act as empathic guides for carers, making that proxy healthcare decisions are highly valued.

### Strengths and limitations of the study

This systematic review is novel in that it explores proxy healthcare decision-making at earlier stages of the disease trajectory for people with dementia, rather than focusing on end of life care or care home placement decision-making. We applied rigorous quality assurance to each study and identified strengths and gaps in the evidence base as well as synthesising key themes of relevance to practice and policy. We have been guided by the report from eMERGe (The Meta-ethnography reporting guidance), which says there are ‘no bespoke reporting guidance exists for meta-ethnography... Existing generic guidance for reporting qualitative evidence synthesis pays insufficient attention to reporting the complex synthesis processes of meta-ethnography’.<sup>28</sup> With this in mind, we have used the PRISMA checklist for both abstract and article paper in ensuring there was good practice and rigorous, comprehensive analysis, interpretation and synthesis of the evidence.

A systematic review is by its nature dependent on the quality of the original studies. Of the 15 studies in this review, only one (Livingston) provided detailed demographic data on participants. This study recruited a diverse population in terms of ethnicity, educational background, age and gender. The lack of demographic information in the other studies may suggest a lack of diversity, but certainly suggests a lack of consideration of diversity by the authors. The studies were all conducted in English and excluded the voices of people for whom English is not their first language.

The goal of this review was to focus on the support needs of carers making proxy healthcare decisions for people with dementia. Few of the included papers focused entirely on healthcare decisions from a carer perspective; many dealt with a range of decision types, others included views of other parties such as the person with dementia or the healthcare professional. As a result, there were often only small sections of the included papers, which yielded relevant quotes.

The thematic synthesis was conducted by four academic general practitioners; VJH, CM, CH and SL. While every effort was made to maintain a reflexive approach, there will undoubtedly have been shared assumptions and blind spots, which could have been mitigated with a more diverse research team.

### Comparison with existing literature information and knowledge about dementia

A lack of knowledge about dementia and the disease trajectory was a common theme throughout this review.

A recent systematic review of the public’s knowledge and understanding of Alzheimer’s disease and dementia found that there was a common misconception that dementia was a normal part of ageing.<sup>29</sup> Carers described a need for a postdiagnosis training programme to teach them what to expect. Key within this was the importance of early advanced care planning. Many participants missed the opportunity to have advanced care planning discussions with their loved ones, in part because they did not realise the inevitable downward trajectory of dementia with resultant loss of capacity. Proxy healthcare decisions were much easier to make and accept when carers had a clear understanding of their relative’s wishes. Supporting carers and people with dementia to have those conversations early facilitates proxy decision-making later on.

### Shared decision-making

Shared decision-making is a key component of the NHS long-term plan.<sup>4</sup> It is widely accepted that shared decision-making facilitates patients to make decisions that are best for them. A 2011 report by The King’s Fund<sup>5</sup> states at the heart of decision-making ‘is the recognition that clinicians and patients bring different but equally important forms of expertise to the decision-making process’. In the context of proxy decision-making, the carer should take the role of the second expert; however, our review suggests that their expertise is commonly disregarded.

These findings echo the Care Quality Commission’s 2016 review of how people are involved in their care, which found limited understanding, recording and monitoring of people’s wishes and preferences, inadequate family and carer involvement and insufficient information and explanation of care and support options.<sup>30</sup> Some of the barriers to the implementation of shared decision-making identified in the literature include practical factors such as a lack of continuity of care and time constraints. Additionally, the challenges involved in building good rapport between both parties have been identified.<sup>31</sup> Some professional groups have proposed solutions such as templates that can be used at various levels of service delivery,<sup>32</sup> while other authors argue that more research is still needed in the area of shared decision-making in primary care in order to better conceptualise the barriers and solutions.<sup>33</sup>

### Continuity of care

Many studies have shown the benefits of continuity of care both in terms of patient experience and clinical outcomes.<sup>34–37</sup> The 2018 National Institute for Health and Care Excellence (NICE) dementia guidelines recommend that people living with dementia be provided with a single-named health or social care professional who is responsible for coordinating their care and that a programme of postdiagnostic support be offered to carers.<sup>38</sup> In practice, delivery of this support is inconsistent across the UK, with multiple sectors delivering a range of services with the potential for duplication or gaps.<sup>39</sup> Our review found similarly inconsistent access to care coordination, but where it was available, carers valued it.

## Digital signposting

The emotional burden of decision-making for a person with dementia can be enormous. One of the many consequences of the COVID-19 pandemic is the loss of in person support and support networks.<sup>40</sup> Increasing use of online support forums offers an alternative for some, but 29% of people aged over 65 in the UK have never used the internet.<sup>41</sup> The movement of services online that has been hugely accelerated by the pandemic risks leaving those without internet access or skills unable to access a wealth of informational, practical and emotional support options.

## Implications for future research and clinical practice

The NHS aspires towards making person-centred care, including shared decision-making, part of routine practice. Research is needed to establish how we can achieve this meaningfully for proxy decision-makers, so that both they and the person with dementia have access to the benefits of person-centred care. Patients with dementia suffer from inevitable decline in cognition and most will reach a point where they are unable to make healthcare decisions independently. If people with dementia are to benefit from the drive towards patient-centred care, it is vital that we consider the support needs of their carers.

Continuity of care can be difficult to achieve in the modern health system but has undoubted benefits for patients with complex comorbidity.<sup>42</sup> Commissioners should consider how continuity can best be achieved. It should be clear to practitioners and service users who that single point of contact is and how to access necessary support.

In an increasingly digital world, there is a potential for widening health inequalities by reducing access to services for those who do not have internet access or computer literacy. A significant minority of older adults does not use the internet, and policymakers and commissioners must take measures to ensure that services remain accessible to all, while also providing opportunities for people to improve their digital literacy.

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**Acknowledgements** The authors would like to thank Anthea Tucker for help with search strategies and Professor Christopher Burton for advice on the manuscript.

**Contributors** Conception or design of the work: CH, CM and VH. Data collection: VH and SL. Data analysis and interpretation: VH, SL and CM. Drafting the article: VH and CM. Critical revision of the article: VH, SL and CM. Final approval of the version to be published: all authors. Guarantor: CM

**Funding** This work was supported by The RCGP Scientific Foundation Board, grant number SFB2018-07.

**Competing interests** None declared.

**Patient consent for publication** Not applicable.

**Ethics approval** This study does not involve human participants.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** All data relevant to the study are included in the article or uploaded as supplementary information. No additional data are available

**Supplemental material** This content has been supplied by the author(s). It has not been vetted by BMJ Publishing Group Limited (BMJ) and may not have been

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