

# A UK qualitative study of living and dying with dementia in the last year of life

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## Abstract

**Background:** Dementia is a life-limiting illness, but the trajectory of dying can be difficult to establish and care at end of life can be variable and problematic.

**Methods:** This UK study was carried out to explore the end-of-life-care experiences of people with dementia from the perspective of their family carers. In-depth interviews were conducted with 40 bereaved family carers of people with dementia.

**Results:** Forty family carers (male  $n=9$ , female  $n=31$ ) age range: 18–86 years were interviewed. Issues with poor communication were common. The hard work of caring and issues regarding unpredictability of living and dying with dementia were also commonplace within the study. Only three patients were referred for specialist palliative care support at the end of life, all of whom had a dual diagnosis of dementia and cancer.

**Conclusion:** This qualitative study has identified that there are several gaps in the end-of-life care of people with dementia, and frequently, there is poor communication during the last year of life. The need for high-quality integrated care for people dying with dementia with appropriate support during the last year of life is identified. COVID-19 has disproportionately affected people with dementia, and in the post-pandemic era, there is an urgent need to ensure every person dying with dementia is supported to die in their preferred place and that family members are supported and enabled to be treated as the ‘expert’ in terms of their knowledge of their relatives’ care and preferences.

**Keywords:** communication, COVID-19, dementia, end-of-life, family carers, hospice, palliative

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## What is already Known About the topic

- Dementia is a life-limiting illness, but the diagnosis of dying can be difficult.
- Many patients die with dementia in hospital or in care homes.

## What this paper adds

- This qualitative study of family carers revealed that communication with the person with dementia and also with professionals was a major issue.
- Family carers felt worn down by the constant ‘battles’ they perceived they experienced in

negotiating the healthcare system on behalf of the person with dementia.

- Dying of dementia was traumatic for family carers of those interviewed with little support and privacy and frequently no support from specialist palliative care.

## Implications for practice theory or policy

- This study suggests that specialist or generalist palliative care is frequently not available for those with dementia dying in hospital or in care homes.
- Sensitive communication and respect for family carers is a basic necessity of good end-of-life care.

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- Where advance care plans are not in place, family carers should be consulted and considered within the clinical decision-making process

### Introduction

It is estimated that there are approximately 820,000 people with dementia in the United Kingdom,<sup>1</sup> and the incidence and prevalence of dementia will continue to rise with an ageing population. It is predicted that deaths from dementia in the United Kingdom will increase from around 59,000 per year in 2014 to around 220,000 per year by 2040.<sup>2</sup>

Research suggests that people with dementia receive poorer end-of-life care,<sup>3-5</sup> inadequate pain relief, and limited access to palliative and hospice care.<sup>6-9</sup> Studies exploring end-of-life care for people with dementia have focused mainly on 24-h care environments, that is, hospital, nursing, and residential care, and frequently, the focus of research has been with paid carers and their understanding and approach to care towards the end of life. There is relatively little research and literature exploring personal experiences of family carers who have cared for a loved one with dementia up to and including death. Dementia is a challenging illness, and in the later stages, there is not only cognitive deterioration but also physical deterioration in terms of mobility, issues with nutrition, faecal and urinary incontinence, and in the later stages becoming bedfast.

In a study to explore decision-making at the end of life, interviewing carers and professionals, uncertainty and poor communication were reported as the main areas of difficulty.<sup>10</sup> A further qualitative study of professionals, along with people with dementia and family carers, reported seven key areas namely timely planning of discussions around end of life; recognition of patient being at the end of life and provision of supportive care; co-ordination of care; effective working relationships with primary-care teams; managing hospitalisation; continuing care after death; and valuing staff and ongoing learning.<sup>11</sup>

Longitudinal studies are particularly valuable to capture experiences at different time points and a study from the Netherlands<sup>12</sup> to determine what should be available to enable good palliative care for people with dementia at the end of life, interviewed 10 family carers of people with dementia

in focus groups at three time points. Family carers wanted familiarity at the end of life of having familiar people caring for the person with dementia and also wished care to be at home if at all possible and communication with professionals that they knew and trusted.

The aim of our study and this paper was to explore the direct personal experiences of a diverse group of family carers who had cared for people with dementia in the last year of life and up to death.

### Methods

We report additional analysis of our national study<sup>4</sup> which recruited bereaved family carers from Scotland, England, and Wales. Participants were recruited via organizations, for example, Alzheimer's Society and Age UK, social media, and community networks in order to obtain a broad range of experiences of care during the last year of life, and this paper reports additional analysis from the original study. As data collection and analysis progressed recruitment became more focused on certain under represented groups and locations, that is, male carers, semi-rural and rural areas. To facilitate this process, organisations such as the Alzheimer's Society, Age UK, and Alzheimer's Scotland were contacted and invited to publicise the appeal through newsletters and carers groups held within local branches. Full ethical approval from University of Liverpool ethics committee was obtained (RETH000206). Inclusion criteria included unpaid carer of someone with dementia in their last year of life and at the time of death; aged 18 years or over; death to have occurred within the last 5 years in any care environment (family home, care home, and hospital). Exclusion criteria included paid/formal carers; under 18 years of age; death occurred more than 5 years previously.

Family carers were invited to contact the first author if they were interested in participating in the study and were sent an information pack which included an information sheet and reply letter to invite the first author to contact them. Following written consent being obtained, interviews were conducted with participants and digitally recorded and transcribed verbatim. Interviews lasted between 30 and 80 min. Interviews were conducted face to face usually at the participants home, with a small number being conducted by telephone. The interview process was informed by narrative interviewing,<sup>13</sup> with

the unstructured narrative interview designed to provide an opportunity for the participant to give a detailed account of a particular experience, event, or point in time.

Participants were encouraged to tell ‘their story’ as a narrative with minimal interruption from the first author which ensured events and issues important and significant to the participant were reported. The participants were encouraged to talk about the diagnosis and illness trajectory; what support was offered and how effective was support in the last year of life; were palliative care needs addressed; to discuss what happened in the last few weeks of life. This method was utilised in preference to a semi-structured interview design would have only allowed participants to select isolated parts from their own story and in effect filling in or completing pre-existing narratives by the first author. Field notes were collected to supplement the interpretation and analysis. The study was ongoing for 3 years with 18 months of this time spent on data collection. This prolonged period of time in the field helped the researcher who was an experienced mental health practitioner to acclimatise to researching an area of extreme sensitivity. It also supported development of skills that would help with conducting and understanding interviews and facilitated reflexivity which contributed to incorporating issues and theories from previous interviews into subsequent interviews. The field notes added to the context, nature, and circumstances of the interviews carried out.

During the research process and throughout interviews, the researcher attempted to create a climate of openness with participants in an attempt to reduce researcher effect. All participants were fully aware of the nature and purpose of the study. All transcripts were returned to the participants for verification and to ensure that participants’ narratives were recorded correctly. There were no requests for amendments following this process; however, many participants stated they had valued taking part and appreciated having a copy of their interview.

The study adopted a qualitative approach informed by phenomenology<sup>14</sup> and grounded theory.<sup>15,16</sup> Phenomenology as a philosophical stance due to the lived experiences being sought and grounded theory informed the study in an attempt to interpret and explain these experiences.

Analysis of the data using comparative analysis<sup>15</sup> commenced from the outset of data collection and transcripts were read by all authors and re-read by the first author. Line-by-line coding of transcripts, memo writing, development of categories, and emergence of themes followed and emerging themes were compared, discussed, and agreed by all authors who were part of the study team. Data saturation began to occur when recruitment reached 35 participants and a further five participants were recruited to ensure saturation had been fully achieved.

## Results

Participants were recruited from the North West of England:  $n=21$ , North East of England:  $n=4$ , Wales:  $n=9$  and Scotland:  $n=6$  and included participants living in urban, rural, and semi-rural areas. Thirty-one female and nine male family carers who had cared for people with dementia with an age range of 69–96 years (mean age 81.5 years) participated and included all socio-economic backgrounds. Efforts were made to recruit family carers where death had occurred in different care settings; however, the majority of participants had experienced death in hospital or care home with only four participants caring for a person with dementia within their family home until the end of life. No deaths had occurred in a hospice. Within the study, 22 people with dementia had died in Hospital, 14 within care homes and four within the family home (Table 1) and the majority of family carers had experienced care in several different care settings in the year prior to death. Participants described how they had cared for the person with dementia for between 18 months to 20 years before death with a mean of 5.1 years and median of 5 years in a caring role. The deaths had occurred between 3 months and 5 years (mean 1.7 years, median 1.3 years) prior to the interviews.

The mean length of time from formal diagnosis to death was 4.5 years; however, most participants reported cognitive problems for some time prior to diagnosis. Four participants were family carers for people who had a dual diagnosis of cancer and dementia. Of these, three experienced specialist palliative care services: one in a day hospice: one hospital-based and one a community-based specialist palliative care service. From the evidence of the interviews, no patient with a dementia-only diagnosis received specialist palliative care.

**Table 1.** Information regarding participants [reused with permission from Crowther et al.<sup>17</sup>].

Place of death	Number	%
District general hospital	22	55
Care home	14	35
Family home	4	10
<b>Gender</b>		
Male	10	25
Female	30	75
<b>Relationship to person who had died with dementia</b>		
Husband	7	17.5
Wife	17	42.5
Son	3	7.5
Daughter	10	25
Other family	2	5
Friend/neighbour	1	2.5
<b>Age range of person with dementia</b>		
69–96 years	Mean age	81.5 years
<b>Time spent caring</b>		
18 months–20 years	Mean time caring	5.1 years
<b>Time since death</b>		
3 months–5 years	Mean time since death	1.7 years

As a result of constant comparison of individual transcripts, 23 categories emerged from the data. Over a period of time, data were reduced further, and the following key themes began to emerge: communication; family carers as experts; the hard work of caring; and living and dying with dementia in the face of uncertainty. An example of an interview coding is included in Table 2.

*Communication*

Difficulties with communication in its broadest sense were a major theme to emerge from this study. Family carers knew the person and had established non-verbal means of communication

I knew when she was cold she would physically put her arms together and when she was too hot she

would be unbuttoning her blouse I tried to get the staff to understand we had to look for non-verbal . . . when they don't speak at all you're having to work out what their needs are. (Family carer 36)

Family carers searched their creative knowledge of their loved ones in attempts to communicate and connect with the enduring self. This would involve playing music or having certain activities on a television channel they knew the person with dementia once enjoyed.

there was nothing we could give him, he had a television, we put it onto what we thought he enjoyed . . . in the summer he always liked to watch cricket we would tend to put that on . . . he liked hymns, certain singers, we tried to do this. (Family carer 39)

Just 'being' with the person with dementia became increasingly important for some family carers as the disease advanced and communication skills diminished.

Visiting . . . I couldn't wait to get there . . . I was there every afternoon all afternoon for a fortnight . . . I went in everyday I held her hand . . . she knew me — I held her hand. (Family carer 40)

I'd stay right through to evening . . . sit with mum just sit . . . talk to her . . . put the tv on . . . put some music on or I'd just sit there . . . (Family carer 31)

Communicating about care issues as the person with dementia deteriorated was another source of distress. The language used to inform family carers that the person with dementia was in the terminal phase was not always clear and added to the chaos and uncertainty experienced.

'he's very, very poorly, still very poorly' they said. (Family carer 30)

Occasionally, a deterioration was reported and interpreted to mean the person with dementia was close to death. There appeared to be a subliminal message for family carers within the words used.

"about half past ten the staff nurse rang B and said "her breathing's become a bit distressed" I said "right I'll come now." (Family carer 22)

A number of participants expressed concerns in relation to different languages and different

**Table 2.** Examples of initial coding from text and memos.

Participant	Initial coding	Text:	Memos:
Family Carer 36	Control, collaboration, attempts to include as well as being/ feeling excluded, anger towards formal carers vulnerability of person with dementia	“and then like when they wanted to turn her and change her position, they were very good and she had mouth care and they asked if I wanted to do it and things like that, she really didn’t need a lot of care towards the end, mum she was just never, she was just so undemanding, she was amazing, didn’t really need very much so when we were asked to leave the room, we both went out the room, Dad used to get very angry about that ‘why you putting me out?’ and things like that and so forth . . .”	Person with dementia so dependent upon others now for all activities of daily living interpreted by daughter as undemanding, is this measured by communication and requesting things verbally? Appeared to demand high levels of input from formal carers, could be interpreted as being demanding by them?? Demanding upon resources?? Daughter feeling excluded from care, explanations for this action from formal carers could have reduced anger felt at exclusion, similar to other scripts. Family carer 14

cultures within UK hospitals and care homes. The quote below was the experience of a daughter whose father was Polish and reverting to his native language as dementia progressed – he had attended a memory clinic in the last year of life and the following were the daughter’s recollection of the clinic visit

he couldn’t write his name . . . my dad was Polish- the doctor was from another country . . . you can imagine . . . it were like never the twain shall meet. She wouldn’t let us stay in the room with him while she asked him these questions and we’d have to stand outside, we could hear what she was saying and she was getting quite agitated my dad wasn’t responding . . . he didn’t know how to respond . . . basically she wasn’t interested in him . . . she said there was no point giving him any tablets. (Family carer 21)

As dementia progresses, people often revert to the use of their native language and may totally lose their skills to speak or understand their second or third language. The importance of being able to communicate in the native language in order to facilitate assessment of cognitive deficits is demonstrated below.

she was lovely and spoke Welsh to him, she went through this rigmarole of questions and drawing then she said “will you write me a sentence?” . . . I thought “what’s going to happen here?” he said “of course I will” he picked up the paper, he wrote a sentence in Welsh do you know what that sentence was translated?.” it’s wonderful to have a young lady like you to visit me. (Family carer 39)

As dementia progressed, the ability to converse became more limited, and some family carers went to great lengths to choose 24-h care facilities which employed staff who could speak the native language of the person with dementia.

I really wanted him to go to a Welsh speaking care home I wanted people there who spoke to him in his mother tongue, that was very important. Not all of them did speak Welsh, but most of them understood Welsh and would know enough words to communicate. (Family carer 39)

#### *Informal family carers as experts in care*

Family carers within the study believed they were the “experts “ in care and in care preferences of their relative – in most cases, they had lived with, known, and cared for the person with dementia for many years prior to diagnosis and had witnessed the changes in the person with dementia following the diagnosis. Participants expressed specific wishes in relation to aspects of care. Informal family carers believed their level of knowledge and skill acquired, over many years of caring, was devalued, negated, and frequently ignored by professionals. Some expressed explicit wishes relating to the care of the person with dementia. The following quote was a patient with dementia and a cancer diagnosis – his wife found it unbearable that the oncologists insisted on informing her husband of his diagnosis at every clinic visit. Due to his dementia, he had no memory of previously being told his diagnosis but had sufficient insight to be devastated each time he was told his cancer diagnosis.

it was my belief he'd not got the mental capacity to know, every time he was told it would be like telling him again. She (oncologist) was really quite . . . not aggressive . . . it was her opinion he should know that was it I think relatives know - well I knew my husband better than anybody else, we'd been married for forty five years and it wasn't appropriate to tell him . . . (Family carer 32)

As is demonstrated in the quote below, one of the most complex but important areas faced in caring for those with advancing disease is deciding when and how far to intervene when patients deteriorate. Including family carers in such decisions and listening to their views, where possible, can support the decision-making process and help arrive at solutions based on knowledge of that person and what maybe in their best interests.

they said about feeding him through his nose, I said "no" I knew he'd be traumatised, I knew he'd pull it out, he wouldn't like being held down having that done so I said "absolutely no, no way that" When I go back in the afternoon they'd done it, he'd been very traumatised, I was furious. (Family carer 07)

The difficulty for family carers in hospitals when staff did not take notice of family carers' views is illustrated below from the daughter of a patient who was sectioned (detained in a psychiatric hospital against their will) and admitted to a psycho-geriatric ward

. . . he got put into ward X when he was sectioned, . . . "you're in here Mr. H because you've hurt your wife" and I used to think, why are they saying that to him-how can you say that to somebody whose mind is like that . . ., It would make him so angry and he'd say "I do not, I do not hurt my wife!" you know and I feel me dad really, really suffered because he would not have hurt a fly and to keep being told . . . He'd say "this is punishment" he'd sit on ward X with his head in his hands and say " ooh, they've said I've hurt P (wife), I love P, I'd never hurt P" you know and they were telling him all the time. It was terrible, it was absolutely dreadful and then he went into the nursing home thank God but I do feel for these people who haven't got any family-what happens to them? (Family carer 09)

### *The hard work of caring*

All interviews were retrospective accounts of events which had occurred months or some years previously, but recollections were vivid

and emotional. Powerful words such as "fight," "battles," and "traumatic," illustrated the difficulties confronting families and the hard work involved. Choice of words and language used were indicative of the enduring effect of the experiences and memories for the study participants.

then began the battle to get him out of hospital, it was a battle . . . they knew I wanted to get him home as soon as possible, it took 21 days to get him home, they told me it's within the time limit. I pointed out to them S died 21 days after he came home so it may have seemed within their time limits, but it wasn't within our time limits . . . we lost valuable time where he could have been at home didn't we? (Family carer 32)

I'd have to put him to bed, I think as a daughter, I think that's been one of the hardest things which I have got over now, it would have made me cry so much it was just so upsetting. This fantastic man who'd done so much for so many other people, just become this shell terribly frightened, he just didn't know where he was, kept asking for his own mother, I think quite a few times he thought I was his mum putting him to bed which for a daughter to think your father thinks you're his mother was so very, very upsetting . . . (Family carer 03)

There was also the difficulties perceived by the attitude of hospital staff towards patients with dementia and pressure to move patients quickly to a care home. This very event for many families was traumatic, and the importance of going to a care home the family had chosen and wanted was important as illustrated below

. . . there was quite a bit of pressure actually from the local NHS here basically to get him out which I resisted because I wanted him to go into this particular nursing home, they wanted us to put him somewhere else . . . and wait for a bed . . . I felt that it was much better in one stage. (Family carer 39)

### *Living and dying with uncertainty and unpredictability – the last days*

The level of uncertainty family carers of people with dementia may experience as death approached or appeared to approach caused distress to many family carers. Although told many times that a person with dementia may be near death, death could sometimes occur suddenly and unexpectedly. Uncertainty and unpredictability persisted sometimes over many months and

occasionally years. Some family carers found themselves in situations where they were advised by medical staff the person with dementia was close to death only to see them recover, and for some, this occurred on several occasions during the disease trajectory and was a source of considerable anxiety and distress.

doctors were saying “he’s very poorly”, she was saying “you don’t know my dad, I’ll come in tomorrow, he’s going to be as right as rain, he’ll be off this mask” They were sort of like “right, right ok” that’s what happened to us so many times, then it got to Monday morning they said “he’s not going to last 24 hours. . . . (Family carer 20)

he was a fighter that time he went in with pneumonia he wasn’t expected to come out . . . but he did. (Family carer 37)

Most family carers experienced death within a hospital setting and although for some, the care experience was good, it was common for people with dementia to die on an open busy ward with the promise of transfer to a side room not materialising.

it was horrible the way me dad died, absolutely horrible . . . it was dreadful . . . if he’d have been in a side room . . . had a little bit of dignity where it could have been quiet . . . (Family carer 9)

Of the four patients who had a dual diagnosis of cancer and dementia, one participant reported that her mother who had lung cancer and dementia had received day care in a local hospice while at home but died in a care home. Individual experiences of specialist palliative care services varied with one referral to a hospital team advising the family they were unable to help – this person died at home 4 weeks later. Only one family experienced palliative care in a hospital setting for a patient who had a diagnosis of gastric cancer and dementia. This participant was the only participant to mention the possibility of her father going to a hospice for end-of-life care, although this did not happen and he died on a hospital ward.

The one thing that I would have liked is for him to perhaps not have to stay so long in a clinical setting, he didn’t like hospitals at all and possibly, I think, we did discuss this with the doctors. . . . I think they thought that it wasn’t worth arranging to move him to a hospice or whatever because he wouldn’t survive . . . (Family carer 7)

## Discussion

Our study aimed to explore the experience of dementia in the last year of life in a diverse group of bereaved family carers from the UK in an attempt to identify and interpret what were the specific perceived needs of people with dementia and of their families at the end of life. Although a retrospective account, in all cases, carers gave an emotional and vivid account of events leading up to the death of the person with dementia. Communication in its broadest sense was the overarching issue of concern within this study and communication impacted on every aspect of care at the end of life.

### *Communication*

As previously reported<sup>18,19</sup> communication issues were the main areas of concern in this study and were perceived as problematic by family carers in a range of circumstances, environments, and contexts and influenced every experience of care received. It was evident how difficulties with communication impacted on care and in this study, the experiences of communication were mostly negative. Non-verbal messages such as body language or para-verbal messages including tone and volume of voice have equal importance to verbal components of communication.<sup>20</sup> All aspects of communication influenced family carers’ experiences of end-of-life care. It is acknowledged that for many who work in health and social care in the United Kingdom, English is not their first language. Family carers experienced difficulties communicating with professionals in some circumstances and expressed concerns regarding the person with dementia who already had compromised communication skills as a result of their illness. For Welsh speaking family carers in Wales who participated in the study in particular, there was concern regarding the lack of access to support and care within their own native language and lack of access to care that was culturally acceptable. Sensitive communication and respect for family carers is a basic essential of good end-of-life care as is ensuring that family carers understand what is being said and listening to the family carers views and opinions.

### *Carers as experts*

An expert is defined as ‘a person who is very knowledgeable about or skilful in a particular area’. Development of competent skills and extended knowledge about a particular subject, place, issue,

or person is crucial to being assigned the title 'expert'. There appeared to be a combination of experts in this study. Those who were professionals providing a service in which they were viewed as experts by lay people (i.e., the family carers interviewed for the study) and lay people (the family carers themselves) who considered themselves as experts in the care of the person with dementia. There was evidence of conflict and criticism mainly attributable to lack of acknowledgement and value perceived to be placed upon informal family carers expert knowledge and skills by professionals. Family carers felt they knew the person with dementia extremely well and based proxy decisions and choices on vast prior knowledge. They felt qualified as experts in care and found themselves, at times, in conflict and confrontation with professionals. Family carers considered themselves as expert in terms of knowledge and care of their loved ones<sup>21</sup> and what was in their best interests, while professionals appeared to consider themselves the experts in relation to dementia, disease trajectory, symptom management, and treatments. Families of people with dementia have frequently been living with the condition for a number of years prior to diagnosis and may have been making decisions based on their knowledge and previous wishes expressed by the person with dementia. These may, or may not, have been documented in a care plan. It was clear from this study that key areas of decision-making which created difficulties for the expert family carers and professionals alike included artificial hydration and nutrition, communication, and hospital admission.<sup>22</sup>

Two recent papers based on a qualitative study of 30 bereaved carers of patients who had died of Lewy Body Disease also reported the lack of communication between health care teams and families and difficulty predicting death timing were two frequently expressed challenges.<sup>23,24</sup> Within our study, carers perceived professionals as inflexible; policy and procedures appeared to be followed regardless of information shared by informal family carers. It should be noted, that in this further analysis of a retrospective study, none of the participants in the study had an Advanced Care Plan (ACP);<sup>25,26</sup> however, a recent paper<sup>27</sup> reported that of over 6000 patients presenting with an acute medical emergency, only 4.8% had an ACP available for admitting medical team. In the study,<sup>27</sup> although 9.5% of patients over 80 and 12.6% of patients over 90 had an ACP, it is clear that the vast majority of older people, many of whom will have dementia as primary or co-morbidity do not have any documentation to state their

wishes. Advance care planning (ACP) is a process of reflection on and communication of a person's future health care wishes;<sup>28</sup> however, the process itself can be challenging as a recent systematic review reported and uncertainty with decision-making requires strategies and support to aid this complex process.<sup>29</sup> Since introduction of the Mental Capacity Act in the United Kingdom in 2005,<sup>30</sup> there has been increasing focus on ACP and treatment directives. This is in anticipation of loss of capacity and ability to make informed choices regarding treatments and wishes as capacity is lost and death may be approaching. In dementia, timing is crucial, as the person with dementia can be involved at an earlier phase but not necessarily later due to cognitive decline; however, for people newly diagnosed with dementia, it can be difficult to anticipate future care needs. What appeared most challenging for family carers within this study was the fact they felt they were not being listened to nor recognised by professionals.

#### *The hard work of caring*

The effects and impact of being a family carer for people with dementia has already been reported in the literature.<sup>31,32</sup> It became apparent that there were different elements to the hard work of caring namely the practical hard work and organisation of care; the physical hard work and the caring tasks required on a regular basis to support daily living and the emotional hard work related to burden, stress, anxiety, and guilt. The constant 'battles' family carers described when trying to negotiate the world of professional care was a drain on their emotional resources and such situations impacted on family carers causing stress and distress.<sup>33</sup> These findings are also echoed by a study which found that bereaved and current carers found it exhausting to co-ordinate care for the person with dementia especially regarding end-of-life care.<sup>34</sup>

#### *Living and dying with uncertainty and unpredictability – the last days*

Uncertainty has been described as a common experience during illness, and dementia is no exception.<sup>35,36</sup> It could be argued that dying with dementia may be challenged with more uncertainty due to the potential length and unpredictable nature of the disease trajectory. The narratives shared within this study appeared to be fraught with chaos. Nothing within the last year of life including death itself appeared to be ordered or predictable. Issues regarding prognostication and



dying in life-limiting illness remain problematic, and transfer from nursing home to hospital at end of life is common.<sup>37</sup> Many people with dementia also have co-morbidities.<sup>38</sup> It was of note that specialist palliative care services were rarely involved, and involvement in this study appeared limited to those with a dual diagnosis of dementia and cancer. Palliative care services for people with dementia were and are being developed but remain limited<sup>17,39</sup> and the debate regarding early introduction of palliative care in dementia continues. Currently, in the United Kingdom, less than 1% of people with dementia in the United Kingdom die within a hospice. In the United Kingdom, Admiral Nurses who are specialist nurses supporting people with dementia and their families are working in many areas including acute hospitals and can support both families and staff who are caring for patients with dementia at the end of life. Our findings in this study echo those of Bolt *et al.*<sup>40</sup> who found family members wanted to be recognised as an important caregiver and that a lack of person-centred care was an issue for many family members throughout the dementia illness.

### *Strengths and limitations*

To our knowledge, this is one of the largest qualitative studies exploring the needs of patients with dementia at the end of life from the perspective of a diverse sample of bereaved family carers. Although every effort was made to include people from different ethnic backgrounds, this was not possible which limits the extent to which findings can be applied in other populations. The self-selecting nature of the sample could represent family carers with a more difficult experience wishing to participate and to share their experiences and those family carers who wished to participate may have been more engaged in caring for the person with dementia than the average family carer, and their desire to be heard, therefore greater. Conversely, it is possible that people with worse experiences of end-of-life care may not have wished to re-live the experience in an interview and that those interviewed for the study were possibly portraying better experiences of care. This was a United Kingdom-based study, and we acknowledge that findings may not be generalizable to other countries where provision of care is different.

### **Conclusion and recommendations**

This large qualitative study of family carers revealed that communication in its broadest

sense with the person with dementia and with professionals was a major issue. Family carers felt worn down by the constant ‘battles’ they experienced in negotiating the healthcare system on behalf of the person with dementia. Dying of dementia was frequently traumatic for family carers with little support and privacy and no support from specialist palliative care. Despite many publications and research on palliative care and dementia,<sup>41</sup> it is still important that all research is based on the experience of patients or their family carers who at the end of life are the advocates and the voice.

This paper is being written as we hopefully begin to emerge from the COVID-19 Pandemic which has seen a disproportionate number of people with dementia die of COVID-19. COVID-19 has disproportionately affected people with dementia, and in the post-pandemic era, there is an urgent need to ensure every person dying with dementia is supported to die in their preferred place and that family members are supported and enabled to be treated as the ‘expert’ in terms of their knowledge of their relatives’ care and preferences.

Communication with family members and determining their views regarding care at the end of life is essential as is ensuring people with dementia can die in their usual place of care among familiar surroundings. Although there is a belief that an ACP appears integral to aid delivery of good end of life for people with dementia, their completion can be problematic and very few people currently have a completed ACP. In such situations, it is essential to discuss with and include close family carers as partners in the care of the person with dementia as they know the person. If end-of-life decisions have not previously been discussed, family carers will be able to advise what may be the best care based on prior knowledge of what the person with dementia may or may not want. It is unclear whether the increase in numbers of people with dementia dying at home in the United Kingdom will continue, but what remains clear is the need for excellent communication along with support and respect for carers acknowledging their expertise, which with co-ordinated care will allow those with dementia to die in comfort and with dignity in the location of their choice.

### **Ethics approval and consent to participate**

Full ethical approval was awarded to this study by the University of Liverpool ethics committee.

The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. All data collected for this study was with the full informed consent of all participants. Full ethical approval from University of Liverpool ethics committee was obtained for this study (RETH000206).

### Consent for publication

All family carers who participated in the study consented to the publication of anonymised qualitative data.

### Author contribution(s)

**Jacqueline Crowther:** Data curation; Formal analysis; Investigation; Methodology; Writing – review & editing.

**Siobhan Horton:** Formal analysis; Methodology; Project administration; Writing – original draft; Writing – review & editing.

**Kenneth Wilson:** Formal analysis; Project administration; Writing – review & editing.

**Mari Lloyd-Williams:** Conceptualisation; Formal analysis; Funding acquisition; Investigation; Methodology; Supervision; Writing – original draft; Writing – review & editing.

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### Conflict of interest statement

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Availability of data and materials

Raw data as in qualitative interviews is available by contact with authors

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