

# Family caregivers' and professionals' experiences of supporting people living with dementia's nutrition and hydration needs towards the end of life

Yolanda Barrado-Martín BA, MSc, PhD<sup>1</sup>  | Pushpa Nair MBBS, BSc<sup>1</sup>  |  
Kanthee Anantapong MSc, FRCPsychT<sup>2,3</sup>  | Narin Aker BSc, MSc<sup>1</sup>  |  
Kirsten J. Moore BSc, MSc, PhD<sup>2,4</sup>  | Christina H. Smith BSc, MSc, PhD<sup>5</sup>  |  
Greta Rait MD, MRCPGP<sup>1</sup>  | Elizabeth L. Sampson MD, MRCPsych<sup>2,6</sup>  |  
Jill Manthorpe MA<sup>7</sup>  | Nathan Davies BSc, MSc, PhD<sup>1,2</sup> 

<sup>1</sup>Centre for Ageing Population Studies, Research Department of Primary Care and Population Health, University College London, London, UK

<sup>2</sup>Marie Curie Palliative Care Research Department, Division of Psychiatry, University College London, London, UK

<sup>3</sup>Department of Psychiatry, Faculty of Medicine, Prince of Songkla University, Hat Yai, Thailand

<sup>4</sup>Melbourne Ageing Research Collaboration, National Ageing Research Institute, Melbourne, Victoria, Australia

<sup>5</sup>Language and Cognition, Division of Psychology and Language Sciences, University College London, London, UK

<sup>6</sup>Barnet Enfield and Haringey Mental Health Trust Liaison Team, North Middlesex University Hospital, Edmonton, UK

<sup>7</sup>NIHR Health and Social Care Workforce Research Unit and NIHR Applied Research Collaborative (ARC) South London, King's College London, London, UK

## Correspondence

Yolanda Barrado-Martín, Centre for Ageing Population Studies, Research Department of Primary Care and Population Health, University College London, Upper 3rd Floor, Royal Free Campus, Rowland Hill St., London W3 2PF, UK.  
Email: y.barrado@ucl.ac.uk

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## Abstract

The aim of this paper was to understand the needs of family caregivers and professionals supporting people living with dementia with eating and drinking difficulties towards the end of life and the strategies they use to overcome them. A total of 41 semi-structured interviews with family caregivers ( $n = 21$ ) and professionals ( $n = 20$ ) were conducted in London and surrounding areas of England. Interviews were audio-recorded and transcribed verbatim. Four themes were identified: caregivers accessing and seeking help, perceived priorities of care, professionals' supportiveness and educational role, and strategies. Caregivers often struggle as they are not aware of the eating and drinking difficulties associated with dementia's progression. Care can change over time with families prioritising a person's comfort towards the end of life rather than ensuring a particular level of nutrition. Mutual support is required by both professionals and caregivers to enhance the care of the person living with dementia. Cognitive difficulties are often behind initial eating and drinking challenges in dementia, whereas physical challenges take over towards the later stages. Flexibility and creativity are key to adapting to changing needs. There is a need to raise awareness of the eating and drinking challenges associated with the progression of dementia. Professionals can help caregivers embark on the transition towards focussing on comfort and enjoyment of eating and drinking near the end of life rather than nutrition. This is particularly relevant for those caring for a relative living at home. Caregivers' input is needed to tailor professionals' recommendations.

## KEYWORDS

challenges and strategies, dysphagia, eating and drinking, palliative care, qualitative research

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### What is known about this topic?

- People living with dementia tend to develop eating and drinking difficulties towards the end of life.
- Family caregivers find it difficult to acknowledge and support eating and drinking difficulties.
- Artificial nutrition and hydration is not recommended towards the end of life in dementia.

### What this paper adds?

- Family caregivers need to be aware of potential eating and drinking difficulties before these occur.
- Family caregivers supporting the person living with dementia in the community need practical advice and strategies to support eating and drinking difficulties.
- Professionals need to facilitate family caregivers' transition towards a care approach focused on comfort rather than nutrition when the end of life is approaching.

## 1 | INTRODUCTION

It is estimated that globally, every 3 s a person is diagnosed with dementia, and most people with dementia live at home. The contribution of family caregivers is estimated worldwide as representing 82 billion hours annually (Wimo et al., 2018) with considerable impact physically, emotionally and financially. Professionals are encouraged to see the support of caregivers as an essential part of dementia care (World Health Organization, 2017).

The trajectory of dementia affects people differently (National Health Service, 2020). However, greater reliance on others is common (Giebel et al., 2015). Towards the later stages and nearing the end of life people are often completely reliant on others. They often experience a loss in appetite, a reduction in food and drink intake and difficulties with swallowing or dysphagia (Arcand, 2015). Swallowing problems may lead to further health complications such as malnutrition, dehydration, aspiration and pneumonia (Arcand, 2015; Guigoz et al., 2006; Neuberger, 2013; White et al., 1996). Managing difficulties with eating and drinking often worry caregivers (Papachristou et al., 2017), who fear their relative is not eating enough (Ball et al., 2015).

Little is known about the needs of caregivers and the strategies they use to manage these eating and drinking difficulties at any stage of the dementia trajectory (Ball et al., 2015; Mole et al., 2019), including the end of life. A systematic review of the experiences of family caregivers and practitioners supporting people living with dementia with eating and drinking towards the end of life revealed most studies focused on the experience of practitioners working in medical or long-term residential settings rather than the views of caregivers (Barrado-Martín et al., 2020). Practitioners reported lacking the training and confidence to support caregivers in making decisions about eating and drinking towards the end of life (Chang et al., 2009; Smith et al., 2016).

Qualitative studies have focused mainly on exploring professionals' or caregivers' views on the use of artificial nutrition and hydration (ANH) at later stages (Pasman et al., 2004; The et al., 2002) rather than alternative ways of supporting oral nutrition and hydration (Barrado-Martín et al., 2020). However, ANH is not currently recommended towards the end of life in dementia in the United Kingdom

(NICE, 2018; Sampson et al., 2009). Likewise, research has concentrated on exploring challenges rather than the strategies employed and recommended by caregivers and professionals (Barrado-Martín et al., 2020). Particularly, strategies used by caregivers are underexplored (Barrado-Martín et al., 2020) and might differ notably from those used in medical or long-term residential settings. Hence, we need to understand both the needs and strategies used at home by caregivers and professionals supporting people living with dementia towards the end of life. This could help inform practice, information and resource development.

The aim of this study was to explore family caregivers' and professionals' awareness of eating and drinking difficulties experienced by people living with dementia towards the end of life at home, as well as caregivers' needs and ways of overcoming such difficulties. We had four research questions:

1. What are caregivers' and professionals' understandings of eating and drinking difficulties towards the end of life in dementia?
2. What are the changes in nutrition and hydration needs experienced by people living with dementia and caregivers towards the end of life?
3. What eating and drinking challenges are encountered by caregivers and professionals when supporting the person living with dementia towards the end of life?
4. What strategies are used by caregivers and professionals to overcome eating and drinking challenges when supporting the person living with dementia towards the end of life?

## 2 | METHODS

### 2.1 | Participants

We recruited 21 caregivers and 20 professionals. We invited 64 carers and 36 professionals; of those who agreed to take part, none subsequently withdrew. Professionals were recruited from five National Health Service (NHS) organisations, a primary care practice, and a

not-for-profit dementia organisation using a combination of purposive and convenience sampling, capturing a range of different roles, expertise and experiences. Current and former caregivers were purposively recruited from five NHS organisations, four primary care practices, the Join Dementia Research website and the Alzheimer Society's forum.

Reflecting inclusion and exclusion criteria (see Table 1), caregivers were recruited if they self-identified as looking after someone living with dementia at the later or end of life stages. Professionals were recruited if working with people living with dementia and caregivers and advising on eating and drinking difficulties towards the end of life.

Caregivers' and professionals' characteristics are summarised in Table 2.

## 2.2 | Design

Guided by a constructivist approach, this was a qualitative study which adopted an inductive approach to data collection and analysis. Separate interview schedules were developed for professionals and caregivers based on literature review and feedback from experienced clinicians and researchers. The interview schedule included open-ended questions and three case vignettes to facilitate discussion around aspects that might have not been covered in full during the interview. Caregivers' semi-structured interviews included questions about their experiences supporting their relative with eating and drinking, caregiving's impact on their wellbeing, sources of support used and unmet needs. Professionals were asked about the causes of eating and drinking difficulties, strategies they recommend for managing those, more generally about their experiences of providing support and what is relevant at the end of life. Interviews were audio-recorded. Following the interview, participants completed a demographic questionnaire.

## 2.3 | Procedure

Participants were provided with an information sheet and given 48 hr to consider participation. Professionals were contacted by email, whereas caregivers were first contacted by letter, phone or email depending on recruitment source and preferences. Those

expressing interest in participation were contacted about arranging a convenient interview date, time and place.

Interviews took place between June 2019 and May 2020. Participants could choose to travel to the University hosting the research to be interviewed or be interviewed elsewhere (e.g., workplace, café or at home). With the advent of Covid-19, interviews took place by telephone. Before starting the interviews, participants were reminded of the purpose of the study, and informed consent was collected. Participants were given a £20/\$22 voucher in thanks for their time.

Interviews with professionals lasted between 45 and 105 min; those with caregivers, between 35 and 134 min. Interviews were transcribed verbatim, listened back, checked for accuracy and anonymised.

## 2.4 | Ethical considerations

Ethical approval was received from a National Research Ethics Committee (19/LO/0369). There was a distress protocol created before we started data collection which outlined steps if a participant became distressed, approved by the ethics committee. The protocol included signposting participants to dementia charity support lines, and if there was a risk to the participants or someone they provide care for, we followed local safe guarding procedures. However, no participants became distressed during the interviews.

## 2.5 | Researcher characteristics

Two female researchers in their thirties (first and second author) with backgrounds in psychology and medicine and both with experience of working with and interviewing people living with dementia and caregivers conducted the interviews. Researchers had no previous relationship with participants. Participants did not necessarily know the interviewer's background.

## 2.6 | Data analysis

Transcripts were organised in separate Nvivo 11 files and thematically analysed following the six steps outlined by Braun and Clarke

**TABLE 1** Participants' inclusion and exclusion criteria

Participant	Inclusion	Exclusion
Family caregivers	Family member or friend for person with dementia who identifies as a caregiver (current or bereaved/former) Participants must be able to provide informed consent Participants must be able to read and speak English	They have cognitive impairment themselves Caregivers bereaved in past 3 months
Professionals	Practitioners in either health or social care, supporting someone with dementia Experienced in providing end of life care and nutrition/diet advice Participants must be able to provide informed consent Participants must be able to read and speak English	

**TABLE 2** Participants' demographic characteristics

Participant	Item	Frequency or mean (SD)
Family caregivers (n = 21)	Gender	
	Male	7
	Female	14
	Age	
	M (SD)	60 (11.79) [Min 28, Max 81]
	Caregiving situation	
	Currently caring for someone with dementia	14
	Previously cared for someone with dementia (bereaved)	7
	Relationship with the person living with dementia	
	Daughter	9
	Son	2
	Wife/partner	3
	Husband/partner	2
	Granddaughter	1
	Son-in-law	3
	Daughter-in-law	1
	Type of dementia diagnosed to the person living with dementia (if mentioned during the interview)	
	Alzheimer's	5
	Mixed (Alzheimer's and vascular)	2
	Vascular	3
	Frontotemporal	2
Lewy body	1	
Multisystem atrophy	1	
Not reported	7	
Marital status		
Married/civil partnership	10	
Co-habiting with partner	2	
Single, never married/in a civil partnership	4	
Divorced	2	
Widowed	3	
Ethnicity		
White – English/Welsh/Scottish/Northern Irish/British	9	
White – other (European)	2	
Mixed/multiple ethnic groups – White and Asian	1	
Asian/Asian British – Indian	3	
Asian/Asian British – Pakistani	2	
Asian/Asian British – Bangladeshi	1	
Asian/Asian British – Chinese	1	
Black/African/Caribbean/Black British – Black Caribbean	2	
Age when left full time education		
Before the age of 15 years	1	
At the age of 15 or 16 years	1	
Between the age of 17 and 20 years	3	
After the age of 20 years	16	

(Continues)

TABLE 2 (Continued)

Participant	Item	Frequency or mean (SD)
Professionals (n = 20)	Gender	
	Male	5
	Female	15
	Age	
	M (SD)	45 (11,47) [Min 28, Max 64]
	Current occupation	
	Dietitian	1
	Nurse (clinical lead/end-of-life facilitator/admiral nurse/memory service/clinical specialist/palliative care)	6
	Doctor (old age psychiatrist/specialty doctor (memory service)/general practitioner (GP)/palliative care doctor/geriatric medicine registrar)	6
	Occupational therapist (clinical lead/senior)	2
	Speech and language therapist	3
	Dementia link worker	1
	Day care centre team manager	1
	Current position based at...	
	Community	14
	Hospital	2
	Care home	1
	Combination (community and hospital, community and care-homes or hospital and hospice)	3
	Years in current role	
	Less than 1 year	1
	1–5 years	5
	5–10 years	5
	More than 10 years	9
	Years working with people living with dementia	
	1–5 years	3
	5–10 years	7
	More than 10 years	10
	Marital status	
	Married/civil partnership	8
	Co-habiting with partner	4
Single, never married/in a civil partnership	5	
Divorced	3	
Ethnicity		
White – English/Welsh/Scottish/Northern Irish/British	13	
White – Other (European)	3	
Mixed/multiple ethnic groups – White and Asian	1	
Mixed/multiple ethnic groups – Other not specified	1	
Asian/Asian British – Pakistani	1	
Asian/Asian British – Chinese	1	

(2013). After familiarisation with the data an initial coding framework was developed, shared and discussed with the authors. This initial framework was common for both caregivers and professionals' interviews as the content of interviews was similar. After thematically

analysing the interviews separately, comparisons were made between findings from caregivers and professionals, as reflected in the findings section. Themes were identified after re-reading the content of the codes once initial coding of interviews was complete.

### 3 | FINDINGS

Four main themes were identified: caregivers accessing and seeking help, perceived priorities of care, professionals' supportiveness and educational role and strategies used to support eating and drinking.

#### 3.1 | Caregivers accessing and seeking help

Some caregivers did not seek advice at the onset of difficulties with eating and drinking among those supported but struggled on their own or did their own research before reaching an understanding of the person's changing needs. Some felt general practitioners (GPs) did not know how to support people with dementia 'I mean they are very good GPs. Don't get me wrong. They don't have a clue. They don't have a clue [about dementia]. (Carer, C23)'. Additionally, several reported limited follow-up from community services and limited communication between services 'It's back and forth and there was no communication [between memory clinic, GP and care of the elderly specialist]' (C22). Others felt advice was over-general '...[dietitians] gave me a list of things to buy (...) I did try her for cereals and (...) she said, no, I don't like that, so I didn't do that anymore' (C13). Experiences of oscillating between services had prompted a need to seek their own solutions:

Sometimes you're on the frontline and you don't know what to do, but I would say at the end of the day it seems everybody reverts back to the GP. So that's what everybody seems to do. I always check in with the GP and we go by what they say. But just sometimes the people at the Memory Clinic have different information which the GP doesn't have. So that was a bit of ... I found myself being 'ping ponged'. (C09)

On the other hand, professionals felt caregivers should seek early help '...if they're worried, they should go and seek help' (Professional, PF11). and that this was easy to access, although there might be other cultural barriers at play:

I mean the best thing is to have discussed with them at the beginning, with patients, and then to have an awareness of this might happen later on in their dementia and then to have made their own opinions, I suppose, about what they wanted. But I suppose in carers (caregivers) there's no harm in them as if they're got any worries to seek the help of professionals to reassure them or investigate... (PF08)

I think people from the Indian subcontinent particularly. I find that they do a great job looking after their parents, but I think there's probably a point where actually, really they need to get some sort of professional help. (...) And sometimes it's seen as shameful, if they do that. (PF16)

However, for some caregivers before they sought support, they were often unaware of the eating and drinking difficulties associated with the progression of dementia. This lack of understanding instead contributed to some frustration when difficulties appeared.

For example, when a caregiver had spent a long time cooking and only a little was eaten: 'There are times when I'm frustrated, and I say, no, look how much I've done. And then I say to her, mum, shall I eat it?' (C22). Much time could be spent trying to please the person with food they always enjoyed:

...for a lot of time I'd get quite frustrated with her for not eating the things that I'd bought, even though I knew that traditionally those were the kinds of things she liked. Sometimes she'd be quite difficult about eating them and I'd get quite angry about that because I thought I'd bought this specially for you and why you not eating it? (C18)

Likewise, frustration arose with constant prompting to eat: 'I do get frustrated when every meal, you think about every meal, I have to talk her through and through, through [encouraging the person to keep eating]' (C27). or meals required substantial time and energy. Even with knowledge of eating and drinking difficulties, meals could be a further source of distress for caregivers when managing aspiration risks:

I find the whole thing stressful. Even swallowing tablets; she struggles so much. Sometimes with her eating she does struggle. Sometimes you try to reduce the risk of aspiration as much, as much as possible. And sometimes trying to persuade her to eat something savoury she doesn't like it or she starts coughing then the whole thing is a disaster. I can't feed her when she's in a coughing fit like that with food coming out. (C09)

The experience of most caregivers was that early help had not been forthcoming and had allowed their frustrations to continue. On encountering difficulties supporting the person living with dementia with nutrition and hydration, particularly due to the unpredictability of their changing needs and preferences, most felt they were on their own. '...At the moment, I think that I am managing okay, but after 4 years of struggle, I'm learning myself and also going on to Alzheimer's website and asking questions on the blog. I've learnt myself, you know' (C23). They spoke of using 'trial and error' strategies and would have appreciated professional support to identify suitable strategies earlier. There were differences in perceptions of the right time for such support, ranging from diagnosis to when the problems occurred. However, most would have liked to learn about potential eating and drinking difficulties either soon after diagnosis 'I think probably when she got the diagnosis, actually, they ought to have been quite up front with what's likely to happen to you, well, certainly with the family...C06' or shortly after, during follow-up consultations.

### 3.2 | Perceived priorities of care

Initially, caregivers focused on ensuring their relative was having a healthy, balanced diet. At this point, some hoped a healthy diet might help stop or slow the progression of dementia '...without a balanced diet... I've seen the progression come about. (...) But I realise, if I put that effort in now, I'll probably save them downward progression' (Current caregiver, C22). However, caregivers came to realise as dementia progressed to advanced stages that ensuring a balanced diet was no longer a priority, favouring comfort and enjoyment of food instead:

I fairly quickly decided it had reached a point where I didn't really need to bother about that [getting enough fibre, vitamins and wholegrains] either, because if, if healthy eating is going to, you know, delay the onset of dementia, then it was too late, it had already happened. (Former caregiver, C02)

There appeared differences between current family caregivers, some of whom still worried about providing a balanced, sufficient diet and former caregivers. Generally, former caregivers had modified their priorities. Their approach to supporting eating and drinking difficulties at the end of life was aligned with those of professionals who stressed the need to re-direct care towards comfort and pleasure: 'I think it is less to do with nutrition, (...) and actually looking at what is comfortable for the patient. So, I think, kind of, the focus that we really shift to is that quality of life' (PF04). Some caregivers reported coming to realise, on their own, they need not worry about ensuring nutrition at the later stages:

He was literally living on a couple of teaspoons a day of food and he lasted for months like that. (...) I read up a lot about end stage. Some of them were saying, it's more important to make sure that they're comfortable rather than forcing them to eat food because they don't feel hungry like we do. And it's like when you're ill, you're not hungry. (Former caregiver, C11)

Being in charge of nutrition and hydration was for some caregivers a role reversal (for adult children caring for a parent). For others, reminding about their relatives about eating behaviours, reinforcing a healthy sweet (candy) free diet and 'eating up' could seem a generational reversal:

And for me, it was amusing because I'm a very fussy eater, and as a child my parents were trying to make me eat. And I had the reverse trying to persuade my mother, mum, just have a few more mouthfuls of meat then you can have your pudding. It's one of the things, a role reversal that comes so often. (Adult Child, C20)

Towards the end of life, caregivers reported adapting to their relative's nutrition and hydration needs, accompanied by changes in their

own caring role and needs. Over time, many had moved from an initial supporting role (providing little help, but reminders) to taking charge of their relative's food and drink (e.g., when taking over the cooking and shopping). Later, some stopped worrying and focused more on spending quality time with their relative. Such acceptance seemed to have been a sudden realisation, prompted by encounters with information about end-of-life care, or their certainty that the person was expressing a decision to stop eating:

That seemed to work quite well for a little while and then I was actually making meals and taking them ... (to relative)... Putting them in the fridge. They only need to go in the microwave for a short time. Then after a little while I noticed that those weren't being eaten either. (C14)

...quite close to the end of her life I, I suddenly remember thinking well, did I, did I really, well the time I have with her is quite limited (...) I wanted it to be sort of quality time. (...) I'm going to either leave somebody else to worry about it or let nature take its course. (C02)

I was advised by somebody to ask for the swallowing test (...) Obviously the professional was there, but I gave her the juice or whatever it was. I said this is very important [to proof professionals that you can swallow but you do not want to], I'm going to put this, and I want you to swallow it and she did. That was the first thing after several weeks in hospital that went through her mouth. Then whatever they... I whatever it was next [mousse], same thing. I put a spoon of that in her mouth and she swallowed it. We satisfied the hospital that she was making the conscious decision to refuse the food. (C20)

### 3.3 | Professionals' supportiveness and educational role

Professionals and caregivers seemed to have different levels of understanding of the eating and drinking difficulties commonly encountered towards the end of life in dementia. Whereas professionals are familiar with the progression of dementia and its impact on nutrition and hydration, 'it's a pretty good indicator that someone's going downhill with their dementia when they're no longer wanting to eat and drink much' (PF02); they know family caregivers often lack this knowledge. Some professionals had encountered relatives being over-insistent on feeding:

...a lot of families that I saw [in the care home] used to get very stressed. They had to feed them

TABLE 3 Strategies reported by family caregivers and professionals, and illustrative quotes

Strategies	Example quotes (participant)
Strategies to support eating and drinking at any stage	
Encouragement, persistence, prompting, support and supervision of meals	<p><i>She can't concentrate on more than one thing at a time, so if she looks away, you're never sure what she's looking at, and she stops, and you've got to say, now, come on, just keep on... (C13)</i></p> <p><i>So I remind her, you have to drink or else you'll end up in hospital on the drip again, and she doesn't want to go to hospital she says, and she doesn't want drips because the cannula is quite painful to have it there. (C09)</i></p> <p><i>...trying to persuade my mother, mum, just have a few more mouthfuls of meat then you can have your pudding. (C20)</i></p> <p><i>Nine out of ten, she will not remember to take it [medication]. So you have to keep an eye on it and say, have you finished your breakfast? Now take your medicine. (C29)</i></p>
Making adaptations (to the food and diet, but also times, speed, volume/portions, to the way food is prepared and presented – tasty and colourful, medications, and also to the environment – including social mealtimes and cutlery adaptations)	<p><i>I just add a tiny amount of food thickener into that [blended meal] to thicken it up to the right thickness. (...) we were told to do things like putting extra butter in and extra food... milk powder. (C06)</i></p> <p><i>She used to eat one full plate (...). She now only probably has a quarter of it, and the quarter that she does have is constantly prompting her and making sure that she eats. (C26)</i></p> <p><i>The meat and chicken, I try and make it as soft as I can. (C26)</i></p> <p><i>...going around with different colours of drinks, and different flavours. To try and encourage people. Even making ice cubes or ice lollies. (C14)</i></p> <p><i>...if she's just sat there with loads in her mouth, that's when, you know, probably need to be looking at a more 'little and often' type approach. (PF03)</i></p> <p><i>I think eating collectively does work. It really does because if my friend comes around we go and eat with mum. She eats because it's a social interaction. (C28)</i></p> <p><i>No. It makes no difference [when the person living with dementia has people around during meals]. (C26)</i></p> <p><i>...she'll grab the spoon because that's easier for her to control. Sometimes she uses her right hand and sometimes she uses her left. But it doesn't matter, it could be a teaspoon, or it could be a medium sized, like a dessert spoon. As long as she eats something. (C07)</i></p>
Using a flexible approach, by using trial and error	<p><i>It's just all distraction, but there's no way I could write a scenario and tell you what's going to work tomorrow. (C17)</i></p> <p><i>Only what I've told you and how I learnt it myself was trial and error, really, about when he stopped eating when he was ill. (C11)</i></p>
Artificial nutrition and hydration (ANH)	<p><i>I think you just have to accept, um, that, you know the, it's probably best this is the time they're going to die and you know, just keep them comfortable, rather than put them in [ANH]. Although dehydration's not a particularly great way of dying. I mean that might have to be. Sometimes if people get delirium and get acutely confused and stop drinking, I know sometimes you can put sub cut [subcutaneous fluid] in, in the community. As a way of keeping fluids up. For a very short time, that's not something you'd want to do but just while there's a reversal situation, so you can try that. Um, so well I think with everything it's an individual, you know, depending on the carers (family), the patient, what would be best on the individual case. (PF03)</i></p> <p><i>If you think about it, in all honesty, if you've reached that [end of life] stage unless it's for symptom relief, I think we'll have to think really hard about whether or not [artificial hydration] it's worthwhile, if they are struggling with obviously thirst and they are unable to swallow for whatever reason and they don't have a PEG, I would certainly consider it just to make sure that they're not suffering in any way from that thirst. It is sometimes hard to administer subcutaneously in the community. I think it's more likely to happen in a hospice or in a hospital. (...) I think if I had a younger patient with dementia. We have the odd few in their fifties I think I would consider that [ANH]. The majority our patients are above 80, to be honest. And I think in that instance I don't think it would be appropriate. (PF16)</i></p> <p><i>...in some cases we have to be pragmatic about that. But I think dementia, where whilst the swallow may be impaired, it's more the desire to eat, and the cognition to do the chewing and the eating, and the understanding the need to eat; that can't be fixed with the tubing. Whereas if it's a purely muscle problem, then a tube will fix that for you. (PF19)</i></p> <p><i>...if we had a robust district nursing service that could go and set up little bags of fluids, I think possibly there'd be some people with advanced dementia that might occasionally have a little bag of fluid. I would question whether that's for the patient's benefit or the family's, and the anxiety. But, equally, when you look after someone, you've got to look after someone as a whole. And if it's not going to do any harm, but we're not going to lengthen anything either, then I guess you'd have to look at that. (PF20)</i></p> <p><i>I will admit, I'm not 100% sure about the guidelines [on ANH]. (PF15)</i></p> <p><i>There are national guidelines on enteral feeding, on ... for assisted hydration and nutrition. Lots of national standards and guidelines. (PF17)</i></p> <p><i>[Asked if ANH would be an option in a scenario depicting eating and drinking difficulties] Not unless they were very, very impaired and they were perhaps during their latter stage of life. When you see artificial nutrition and hydration I'm thinking of drips and tubes basically. So I would think that's a last resort. (C09)</i></p> <p><i>If they really can't swallow, I think there would be very few cases where artificial nutrition would be appropriate. (C20)</i></p> <p><i>My mum-in-law has got these tubes, and she wasn't happy, even the doctor said, yes she's not happy with those tubes, and she's not actually taking the liquids in and stuff. But they had to because she was in ICU, her body had stopped functioning, so they were forced to do that. And that's I think the last, last resort I guess. In a normal home environment I do not think that would work, frankly. (C25)</i></p> <p><i>If they can't eat anything through the mouth, there is no choice, you have to feed them through the tube. (...) They should have a peaceful life and peaceful death. Taking her to the hospital and putting a tube, that is going to ruin the whole... As a person, that's going to ruin everything, make it more stressful, more painful. That's not a good choice. Of course, you have to maintain the nutrition. It's like putting them in more danger and more trouble. Try alternate ways. Other than taking them to hospital just for feeding needs, look for alternate ways. (C35)</i></p>

(Continues)

TABLE 3 (Continued)

Strategies	Example quotes (participant)
<i>Strategies incorporated towards the end of life</i>	
Adapting communication	<i>...it's difficult when you give her a choice because she can't remember what the choice is. You run off two or three things, and she says, yes, yes, and I'll say, which one, and I'll have to go through them slowly. (C13)</i> <i>So the other day, I said, will you have a scone with tea? Because that's something that comes out naturally and he looked at my face. So I got him the scone and I got him the biscuit and I said, you'd like that... So he said, I'll have that. (C23)</i>
Keeping a routine	<i>I still think routines help. (...) So, certainly, I am too, very much, a creature of habit. We do things that probably help. (C14)</i> <i>I've got him in the routine of fruits, homemade fruit juice with carrots and things like that, a breakfast. (C23)</i> <i>I tried to have some kind of structure, but at the time, to be honest, I don't even know, if she gets up, I get up and make sure that she's all right. (C24)</i>
Mouth care	<i>...mouth care, so, [food] it's not left in her mouth. (...) ... oral hygiene, using mouth washes, uh, and things like that. So if she was going to aspirate it would be less bacteria on the aspirate. (PF03)</i> <i>Oral care is another really important thing, so mouth care. We know that, actually, dysphagia in itself isn't a, kind of, the primary cause of aspiration pneumonia, its actually aspirating air bacteria, so mouthcare is a really, really important thing. (PF04)</i>
Comfort feeding and making of eating and drinking a pleasurable experience	<i>If she's at the end stages, I'd just, sort of, say maybe this is, kind of, progression of the disease, and just try your best, see how you go. Um, just give her as much as she can tolerate. (PF01)</i> <i>When their life expectancy is short, provide them with comfort rather than trying to be overly medicalising everything. (PF19)</i> <i>If somebody isn't taking any pleasure out of what they're eating, then they're not going to want to eat it, firstly. But it's also about tapping into those senses that are left with somebody in the later stages of dementia. Because the senses, obviously, are so important in terms of the smell of something. I think being able to tempt people with dementia with the smell of food is really, really important. Literally, whet their appetite and bring back any memories. (PF12)</i>
Body position and ensuring full awareness	<i>I have to gauge how she is. I have to see is she awake enough... (C09)</i> <i>...she is very dependent on staff being able to sit her up for meals and make sure she's in the right position. And left to herself, even when she's not eating, she will tend to list sideways to the left and compress her chest and have a lot of dribble down her left side. So, she's at risk of choking from the dribble. (C18)</i>
Use of nutritional supplements	<i>The Ensure drinks [nutritional drink] are the big things. Pro-Cal shot [nutritional drink], you get from a prescription as well and it's a little container, this sort of shape, smaller, and it will have say 120ml in this container. And then it comes with a little pot and it will measure out 30mls which is about three tablespoons. (C07)</i> <i>...a lot of people would use Ensure drinks, so the high calorie, very sweet, kind of sickly sweet drinks, and often, that would be used as a way to supplement people's diets if they weren't able to consume. We very often liaise with GPs to get those prescribed for people. (PF06)</i>

[relatives living with dementia] and you could see that they're almost force-feeding their loved ones (...) But what I learnt [through reading and experience] was the most important thing was to make sure somebody was comfortable. They don't need that much food. (C11)

In such circumstances, professionals thought that caregivers needed professional support to understand and accept dementia progression. Caregivers themselves would have liked both emotional support to accept and adapt their caring role towards the end of life and practical information on how best to help meet nutrition and hydration needs. One commented: 'Don't tell me I'm doing a fantastic job because I know I'm doing it, but I don't want to hear it from... I want you to advise me. What do I do [about looking after X]?' (C23). Professionals said they were aware of these transitions and how adaptations were not always intuitive for caregivers and felt they should not need to find answers on their own:

You'll have some patients' families who are going to struggle coming to terms with it a lot more. I've had a patient like that this week who... I think the daughter

actually, once we'd sat down and had a longer conversation... (...) once I sat down and gave information on mouth care, she actually... because that, again, I guess, gives you an alternative, something you can focus on. Because, I think as carers (caregivers) they want to have something, don't they? It's something that you can do to improve someone's quality of life. (PF04)

Professionals acknowledged the potential for caregiver distress when the person living with dementia was eating and drinking less. Some felt this was the time to exchange information during assessments, to support caregivers and to tailor interventions:

So, instead of isolating the carers, encouraging the carers to reminisce on what they knew and use that information. So, working together rather than we're the professionals, you're the family but we know better. We don't. You know them better than we do, so tell us. (PF10)

...you can think together [carer and professional] about how you might get food into them in one way

or another... But, yes, it's not the end of the world if they don't. (PF05)

Professionals thought carer education was particularly important so families would be aware of the natural dying process to prevent feelings of guilt if the person rejects food and drink or when artificial means of nutrition and hydration are not taken up:

I guess it's trying to help her [caregiver] understand that it's end-of-life and that's what end-of-life ... this is the natural part of end-of-life and it's part of it even though it's ... It's quite distressing [for caregiver] but maybe not distressing for [person living with dementia] ... it may be more distressing for her mother to be trying to eat and drink than not having anything to eat and drink. It might be more comfortable for her not to be eating and drinking. It's not necessarily painful, um, trying to swallow maybe is more painful. (PF07)

Professionals and caregivers reported similar challenges overall; however, caregivers seemed less aware of how depression, anxiety or delirium might be impacting on nutrition and hydration. Caregivers talked more about the practical challenges of care, such as accommodating changes in preferences or behaviour.

### 3.4 | Strategies used to support eating and drinking

Strategies evolved and frequently required a trial and error approach by caregivers. Towards the end of life the use of comfort feeding (by providing only the food and drink that the person wants), reducing the time spent on food preparation (e.g., relying on pre-prepared meals) or focusing on making the eating and drinking process enjoyable were widely adopted and recommended. Specific strategies reported by caregivers and professionals are reported in Table 3.

Professionals also referred to trial and error, or the use of creativity to find the best way of supporting the person living with dementia towards the end of life, to identify suitable and pleasurable food/drinks towards the end of life. They placed more emphasis on oral hygiene and mouth care as a good strategy towards the end of life. Professionals also seemed more aware of the ethical implications of misusing strategies like covert medication and 'lure and trick', whereas caregivers reported using these as strategies. Lastly, caregivers spoke more about using nutritional supplements and making environmental changes, such as sharing mealtimes or preparing food in tasty and colourful ways to raise the person's interest.

Finally, most caregivers said ANH should only be used as the last resort or when there is no alternative; indeed, most professionals seemed opposed to its use. Professionals reported leaving their personal views aside and providing families with pros and cons of each treatment option. However, some did not discuss the option of ANH, which could be a reflection of personal views.

## 4 | DISCUSSION

To our knowledge, our study is the first to focus on the needs of and the strategies used by those supporting a person living with dementia with eating and drinking difficulties in the community towards the end of life. Qualitative studies exploring the experiences of caregivers and professionals have often focused on ANH and not covered other aspects of eating and drinking in dementia. Family caregivers' views are under-explored in the literature, meaning we have little evidence of what they consider to be acceptable and effective strategies to promote oral nutrition.

Professionals and caregivers in our study expressed some different understandings of the eating and drinking difficulties commonly encountered towards the end of life in dementia. Unsurprisingly, professionals appeared more aware of the progression of dementia and characteristics of the dying process that impact on nutrition and hydration. This contrasts with other studies reporting professionals' limited understanding of the progression of dementia or the dying process (Kuven & Giske, 2015; Lopez et al., 2010; The et al., 2002). Our study revealed that caregivers were not necessarily aware of the impact of dementia on eating and drinking when nearing the end of life, did not necessarily seek professional help when difficulties emerged and often struggled for some time before seeking help or finding a strategy that worked for them.

Towards the end of life, people living with dementia and caregivers undergo a change in needs and roles that may benefit from skilled professional facilitation. This would need to include both emotional support to understand changing needs at end of life and practical advice (Mole et al., 2019) rather than simply reassurance. Regular contact with families might promote a bidirectional exchange of knowledge between professionals (passing their knowledge about processes) and caregivers (sharing their knowledge of the person living with dementia's preferences and changes in eating and drinking patterns).

Both professionals and caregivers agreed that there is no 'one-size-fits-all' solution to eating and drinking challenges and advocated a 'trial and error' approach. This aligns with other research not focused on the later stages of dementia (Ball et al., 2015), which also found caregivers needing to be patient yet persevering, particularly when meals become time-consuming (Austbo Holteng et al., 2017; Bryon et al., 2010). However, caregivers would appreciate professional help in finding successful strategies to adapt to the changing needs of their relative. Such support could reduce their frustration, as reported by others (Lopez & Amella, 2011).

As with other studies, caregivers in our study described ANH as a last resort (Gessert et al., 2006; Gil et al., 2018; Pasman et al., 2004). Likewise, professionals in our study maintained that ensuring comfort was key at the end of life (Bryon et al., 2010) and emphasised they would not recommend artificial nutrition (Berkman et al., 2019; Bryon et al., 2012). However, in our study, most professionals were not against the use of artificial hydration although those with more experience in end-of-life care noted the lack of benefit if liquids accumulate in certain areas of the body, leading to discomfort.

## 4.1 | Strengths and weaknesses

Among the strengths of this study are the efforts made to include a diverse sample, by including minority ethnic participants representing the demographics of the study areas. Likewise, we interviewed former and current caregivers which enabled us to obtain broad perspectives about caring. Finally, most professionals interviewed were community-based, but some worked in more than one setting, offering a range of practice experiences.

In terms of covering a broad range of perspectives, inclusion of more participants with different cultural or demographic backgrounds (most caregivers had substantial years of full-time education) would add to understandings about access to information and attitudes to professionals. We did not recruit domiciliary care workers who may have provided help with meals and observed interactions.

## 4.2 | Implications for research and practice

Firstly, professionals may have information that is timely and meaningful for caregivers when the focus of care changes with the approach of the end of life. Research is needed to establish how best to help caregivers identify the time to shift their focus on nutrition to comfort. This is a time when there is likely to be increased engagement with healthcare professionals (over continence, medications, skincare, other illnesses) so the subject of nutrition could be addressed.

Secondly, our finding that many caregivers are not aware of the potential impact of dementia on nutrition and hydration, particularly in the long-term, suggests a need for information to prompt discussions, should they wish, before dementia progresses. This could include information about the use of ANH, which may seem the only option if the person is not eating and drinking. Research could explore how to promote professionals' engagement in such conversations, how they engage families with decisions and their ethical reasoning for each option.

Finally, professionals could develop a common message and approach, to avoid caregivers feeling they are provided with different information depending on the service consulted, as well as inter-professional sharing of information. Other studies have observed that professionals concentrate on immediate priorities or crises and are not available to families (Manthorpe et al., 2018). Such delays may foster a lack of trust in professionals yet reflect limits in service capacity to support carers. Improved post-diagnostic support in UK dementia care could include more attention to nutrition and hydration in both its practical and emotional aspects, the components of which need to be agreed upon with professionals, caregivers and people with dementia.

## 5 | CONCLUSION

Caregivers are often unaware of the emerging eating and drinking challenges as dementia progresses, which leaves them struggling when

these appear. Post-diagnostic support should sensitively cover these subjects. Mutual collaboration and knowledge sharing between family caregivers and professionals may promote the successful identification of strategies to support comfort and enjoyment towards the end of life.

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### CONFLICT OF INTEREST

Authors report no conflict of interests.

### AUTHOR CONTRIBUTION

Y. Barrado-Martín contributed to study design, recruited participants, acquired all data from professionals and half from the sample of family caregivers, analysed and interpreted the data and wrote the paper. P. Nair contributed to the design of the study, recruited half the sample of family caregivers and acquired data from them, contributed to data interpretation and revising the paper and approved the final version to be published. K. Anantapong contributed to data analysis, data interpretation and revising the paper and approved the final version to be published. K. J. Moore contributed to study design, data interpretation and revising the paper and approved the final version to be published. C. H. Smith contributed to study design, data interpretation and revising the paper and approved the final version to be published. G. Rait contributed to study design and revising the paper and approved the final version to be published. E. L. Sampson contributed to study design and revising the paper and approved the final version to be published. J. Manthorpe contributed to study design and revising the paper and approved the final version to be published. N. Davies conceived and designed the study, supervised data collection and data analysis, contributed to the interpretation of the data and revising the paper and approved the final version to be published.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

### ORCID

Yolanda Barrado-Martín  <https://orcid.org/0000-0002-9912-6345>

Pushpa Nair  <https://orcid.org/0000-0001-7326-7716>

Kanthee Anantapong  <https://orcid.org/0000-0003-3190-4355>

Narin Aker  <https://orcid.org/0000-0003-1618-1072>

Kirsten J. Moore  <https://orcid.org/0000-0002-8631-3213>

Christina H. Smith  <https://orcid.org/0000-0001-7803-9616>

Greta Rait  <https://orcid.org/0000-0002-7216-7294>

Elizabeth L. Sampson  <https://orcid.org/0000-0001-8929-7362>

Jill Manthorpe  <https://orcid.org/0000-0001-9006-1410>

Nathan Davies  <https://orcid.org/0000-0001-7757-5353>

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