

QUALITATIVE PAPER

Communication between the multidisciplinary team and families regarding nutrition and hydration for people with severe dementia in acute hospitals: a qualitative study

KANTHEE ANANTAPONG^{1,2}, NATHAN DAVIES^{1,3}, ELIZABETH L. SAMPSON^{1,4}

¹Marie Curie Palliative Care Research Department, Division of Psychiatry, University College London, London, UK

²Department of Psychiatry, Faculty of Medicine, Prince of Songkla University, Hat Yai, Thailand

³Centre for Ageing Population Studies, Research Department of Primary Care and Population Health, University College London, London, UK

⁴Department of Psychological Medicine, Royal London Hospital, East London NHS Foundation Trust, London, UK

Address correspondence to: Kanthee Anantapong. Email: anantapong.l8@ucl.ac.uk, kanthee.anan@gmail.com

Abstract

Background: When a person with severe dementia is in hospital and has eating and drinking difficulties, communication between the multidisciplinary team and families can be challenging and lead to suboptimal care.

Objective: To gain in-depth understanding about the experiences, views and needs of family carers and hospital staff, regarding communication and conversations about nutrition and hydration, for hospital patients with severe dementia.

Design: Qualitative semi-structured interview study.

Setting: Acute hospital in England.

Methods: From January to May 2021, semi-structured interviews were conducted with 29 family carers and hospital staff. Interviews were transcribed verbatim and analysed using reflexive thematic methods.

Results: Four overarching themes were developed: (i) prerequisites to initiating communication about eating and drinking; (ii) communication aiming to develop agreed care plans; (iii) difficulty discussing palliative and end-of-life care; and (iv) needs of information and plans about future eating and drinking difficulties. Families tended to wait for hospital staff to initiate discussions but usually experienced frustration with delays and repeated conversations with different staff. Some staff felt unprepared to manage these conversations and found it challenging to work across the multidisciplinary team. During discharge processes, key information and care plans about eating and drinking were not regularly passed on to people involved to avoid unnecessary readmissions.

Conclusions: In acute hospitals, family carers and hospital staff can have disjointed communications and conversations about nutrition and hydration for persons with severe dementia. Timely reassurance, ongoing discussions and clear information sharing will support communication between those involved.

Keywords: dementia, eating, drinking, hospital care, person-centred, communication, carer, qualitative research, older people

Key Points

- Communication about eating and drinking in acute hospitals was often fragmented, so that family carers often frustrated in repeating conversations with different staff.
- In the acute hospital, there was a process whereby hospital staff needed to understand the overall situation before they felt ready to start conversations, but family carers can perceive this as a delay, whilst waiting to speak to staff.

- Hospital staff valued multidisciplinary teamwork, but reported it was not uncommon for their colleagues to be reluctant to involve other members of the multidisciplinary team, especially the palliative care team.
- Decisions and care plans made during hospital admissions were not regularly passed on after discharge, and this might cause unnecessary readmissions of people with severe dementia.

Background

Eating and drinking difficulties are common and can occur at any point in dementia. However, people living with dementia often develop changes in their eating patterns and feeding and swallowing difficulties in the severe stages [1, 2]. These difficulties may worsen during hospital admissions where the environment is often busy and demanding, and basic needs, including eating and drinking, can be overlooked [3, 4]. For example, hospital staff may not notice eating difficulties and offer food that the person cannot chew, swallow or cut up [3].

People with severe dementia may not have the capacity to communicate and make complex decisions for themselves [5], including about eating and drinking. Decisions may be made by healthcare staff and family carers or family caregivers (henceforth family carers), who provide informal, unpaid care for someone living with dementia and have a social relationship with them, such as a spouse, parent, child, other relative, neighbour, friend or other non-kin [6]. However, family carers and staff may be uncertain about the preferences and wishes of the person with dementia [7, 8]. In addition, people living with mild dementia may not want to engage with advance discussions and decisions about eating and drinking difficulties [9].

A recent systematic review showed that decision-making about eating and drinking in dementia involves complex discussions, considering medical evidence, cultural beliefs and legal frameworks [10]. Although evidence has found that tube feeding has no benefits in people with severe dementia [11], in some cultures, families and healthcare staff find it difficult to forego artificial nutrition and hydration (ANH) [12, 13]. Daily decisions can also be emotive, for example, whether to continue encouraging the person to eat if they decline every meal [10].

Previous studies reported that in acute hospitals, communication between families and hospital staff were often insufficient and lacked support, including discussions about personal care [14–16]. However, very few studies have explored communication specific to eating and drinking for people with severe dementia in hospitals, particularly beyond the scope of ANH [10]. Understanding and improving communication may lead to greater satisfaction with the decision-making process and care for people with dementia [17].

This study aimed to understand the experiences, views and needs of family carers and hospital staff about communication and discussions of nutrition and hydration for people with severe dementia during hospital admissions. The specific research questions are:

1. How do family carers and hospital staff initiate and have conversations about nutrition and hydration for people with severe dementia during acute hospital admissions?
2. How do hospital staff communicate with family carers when planning care for nutrition and hydration for people with severe dementia in acute hospitals and after discharge?
3. What are the potential strategies to improve communication about nutrition and hydration for people with severe dementia in acute hospitals?

Design

Semi-structured individual qualitative interviews were conducted with family carers and hospital staff. This study interwove Patient and Public Involvement (PPI) to include members of public in research designs, conducts and dissemination [18].

Population and participants

Potential participants were screened against eligibility criteria (Table 1).

Participant recruitment and consent process

The original plan was to recruit family carers and hospital staff directly from two acute hospitals in London. However, due to COVID-19, there were restrictions and delays in gaining access to the hospitals. Participants were recruited using online platforms and snowballing methods, with the approval from relevant ethics committees.

Family carers

Family carers were recruited from Join Dementia Research (JDR) and online social media. JDR is an online self-registration service enabling volunteers with memory problems or dementia, their family carers and healthy volunteers to register their interest in taking part in research. Snowballing methods were used with some family carers referred to the study through their networks to supplement recruitment [19]. Interested participants contacted the research team and were sent an information sheet and consent form. Participants were given 48 h to consider the study. Written informed consent was obtained prior to interviewing.

Table 1. Eligibility criteria for study participants**Family carers**

Inclusion criteria

- Family member or friend who is a key decision-maker for a person with severe dementia (current or bereaved/former)
- Able to provide informed consent
- Able to read and speak English
- Over the age of 18 years

Exclusion criteria

- Family carers bereaved in the past 3 months

Hospital staff

Inclusion criteria

- In a caring role, either health or social care, for someone with severe dementia
- Experienced in providing dementia care and contributing to decision-making related to nutrition and hydration in acute hospital settings
- Able to provide informed consent
- Able to read and speak English

Hospital staff

Hospital staff (henceforth staff) were recruited through Twitter, via known contacts of research team, and snowballing methods [19]. Staff were purposively sampled with a range of roles that would make up a multidisciplinary team caring for people with severe dementia. The same consent process with family carer participants was used with staff participants.

Data collection methods

From January to May 2021, the first author, with a background in psychiatry and gerontology, conducted semi-structured interviews with family carers and staff. All interviews were conducted via online platforms (Zoom or Microsoft Teams) or telephone and audio-recorded using an encrypted audio-recorder.

The interview schedules (see [Appendix 1](#)) were used to build rapport with participants and generate rich and detailed accounts relevant to research questions [20]. The interview schedules were developed for this study, informed by the inter-professional shared decision-making (IP-SDM) model [21], and findings from our previous studies [9, 10]. The interview schedules explored conversations and decision-making about nutrition and hydration, specifically within acute hospital situations.

The interview schedules also included case scenarios that provided a hypothetical situation that required a series of discussions and decisions in acute hospitals, to invite participants to consider events which they may not have encountered as yet, as well as allowing the introduction of difficult topics [22], including the use of tube feeding which is relatively uncommon in the UK. Separate interview schedules and case scenarios were designed for family carers and staff, with consultations with an expert in palliative care and communication skills, and PPI panel.

Data analysis

Interviews were transcribed verbatim, pseudonymised and checked against the audio files [23]. Interview transcripts

were organised in QSR International NVivo version 12 and analysed using reflexive thematic methods [24, 25].

The first author started analysing data after the first few interviews were conducted, as such the process was ongoing and informed the subsequent sessions. Codes and themes were developed through regular, iterative discussions among the research team, who had clinical and research experiences in old age and consultation liaison psychiatry, psychology, gerontology, and dementia and palliative care, with feedback from PPI members [26].

Ethical considerations

Ethical approval was granted by the Health Research Authority committee of England (Camden & Kings Cross Research Ethics Committee, REC reference: 20/LO/0049).

Results**Participant characteristics**

Twenty-nine participants were interviewed (12 family carers and 17 staff). Most of them were female and White British ([Table 2](#)). Each interview lasted ~ 1 h.

To maintain the confidentiality of cited participants' quotes, the authors do not report participant's gender or family carers' relationships to the person with dementia. The authors also grouped quotes from a dietitian, clinical psychologist and speech and language therapists as a group of 'therapy staff.'

Key findings

Family carers and staff often found communication between each other difficult and fragmented amid the distressing context of hospital settings, for example, the noisy and chaotic environment and constant staff rotation. This further worsened during the COVID-19 pandemic. Miscommunication about the person's baseline and food and drink preferences could lead to emotional distress and not meeting the needs

Table 2. Participant characteristics

Participant characteristics	Family carers (N = 12)	Hospital staff (N = 17)
Age (years)		
Mean	53.2	38.9
Range	29–78	28–54
Gender		
Female	10	16
Male	2	1
Ethnicity		
Asian/ Asian British	2	4
Black (Caribbean)	1	0
White (English, British)	7	11
White (Irish)	0	1
White (other European)	2	1
Family carers characteristics		
Current caring situation		
Bereaved/former carer	8	-
Current carer	4	-
Relationship to the person with dementia		
Daughter/son (caring for mother)	10	-
Spouse (wife)	1	-
Friend	1	-
Hospital staff characteristics		
Professions		
Dietician	-	1
Clinical psychologist	-	1
Nurse (N = 5)		
• Clinical nurse specialist in older adult	-	1
• Consultant nurse in palliative care	-	2
• Lead nurse in nutrition	-	1
• Ward sister	-	1
Physician (N = 3)		
• General medicine consultant	-	1
• Geriatrician consultant	-	1
• Palliative care consultant	-	1
Speech and language therapist	-	7
Years in working with older people with dementia		
Less than 1 year	-	1
1–5 years	-	5
5–10 years	-	3
More than 10 years	-	8

of the person with dementia and their family. Multidisciplinary approaches were helpful and available in hospitals but sometimes underused. Four overarching themes were developed. They are listed in Table 3 and narratively described below.

Prerequisites to initiating communication about eating and drinking

In the acute hospital, there was a process whereby staff needed to gain confidence in their initial ideas and knowledge about the overall situation before they felt ready to start conversations with family carers. Although staff perceived this process as important to do, family carers saw this as a delay or poor communication because they might have been waiting to share information and help communicate with the person with dementia.

Staff thought it was important to check if family carers were ready for conversations and *‘what sense they’re making*

of the [current] situation’ (Nurse, PF03) about dementia progression, eating and drinking difficulties and acute conditions of the person with dementia. For example, some families might think *‘it’s their fault [and they have been] doing something wrong’* (Nurse, PF05). Staff usually tried to explain the situation to the family in the simplest way and usually built on what the family had understood and mentioned. Most family carers also thought that eating and drinking issues were sensitive in general, but *‘most [family carers] that are caring for people with dementia become pragmatic quite quickly [and] likely to be used to having slightly difficult conversations’* (Former carer, C03).

‘[Some carers] have seen the progress of changes in their eating and drinking habits. They’ve had input from the medical profession in the past. Whereas for some others, this is the first encounter that they’ve had talking about eating and drinking decisions . . . it’s more difficult . . . if they’re talking about making life-changing decisions in an acute environment when a drama has happened’. (Therapy staff, PF02)

Table 3. Themes developed from interviews with family carers and staff caring for people with severe dementia in acute hospitals

1. Prerequisites to initiating communication about eating and drinking
2. Communication aiming to develop agreed care plans
3. Difficulty discussing palliative and end-of-life care
4. Needs of information and plans about future eating and drinking difficulties

Staff permanently based on a single ward such as nurses and healthcare assistants might have regular, informal conversations and discussions with the person with dementia and their family carers. Physicians and other allied health professionals who work across different wards, such as speech and language therapists and palliative care teams, would first gather information from medical notes and talk to ward staff. Then they would see the person with dementia and assess if the person could discuss with staff, decide on a care plan or express any interest and needs. Some would ask permission from the person for them to speak to their family.

'So, in general, we would normally have a look at the patient first and see whether [they are] able to even express their needs, and especially eating and drinking. [Because] even if they have like advanced dementia, some of them might be able to have nuances, ways to express things'. (Nurse, PF09)

Some nurses stated that *'nurses and especially nursing assistants . . . are [not] necessarily given specialist training about how dementia affects [the persons'] appetite'* (Nurse, PF05). The conversation would normally be led by physicians or clinical nurse specialists. Junior nurses and healthcare assistants might feel reluctant to engage with the conversation, fearing that they had to discuss causes, consequences and specific treatments for eating and drinking difficulties related to dementia, which were beyond their roles and responsibility. This reflected role confusion and the lack of agreed approaches in acute hospitals.

Sufficient time and appropriate space in hospital seemed important to initiate the conversations between family carers and staff. Family carers often perceived that *'[staff] were really busy'* (Former carer, C02), so they tended to be more passive in initiating the conversation about eating and drinking. Staff might also have to prioritise care tasks and *'address the most acute issues first, and sometimes it's not eating and drinking'* (Nurse, PF09).

Many family carers wanted to make staff aware of their relative's pre-existing eating and drinking difficulties before hospital admission. For example, eating and drinking less, eating a different type of food, and having feeding and swallowing difficulties. This included the need for glasses, hearing aids and false teeth, and existing constipation and incontinence problems as well as specific tips used to help the person take their medications. However, on admission, there may be limited time and space for them to speak to staff because of the urgency of the clinical situation or because staff did not ask them about the pre-existing problems and needs.

The COVID-19 pandemic further minimised chances for families to pass on this information, and some carers reported they *'[were just] reading the discharge notes rather than having had a conversation with somebody at the hospital'* (Former carer, C08).

Staff also mentioned limited time to share information within the team. They had to leave messages on patient notes and rely on other staff to read the notes. This meant it was not always possible to make the whole team aware of eating and drinking difficulties and could cause miscommunication and conflicts within the hospital team and between family carers.

'Things are delayed in hospital, then a doctor came in and talked about a feeding tube, and I said "no, you're not talking to nursing staff correctly. You're just assuming on what you've read, and you need to see what's happening here... I had to fight that a lot. They didn't do a feeding tube in the end... luckily the consultant was against any invasive procedure that was unwarranted... For what reason when she was still chewing her own food?' (Former carer, C04)

Communication aiming to develop agreed care plans

Most staff considered the overall progression of the person's dementia when discussing and developing an agreed care plan for eating and drinking difficulties. To understand this, they wanted to work with families and preferred to speak to someone who cared for the person, *'watched [their] decline over several years, and understood where [everything was] heading to'* (Therapy staff, PF13). Despite pre-existing progressive eating and drinking difficulties, staff felt more distant and less involved family members sometimes requested futile nutrition and hydration options because they had a less in-depth understanding of how the person with dementia's condition had changed over time.

Family carers' views on inclusion of more distant family members were mixed. Some wanted to be inclusive, whereas some preferred to keep distant family members away from discussions. However, many carers talked about conflict across all scenarios.

'I do have a brother and sister but they're not really that involved... So, talking to them about things like feeding preferences, they just wouldn't know what's best for her... I probably wouldn't ask for their opinion'. (Current carer, C07)

'I'm the youngest... It was so hard, being heard and being able to put in that this is an important thing... to alter the thinking of... your dad or your older [sibling].... If we'd have been more prepared as a group and we would have been more help... it probably wouldn't have been like that'. (Former carer, C09)

Staff wanted to know from family about *'how long the eating and drinking difficulties [have] exactly been going on for, [and]*

what [person and family] were managing at home' (Therapy staff, PF02). For example, family carers might support the person with shopping for food, preparing meals, keeping a regular eating routine, reminding them to drink enough water and giving food and drink at mealtimes. Many staff thought it was important to reassure, validate and encourage the family for their efforts in caring for their relative.

'A lot of the time, I find [families are] actually doing the things that we would recommend they do anyway. They know what to do intuitively and they just need to be reassured that they're doing enough and they're doing the right thing'. (Therapy staff, PF14)

Although most family carers and staff reported they did not routinely use ANH for people with severe dementia, conversations and discussions about nutrition and hydration to reach these specific decisions were emotionally draining. Most staff agreed that eating and drinking decisions are significant and should be made by the clinical team with consultation with families. However, some staff had knowledge gaps about the persons, especially physicians who *'would not be able to pick up tiny things because [they] don't sit and stare at the patient for full hours of [their] shift'* (Physician, PF07).

Most staff spoke highly of the multidisciplinary team approach and valued input from every team member. Allied health professionals, for example, speech and language therapists and healthcare assistants, can *'largely contribute information to the team [because they] do have more time to find out the detail about a person's baseline and history'* (Therapy staff, PF14). They also noticed and reported subtle abnormal eating behaviours. These inputs could fill the whole team's knowledge gaps and help them with decisions. However, multidisciplinary team meetings did not routinely happen for every case.

'OK, [multidisciplinary teamwork] makes the meeting longer, but you need to find out the person behind that body in the bed. And so many healthcare professionals realise this and do it, but a lot of them still don't'. (Nurse, PF15)

However, the downside to multidisciplinary team involvement was a lack of consistency. Family carers reported the need to repeat the same conversations to different staff, and the responsibility was placed on families to share information across the team, causing frustration. Some family carers felt anxious about the uncertainty of the situation and were confused about why it had to involve so many staff.

'People in the NHS hospital... were brilliant, but I think that the system is set up for so much rotation of staff... Because each time, you'd have to explain, from beginning to end... you'd have some information on the chart... anecdotal information was being passed on... it's incredibly important'. (Former carer, C09)

During admission, families generally thought that *'communication [between staff and family] is missing... [or]... not enough of it'* (Former carer, C09). They wanted to know more and be kept updated about eating and drinking difficulties and approaches to help with this. Signs or charts placed over

the person's bed were useful, but they should be more informative and regularly checked. Otherwise, these lead to misunderstanding between people involved and subsequently mistreatment of the person with dementia.

'[Hospital staff] said, "Ah, but it says, 'nil-by-mouth'." I said, "Why? That's not his name" They hadn't bothered to change the name from the person who'd been in the bed before'. (Former carer, C10)

Difficulty discussing palliative and end-of-life care

At the end of life, staff felt the conversations were particularly difficult because they *'can't just jump in and start talking about nutrition and hydration and [feeding and] swallowing at the end of life'* (Nurse, PF10). There could be *'a lot of questions about how long someone is [going to] live and if they're [going to] starve to death or die of thirst'* (Therapy staff, PF06). Staff needed to understand overall dementia progression, have some indication of prognosis and be sure that the family was ready to discuss end-of-life care.

'[Families] can see the patient's deteriorating. [feeding and] swallowing's getting more difficult, appetite's deteriorating. They know this conversation has to happen, and maybe for many different reasons a family is resistant to that conversation. They're fearful of what's coming, fearful of the motives of staff, fearful that this means death is more imminent, any combination of those things'. (Nurse, PF10)

For most staff, the palliative care team could help communication with family carers and plan for care at the advanced stage of dementia, including an end-of-life care plan. However, *'there's still sometimes a reluctance to involve palliative care unless the person is [imminently] at the end of life'* (Therapy staff, PF08). Some staff thought it was because many families did not understand that dementia was a life-limiting disease and what the roles of the palliative care team are. Therefore, it might upset the family, and staff would *'need to do a significant amount of work just to explain why [the palliative care team] are there'* (Nurse, PF10), further created fears and reluctance among the clinical team to endorse a palliative care approach. Staff emphasised the need to explain and reassure the family that with palliative team involvement, there would still be a care plan in place, for example, mouth care, pain control and risk feeding, where they would help the person to eat orally as long as it does not cause them distress, despite knowing risks of choking and aspiration.

However, most participants acknowledged and respected that everyone had *'the instinct to feed and to hydrate [and that would] never go away'* (Nurse, PF10). It could be particularly demanding in some cultures where food and drink are regarded as the way family expressed love and care for their relative.

'When it comes to the artificial feeding, a good conversation is one where you go in with an open mind and you listen to [them]... So, when somebody says well

it's against my religion for people not to be fed... "explain a bit more of that to me, we probably don't share the same religion. So, tell me what that really means and let me understand it" ...'. (Physician, PF04)

Family carers wanted staff to explain all treatment options and timelines. Some family carers also wanted to be sure that they *'thought of and tried every [appropriate] option available'* (Current carer, C05). This included discussions around, but not implementation of, inappropriate options like long-term tube feeding and why they were not useful for people with severe dementia. Staff suggested that it was important to clarify with and reassure family carers about what had been done or considered. This was also to help staff to reflect and reassure themselves that they *'are not just giving up on someone [because] they've got dementia'* (Therapy staff, PF06).

Needs of information and plans about future eating and drinking difficulties

Before hospital discharge, most family carers wanted to know more about how eating and drinking difficulties would progress and how to manage them at home. However, some hospital admissions were short, and many family carers did not receive enough information about eating and drinking, especially during the COVID-19 pandemic.

'But these were special circumstances... COVID was coming in... Understandably, they wanted them to leave the hospital, but I did feel like it was like 'quick, quick, quick, come on, hurry up, hurry up'. So, the emphasis was wholly on how to keep your mother mobile after the operation, rather than eating and drinking'. (Current carer, C06)

Most staff would send a discharge summary to the person's GP and explain eating and drinking difficulties and the home care plan (or residential aged care facility) to family carers (or facility managers). However, some family carers and staff reported a problem with sharing the information when a person with dementia was discharged at weekends because specialist consultants or allied health staff had no chance to speak to family carers.

'...because often our recommendations in hospital, the doctors don't always put it on the discharge summary for the patient. We're not there at the weekend, so if a patient gets discharged at the weekend and it comes to Monday and we realise the patient has gone home, it can happen sometimes that information doesn't get handed over as promptly as it should be'. (Therapy staff, PF02)

If risk feeding was used for someone with severe dementia, many staff would help the person and their families to develop *'an advance care plan to avoid future [unnecessary] admissions'* (Therapy staff, PF02) because people could be *'panicking of the [person] being coughing [or] choking'* and try to *'send [them] in and out of the hospital'* (Therapy staff, PF12). The care plan could also prevent the person from being designated nil-by-mouth unnecessarily for subsequent admissions. However, frequently they *'could not get the advance care plan in place quickly enough'* (Therapy staff, PF02), and the person came straight back into hospital with the same eating and drinking difficulties.

Discussion

To our knowledge, this is the first study to examine conversations and discussions between family carers and staff about nutrition and hydration for people with severe dementia in acute hospitals. Previous studies in hospital settings have explored the issues in terms of decision-making problems, ethical dilemmas, care outcomes and overall experiences, especially regarding ANH [10]. Most studies only involved healthcare staff, particularly among those in residential aged care facilities and with a nursing background [27, 28]. This study highlights suboptimal processes, within the constraints of a challenging and busy environment, and suggests possible solutions to improve communication within the multidisciplinary team and between family carers.

When and how should we start talking about eating and drinking in hospitals?

Consistent with this study and person-centred care approaches [29], family carers can help communicate with the person with dementia, and their knowledge about the person's baseline, wishes and preferences about eating and drinking can help guide care plans in acute hospitals [15, 30]. However, this study found that family carers did not want to interrupt busy hospital routines and therefore waited for staff to start the conversations. In acute hospitals, family carers' involvement is often absent or reactive due to the lack of agreed and inconsistent approaches [15], even across wards in the same hospital. From the current study, this was even more challenging during COVID-19, where family carers were restricted to present in hospitals.

Staff might avoid these conversations, perceiving them as time-consuming and preventing them from completing scheduled tasks for acute care [31, 32], resulting in hurried decision-making about fundamental care, including eating and drinking [14, 28, 30]. Some staff had less confidence in starting conversations about eating and drinking unless they had a complete picture of the person's health and background. However, this could put families through a long, difficult time, waiting to speak to staff and make sense of the whole situation about their relative. Previous studies have shown that such delays could make families feel suspicious, seek out evidence of poor care and lead to conflict with staff [31].

Timely and ongoing conversations between families and staff can be a more suitable approach to communication about eating and drinking in acute hospitals, rather than a one-off session. Open and sensitive communication and acknowledgement of uncertainties can reassure the person and families [33, 34]. This communication may be early, and relatively short and informal. Early discussions might gradually build trust and relationships between people, prevent delayed or extended care planning discussions and reduce the length of hospital admission for people with dementia [35]. In Table 4, the authors propose potential strategies to initiate and engage with conversations about eating and drinking for people with severe dementia in acute hospitals.

Table 4. Potential strategies to the conversations about nutrition and hydration in acute hospitals

-
- Observe or speak to the person with dementia first
 - Identify an appropriate family member and hospital staff
 - Have early and ongoing discussions
 - Involve multidisciplinary team including palliative care team
 - Discuss overall dementia progression and goals of care
 - Review current treatments
 - Build dialogues on information from and understanding of the person with dementia and family carers
 - Encourage validation and use empathic reassurance
 - Have honest discussions but be aware of varying levels of readiness
 - Be sensitive to emotions and values
 - Set clear steps ahead (consider treatment escalation plans)
 - Ensure clear documentation and information sharing
 - Explain and reassure continuing care plan for the end of life
-

Families can be supported by a review of current treatments in hospital and of the care provided by the families at home. Open discussion and empathetic reassurance that all appropriate treatments have been considered and that the person would no longer benefit from unnecessarily aggressive options would help.

Multidisciplinary team approach to the conversations

Communication regarding eating and drinking required a multidisciplinary team approach to gathering information about persons' overall dementia progression and existing eating and drinking difficulties. However, this requires family carers to act as information coordinators and distressing following repeated discussions with different staff. It was important that the multidisciplinary team worked jointly, and staff shared their knowledge about the person and family to other team members [28, 35], perhaps using notes and regular informal meetings.

This may reduce fears among staff about laborious conversations and competing with other tasks. However, consistent with this study, staff within different disciplines and levels of experience can have different attitudes and willingness to seek information from the persons and families and share the information with the team [14, 30, 35].

Family carers should be provided with clear goals of care and a palliative care plan to support eating and drinking at the end-of-life, for example, risk feeding, mouth care and positioning [36]. Expression of a commitment to continuing care and regular communication could also restore the hope of those involved and prevent guilty feelings towards the death of the person with dementia [34, 37].

Communication about post-discharge support and care plans

Although eating and drinking difficulties could be temporary, most families still wanted more information about possible progression and support required at home. Many families receive inadequate information, and their needs and preferences are not considered in the discharge process

[14, 31, 35]. Discharge planning can also be poorly documented, disjointed among multidisciplinary staff and rushed to meet the hospital bed pressures [38], particularly during COVID-19, as reported in this study. Care for eating and drinking could be assumed to be known by families or given lower priority compared with care for other medical problems. Unavailable community services may also have discouraged staff to readily link up persons and families with services [30, 38, 39].

Conversations and decisions that have been made during an admission should be recorded and passed on. Clear communication among staff and families will ensure appropriate care at home and that families have the accurate information. The optimal discharge process can prevent avoidable readmissions [14, 35]. For example, discharge care plans with agreed risk-feeding decisions will prevent persons from unnecessarily being deemed nil-by-mouth when readmission is required.

Strengths and limitations

The study involved both family carers and staff with a variety of backgrounds, enhancing the richness of data. The authors regularly discussed the research process and findings with feedback from PPI members to ensure their relevance and application to clinical practice. Codes and themes were developed and refined using an iterative team approach to enhance its rigour [26, 40].

Most study participants were people who had thought carefully about the quality of life of people with severe dementia and wanted to continue eating and drinking orally and avoid tube feeding for the persons. Despite an attempt to maximise participants' background, remote participant recruitment and data collection used during COVID-19 might have prevented some eligible people from participating. For example, difficulty with access to the internet or using online platforms. Family participants might have had negative experiences in hospitals, especially about care for eating and drinking, i.e. inclusion of extreme cases, and therefore be more eager to contribute to this study. Some key staff, for example, healthcare assistants, were not interviewed despite extensive attempts by the authors to recruit

these groups. Healthcare assistants may not think they are routinely involved in these conversations and care planning, so declined the invitation.

Some staff who were involved in an initiative to reduce tube feeding in dementia, and many speech and language therapists were keen to participate in this study. They may have different experiences and perspectives to other family carers and staff who have different cultural backgrounds or work under different professional and legal frameworks.

Implications for policy and clinical practice

It is vital to prevent and recognise emotional difficulties and conflicts caused by repetition, misunderstanding and delay in communication between family carers and hospital staff, especially when discussing eating and drinking at the end of life. The authors suggest a system or tool to support regular and compassionate communication between the people involved, including clear and consistent protocols to engage multidisciplinary teams working across wards and healthcare settings. However, communication between hospital staff and families regarding hospital dementia care, including eating and drinking, is hindered by tightening hospital duties and a fragmented system. Adequate time and staff resources, as well as a positive ward culture about dementia care, still need to improve to meet personalised care for people with severe dementia.

Implications for future research

It may be interesting to explore issues around lasting power attorney and see how people with dementia, family carers and healthcare staff apply their decisions about eating and drinking to guide other dementia care decisions (or vice versa). Interventional studies that help support conversations and decision-making are much needed. The authors developed a decision guide about nutrition and hydration for people with severe dementia in hospitals [41], which aimed to support conversations between families and staff, elicit values and preferences of people involved and enhance the person-centred care. However, the decision guide still requires evaluation work in real practice.

Conclusions

In acute hospitals, family carers struggle with disjointed and delayed communications about eating and drinking for people with severe dementia. Hospital staff often feel unprepared to manage these conversations and find it challenging to work across the multidisciplinary team. Timely, honest and engaging conversations would help support those involved and enhance person-centred care for eating and drinking for people with severe dementia in hospital.

Acknowledgements: The authors would like to thank participants for their time and contribution through their interviews. We thank Dr Andrew Thorns, a consultant in

Palliative Medicine and medical director of the Pilgrims Hospice in East Kent, and members of the Nutri-Dem Public and Patient Involvement (PPI) advisory group, including Anne Walford, for their feedback throughout the study. Ethical approval was granted by the Health Research Authority Committee of England (Camden & Kings Cross Research Ethics Committee, REC reference: 20/LO/0049). All participants gave written informed consent.

Declaration of Conflicts of Interest: None.

Declaration of Sources of Funding: This study was supported by the Faculty of Medicine, Prince of Songkla University, Thailand. The funder had no role in the design of the study and collection, analysis and interpretation of data and in writing the manuscript.

References

1. Mitchell SL. Advanced dementia. *N Engl J Med* 2015; 373: 1276–7.
2. Shinagawa S, Honda K, Kashibayashi T *et al.* Classifying eating-related problems among institutionalized people with dementia. *Psychiatry Clin Neurosci* 2016; 70: 175–81.
3. Lawrence V, Samsi K, Murray J *et al.* Dying well with dementia: qualitative examination of end-of-life care. *Br J Psychiatry* 2011; 199: 417–22.
4. Royal College of Psychiatrists. National Audit of Dementia Care in General Hospitals 2018–2019 Round Four Audit Report. London: Royal College of Psychiatrists, 2019.
5. Samsi K, Manthorpe J. Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers. *Int Psychogeriatr* 2013; 25: 949–61.
6. Broese van Groenou MI, De Boer A. Providing informal care in a changing society. *Eur J Ageing* 2016; 13: 271–9.
7. Anantapong K, Davies N. Talking about future decision-making capacity and advance care planning in diagnosis disclosure of dementia. *Int Psychogeriatr* 2021; 33: 1119–21.
8. Denning KH, Jones L, Sampson EL. Preferences for end-of-life care: a nominal group study of people with dementia and their family carers. *Palliat Med* 2013; 27: 409–17.
9. Anantapong K, Barrado-Martin Y, Nair P *et al.* How do people living with dementia perceive eating and drinking difficulties? A qualitative study *Age Ageing* 2021; 50: 1820–8.
10. Anantapong K, Davies N, Chan J *et al.* Mapping and understanding the decision-making process for providing nutrition and hydration to people living with dementia: a systematic review. *BMC Geriatr* 2020; 20: 520. <https://doi.org/10.1186/s12877-020-01931-y>.
11. Davies N, Barrado-Martin Y, Vickerstaff V *et al.* Enteral tube feeding for people with severe dementia. *Cochrane Database Syst Rev* 2021; 8: CD013503. <https://doi.org/10.1002/14651858.CD013503.pub2>.
12. Henao D, Gregory C, Walters G *et al.* Race and prevalence of percutaneous endoscopic gastrostomy tubes in patients with advanced dementia. *Palliat Support Care* 2022; 1–6.
13. Malhotra C, Hazirah OT *et al.* Discordance between dementia caregivers' goal of care and preference for life-extending treatments. *Age Ageing* 2021; 50: 1382–90.

14. Fogg C, Griffiths P, Meredith P *et al.* Hospital outcomes of older people with cognitive impairment: an integrative review. *Int J Geriatr Psychiatry* 2018; 33: 1177–97.
15. Kelley R, Godfrey M, Young J. The impacts of family involvement on general hospital care experiences for people living with dementia: an ethnographic study. *Int J Nurs Stud* 2019; 96: 72–81.
16. Rosvik J, Rokstad AMM. What are the needs of people with dementia in acute hospital settings, and what interventions are made to meet these needs? A systematic integrative review of the literature. *BMC Health Serv Res* 2020; 20: 723. <https://doi.org/10.1186/s12913-020-05618-3>.
17. Geddis-Regan A, Errington L, Abley C *et al.* Enhancing shared and surrogate decision making for people living with dementia: a systematic review of the effectiveness of interventions. *Health Expect* 2021; 24: 19–32.
18. Health Research Authority. Public involvement. <https://www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement/> (2 December 2021, date last accessed).
19. Murphy E, Dingwall R, Greatbatch D *et al.* Qualitative research methods in health technology assessment: a review of the literature. *Health Technol Assess* 1998; 2: iii–x 1–274.
20. Braun V, Clarke V. *Successful Qualitative Research: A Practical Guide for Beginners*. London: SAGE Publication Ltd, 2013.
21. Legare F, Stacey D, Gagnon S *et al.* Validating a conceptual model for an inter-professional approach to shared decision making: a mixed methods study. *J Eval Clin Pract* 2011; 17: 554–64.
22. Bradbury-Jones C, Taylor J, Herber OR. Vignette development and administration: a framework for protecting research participants. *Int J Soc Res Methodol* 2014; 17: 427–40.
23. Bailey J. First steps in qualitative data analysis: transcribing. *Fam Pract* 2008; 25: 127–31.
24. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3: 77–101.
25. Braun V, Clarke V. One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qual Res Psychol* 2021; 18: 328–52.
26. Barbour RS. Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? *BMJ* 2001; 322: 1115–7.
27. Barrado-Martin Y, Hatter L, Moore KJ *et al.* Nutrition and hydration for people living with dementia near the end of life: a qualitative systematic review. *J Adv Nurs* 2021; 77: 664–80.
28. Turner A, Eccles FJ, Elvish R *et al.* The experience of caring for patients with dementia within a general hospital setting: a meta-synthesis of the qualitative literature. *Aging Ment Health* 2017; 21: 66–76.
29. Brooker D, Kitwood T. *Dementia Reconsidered, Revisited; the Person Still Comes First*. London: Open University Press, 2019.
30. Donnelly S, Coimin DO, O'Donnell D *et al.* Assisted decision-making and interprofessional collaboration in the care of older people: a qualitative study exploring perceptions of barriers and facilitators in the acute hospital setting. *J Interprof Care* 2021; 35: 852–62.
31. Dewing J, Dijk S. What is the current state of care for older people with dementia in general hospitals? A literature review. *Dementia (London)* 2016; 15: 106–24.
32. Featherstone K, Northcott A. *Wandering the Wards: An Ethnography of Hospital Care and its Consequences for People Living with Dementia*. Abingdon: Routledge, 2020.
33. Harwood RH. Feeding decisions in advanced dementia. *J R Coll Physicians* 2014; 44: 232–7.
34. Medendorp NM, Stiggelbout AM, Aalfs CM *et al.* A scoping review of practice recommendations for clinicians' communication of uncertainty. *Health Expect* 2021; 24: 1025–43.
35. Kelley R, Godfrey M, Young J. Knowledge exchanges and decision-making within hospital dementia care triads: an ethnographic study. *Gerontologist* 2021; 61: 954–64.
36. Barrado-Martin Y, Nair P, Anantapong K *et al.* Family caregivers' and professionals' experiences of supporting people living with dementia's nutrition and hydration needs towards the end of life. *Health Soc Care Community* 2021; 30: 307–18.
37. Courtright KR, Srinivasan TL, Madden VL *et al.* "I Don't Have Time to Sit and Talk with Them": hospitalists' perspectives on palliative care consultation for patients with dementia. *J Am Geriatr Soc* 2020; 68: 2365–72.
38. Stockwell-Smith G, Moyle W, Marshall AP *et al.* Hospital discharge processes involving older adults living with dementia: an integrated literature review. *J Clin Nurs* 2018; 27: e712–25. <https://doi.org/10.1111/jocn.14144>.
39. Leung D, Todd J. Dementia care in the acute district general hospital. *Clin Med (Lond)* 2010; 10: 220–2.
40. Mays N, Pope C. Rigour and qualitative research. *BMJ* 1995; 311: 109–12.
41. Anantapong K, Bruun A, Walford A, *et al.* Co-design development of a decision guide on eating and drinking for people with severe dementia during acute hospital admissions. *Health Expectations* 2022. <https://doi.org/10.1111/hex.13672>.

Received 30 March 2022; editorial decision 30 August 2022