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O'Neill, M., Duffy, O., Henderson, M., Davis, A., & Kernohan, W. G. (2023). Exploring the connection between dementia and eating, drinking and swallowing difficulty: Findings from home-based semi-structured interviews. *International Journal of Language & Communication Disorders*. <https://doi.org/10.1111/1460-6984.12899>

[Link to publication record in Ulster University Research Portal](#)

### Published in:

International Journal of Language & Communication Disorders

### Publication Status:

Published online: 23/05/2023

### DOI:

[10.1111/1460-6984.12899](https://doi.org/10.1111/1460-6984.12899)

### Document Version

Publisher's PDF, also known as Version of record

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## RESEARCH REPORT

# Exploring the connection between dementia and eating, drinking and swallowing difficulty: Findings from home-based semi-structured interviews

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## Funding information

Department of the Economy, Grant/Award Number: 10.13039/100016337; Department for the Economy

## Abstract

**Background:** Eating, drinking and swallowing (EDS) difficulties are important to identify early. Awareness of EDS changes starts with those living with dementia or their family carers. However, little is known about early identification from the perspective of people with dementia.

**Aim:** The aim of this study was to understand the experience of EDS by people living with dementia in their own home.

**Methods:** Published evidence pertaining to EDS difficulties in dementia was used to inform an online semi-structured interview guide. Four people living with dementia and a third-sector Empowerment Lead were invited to become co-researchers. People living with dementia and their carers were invited to be interviewed. We enquired about their past and present experiences, and future expected changes in EDS, information needs, opinions on early problem identification, and lifestyle modifications following onset of EDS difficulty. Narrative concepts of heroes and villains in their 'stories' were identified. Responses were subjected to framework analysis informed by narrative enquiry.

**Results:** Seven people living with dementia and five family carers were interviewed. The overarching theme was a 'missed connection' between EDS difficulty and dementia. Where EDS difficulties were identified, 'compensatory changes' and a need for 'access to information' were noted.

**Conclusions:** The connection between potential EDS difficulties and a dementia diagnosis may not be made, even though EDS changes were recognised by people living with dementia and their family carers. This may be explained by behaviours that mask problems or allow individuals to cope or compensate. Reduced awareness may also be due to inadequate access to information and lack of specialist services. If the connection between dementia and EDS difficulty is missed it could further delay access to support services.

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**KEYWORDS**

dementia, drinking, eating, semi-structured interviews, swallowing

**WHAT THIS PAPER ADDS***What is already known on the subject*

- The prevalence of dementia is increasing and is expected to affect 9% of the population by 2040. EDS difficulties are common in people living with dementia and predispose to poorer outcomes. Better awareness of EDS changes early in the disease process of dementia or at preclinical stages can identify individuals at risk and allow for intervention prior to advanced EDS difficulties developing.

*What this paper adds to existing knowledge*

- This paper reports the perspective of people living with dementia and family carers and provides insights into experiences of EDS and the challenges faced and identifies commonalities. The connection between potential EDS difficulties and dementia is missed despite various changes reported by both people living with dementia and their family carers, who tend to make compensatory lifestyle changes without support.

*What are the potential or actual clinical implications of this work?*

- Lack of awareness of the connection between potential EDS difficulties and dementia may arise due to inadequate access to information to support people living with dementia and their family carers. Access to such information is needed and the quality assurance of information from reputable sources is important to people living with dementia. There is a need for greater service user awareness of signs of EDS difficulty and how to access specialist services.

**INTRODUCTION**

In 2019, the prevalence of dementia among older people in the United Kingdom was estimated to be 7.1% (Wittenberg et al., 2019). The average age of the population is accelerating in the United Kingdom. Accordingly, the proportion of people living with dementia is expected to reach 8.8% by 2040 (Livingston et al., 2017).

Eating, drinking and swallowing (EDS) difficulties, also known as dysphagia, have been reported to occur in up to 57% of individuals living with dementia (Alagiakrishnan et al., 2013). EDS difficulty can lead to aspiration pneumonia, the commonest cause of death in dementia (Parlak et al., 2022). Other sequelae include malnutrition, dehydration, weight loss (Sato et al., 2014), reduced quality of life (Boccardi et al., 2016), caregiver stress (Papachristou et al., 2013) and social isolation (Gillies, 2012). EDS difficulty is a significant independent risk factor for poorer

outcomes during hospitalisation and increased use of resources (Paranji et al., 2017).

Better awareness of EDS changes early in the disease process of dementia or at preclinical stages may identify individuals at risk and allow for intervention prior to advanced EDS difficulties developing (Rogus-Pulia et al., 2015). Speech and language therapists (SLTs) use compensatory strategies in this client group and frequently cite the need for family and care staff training in mealtime support (Egan et al., 2020).

It has been shown that many people can contribute and meet their own care needs (Thorstensen-Woll et al., 2021). They may even monitor and drive the quality of care provided by professionals (Robert et al., 2015). To achieve optimal outcomes, it is important to identify the support needed for EDS by people living with dementia and also their family carer's need. A better understanding of the needs of people living with dementia and the

impact of EDS on daily life will assist identification of EDS difficulty. Tailored interventions to improve the delivery of support services could then be formulated. This may be achieved through collaborative approaches such as 'co-design' (Swarbrick et al., 2019).

Research 'co-design' has been defined as the meaningful involvement of research users during the study planning phase of a research project (Slattery et al., 2020). User involvement is considered essential for the high-quality and relevant research but often people living with dementia are not included in design work due to perceived and actual challenges with their health, memory, concentration and communication (McArthur et al., 2021). In the design of this study people living with dementia were recruited as 'experts by lived experience' to inform, influence and co-produce the work.

## CLINICAL APPLICATION

Improving EDS services for people living with dementia and their family carers requires understanding of the evolution of EDS difficulties in dementia and an insight into the experience of those affected. Early identification of physiological signs of EDS in the literature base often sits separately from lived experience and the impact on the person affected. This literature should be merged with the psychological impact and lived experience of EDS difficulty in dementia to provide more holistic understanding.

To shape priorities for clinical healthcare professionals and inform population approaches to EDS care, it is important to understand the expectations, needs and priorities of people living with dementia, so that all their requirements (whether clinical, psychological and social) may be fully addressed.

## AIM

The aim of this study was to understand the experience of EDS by people living at home with dementia.

## METHODS

### Design

In order to understand the experience of EDS by people living with dementia and their carers in their own home an online semi-structured interview was designed. This provided information from a service user perspective including the overall well-being of those affected. In line

with the recommendation that researchers can conduct highly meaningful projects with interviews of 8–12 participants (DeJonckheere et al., 2019), a sample of up to 12 participants with dementia and their carers was estimated to be sufficient. Semi-structured interviews were selected for flexibility and versatility. Online videoconferencing (Zoom®) was used for data collection as previously used for semi-structured interviews (Archibald et al., 2019). We concentrated on those with experience of living with or caring for people living with dementia. The focus was on EDS changes over time from the point of dementia diagnosis.

Published evidence was used to inform question generation (Affoo et al., 2013, Alagiakrishnan et al., 2013) and an interview guide was formulated (Kallio et al., 2016) (Table 1). Separate interview guides were formulated for people living with dementia and family carers (Webster et al., 2015). A summary of the questions posed to each group is provided in Appendices 1 and 2. No ethical concerns were identified through the university governance process: approval was granted on 2 August 2020 (REC.20.0071).

### Patient and public involvement

A partnership was developed with a local member-led, third-sector advocacy group providing a voice for people living with dementia called Dementia NI. People living with dementia were recruited by a Dementia NI advertisement as 'experts by lived experience' to inform, influence and co-produce the work. Their contribution at online planning meetings (e.g., discussing recruitment, consent and interview format) and document design (e.g., lay protocol, participant information sheet, consent forms and interview guides) fulfilled the definition of co-design in achieving 'meaningful end-user engagement' (Slattery et al., 2020, page 2).

### Recruitment and data collection

Five pilot interviews were conducted on the chosen online platform (Archibald et al., 2019) with the empowerment lead of the group and four co-researchers. The focus was to discuss pre-interview logistics, the research protocol, participant information sheet, consent process, introduction by researcher to interview questions and the content of interview questions. Feedback suggested the need for reminders on the day of the interview, sharing participant information sheets in large font on-screen while reading aloud and the opportunity to have carers present for interviews.

**TABLE 1** Semi-structured interview design showing the five steps used to prepare the interview guide (Kallio et al., 2016)

Steps		Process
(a)	Identifying the prerequisites for using semi-structured interviews	Literature review provided a prerequisite for using semi-structured interviews in terms of having prior knowledge of the phenomenon under investigation
(b)	Retrieving and using previous knowledge	See above
(c)	Formulating the preliminary semi-structured interview guide	Previous knowledge was used to formulate a provisional interview guide
(d)	Pilot testing the guide	A provisional interview guide that was 'field tested' with Dementia NI members who agreed to participate in co-production of the study and pilot interviews
(e)	Presenting the complete semi-structured interview guide	Incorporation of feedback from the previous pilot was used to confirm the use of questions

Due to the rich data obtained and because interview questions were unchanged, pilot data were included in subsequent analysis. A purposive sample of additional people living with dementia and their family carers were then approached via the charity and invited to participate. We recruited through the charity volunteers who were affected by a confirmed diagnosis of dementia and had the ability to participate in an interview. No exclusion criteria were applied. All interviews were conducted over the same online platform as pilot interviews. The interviews were audio-visually recorded and managed according to General Data Protection Regulation 2018 (Ulster University, 2018)

## Data analysis

Framework analysis was selected for data analysis because it can be influenced by existing ideas, permits the analyst to play a greater role in deriving themes, provides a structured approach to transcript analysis and leaves a transparent audit trail (Ward et al., 2013). It also allows researchers and co-researchers to work together (Furber et al., 2009). Published evidence was used to devise an initial draft framework (Affoo et al., 2013, Alagiakrishnan et al., 2013). Data from the transcripts were imported into a qualitative data management system (NVivo 12). Analysis began with data familiarisation, immersion and group discussion to further refine an initial theoretical framework. Core ideas were documented in handwritten notes in a reflexive journal. A sample of transcripts was shared with co-authors and core ideas were openly discussed. Following data immersion and group discussion, recurring ideas from the familiarisation process were grouped into draft themes, which were refined to reach a consensus at further meetings. The initial theoretical

framework was also guided by narrative themes. To enable narrative analysis of individuals or processes regarded as helpful (or unhelpful) in the person living with dementia or their carer's experience of EDS, responses were dramatically framed into symbolic roles under the draft themes of heroes and villains (Wagner-Egger et al., 2011). This analysis was guided by Propp's classic narrative theory (1968) in which he distinguished several basic character types. Data indexing, summarisation of indexed data into codes and thematic charting were used to formulate the final theoretical framework (Furber, 2010). To enhance trustworthiness, an audit trail of raw data extracts (in quotation marks) from the original transcripts is provided with the participant number documented in parentheses.

## RESULTS

Including the four pilot interviews with co-researchers, 12 people took part in semi-structured interviews (23 February–24 June 2021). Of these, seven were people living with dementia (four male and three female) and five family carers (two male and three female). Two people living with dementia requested for their interviews to be conducted jointly with their carer's. The average interview time was 31 min. The interviews were transcribed verbatim (total 18.5k words). All data from all participants was included in analysis.

### Initial understanding of EDS difficulties

The data explored the use of themes past and present experiences, and future expected changes in EDS, information needs, early problem identification and lifestyle modifications following onset of EDS difficulty. The concepts

**TABLE 2** Initial theoretical framework refined by data familiarisation, immersion and group discussion by the research team. Draft theme working definitions were agreed by consensus of the research team

Draft Theme	Working definition
Past	Initial changes in eating, drinking and swallowing when diagnosed with dementia
Present	Currently what eating, drinking and swallowing is like when living with dementia
Future	What is needed to help with eating, drinking and swallowing in the future when living with dementia
Information	The type and timing of information (if any) on eating, drinking and swallowing that the respondent would prefer to receive
Early problem identification	Preferences regarding eating, drinking and swallowing input
Lifestyle modifications	Lifestyle modifications of participants to eating, drinking and swallowing changes
Heroes	Individuals or processes reported to be helpful in the person living with dementia or their carer's journey with eating, drinking and swallowing
Villains	Individuals or processes reported to be unhelpful in the person living with dementia or their carer's journey with eating, drinking and swallowing

of heroes and villains (Wagner-Egger et al., 2011) in the EDS journey were integrated into the framework analysis (Table 2).

## Initial themes

The initial themes were past and present experiences, and future expected changes in EDS, information needs, early problem identification, lifestyle modifications following onset of EDS difficulty, heroes and villains. The final overarching theme was a 'missed connection' between EDS difficulty and dementia. Where EDS difficulties were identified, 'compensatory changes' and a need for 'access to information' were noted.

### Past

When asked about their earliest recollection of EDS difficulties, three people living with dementia and two carers recalled changes to their eating habits. One person living with dementia said:

'I noticed that I became slower in eating and swallowing. I was not aware that there was food there. I tend to drift off, but not sleeping, because it was taking so long to chew even pureed food [P2].'

These reported changes were summarised by the codes '*eating slowly*' and '*forgetting food in the mouth*' (Table 4).

Other reported changes at the time of diagnosis were summarised by the codes '*dry mouth*', '*voice changes*', '*throat tightness*' and an '*aversion to eating*'. Examples of raw data extracts included:

'I noticed that my mouth became very dry and I was sort of slabbering quite a lot so I know now that this was probably an indicator [P2].'

'My voice first, certainly my voice first changed [P12].'

'*Forgetting to eat or drink*' was also reported as an EDS change at the time of dementia diagnosis and one person living with dementia said:

'It is just the memory side of eating and drinking I would struggle with at times and it sounds hard to believe, you don't know when you are hungry or not [P4].'

There was also a report from a carer of needing to provide '*prompting*' for their spouse to eat or drink.

'The differences would be that he would have to be prompted to eat and when he drank he gulped a wee bit and not taking his time [P5].'

These responses suggest that EDS changes were present at an early stage and had a corresponding impact on well-being.

## Present

When asked about EDS at the present time, people living with dementia ( $N = 4$ ) and their carers ( $N = 3$ ) reported ongoing changes at mealtimes. One said:

'I am aware now that people finish their food round me and I am still there an hour and a half later, but that's just part of it (dementia) [P2]'

This was coded 'finishing food after others'. Another person living with dementia said:

'This last couple of years I feel like sometimes that my throat has closed in. Sometimes I hate the idea of eating anymore. There is a lot of pressure trying to swallow. It's become a major issue [P12]'

Other codes included eating slowly, gulping, coughing, spluttering, choking, loss of taste, loss of appetite, aversion to eating, sensation of throat closing and need for prompting to eat or drink (Table 4). The responses generated suggest that the current EDS difficulties overlap to a degree with past symptoms of EDS difficulty and impacts on quality of life. This suggests that EDS difficulty might be noted at an earlier stage if awareness was improved and quality of life may benefit.

## Future

Factors to support EDS in future included 'availability of a background history of previous EDS issues', 'need for results of tests with understandable explanations', 'access to open and transparent medical records', 'understanding and patience from the public' and 'reminders of when to eat and drink' (Table 4).

Examples of raw data extracts summarised by these codes included:

'Everyone should have a background history of swallowing and eating [P2]'

'As long as they (members of public) are aware that I am not going to get any better, probably just a bit of understanding. Understanding of the condition and probably patience of which many people have not got. Patience with you

and time, just a little bit more time with you [P12]'

'Something specific to remind you that you need to take a drink or you need to take mealtimes. Some sort of timer you could set all the time [P4]'

Clearly, there are unmet needs for people living with dementia and EDS difficulties.

## Information needs

Overwhelmingly people identified that they would like more information about EDS at the beginning of their journey ( $N = 6$  people living with dementia and  $N = 4$  carers). One person living with dementia said:

'So I think to get information that you can trust and you know that if you read it, it is factual and you know it is right, rather than from some random person of the internet [P1]'

This was coded as '*trustworthy information*'. When asked if there is anything that would be useful to support EDS in the future, this person living with dementia said:

'I think relevant and safe information [P1]'

This was summarised by the code 'reliable information'. Other summary codes about information included 'who to contact', 'what to look out for', 'anxiety with online information', 'something written to refer back to', 'what to do if choking', 'awareness from public' and inclusion of 'relevant education in courses for carers' (Table 4). One carer for a person living with dementia said:

'From the Alzheimer's Society point of view, it would be good for them to include that there may be an issue with your loved one having an eating, drinking or swallowing problems and if that was the case, maybe what to look out for. That wasn't as far as I remember part of the course [P8]'

Collectively these responses suggest that for people living with dementia and EDS difficulties there is a need for reliable and timely information.

## Early problem identification

When asked whether they would have wanted their EDS screened at the beginning of their journey, four carers and three people living with dementia replied 'yes'. Regarding EDS screening one carer said:

'I would have probably questioned it in relation to why it was actually necessary [P8]'.

This was coded '*would need awareness of rationale*'.

One of the reasons reported by a person living with dementia who would not want an EDS screen was as follows:

'At the beginning you are overwhelmed by what has been told to you and for someone to throw that into the mix as well, I think I just would have found this hard to deal with [P1]'.

This was summarised by the code '*too much at the time of diagnosis*'.

Another person living with dementia said:

'At the very beginning I would have felt violated. I wouldn't have wanted that. I would have been totally against it. Now, looking back, I would be accepting of it but at that particular time I would not have wanted it. [P4]'.

This was summarised by the code '*viewed as intrusive*'. These responses suggest it is imperative to respect the difficulty of receiving a new dementia diagnosis when considering assessment of EDS difficulty.

## Lifestyle modifications following the onset of EDS difficulty

When asked about how they responded to EDS changes, one person living with dementia responded to EDS changes as follows:

'You get yourself into a system, it's maybe eating some then leaving it for a while, and then coming back later and eating some more [P12]'.

This was coded as 'coming back to finish food after a break'. Other responses of people living with dementia to EDS changes were summarised by the codes 'avoid

talking when eating', 'need to concentrate when eating', 'need for softened foods', 'need for liquids at specific temperatures', 'need for eating aids', 'avoidance of food that is difficult to swallow', 'chewing properly', 'using straws to drink', 'eating at home', 'avoiding pressure of being watched', 'using smaller glasses' and 'cutting food into smaller pieces' (Table 4).

One carer responded to EDS changes as follows:

'We would normally sit down together and just sit at the table the two of us and have our meals together so that if anything happens, I am there. I encourage him to come to the table and start eating. He will always say he is not hungry but he will eat [P5]'.

This was summarised as '*having a carer present*' (Table 4).

Another carer responded to EDS changes as follows:

'I am just aware of her eating. I am not staring at her, I am just looking and making sure that she is doing okay. I am doing it very subtly, I am not in her face, I am just making sure that things are okay [P8]'.

This was summarised by the code '*carer covertly observing*'. This response suggests that carers may not want to disempower people living with dementia who value their independence.

One person living with dementia said:

'Even simple solutions to mash the food down, to get a plate guard, to sit up straight, to use a small teaspoon instead of a knife and fork so that I wasn't putting large amounts of food into my throat [P2]'.

This was summarised by the code '*simple solutions*'. This response suggests that if EDS difficulty is recognised, interventions to support people living with dementia do not need to be complex in order to be effective.

## Heroes

Healthcare professionals reported to be helpful in the person living with dementia or their carer's journey with EDS included a '*community psychiatric nurse*', '*general practitioner*' and '*SLT*'. One person living with dementia said:



'I appreciated the speech and language therapist because obviously she knew what she was on about and you know she tried to improve my living with food and eating food [P2]'.

'Family' were reported to be helpful in the person living with dementia or their carer's journey with EDS.

One carer for a person living with dementia also said:

'I am on that group for TIDE NI and some of the girls, their husbands may be on a different part of the journey, a wee bit further down the line, and one of the girls has actually touched on the swallowing and drinking, it's amazing what you do pick up through our general wee coffee chat that we have every fortnight [P5]'.

This was summarised by the code '*support groups*'.

## Villains

Individuals or processes reported to be unhelpful in the person living with dementia or their carer's journey with EDS were summarised by the codes '*google*', '*missing hospital records*', '*lack of access to information about yourself*', '*lack of information at time of diagnosis*' and '*too much time between hospital check ups*'. Examples of raw data extracts are shown in Table 3.

## The connection between dementia and eating, drinking and swallowing difficulty

Those with personal experiences of dementia were willing to explore EDS symptoms. However, reduced awareness of the potential for EDS difficulty in dementia may lead to a delay in seeking support.

'I was surprised, to be honest, when I heard that people with dementia could suffer problems with swallowing and it came as quite a shock' [P9].

As such, there is a stark need for *access to information* to support individuals, which was apparent as a theme and was supported by the following raw data extracts:

'I think having at hand good clear, concise information that can sort of direct you and I think for family as well that support because they might know the signs that you might nec-

essarily miss and they can sort of be keeping a check [P1]'.

'Being informed about in the future what will happen with down the line. What will really happen. That is the scary side of it. Being informed is the key I think [P11]'.

As highlighted in the initial theme of information, the source of this information appears to be important with a reluctance to engage with online search engines for fear of finding untrustworthy information:

'When (she) was diagnosed at first, I didn't go on the Mr Google and find out what was said because to me that was quite dangerous. [P8]'

In the absence of the information to raise awareness of EDS difficulty, the ability of people living with dementia who '*value their independence* [P12]' and carers who '*don't want to disempower* [P8]' leads to a range of *compensatory changes* or behaviours to adjust to EDS difficulty:

'I like eating alone and doing it my way now and taking my time. I think the biggest thing now is feeling under pressure with other people around you watching you trying to struggle with that [P12]'.

'Say I wanted fish to eat. I would mash the fish up and make sure there is milk and mash it up to liquid form and that's the process. You can't do that in a restaurant. It's the fear of swallowing [P12]'.

There was an impact on social life by the compensatory changes made for EDS difficulty:

'For me to go out to a restaurant with somebody, if they could see how slow I am trying to get something down and watching everything I eat. I just try and avoid all that. It has an impact on your life [P12]'.

Also, despite the compensatory changes made, there were still serious choking incidents reported:

'When she is choking, she can't say she is choking, she waves her arms, and it takes me a few seconds to realise there is something going on and I realise she is choking [P11]'.

TABLE 3 Examples of raw indexed data under the themes of initial theoretical framework

Draft themes	Example extract from transcript
Past	'Occasionally when she was eating, the impression was that a piece of food went down the wrong way or something got stuck and she was coughing [P8]'
Present	'I haven't got the same appetite. To be honest I think too a lot of food, it might be lovely food to other people but to me it's tasteless [P9]'
Future	'Having the information and having the score from the Drs as well as the Speech and Language Therapist. A lot of the time there are so many people but they don't talk to each other so you are only getting jigsaw pieces sent through and you know there is no way you are going to understand it [P2]'
Information	'If you had something written down as guidance as to what to look out for and what changes can happen as a result of dementia affecting, like how it (eating, drinking and swallowing [EDS]) is going to change as they deteriorate so that I am aware of what actually to look out for because at this moment I don't know [P5]'
Early problem identification	'I would have probably questioned it in relation as to why it (EDS assessment) was actually necessary but if you become well informed that if there is a link to say statistically people are more likely to have eating, drinking and swallowing issues with dementia more than other people, then I think it is important that we know that [P4]'
Lifestyle modifications	'I have noticed lately she would choke on water, sometimes taking a drink of water. She has to use a straw. When she was drinking from the glass, too much water was going down and she was choking [P11]'
Heroes	'I appreciated the Speech and Language Therapist because obviously she knew what she was on about and you know she tried to improve my living with food and eating food [P2]'
Villains	'You can google stuff, look things up online, but you don't know if it's factual or whether it is some eejit that has put this up [P1]'

The overarching theme was a *connection* between EDS difficulty with dementia that appears underappreciated either because of compensatory changes used or a lack of access to information. If the connection between dementia and EDS difficulty is missed it could delay access to support services.

'I just thought that when she had that coughing incident, it was just a coughing incident, however there may have been a connection with her dementia [P8]'

The *connection* is currently not being made despite the changes reported in EDS in the past and present by both people living with dementia and their carers. Even for those who have an awareness of the potential for EDS difficulty later in dementia, there is a lack of awareness that it can be an issue earlier on, as exemplified in the following:

'I knew eating, drinking and swallowing could be a problem at a later stage but I never thought it would potentially be a problem at the early stages' [P8].

'I thought it was something that maybe happened later on in the dementia process' [P10].

Overall, there are various EDS changes reported in the past and present by people living with dementia and their carers but little appreciation that of the link between EDS difficulty and dementia. The final theoretical framework with final theme and subtheme definitions are provided in Table 5.

## DISCUSSION

The aim of this study was to understand the experience of EDS by people living at home with dementia, with the view to gaining understanding of expectations, priorities, difficulties and support needs in relation to EDS. The overarching theme was a *missing connection* between EDS and dementia that was underappreciated by those effected. The *connection* between EDS and dementia was not made despite various changes reported in EDS in the past and present by both people living with dementia and their family carers. People living with dementia and family carers

TABLE 4 Summary codes of raw data extracts showing meanings drawn by participants

Initial themes	Data summary codes
Past	Eating slowly, forgetting food in mouth, dry mouth, choking, voice changes, throat tightness, aversion to eating, forgetting to eat or drink and need for prompting to eat or drink
Present	Eating slowly, gulping, coughing, spluttering, choking, loss of taste, loss of appetite, aversion to eating, sensation of throat closing and need for prompting to eat or drink
Future	Availability of a background history of previous eating, drinking and swallowing (EDS) issues, need for results of tests with understandable explanations, access to open and transparent medical records, understanding and patience from the public, reminders of when to eat and drink
Information	Who to contact, trustworthy information, reliable information, what to look out for, anxiety with online information, something written to refer back to, what to do if choking, awareness from public, and include relevant education in courses for carers
Early problem identification	Too much at time of diagnosis, viewed as intrusive, and would need awareness of rationale
Lifestyle modifications	Need to avoid talking when eating, need to concentrate, finishing food after others, need for softened foods, need for liquids at specific temperatures, need for eating aids, avoidance of food that is difficult to swallow, chewing properly, using straws to drink, eating at home, coming back to finish food after a break, avoiding pressure of being watched, using smaller glasses, having a carer present, carer covertly observing, cutting food into smaller pieces, simple solutions
Heroes	Community psychiatric nurse, general practitioner, speech and language therapist, family, support groups
Villains	Google, missing hospital records, lack of access to information about yourself, lack of information at time of diagnosis, too much time between hospital checkups

need education and support for EDS (Correia et al., 2010). There is also limited public knowledge of EDS difficulties with a need for greater general awareness of this largely invisible disorder (McHutchion et al, 2021).

The lack of awareness of the *connection* between EDS changes and dementia may be explained by *compensatory changes* that may mask problems or allow individuals to cope. Family carers can provide a unique insight into these behaviours. In the Alzheimer's Society 'Food for thought' project, it was identified that one third of caregivers of individuals with dementia worried about swallowing problems (Alzheimer's Society, 2000). In previous studies, carers of people living with dementia have reported similar problems of passivity, distraction, inappropriate feeding velocity and refusal to eat (Correia et al., 2010).

Lack of awareness of the connection between EDS difficulties and dementia may also arise due to inadequate access to information to support people living with dementia and their family carers. The timing, source and format of this information are important to both groups and are highlighted by anxiety around online information and from unrecognised sources. A well-designed scoping

review suggested that future interventions on information delivery to people with dementia and caregivers should focus on having required information on central platforms (e.g., Alzheimer's Association website) (Soong et al., 2020).

'Connection' is a term that was also used by participants themselves. When used by participants it may be an oversimplification of a complex multifactorial issue relating to a lack of knowledge or lack of awareness of EDS difficulty in dementia. As a final theme of this study 'connection' was defined as the underappreciated linkage between living with dementia and the potential for changes in EDS. Previous qualitative research supports this finding as it has been identified before that EDS problems are not discussed with people living with early-stage dementia as they are felt to be unrelated to them or irrelevant (Anantapong et al., 2021).

In this study, changes reported in EDS by people living with dementia and their carers included difficulty with eating and drinking independently, changes in eating patterns and evidence of altered sensation. In dementia difficulties are known to occur throughout the eating process, which encompasses all aspects of eating and drinking

**TABLE 5** Final theme and subthemes in final theoretical framework showing that the overarching theme was a 'connection' between EDS difficulty and dementia. Where EDS difficulties were identified, 'compensatory changes' and a need for 'access to information' to support individuals, were noted as subthemes

Final theme	Definition	Final subthemes	Definition
Connection	The underappreciated connection between living with dementia and the potential for changes in eating, drinking and swallowing	Compensatory changes	Changes in eating, drinking and swallowing from a personal perspective and compensatory strategies used to overcome these deficits
		Access to information	The people and processes needed to support eating, drinking, and swallowing for person living with dementia and their carers. The need for trustworthy information from a reliable source, accessible and transparent records, education for carers and public, timely access to the individuals who can help

independently as well as swallowing function (Rogus Pulia et al., 2015). Impairment of independent eating and drinking has been observed in patients with mild Alzheimer's disease, and while not linked directly to changes in swallow on videofluoroscopic swallowing studies, it raises the potential for loss of independence with eating and drinking to be an important link or precursor to swallowing difficulties (Priefer & Robbins, 1997). Functional magnetic resonance imaging during swallowing has also identified decreased cortical function in areas of the brain involved in swallowing in individuals with mild Alzheimer's disease compared to age-matched controls and is suggestive that changes in cortical control of swallowing may begin before swallowing difficulty becomes apparent (Humbert et al., 2010). Indeed, an association has been identified in the reverse direction with swallowing difficulty reported as an independent predictor of decreased independence in eating (Edahiro et al., 2012). Decreased independence with eating and EDS difficulty are clearly linked.

In people living with dementia, changes in taste and smell may adversely affect appetite (Rogus-Pulia et al., 2015) as well as food recognition (Suto et al., 2014). This can happen early, with individuals with mild cognitive impairment and early-to-moderate Alzheimer's dementia experiencing changes in food preferences (Winchester & Winchester, 2016). Taste (Broggio et al., 2001) and smell (Behrman et al., 2014) also deteriorate in Alzheimer's disease, and it has been suggested taste and smell receptor stimulation using sensory enhancement techniques may be effective in eliciting faster oral and pharyngeal initiation of the swallow (Rogus-Pulia et al., 2015) or reducing aspiration risk (Pelletier & Lawless, 2003).

## Importance, strengths and limitations

The findings of this research are important because they describe the lived experience of EDS in dementia from the perspective of 'experts through experience'. Advocates for people living with dementia call for active involvement of people living with dementia in research (Bryden, 2015), and co-design is a process that can facilitate meaningful involvement of people living with dementia in research studies (Swarbrick et al., 2019). A particular strength of the semi-structured interview process was that it was co-designed and piloted with people living with dementia as co-researchers.

The limitations of the semi-structured interviews includes that they were conducted over an online platform, therefore the body language of participants could not be fully observed. However, the fact interviews were conducted mostly from the comfort of the participant's home environment allowed for time to build rapport, leading to an open discussion despite the potentially emotive nature of the content (Archibald et al., 2019).

Pilot semi-structured interviews should be carried out with participants that are similar to the participants that are recruited for further interviews (Turner, 2010). The feedback of people living with dementia in pilot interviews streamlined the further interviews for people living with dementia and their carers, thus allowing further respondents (at various stages in their dementia journey) to provide full responses regarding their experiences. Gathered data from pilot studies are considered 'rich' when participants provide elaborated answers to interview questions (Malmqvist et al., 2019). The rich data from the pilot interviews warranted inclusion. However, because further participants in interviews were recruited from the same

charity selection bias may have been introduced into the study.

In this study people with all stages of dementia and types of dementia were invited to participate. The focus was on EDS changes over time and the involvement of a wide range of participants gave an overview of the evolution of EDS difficulties. Future care needs in anticipation of a deterioration of swallowing were not raised during the interviews. Previous research has identified that people living with early-stage dementia may prefer for their quality of life to override medicalisation of their condition (e.g., by artificial nutrition) when severe EDS difficulty develops (Anantapong et al., 2021). Future research should therefore focus on the challenge of future care needs in anticipation of EDS deterioration.

Like disease severity, the underlying neuropathology of dementia may also influence the specific swallow disorders observed (Rogus-Pulia et al., 2015). A systematic review by Alagiakrishnan et al. (2013) identified that swallowing difficulties developed earlier in Alzheimer's disease and in the late stages of frontotemporal dementia. This study did not concentrate on a particular type of dementia. Alzheimer's disease is the most frequent variant of dementia, although it is frequently associated with other neuropathology and most commonly cerebrovascular disease. This makes mixed dementia the most common form of dementia overall (Arvanitakis et al., 2019).

## Conclusions

The *connection* between EDS difficulty and dementia is currently not being made despite various changes in the past and present by both people living with dementia and their family carers. This may be explained by *compensatory actions* that may mask problems or allow individuals to cope. Lack of awareness of this connection may also arise due to inadequate *access to information* to support people living with dementia and their family carers. More high-quality research on indicators of EDS difficulty in dementia is needed in order to better inform people living with dementia. Future research could consider the experience of key staff such as SLTs involved in the management of EDS difficulties and consider how better awareness of EDS difficulty may translate into earlier presentation for assessment, better care and treatment.

## ACKNOWLEDGEMENTS

Dementia NI co-researchers. Department of the Economy 10.13039/100016337.

## APPENDICES

Uploaded as supplementary files.

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**How to cite this article:** O'Neill, M., Duffy, O., Henderson, M., Davis, A., & Kernohan, W.G. (2023) Exploring the connection between dementia and eating, drinking and swallowing difficulty: findings from home-based semi-structured interviews. *International Journal of Language & Communication Disorders*, 1–14. <https://doi.org/10.1111/1460-6984.12899>

## APPENDIX A1

### Questions for people living with dementia

Can you tell me a little bit of what it was like in the early days of living with dementia at home?

About the Past

At the start of your journey living with dementia can you tell me a little bit about your eating, drinking and swallowing?

Is there anything that would have been helpful for you at the beginning?

At the beginning of this journey would you have liked some information about eating, drinking and swallowing?

How would you have felt about someone checking your eating, drinking and swallowing abilities at the beginning?

About the Present Situation

As time has gone on have there been changes in how you eat, drink or swallow?

If there has been can you tell me some about what these earliest signs or changes were?

Is there anything that helps you when you are eating, drinking and swallowing?

Is there anything else that you think would be helpful now?

Questions Looking to the Future

Thinking ahead is there anything that you think would be useful for you and your family for the future to support you with eating, drinking and swallowing?

Narrative Enquiry

Have there been any individuals who have supported you with changes in eating, drinking and swallowing?

Is there anything else that would have been useful to support you earlier, now and in the future?

Conclusion

Thank you very much for answering these questions and sharing your experiences about eating, drinking and swallowing. Is there anything else you would like to share with me before we stop? Would you be willing to help us check that we have understood what you have told us today?

Would you like us to contact you again in a few months with a summary of the findings?

## APPENDIX A2

Questions for carers of people living with dementia

Can you tell me a little bit of what it was like in the early days of living with a family member with dementia at home?

About the Past

At the start of your family member's journey living with dementia can you tell me a little bit about your family member's eating, drinking and swallowing?

Is there anything that would have been helpful for you or them at the beginning?

At the beginning of this journey would you have liked some information about eating, drinking and swallowing in dementia?

How would you have felt about someone checking your family member's eating, drinking and swallowing abilities at the beginning?

About the Present Situation

As time has gone on have there been changes in how your family member eats, drinks or swallows?

If there has been can you tell me some about what these earliest signs or changes were?

Is there anything that helps you when they are eating, drinking and swallowing?

Is there anything else that you think would be helpful now?

Questions Looking to the Future

Thinking ahead is there anything that you think would be useful for you and your family for the future to support your family member with eating, drinking and swallowing?

Narrative Enquiry

Have there been any individuals who have supported your family member with changes in eating, drinking and swallowing?

Is there anything else that would have been useful to support you earlier, now and in the future?

Conclusion

Thank you very much for answering these questions and sharing your experiences about eating, drinking and swallowing in persons living with dementia. Is there anything else you would like to share with me before we stop? Would you be willing to help us check that we have understood what you have told us today?

Would you like us to contact you again in a few months with a summary of the findings?