

# **Family carers' experiences of dysphagia after a stroke: an exploratory study of spouses living in a large metropolitan city.**

Running head: Post-stroke dysphagia: family carers' experiences

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# **Family carers' experiences of dysphagia after a stroke: an exploratory study of spouses living in a large metropolitan city**

## **Abstract**

**Background:** People with post-stroke dysphagia often require informal care from family to facilitate safe swallowing, modify food/drink or administer tube-feeds. Previous survey studies have found dysphagia may increase family caregiver burden. However, the experiences of family members in this population have not been fully explored.

**Aim:** To explore family members' experiences of living with a spouse with post-stroke dysphagia.

**Methods:** This exploratory qualitative study used one-to-one semi-structured interviews to explore family members' experiences. They were asked open questions about previous eating routines, dysphagia onset, their role and future hopes. Interviews were audio-recorded, transcribed and analysed thematically with an inductive approach to determine key features of family members' experiences.

**Findings:** Five spouses aged 70-93 years participated. Their relatives' strokes happened three months to three years before the interview. Five themes were identified: 'I do all of it'; making sense of dysphagia; emotional responses; reflecting on relationships; and redefining lifestyle.

**Conclusions:** It is important to consider family members' perspectives as they often provide vital care to loved-ones with dysphagia. In relation to eating and drinking, maintaining elements of previous routines seems important to families. Healthcare professionals should consider these when making recommendations for rehabilitation. Family members have differing perspectives of the comparative impact of dysphagia;

patient and family priorities should be explored for healthcare professionals to provide better-targeted support.

### **What is already known on this subject?**

- Informal caregivers, often spouses, play a vital role in supporting the health and wellbeing of older people with health conditions
- The presence of post-stroke dysphagia may present increased challenges for the informal caregiver.
- There are limited studies qualitatively exploring the experiences of informal caregivers in this population.

### **What this study adds**

- Current health and social care provision for this population leaves informal caregivers feeling they have been left to manage dysphagia alone.
- Informal caregivers demonstrate a breadth of knowledge about their spouse's dysphagia, problem-solving effective solutions.
- Informal caregivers have a range of interpretations of the nature and cause of dysphagia; leading to miscommunication with health professionals and complex emotional responses.

### **Clinical implications of this study**

- Healthcare professionals might consider ways in which to support dysphagic patients' families later in their care pathway, through scheduling reviews or running dysphagia patient and family groups.

- Health and social care professionals and policy-makers should learn from informal caregivers' expertise to promote better health and quality-of-life outcomes for the patient and caregiver.
- Equal, open conversations between health and social care professionals and patients/families on their understanding of dysphagia may help informal caregivers to better voice their concerns and support mutual understanding. This has implications for adherence to recommendations, psychological wellbeing and patient safety.

## **Introduction**

The number of people over the age of 80 is expected to triple in the next 30 years (United Nations, Department of Economic and Social Affairs, 2019). As the population expands and life expectancy increases, there is growing concern about the provision of care for those with long-term health conditions (Al-Janabi, Nicholls and Oyebode, 2016). Already, much care is provided by informal caregivers, who are generally family or friends of the person with a health condition, and this has been encouraged by a number of European countries in order to reduce public healthcare spending (Bremer et al., 2017). In the UK, in 2018/19, around 7% of the UK population were providing unpaid care (Department for Work and Pensions, 2020). The older generation supplies a disproportionate amount of care (The King's Fund, 2006) and unpaid care being provided by older people is increasing at the fastest rate; the number of people aged 65 and over caring for a loved-one has increased by 35% in 10 years, compared to an 11% increase for carers of any age (Carers UK and Age UK 2015).

Worldwide, stroke is recognised as one of the major causes of complex, long-term disability in adults (Feigin et al., 2015). Many stroke survivors require informal care; approximately half of stroke survivors are dependent on others following their stroke (National Audit Office Department of Health, 2005). Previous research has documented the wide-ranging impact of stroke on family caregivers, including changes to roles/relationships and interdependence (Theadom et al. 2019). Informal caregiving after stroke may have negative psychological consequences for the caregiver; a Stroke Association report (2013) documented that 64% of informal carers suffer from the emotional impact of stroke. Within the Stroke Association's (2021, p.13) identified priority areas for stroke research, one priority is to identify "what personalised training and support is available for carers to enable them to support stroke survivors and their recovery"

Dysphagia, or difficulty swallowing, is a common consequence of stroke and previous quantitative studies have documented an association between presence of dysphagia in stroke patients and presence of depression in their caregivers (Hultman et al. 2019). The presence of dysphagia in the care recipient may present increased challenges for the informal caregiver. A 2019 survey assessing the impact of dysphagia on informal caregivers found that “caregivers of spouses with dysphagia were significantly more likely to experience emotional burden” than of those who did not have dysphagia (Shune and Namasivayam-MacDonald, p.172). A related systematic review (Namasivayam-MacDonald and Shune, 2018 p.1) explored the burden of dysphagia on family carers of the elderly, concluding “although aspects of dysphagia play a role in the caregiver burden, the specific reasons for the increased burden are unknown”.

Nund et al. (2014) qualitatively explored the impact of dysphagia on caregivers in the head and neck cancer population, finding that caregivers generally felt ill-prepared for their role in dysphagia management. Eltringham et al. (2019) investigated the experiences of people with post-stroke dysphagia and their informal caregivers at an acute phase, with their findings highlighting the impact of dysphagia on the person who had a stroke and their informal caregivers, and identifying a need for effective communication at an early stage. Johansson and Johansson (2009, p.25) explored the experiences of family carers of people with eating difficulties after stroke, focussing on the practical aspects of eating such as food preparation, and concluding that “it is important to support informal caregivers, to provide adequate information, and to share responsibility”.

These qualitative studies provide insight into the wide-ranging experiences of informal caregivers at the acute phase after stroke and those caring for people with eating difficulties

more generally. Further exploration of the needs of informal caregivers who are looking after loved-ones with chronic post-stroke dysphagia is required. In particular, exploring the experiences of informal caregivers from a range of cultural and socio-economic backgrounds may permit identification of a broader range of experiences and identify novel themes with clinical implications.

The aim of this research study was to explore family caregivers' experiences of living with a spouse with post-stroke dysphagia within a metropolitan population. By qualitatively exploring the effects of dysphagia through the perspectives of informal caregivers from a multi-cultural and socio-economically diverse city, the findings may help to identify the specific support needs for this group as well as providing insights to be considered in health and social care planning. The findings may have implications for: health and social care professionals directly working with caregivers; future research directions; and policy makers determining the best ways to support informal caregivers' health and wellbeing.

## **Methods**

The study's method is reported using O'Brien et al.'s (2014) Standards for Reporting Qualitative Research.

### ***Approach and paradigm***

An exploratory qualitative methodology (Bradshaw, Atkinson & Doody, 2017) was adopted, because this is the first study that we are aware of to focus explicitly on informal carers of people with chronic post stroke dysphagia. The design adopted an inductive approach to data collection and analysis which was guided by subjectivism, which is based on real-world phenomena, positing that the world does not exist independently of our knowledge of it



(Grix, 2004). A descriptive qualitative approach such as this is suitable for exploratory healthcare research as it allows the researcher to learn from the participants and their descriptions, and to use this knowledge to influence interventions (Bradshaw, Atkinson & Doody, 2017). This study was qualitative in nature in order to build knowledge from participants' subjective experiences, and one-to-one interviews were chosen to permit and illuminate individual perspectives (Fossey et al., 2002).

### ***Researcher characteristics and reflexivity***

This study originated from the first author's concerns about how and whether speech and language therapists adequately consider the needs of informal caregivers of dysphagic stroke patients. Embarking on the study, the first author had beliefs about how and whether family caregivers were affected by a relative's dysphagia. Having worked as a speech and language therapist for four years, two of which were based in the community, the first author had some understanding of the sorts of issues informal caregivers would face, such as, for instance, spending extra time preparing food and drink, no longer eating together, changes to social lives, and worrying about swallow safety. It is recognised that the first author may therefore have assumptions based on their clinical experiences and prior knowledge which have the potential to influence the interpretation of the findings. To minimise as much bias as possible, the first author kept a reflexive journal, providing information about her developing perspectives throughout data collection and how this may be influenced by her clinical experience. The first author met regularly with non-speech and language therapist co-authors to discuss and refine the developing findings.

### ***Context***

Recruitment was via negotiated access through one NHS community therapy team (fig. 1).

This community therapy team was selected as they receive fairly high numbers of referrals of stroke patients and are situated in a socio-economically and culturally diverse area. Speech and language therapists in the community team screened the current patient lists for people with dysphagia after a stroke who lived with a family member who provided some level of care. Clinicians provided invitation letters to the person with dysphagia’s informal caregiver, who was asked for permission to be contacted by, or to contact the researcher if interested in participating.

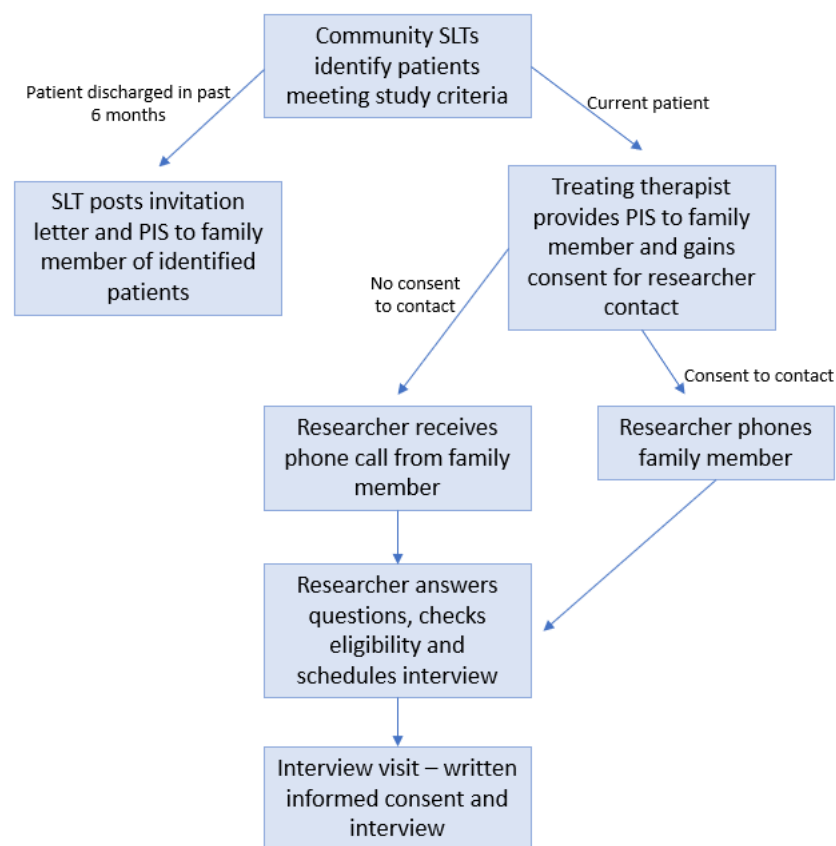


Figure 1 - recruitment flow chart

### ***Sampling strategy***

Purposive sampling was used to identify prospective participants who were especially knowledgeable about the phenomenon of interest (Patton, 2001). Participants were sought

who were a spouse, relation or committed domestic partner of a person with ongoing dysphagia caused by stroke. As the study was interested in the physical, social and emotional aspects of dysphagia caregiving, it was important that participants had a familial relationship with the person with stroke. Participants were sought who lived with the person with dysphagia, as this was likely to influence the level of care they provided. No further criteria were specified, as the study sought to elucidate views of a diverse range of people experiencing a similar phenomenon. The sample size of eight to ten participants was based on the exploratory nature of the study aims, to provide insight and highlight areas for further in-depth qualitative research.

As the study progressed, only spouses were recruited, and therefore the insights from the study are addressed directly in relation to the experience of caring for a spouse with dysphagia. The recruitment of solely spouses may have been due to the spouse being most likely to live with and care for the stroke survivor (Tennstedt, Crawford and McKinlay, 1993). The people with dysphagia themselves were not directly asked to participate. However, they had the option to participate in the interview with their spouse if they wished to.

### ***Ethical issues***

Ethical approval was sought and received from the Health Research Authority, the Harrow NHS Research Ethics Committee (ref: 18/LO/0423, date of approval: 18 May 2018) and the relevant NHS Trust Research and Development department. Informed written consent was obtained prior to any participant undergoing study-related activities. Confidentiality and anonymity of participants was maintained throughout the study.

### ***Data collection method and instruments***

Interviews were conducted between May 2018 and July 2018 by the primary author and were audio recorded using a digital voice recorder. Interviews took place at participants' homes.

Semi-structured interviews were selected as a data collection method as they allowed for key, planned topics to be introduced and subsequently explored within each individual's perspective.

Participants completed a demographic information form pre-interview to provide context.

Interviews followed a topic guide which comprised open-ended questions informed by a literature review and adjusted based on feedback from a Patient and Public Involvement (PPI) group. The PPI group was an established group of stroke patients and caregivers who met on a monthly basis. The primary author presented the study topic area and aims to the group, which comprised 5 stroke patients and 5 caregivers, and then discussed the topic. The PPI group gave feedback about the pilot interview topic guide, advising to shorten it and provide the topics to participants in advance.

The final topic guide comprised three main deductive themes: practical, social and emotional aspects of caregiving, and additionally asked about family roles and eating and drinking routines, with the aim to explore how the caregiving role might threaten or consolidate previous eating habits. The topic guide was also refined iteratively as new topics were introduced by participants.

### ***Data processing***

Data collection commenced with a pilot interview to identify any ambiguous questions (Berg, 2009), raise additional topics and confirm the validity of existing topics. The pilot interview

contained useful data and was therefore also included in the analysis. The first author (blinded for review) transcribed by hand and briefly analysed each interview within two days of it taking place in order to amend the topic guide if necessary. Analysis was facilitated by NVivo 10 software (QSR International Pty Ltd., 2012).

### ***Data analysis***

Interview transcripts were analysed thematically, using the process described by Braun and Clarke (2006) with a data-driven inductive approach. Thematic analysis was deemed an appropriate method of analysis; addressing the study's aim of exploring a range of experiences of dysphagia caregiving and identifying key challenges and aids (Nowell et al. 2017).

The thematic analysis performed followed the below steps:

- 1) The first author familiarised herself with the data through transcribing and reading the transcripts (Braun and Clarke, 2006)
- 2) The first author analysed the transcripts line-by-line into codes.
- 3) The first author re-read the transcripts and discussed the emerging codes with co-authors who assisted with revising codes, and emerging themes were discussed.
- 4) The first author compared the codes with each other, grouping them into theoretical categories which became themes and sub-themes.
- 5) The final set of themes and sub-themes were discussed with the co-authors. Disagreements were resolved through discussion and themes and sub-themes amended accordingly.

This method of revising codes and themes collaboratively with the other authors who were not speech and language therapists supported a broader interpretation of the participants' experiences.

### ***Methods for enhancing trustworthiness***

Lincoln and Guba's (1985) criteria for trustworthiness of qualitative research were referred to when designing the methodology. Credibility was enhanced through the building of rapport with research participants, member-checking of findings and cross-checking of themes by another researcher. The study allows the reader to judge the transferability of the findings through providing information on participant demographics, researcher reflexivity and direct participant quotes. The dependability of the results can be assessed through the provision of thematic maps from various stages of the process, which provide an audit-trail for the process from raw data to findings (Carcary, 2009). Confirmability was enhanced through discussion of themes between the authors and the maintenance of a reflexive journal.

## **Findings**

### ***Participant Characteristics***

The community clinicians identified and sent invitation letters to eight possible participants. Five participants were recruited (table 1). One possible participant declined due to other commitments, and two who were sent the letter did not contact the researcher. Further participants were not recruited due to the limited time scale of the study, and because enough rich data was collected from the five completed interviews to allow in-depth analysis to generate broad themes. Participants were mostly female (n = 3, 60%) with a mean age of 81 years (range 70–93). Most were White British (n = 4) with one Asian. All five were retired spouses of the person with dysphagia and lived with them at home. Couples had been married an average of 50 years. Participants' spouses had dysphagia ranging from moderate

(requiring adaptation of food or drink) to severe (requiring tube feeding with small amounts of food/drink orally). Time since stroke ranged from three months to three years.

Participants were all caring for their relative (i.e. the person with dysphagia was not independently managing day-to-day activities). The person with dysphagia often had additional medical diagnoses alongside stroke which impacted on their day-to-day functioning. Only one of the people with dysphagia was present in the interview (husband of P02) but due to his cognitive difficulties was unable to engage in the discussion. Interviews lasted between 18 and 40 minutes with average duration of 31 minutes. Of the participants, two were previously known to the first author (P01 and P05) as she had been their treating therapist one-two years before. In order to reduce the impact of this as much as possible, these participants were informed that the interview was entirely separate from their usual care, and that the interviewer was no longer working within the clinical role. Pseudonyms have been used for patients' names.

Table 1 - participant demographic information

Age range	Gender	Ethnic group	Occupation	Patient age	Patient ethnic group	Patient occupation	Food/drink intake with IDDSI (Chichero et al. 2017)) level	Tube feeding?	Date of stroke	Co-morbidities noted
65-74	Female	English	Retired	75-90	English	Retired	Tastes for pleasure (liquidised, level 3)	Yes (PEG)	2016	
65-74	Female	Other Asian background	Housewife	65-74	Other Asian background	Retired	Mildly thick fluids (level 2), soft and bite-sized diet (level 6)	No	2017	Vascular dementia
65-74	Male	English	Retired	65-74	English	Retired	Mildly thick fluids (level 2), minced and moist diet (level 5)	No	2018	
90+	Female	English	Retired	90+	English	Retired	Mildly thick fluids (level 2), soft and bite-sized diet (level 6)	No	2018	Dementia
90+	Male	English	Retired	90+	English	Retired	Mildly thick fluids (level 2), soft and bite-sized diet (level 6)	No	2015	Respiratory difficulties, visual impairment



## Thematic Analysis

Five main themes were identified (figure 2 - blue) with a number of sub-themes (brown). The connections of the newly identified themes with the deductive themes asked about directly in the interviews are shown in green. Inductive analysis suggested that informal caregivers do not experience practical, social or emotional changes independently but instead describe their experiences with these areas intertwined. The findings presented here are those that are particularly well-supported by the data (i.e. were discussed in detail by participants) or because they present novel ideas or perspectives not discussed in previous caregiving literature and which are therefore important to highlight as potentially specific aspects of dysphagia caregiving in stroke.

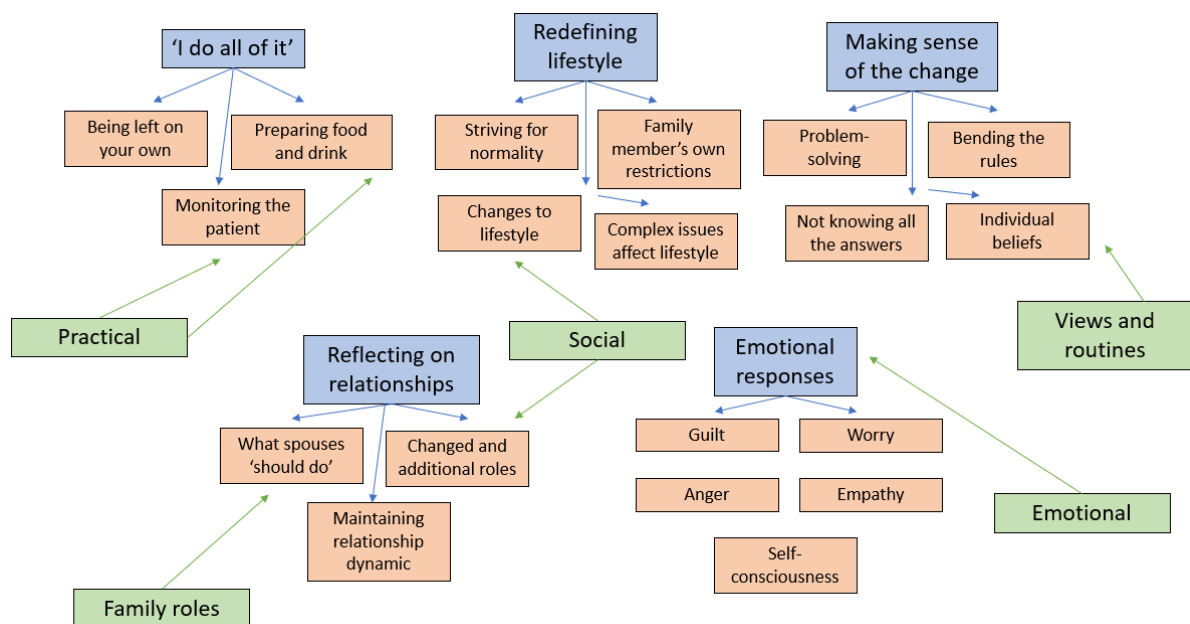


Figure 2 - theme map

## Theme 1: 'I do all of it'

Within main theme 'I do all of it', a sub-theme arose of informal caregivers feeling left on their own. Most of the participants discussed how, following finishing healthcare treatment, they felt solely responsible for the person with dysphagia:

“Everybody that's come has all been really, really kind and really, you know, content. But it's I suppose it's like anything: that all goes away, and then you're left on your own basically, and then you're the one that has to call the shots, and you're the one that has to deal with the day-to-day things” (P01)

Although all participants had received input from healthcare professionals, regular changing of staff, transfers in care, discharge from services and poor communication led to informal caregivers coping with dysphagia on their own:

“But there comes a day when they feel they've done enough and then I just have to manage with the carers [paid carers helping in the house] here” (P05)

“There's no continuity between them [healthcare professionals] and it's very, very difficult to find out who's responsible for what, and then you find somebody good and they get moved [...], it's just total lack of communication” (P04)

Managing alone led to feelings of responsibility, which were not always welcomed: P05 states in relation to providing supper for his wife, “I don't really want to have the responsibility of doing that”. In this instance, having paid carers assisted in reducing the sense of continuous responsibility:

“Oh yes I have to because erm I couldn't possibly imagine, my wife is so handicapped so we have a carer in the morning to get her up, give her breakfast” (P05)

However, despite helpful carers, P05 still felt that he held primary responsibility for his wife:

“Oh I have to do it all yes. I don’t let the, the carers, they’re OK and very helpful but they I don’t let them do any of the medical stuff, I do all that” (P05)

Some, conversely, felt it was easier to manage without paid carers, either due to unreliability of care services, or because the carers were not trained in the necessary duties:

“I stopped them coming in because they weren't turning up properly and that [...] they were unreliable [...] coming late, and not turning up at all [...] so I was doing it all myself” (P03)

“I mean these are carers and yet, I'm the one that has to undo and plug in the food and unplug the food and all that, which seems weird” (P01)

Managing alone, with full responsibility for their spouse, culminated in the family caregiver feeling they were the person with dysphagia’s only means of survival:

“Without me his weight drops dramatically, and it's surviving [...] a surviving matter. If I did not help him, instantly maybe one month or, he can't last” (P02)

## Theme 2: Making sense of the change

In order to manage alone, the participants reported trying to better understand dysphagia. This required problem-solving, learning and bending the rules, where the participants engaged with their own belief systems. Through trial and error, they had found innovative solutions to supporting their spouse to eat enough:

“I choose stuff, sometimes I give her a spoon and it’s better, easier for her to do it, on the main course” (P05)

“Even if with soft food he cannot swallow. In that case I have to prepare all the food in a tray meal, and water, and fruit [...] blueberry or strawberry raspberry. It's really helpful [...] and suddenly, chewing [...] it's a survival game” (P02)

Adding fruit to the main course helped prompt her husband to swallow. Both experience and professional advice had led to increased confidence, particularly in relation to tube feeding:

“I put everything in through a syringe, and give him his medications and that, and it won't go, um, so I but I've learnt how to sort of um unblock that now” (P01)

“just experience isn't it, you learn as you go along” (P03)

“[the] dietician is really good, [...] I followed his advice, his instruction, slowly and little bit little bit better” (P02)

Despite finding professional advice beneficial, some informal caregivers reported “bending the rules” set by healthcare professionals to help their spouse survive, and to maintain aspects of their pre-morbid routines, needing to balance swallow safety, nutrition and hydration:

“They say, you know, he shouldn't drink more than one gulp at a time, but I don't deter him because he's very loath to drink anyway” (P04)

The sense-making process is also evident in the participants' discussions of physical symptoms, cause, and prognosis. Although they have problem-solved some solutions, they are unsure of prognosis:

“But I mean the truth is, I of course, he was tested in hospital and it was seen what his problem was, but to what extent it's improved, I don't know” (P04)

“Just carrying on doing it really, who knows when it's going to end” (P05)

Whilst P02 questions the nature of her spouse's dysphagia:

“Oh did he forget how to swallow? Looks like it to me, but I don't know” (P02)

And she also questions the cause of her spouse's stroke, triggering feelings of self-doubt and guilt:

“But pork belly has lots of fat in it, we shouldn't have it. But I didn't know that. So when he had a stroke, I thought about the white powder, carnation, the coffee mate powder. I hate that. And pork belly [...] those two I regret them very, very much [...]. For some people it could be OK, but with his genes, [it is] not good food. I didn't know that” (P02)

She feels these food choices may be acceptable for others, but not for her husband where his genes predispose him to stroke. She describes feeling regret towards her role in her spouse's health, repeatedly stating ‘I didn't know that’.

### Theme 3: Emotional Responses

Participants discussed a variety of feelings associated with their experiences of their spouse's dysphagia. One key sub-theme mentioned by all participants was guilt. Participants felt guilty for the stroke's cause (described above), for denying their spouse food, and for getting angry at them:

“But it does, there's a guilt thing there all the time, especially knowing how he liked his food, that's the main thing coz he liked his food, you know and he still says things like ‘can I have some of that?’ and you have to be the wicked witch and say ‘no you can't have it’ and that's heart breaking”. (P01)

Whilst anger and guilt arose repeatedly across the interviews, other sub-themes included worrying about their spouse's health, the future, and their weight, as well as feelings of empathy, discussed below.

### Theme 4: Reflecting on Relationships

Three of the participants reflected on what they perceived as the ideal way for a spouse to respond to their partner's ill health. Participants relay their feelings of empathy in terms of reciprocity; treating one's spouse as one would wish to be treated. When asked what one

piece of advice she would give to others in her situation, P02 re-iterated:

“Errr first of all, understand [the] patient [...] not insist on my feelings, not focusing on my feelings. Try to understand [the] patient more” (P02)

P01 similarly possessed an idea of what a spouse should do:

“You know, and everybody says to me 'oh you're doing a wonderful job, oh you look after him so well' you know, and I say 'no, I, I do what all wives would do, or what all wives should do, because I know he would do the same for me'” (P01)

The idea of reciprocity was also noted by P02 - “he treated me like that. So I should do [that] in refund” - and P04. One participant saw ill health as part of their relationship’s natural journey:

“But I will do my best and I hope he is with me as long as possible [...] even if he gives me a hard time [...] I will enjoy the last of our journey” (P02)

In this sense, although their situation had changed, it was important for participants to demonstrate how their underlying relationship dynamic remained the same:

“Interviewer: yeah, yeah. You still have your rows sometimes?  
03: oh god yeah, yeah, we have them regularly [...] mind you she can give me what for anyway, don't worry. She holds her own occasionally” (P03)

The person with dysphagia’s mental strength helped participants cope with the physical changes:

“I mean Mary is very determined to stay alive if you like, I mean she’s thinking all the time [...] but unfortunately as I said she can’t perform [...] oh yeah if I make a slight mistake on the order of giving her medications, she spots it straight away” (P05)

Conversely, communication difficulties on both sides made it more difficult to maintain their relationship dynamic:

“But, problem is his condition he rarely talks, he never talks” (P02)

“He doesn't speak very clearly [...]it's blurred to some extent. I'm hard of hearing [...] so I'm not a good person to judge, but I find it very difficult to understand him” (P04)

#### Theme 5: Redefining lifestyle

Changes to day-to-day life were expected, both practically and socially, when embarking on this study. Whilst previous literature found that participants reflected on *the changes* to lifestyle following dysphagia onset, most of this study's participants described maintaining aspects of their usual routine, both in terms of spousal relationships and day-to-day activities. Participants tried to maintain usual routines by eating together, eating out on occasion, and making small adjustments:

“There's a restaurant here, we eat at the restaurant [...] but obviously I have to watch her very carefully with lots of napkins and stuff to make certain that Mary doesn't spill everything” (P05)

“If we go- if we do, I buy the pouch. I take a spoon with me and I give him that so that he feels he's joining in, and when we're going- like we're going over to our daughter's next weekend, and she'll probably- I think she'll probably do a roast and whatever, but he will sit at the table with us” (P01)

Despite the fact that their spouses cannot eat as they used to, informal caregivers still consider their personal tastes and make sure food provided adheres to these:

“I mean I could get her food sent up, but a) it's expensive, and b) it's not what she eats, so it's easier if I do it all” (P05)

“Sometimes he likes Japanese food, sashimi, something like that. He enjoys that” (P02)

Awareness of their spouse's preferences is also reflected in their organisation of social activities. Informal caregivers make adjustments to ensure they can continue to maintain an

element of socialising:

“[Used to go out for dinner] with friends [...] but now, [only very close friends] can eat with us. Otherwise some, with some not friendly people, there is more choking, more flying food [...]. So [...] very close friends, we can share food with [...] with lots of [kitchen roll]”. (P02)

They are only able to eat with close friends now, as eating with unfamiliar people presented higher risk for her husband’s swallowing. P05 also found that eating out with unfamiliar others could be a strain for his wife, and so they compromised by only eating out with close family.

A key theme related to lifestyle change was that dysphagia was not the sole cause of limitations and, instead, lifestyles were affected by a complex interaction of health and social issues. As P05 states, “well the swallowing is, I mean, it’s there, but I mean that’s just one of the many problems”. Health-factors including bowel (P02, P05), mobility (P01, P03, P04, P05) and voice issues (P05) all presented challenges to socialising. External factors including family issues (P03) and moving house (P05) also impacted on social lives.

P04 felt that her husband’s cognitive and mobility difficulties had the greater impact on their life:

Interviewer: have things changed for you and the family at all?

P04: Well of course, I mean it's, it's not due to the eating but due to everything else (P04)

However, for P01, despite her spouse’s mobility and cognitive impairments, dysphagia had had the greatest impact:

“I think we could have both coped with the stroke, if it had just been the loss of, of the arm and the leg [...], but the fact the stroke took his swallow as well, I think that's the hardest bit” (P01)



## **Discussion**

Dysphagia following a stroke has wide-ranging practical, social and emotional effects, both for the stroke survivor and their informal caregiver. Here, the study's findings will be discussed in relation to previous literature, outlining new areas for consideration in health and social care practice and policy. Previous studies have explored how informal caregivers of people with dysphagia feel a sense of responsibility (Johansson and Johansson, 2009). The present study's informal caregivers also reported feeling isolated in their role. Camak's (2015, p.2378) review of the literature on the burden of stroke caregivers also found that carers struggle "to meet the needs of the stroke survivor, many times without adequate or consistent support". This was reflected here, whilst despite all participants having had input from healthcare professionals and paid carers, the structure of support was not reported to be consistent. In the UK, 56% of stroke patients are referred for appropriate therapy in the community, but this may be short-lived, and only three out of ten stroke survivors needing a six-month assessment receive one (Royal College of Physicians 2016). Some informal caregivers may feel that after the initial therapy input, they are left to manage without future review plans. These feelings of isolation were alleviated for Nund et al's (2014) caregivers of people with dysphagia from head and neck cancer through interaction with other carers in a similar position; and they recommended carer support groups as a way to formalise this support.

Although participants seemed to find healthcare input helpful to some extent, one participant was reluctant to have further therapy input, and similarly, although individual formal carers were perceived as helpful, there was an alternative view that one could not rely on formal carers for medical management (tube feeds, medication) or consistency of arrival time. This may be due to training, communication and service limitation issues within health and social

care. Greenwood et al. (2017, p.1), exploring satisfaction with social care services in England, also found that “participants talked mostly about specific individuals and relationships, [but] unsatisfactory experiences centred on services overall”. Punctual formal care might be particularly important in dysphagia management, as families may have specified meal times for cultural reasons, medications timing or diabetes management.

In the present political context, it may be challenging for health and social care services to provide ongoing, consistent, and timely care. However, increasing our understanding of the impact of inconsistent health and social care services on informal caregivers is important, particularly as the growing population is set to increase the reliance on informal care. As global initiatives are being developed to improve the integration of health and social care services to address these challenges (The King’s Fund, 2014), the present study’s identification of the wide-ranging experiences of and impact on informal caregivers highlights the need for specifically considering the dysphagic population in designing services.

Participants were not always clear on the cause of dysphagia or its prognosis, and depending on their previous experiences, had differing views as to the cause of their spouse’s stroke. Hafsteinsdóttir et al.’s (2011) systematic review around the educational needs of stroke patients and their caregivers found that in the later phases, caregivers “had a poor understanding of the causes of stroke, treatment and rehabilitation” (p.22). Eltringham et al. (2019) found that even in the early stages, participants’ past-future experiences influenced their emotional responses to events around onset of dysphagia. This suggests that healthcare providers should make a concerted effort to understand the caregivers’ perceptions of their

loved-one's dysphagia in order to provide tailored information and education that addresses issues around health and eating and drinking from a shared viewpoint.

This study's informal caregivers had varying perceptions of the relative impact of dysphagia compared with other factors. The complexity of factors affecting family carers is corroborated by LaDonna et al. (2016), whose family carers of dysphagic patients with myotonic dystrophy report mobility and fatigue as prevailing factors. In the present study, dysphagia is, for two participants, the most distressing symptom, whereas for others, mobility and cognitive changes were most difficult. This appeared related to the severity of dysphagia, other symptoms and the importance of food and socialising pre-stroke.

### **Strengths and Limitations**

A methodological strength is the study's involvement of patients and their relatives in the refinement of interview topics. A limitation of this study may appear to be the small sample, but this has to be balanced against the richness of the data and the willingness of the included participants to talk in depth about complex subjects. The rich data presented in this study reveal important insights into seldom heard perspectives, presenting informal carers' voices, which, as shown from the PPI engagement, are considered important to be heard.

Although the findings presented are specific to the small group of participants interviewed, the themes gleaned from the data demonstrate the diversity of caregiver experience. This study's participants' spouses had co-morbidities besides the stroke, reflecting the majority of patients. Indeed, Gallacher et al.'s (2014) study found that within the stroke population, 94.2% had co-morbidities. In this study, dementia, respiratory problems and high blood

pressure all added to the burden of care. Although this study originally aimed to recruit any family member of dysphagia stroke patients, the recruitment of only spouses, who were all aged 65 or over may limit transferability of the findings to other relations or age groups. The specific themes identified in this study which relate to being an older, spousal caregiver, are important to note due to the projected increase in reliance on this age group for provision of care (Pickard et al., 2007). Indeed, as older caregivers are often co-resident, care for longer hours and provide more intimate care than other age groups, their perspectives are particularly relevant for the dysphagic population (Carmichael and Ercolani, 2016).

The findings from this small exploratory study provide a starting point for future research. The difficulties with recruitment indicate that future studies in this population may require a longer recruitment period or multi-site approach in order to capture the perspectives of a larger number of informal carers from a wider range of age groups and cultural backgrounds. As indicated from the study's findings, informal carers are balancing a large number of conflicting demands, and thus research studies must be designed to be as accessible as possible. Some methodological choices were made to assist with this, including giving the option for interviews to take place at participants' homes. Future research could involve patient and caregiver stakeholders earlier in the design process to develop a more effective recruitment strategy. All participants chose to have the interview at home, and the researcher being in this context also helped to provide further insights into the complexity of the caregiver role and their day-to-day dysphagia management. This is something that could be reflected on in the light of Covid-19, where many interview studies are taking place online and may miss out on capturing these contextual elements.

### **Implications for practice and policy**

A well-supported finding was that informal caregivers felt left alone to manage once health input was complete. Healthcare professionals might consider ways in which to support dysphagic patients' families later in their care pathway, through scheduling reviews or running dysphagia patient and family groups. Informal caregivers reported experiencing challenges in aligning dysphagia management and social care support. As current health and social care policy is increasingly focussed on integrating care services, it is important for the views of caregivers of dysphagic patients to be considered to ensure policy supports the provision of reliable, sustainable care along with caregiver wellbeing.

Informal caregivers demonstrated a breadth of knowledge of dysphagia and about their spouse, and problem-solved using this knowledge and experience. It is important that health and social care professionals and policy-makers learn from informal caregivers' expertise to promote better health and quality-of-life outcomes both for the patient and the caregiver. Older carers, whose role providing informal care is growing at a faster rate than other carers, may have particularly useful insights from their life experience. Despite their knowledge and the input families had received from healthcare professionals, participants experienced moments of doubt and feelings of guilt. It is important for healthcare professionals to select the ways in and times at which they provide information to people with dysphagia and their families, considering individuals' pre-conceptions around health and food.

The participants each had different views on the impact of dysphagia, not always directly related to its severity. Therefore, interdisciplinary professionals need to work collaboratively to assess the comparative impact of factors affecting patients/families to identify priorities.

This is particularly important with clinical time-pressures and the increasing need for social care.

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**Data availability statement**

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