

# An exploration of the experiences and attitudes of healthcare professionals towards enteral tube feeding for adults living in the community following stroke

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## Abstract

**Background:** Guidelines recommend enteral feeding via gastrostomy should be considered for adult survivors of stroke with dysphagia who cannot eat or drink sufficiently for >4 weeks. Many people continue long-term tube-feeding via this route in the community where healthcare professionals contribute to their care and nutritional management, although little is known about their experiences of or attitudes towards enteral feeding in this situation. The present study aimed to explore the experiences and attitudes of healthcare professionals working with this patient group.

**Methods:** Healthcare professionals were invited to complete a questionnaire devised for the study which comprised closed and open questions about tube-feeding including their patients' participation in feeding processes and mealtimes and how these might be improved. Responses to closed questions were analysed descriptively and free-text responses analysed using thematic analysis.

**Results:** Fifty-seven participants met the inclusion criteria. They identified patients' quality of life (77% of respondents) and nutritional support (75%) as the most important aspects of tube-feeding. Good communication and training with healthcare teams and carers were considered important. Their patients' participation in tube-feed administration and mealtime involvement were described as variable and potentially beneficial, but both were related to patients' choice and health impairment. Blended tube-feeding was considered an option by 89% provided practical and safety conditions were met.

**Conclusions:** Participants' experiences of and attitudes towards tube feeding in adults living with stroke in the community in the sample in the present study are varied and focussed on individual patients' needs, safety and professional standards.

## KEYWORDS

blended feeding, community, enteral feeding, stroke

## Highlights

- Quality of life and nutritional support are considered the most important aspects of tube-feeding in adults living in the community following stroke.
- Patient choice should be considered in all aspects of decision-making about tube-feeding.
- Good communication and training are considered important for successful tube-feeding in the community.

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- Patients' participation in administering their own feed or involvement in mealtimes is variable and related to their choice and health impairment.
- Blended feeding is considered an option providing practical and safety consideration are addressed.

## INTRODUCTION

People living with stroke are at high risk of malnutrition, which impedes recovery and rehabilitation. Insufficient oral intake arises following stroke from dysphagia, impaired consciousness, cognitive impairment, aphasia and weakness.<sup>1</sup> Dysphagia affects up to 50% of stroke patients.<sup>2</sup> Patients with dysphagia and unsafe or insufficient oral intake require nutrition support via a feeding tube to minimise malnutrition and associated health complications, including frailty and risk of infection.<sup>3</sup> In the short-term after stroke, enteral nutrition is provided via a nasogastric tube<sup>3</sup> and approximately 8%–20% of stroke patients need tube feeding from stroke onset.<sup>4</sup> The Royal College of Physicians<sup>5</sup> recommend that stroke patients requiring tube feeding for >4 weeks are considered for gastrostomy placement and this is most commonly a percutaneous endoscopic gastrostomy (PEG).<sup>1</sup> Home enteral feeding data (2010–2015) show that 40% of PEGs were placed because of vascular disorders and 67% as a result of swallowing disorders, both of which are associated with stroke.<sup>6</sup> In summary, there are clear evidence-based national and international guidelines recommending gastrostomy feeding for stroke patients who are unable to consume sufficient food and fluids orally, and many people experience this.

The experiences of enteral feeding of people living with stroke and their feed-related quality of life (QoL) has received limited attention, for example, whether they feel excluded from eating and might value participating more at mealtimes with their families and friends rather than receiving nourishment as a formula feed.<sup>7</sup> This is significant because food and mealtimes provide a means of social interaction and pleasure, as well as being critical components of cultural identities, in addition to providing essential nutrients.<sup>8</sup> Gomes et al.,<sup>9</sup> in their Cochrane systematic review and meta-analysis, compared PEG versus nasogastric feeding for people with dysphagia including those with stroke. They identified that QoL measures related to inconvenience, discomfort, altered body image and social activities favoured PEG over nasogastric feeding, supporting the use of PEGs for long-term feeding. However, they did not explore the perspectives of mealtime participation or the sociocultural aspects of feeding via a tube or whether being excluded from meals because of tube-feeding may increase feelings of isolation and depression, which are a potential concern in people living with stroke. This lack of evidence means that this

important, patient-centred issue is not addressed in current clinical guidelines for stroke. In summary, there is a clear gap in evidence to support thousands of gastrostomy-fed stroke survivors who are unable to eat orally and thus restricted from participating in meal-related social activities.

Additionally, although the route of tube feeding is clearly recommended in clinical guidelines for stroke patients, there is no guidance about the type of enteral feeds. Developments in enteral feeding present an opportunity to examine this and explore potential benefits including safe blended tube feeding, comprising liquidised food administered via enteral feeding tube.<sup>10</sup> For stroke patients who are able, participating in the preparation of blended tube feeds (in addition to receiving the blended feed) may be beneficial in promoting neural plasticity and executive function via stimulation of motor and sensory pathways for patients with cerebellar damage.<sup>11</sup> Food choices and mealtimes, which are influenced by cultural and religious beliefs, are social activities that generally healthy people participate in together with their families and loved ones. This is especially seen in some minority ethnic groups who are at higher risk of stroke.<sup>12</sup>

At present, there is little evidence about healthcare professionals' experiences of caring for adults following stroke who are living in the community and require enteral feeding or their attitudes towards feeding and optimising this aspect of care. Exploring these aspects with healthcare professionals is important because their experiences and suggestions for improved practice might, first, facilitate a better clinical understanding of the issues and, second, identify potential actions that could be investigated with people who are receiving enteral feeding following stroke. Therefore, the present study aimed to explore the experiences and attitudes of healthcare professionals involved with caring for adults living in the community who receive enteral tube feeding following stroke.

## METHODS

A cross-sectional study was used to explore healthcare professionals' experiences and attitudes towards enteral feeding in patients following stroke and living in the community using a questionnaire designed for the study. Ethical approval was obtained from the University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority (LMS/SF/UH/05304) and participants confirmed they were giving consent before taking part.

## Participants

The inclusion criteria for participants were being a healthcare professional with experience of caring for adults living in the community after stroke who were receiving enteral feed via PEG for  $\geq 2$  months. All participants were required to be aged  $\geq 18$  years, able to communicate in English, and able and willing to give consent. A convenient sample was recruited using a snowballing technique by sharing an invitation to participate via professional networks, social media and the Stroke Association. The sample size was pragmatic because the study findings were not intended to be generalisable but instead aimed to provide information that will inform future research. Respondents who did not meet the inclusion criteria were excluded from the study. All participants were recruited and took part in the study in 2023.

## Questionnaire

A questionnaire was developed specifically for this study and comprised a total of 19 questions, which included 12 closed questions and seven questions requiring a free-text response. Conversations with patients and carers during patient and public involvement interviews were used to inform the researchers' understanding of their perspectives of enteral feeding after stroke. This was used, together with feedback from healthcare professionals working in stroke and the researchers' clinical and research experience in this area, to develop the questions. The questions asked about participants' experiences of tube-feeding in adults living with stroke, including which aspects of feeding they thought important, how feeding practices might be improved, safety concerns they had encountered and their patients' involvement in administering their own feed and any participation in meals and socialising around food. They also asked about awareness of blended feeding (using liquidised food rather than sterile commercial formula feeds), whether it might be considered an option in this patient population, and possible advantages and concerns that might be associated (see Supporting information, Doc. S1). The questions were developed by the researchers and revised following discussion. Revisions included changing the format of some questions (restricted choice or free text) and subdividing questions about blended feeding to explicitly ask about benefits and concerns. The final questionnaire was not piloted with other healthcare professionals. All questions that followed confirmation that participants met the inclusion criteria were optional allowing participants to answer some but not all questions. The final questionnaire was offered to participants online via the Qualtrics platform (<https://www.qualtrics.com/uk>) and as paper copies available on request.

## Data analysis

The responses from the questionnaire were downloaded into Excel (Microsoft Corp., Redmond, WA, USA). Responses to closed questions and numeric answers were sorted and described as totals, percentages and mean/median values. Participants were able to select more than one response to some questions and the results for these questions do not add up to 100%. The numbers of perceived benefits and concerns identified by participants were not normally distributed and, therefore, were compared using a Wilcoxon signed rank test (SPSS, version 29; IBM Corp. Armonk, NY, USA). Text responses to seven open questions were copied into tables in Word (Microsoft Corp.) and each question was analysed thematically using steps developed from Ritchie and Spencer,<sup>13</sup> with respect to reading and familiarisation; generating codes using colours; identifying initial themes by re-organising and grouping common codes; indexing and sorting; reviewing themes with research team discussion; defining final main themes; and reporting the main themes identified for each open question.

## RESULTS

In total, 81 healthcare professionals responded to the invitation to participate but only 57 confirmed that they met the inclusion criteria. Twenty-four participants were excluded because they did not confirm that they met the inclusion criteria. The results presented below are from these 57 except where fewer than 57 participants responded to a question and then the exact number of responses per question is stated. Most participants were dietitians or had trained as a dietitian and were currently working in a specialised role ( $n = 51$ ). The remaining six participants comprised three nurses, two occupational therapists and one medical doctor. All participants qualified at least one year ago and the mean time since graduation was 10.5 years with no significant difference between dietitians and other professions. The responses to the study questionnaire are reported with numeric data for closed questions followed by responses to open questions with main themes and relevant quotes from free-text responses. The responses to closed questions are summarised in Table 1 and the themes are summarised in Table 2. Quotes are presented in italics and, where these included abbreviations or required clarification from text not included in the quote, they have been expanded and the inserted text placed in square brackets. Each quote is followed by the participant's study number. Participants are not identified by their professional group in the quotations to ensure anonymity of the small number who were not dietitians. However, the themes that were identified from the free-text responses showed no obvious differences between the professional groups.

TABLE 1 Summary of participants' responses to closed questions.

Question	Responses (n)	Number (%) of participants selecting answer <sup>a</sup>	
What are the most important aspects of tube-feeding for your patients?	56	Quality of life	43 (77%)
		Sustaining nutritional status	42 (75%)
		Tolerance of tube feeding	34 (61%)
		Energy levels	18 (32%)
Have you identified any safety concerns associated with tube feeding at home?	45	Yes	30 (67%)
		No	15 (33%)
From your experience, do patients get involved in administering their tube-feed?	45	Yes	28 (62%)
		No	17 (38%)
		Patients are too impaired to be involved in administering their feed	12 (27%)
Do your patients participate in social activities with food/drink, that is teatime, dinner, social occasions?	45	Participation varies	27 (60%)
		Yes	9 (20%)
		No	9 (20%)
		They do participate but they are unable to eat or drink	4 (9%)
Have you heard of blended tube-feeding?	45	Yes	42 (93%)
		Yes, and currently using in practice	12 (27%)
		No	3 (7%)
Do you think blended tube-feeding would be an option (solely or in combination with sterile ready-to-feed formula) for stroke patients?	45	Yes	33 (74%)
		Yes, but only in combination with sterile feeding formula	6 (13%)
		Yes, solely	1 (2%)
		No	5 (11%)
Do you think blended-tube feeding could encourage the participation of stroke patients with social activities related to food/mealtimes (i.e., preparing blended tube-feeds, administering blends)	44	Yes	27 (61%)
		No	7 (16%)
		Patients are too impaired to participate	10 (23%)

<sup>a</sup>The percentage was calculated from the number of participants answering the question. Participants were able to select more than one option so the totals do not add up to 100%.

## Important aspects of tube-feeding

Most participants identified QoL (43 out of 56 responses; 77%) and sustaining nutritional status (42 out of 56 responses; 75%) as the two most important aspects of tube-feeding for their patients (participants able to select more than one choice so responses do not add up to 100%). Tolerance of feeding and energy levels were identified as the most important aspects by 61% (34 out of 56 responses) and 32% (18 out of 56 responses) of participants, respectively. Individual responses listed their patients' wishes, fitting

feeding around lifestyle and physical improvements including bowel function as most important.

## How tube-feeding might be improved

Forty-four (77%) participants identified improvements that they thought could be made to tube-feeding patients living with stroke in the community. Four main themes were identified from suggestions for improvement based on participants' daily clinical practice. The first theme

TABLE 2 Themes identified from health professionals' free-text responses to open questions.

Question	Responses ( <i>n</i> )	Main themes
What have you encountered in your daily clinical practice that could be improved in relation to tube-feeding?	46	Discussion and ethical decision-making Health professionals working together Availability of feeds Feeding equipment
Have you identified any safety concerns of tube feeding at home? If so, please specify	30	Delivery of care Feed-related symptoms Patient positioning Feeding tubes
How did you manage the risk?	30	Revising patients' feeding regimes Communication with patients, carers and professionals Training
From your experience, do patients get involved in administering their tube-feed?	28	Variability in involvement Involvement with specific feed-related activity Health impairment impacting on involvement
Do your patients participate in social activities with food/drink, that is teatime, dinner, social occasions? If so, please describe participation	26	Variability in participation Eating with family Positive social aspects Preference to avoid social situations with food and drink Safety
What are your thoughts/reflections around patients being involved with meals or socialising at mealtimes?	41	Benefits of sharing meals Importance of patient-led involvement at mealtimes Challenges of mealtime involvement
Do you think blended tube-feeding would be an option (solely or in combination with sterile ready-to-feed formula) for stroke patients? If yes or no, please specify	37	Benefits for patients Conditions needed for blended feeding Concerns about blended feeding Patient choice

focussed on improving patient care through discussions and ethical decision-making and included several recommendations for formalised and regular review of patients living in the community and receiving tube-feeding long-term, for example, *I think ideally each [patient] should have an annual [multi-disciplinary team] review as to whether tube feeding remains in [their] best interest and if their [quality of life] is being achieved* (53). The importance of patient involvement with decisions about feeding was recognised, for example, *consent especially for those with aphasia* (62). The challenges of feeding decisions being made during hospitalisation for acute care post-stroke followed by discharge to long-term care community settings was noted: *Initial decision making,*

*review of this decision in the community, frequency of review and capacity to work with community stroke services to rehabilitate patient* (70). Two participants described a need for national guidelines or policies to direct decision-making and a third noted that few staff were familiar with existing guidelines. A second theme identified the need for different health professionals to work together closely and communicate consistently, for example: *an [multi-disciplinary team] approach feels important ... especially [for] those with tolerance issues, but not always easily organized. Overall, more health professionals and a more joint approach for the tube fed patients, would be beneficial, in my opinion* (76) and [lack of] *consistency of information and messaging between*



health professionals, often leads to confusion (17). The third theme focussed around feeds including a perceived need for a wider range of bolus feeds which are nutritionally complete for long-term feeding (78), better range of vegan options (9) and improved access to feeds that are more nutritionally complete as sodium and potassium requirements ... can be difficult to meet (28). A fourth theme relating to feeding equipment included a perceived need for equipment to make it easier for people with weak hand grip to still take advantage of bolus feeding or pumps that deliver bolus feeds at faster rates (24), how best to ascertain tubes position where pH is high resulting in delayed feeding (14) and to resolve problems with tubes falling out (47).

### Safety concerns and managing risk

Safety concerns associated with tube-feeding were identified by 30 out of 45 responses (67%) of participants and four main themes were identified from the text descriptions. The first theme, delivery of care, included concerns about who would deliver the feeding, for example, *finding enough carers in the community who are willing to manage feeding tubes* (21) and their competence as *some carers require more support to ensure safe tube feeding* (20). Concerns about patients being left alone when feeding between carer visits or overnight were also identified: *they may be left at home for periods of time when connected to feed, nil person available to do bolus feed so pump is only option, risk of issues occurring ... which [patient] could not self-manage* (11). The second theme focussed on feed-related symptoms including reflux, vomiting and aspiration, gastrointestinal discomfort and change of bowel habit, for example, *complex patients who are often vomiting/regurgitating/having secretions* (11). The third theme, patient positioning, was related to the risk of aspiration and identified by approximately one third of participants who described safety concerns, for example, *where the patient cannot maintain a safe position for feeding* (68). The fourth theme related to feeding tubes including dislodged tubes, lack of tube care, infected PEG sites and buried bumper syndrome where the internal fixation device of the PEG moves inwards along the stoma tract, potentially leading to an abscess and fistula.<sup>14</sup>

Three main themes emerged from responses about how participants manage the safety risks they had identified. The first focussed on revising their patient's feeding regime to address tolerance issues and this included changing the type of feed, for example, *modifying fibre content* (25), changing the feed delivery rate, for example, *reduce rate of feeding, more concentrated feed* (10), or changing the feed delivery method, and, for example, *trailing bolus feeding with close monitoring depending on the indication for the pump in*

*the first place* (68). The second theme addressed safety issues through communication with patients, their family and a wide range of professionals, for example, *get the appropriate [multidisciplinary team] members involved, i.e. positioning can be supported by [occupational therapist]/physio[therapist] input if under the stroke rehab service* (68) and *liaising with discharging hospital team, social services, safeguarding if needed, knowing the care providers in the local area that will be trained or know about tube care* (35). The third theme focussed on training to address issues, for example, *advise on correct way to bolus feed and offering training* (20) and *education and training on tube care, education on use of ENPLUGs* (medical device to keep stoma open if PEG is removed) (79).

### Patients' involvement with their tube-feed

Patients' involvement in administering their tube-feed was reported by 28 out of 45 responses (62%) participants. Three main themes were identified from participants' free-text responses. First, the variability in patients' involvement was described, for example, *great variation [from] starting/finishing the feed to doing everything* (59). The second theme focussed on specific feed-related activities that their patients undertook including giving bolus feeds, setting up feeding pumps, water flushes, cleaning PEG sites and changing fittings. One participant reported that they *had one patient who made a wooden stand to hold his syringes while he was bolus feeding* (51). However, 17 out of 45 responses (38%) participants reported that their patients were not involved in feed administration and non-involvement was mostly associated with health impairment (12 out of 45 responses; 27%). Health impairment impacting on non-involvement was also identified in free-text responses as a third theme, for example, *patients aren't able to due to physical limitations* (78) and *... it depends on their dexterity* (54). Where patients were not physically able to undertake feed administration, some engaged through expressing *wishes about rates/volumes etc.* (77).

### Patients' participation in social activities with food and drink

Most participants described variable patient participation in social activities with food and drink (27 out of 45 responses; 60%). Equal numbers (nine out of 45 responses; 20%) reported that their patients participated and that they did not participate and, of those who participated, four out of 45 responses (9%) were not able to eat or drink. Five main themes were identified from the free-text responses. The first reflected the variability

of patients' participation in social activities with food, for example, *No two patients are the same. Impossible to make a generalisation* (2). The second theme focussed on patients eating with their families, although this was usually limited in quantity and sometimes considered 'at risk', for example, *Some take part in social activities by either having very small portion food or drink* (50) and *some opt to eat and drink at risk on special occasions, some will choose to eat and drink at risk all the time* (67). One participant described a patient who *discretely bolus* fed during social occasions (50). The third theme was based on the positive social aspects of participating either without eating or drinking or with texture modification, for example, some patients *revel in the social aspect of mealtimes and are happy to be in the midst of it despite being [nil orally]* (17) and *a lady whose family would have taken her out to the pub and she would have taken her wine and thickener and had this out with them* (74). The fourth theme identified that some patients preferred to avoid social situations with food and drink, for example, *some patients don't want to know about mealtimes as they feel so left out and are upset that they can't eat* (17). The fifth theme, safety, was threaded through responses and explained answers in terms of actions being safe or at risk, for example, *it wouldn't be safe to do so* (35).

Participants' reflections on their patients being involved with meals or socialising at mealtimes indicated three main themes. The first provided a clear description of the perceived benefits including QoL and psychosocial aspects of sharing mealtimes, for example, *it is very important. Mealtimes are not just about eating. If able the patient can help with the preparation of food. This will give a good sense of wellbeing. Mealtime conversations ensure the patient is involved in discussion* (51) and *being with other human beings is a fundamental need – important to know that they are still valued/loved even if they can't do same things as before. Being present at mealtimes can be helpful way to reinforce those feelings* (54). The second theme focussed on the importance of patient-led decisions about being involved with meals or socialising at mealtimes, for example, *It is the patient's choice whether they feel comfortable doing this or not* (20) and *I try to get a picture of what meals looked like pre-[stroke] ... to rebuild towards that if that's what the person wishes* (17). The third theme identified the challenges associated with mealtime involvement and socialisation, for example, *It is more difficult if solely enterally fed as patient can feel excluded or different from others, may feel like they are missing out on eating and drinking, particularly if they are nil by mouth* (28) and *Some patients due to their impairment post stroke may [have] a preference to eat in their own space where they can take their time and be supported, especially if dysphagic and needing less distractions* (68). Challenges included safety concerns and actions that might be difficult socially, for example, *eating and drinking at risk on special occasions* (67) and *others chewing and spitting food out* (51).

## Blended feeding for people living with stroke

Forty-two out of 45 (93%) participants were aware of the concept of blended feeding and 12 out of 45 participants (27%) reported using this in practice. The three participants who were not aware of blended feeding were a nurse, an occupational therapist and a medical doctor. Forty out of 45 (89%) participants considered blended feeding, with or without formula feed, was an option for adults living with stroke while five out of 45 participants (11%) thought it should not be an option. Twenty-seven out of 44 participants (61%) thought blended feeding might encourage adults living with stroke to participate in social aspects of food and 17 out of 44 participants (39%) either thought that it would not encourage participation or that their patients were too impaired. Forty-three participants identified potential benefits and concerns associated with blended feeding (Table 3). The benefits identified by greater numbers of participants were improved feed tolerance (84%) and improved QoL (74%), whereas the concerns most often identified were being time consuming for carers (86%) and patients (79%). The combined responses from 43 participants who answered these questions totalled 298 benefits and 278 concerns that were selected from the lists of 12 benefits and 15 concerns offered as potential choices (Table 3). There was no significant difference between the median [range] number of benefits and concerns identified by each participant (7 [1–12] versus 6 [1–15],  $p = 0.42$ ).

Participants explained their reasons for their responses in free text and four main themes were identified from these. The first theme focussed on patient benefits from blended feeding that were based on both participants' observations and opinions and included physical and psychosocial effects, for example, *I have seen families embrace it [blended feeding] and patients thrive* (17), *We already have patients who use blended diets to improve stools/bowel habits. Some people want to be included as part of family meals* (38) and *It gives the patient an option of a sense of normality when tube feeding is not normal* (51). However, the second theme, the conditions needed for blended feeds, drew together practical points that should be addressed for blended feeding to be undertaken successfully, for example, *Yes, it is an option but comes with the caveat that it takes enormous effort with ... hygiene, time for meal preparation, and commercial grade equipment to achieve appropriate consistency and nutritionally complete ... feeding* (17) and *If patient/family/carers are motivated and willing to do it, have all the equipment, accept any potential risks* (77). A third theme, concerns, described reasons for avoiding blended feeding including the time and effort required, microbial safety, tube blocking and nutritional adequacy, for example, *This may also have a significant impact on the amount of work the patient, family or carer needs to undertake to support this* (58). The fourth theme,

**TABLE 3** Potential benefits and concerns associated with blended tube feeding for adults living with stroke in the community as identified by healthcare professionals ( $n = 43$ ).

Potential benefits	Number (%) of responses	Potential concerns	Number (%) of responses
Improved feed tolerance	36 (84%)	Worse feed tolerance	8 (19%)
Less diarrhoea	27 (63%)	More diarrhoea	7 (16%)
Less constipation	24 (56%)	More constipation	6 (14%)
Less nausea/vomiting	21 (49%)	More nausea/vomiting	8 (19%)
Less reflux	23 (53%)	More reflux	10 (23%)
Less abdominal discomfort	23 (53%)	More abdominal discomfort	10 (23%)
Improved nutritional status	20 (47%)	Impaired nutritional status	20 (47%)
More involvement with meals	29 (67%)	Micronutrient deficiencies	28 (65%)
Increased pleasure from nourishment	26 (60%)	Unwanted weight gain	6 (14%)
Less stress related to feeding	17 (40%)	More stress related to feeding	23 (53%)
Reduced cost for providers	20 (47%)	Unaffordable cost for family	23 (53%)
Improved quality of life	32 (74%)	Time consuming for patient	34 (79%)
		Time consuming for carers	37 (86%)
		Microbial risk (food poisoning)	27 (63%)
		Increased risk of tube blocking	31 (72%)
Total number of benefits	298	Total number of concerns	278

patient choice, expanded on the idea that blended feeding might be an option, for example, *I think we need to give people freedom to choose. If they don't have a tube we don't dictate their lifestyle choices* (22).

## DISCUSSION

This is the first study to have explored the experiences and attitudes of healthcare professionals involved with caring for adults living in the community who receive enteral tube feeding following stroke, and therefore contributes novel insight into this aspect of care of this patient group. The study population included four healthcare professions, but dietitians comprised 89% of participants, probably reflecting their greater interest in the subject and possibly the snowballing recruitment method used.

The findings show that the participants consider that tube-feeding is about much more than just providing nutrients, although the importance of nutrient provision for this patient group was recognised. Consideration of QoL was repeatedly included in responses throughout the questionnaire and was linked to patient-led choice and decision-making about tube-feeding and engagement with feed administration and mealtimes. This patient-centredness is needed to address the variation in patients' impairments and the individual needs reported by participants and the approach fits well with UK Standards

of Proficiency for dietitians and other registered healthcare professionals which have recently been revised to include 'further centralising the service user'.<sup>15</sup> Similarly, other responses that relate to the Standards included working together across a wider team, which was identified as an area that could be improved, and communication and training, which might help to address possible risks. A need for national rather than local guidelines or policies was identified. This is pertinent to situations where tube-feeding may start in an acute care unit and continue after a patient is discharged to their own home or to community care and optimum care is needed at each stage because of the risk of complications. Receiving enteral feeding is a risk factor for developing complications during post-stroke rehabilitation<sup>16</sup> and for readmission to an acute care unit,<sup>17</sup> although these studies do not explain if these complications were causally related to tube feeding or just associated.

Although participants recognised individual patient preferences in socialising at mealtimes, their responses included descriptions of perceived benefits even if no food or drink was consumed. Although the challenges experienced by people living with dysphagia following stroke have been previously reported and include feelings of exclusion and loss,<sup>18,19</sup> less attention has been given to the effects of socialising (or not socialising) at mealtimes for adults receiving tube feeding following stroke. In a different patient population, a qualitative study in



children receiving tube feed via a gastrostomy reported that they valued mealtimes for social interaction even if they did not eat or drink.<sup>20</sup> The importance of mealtimes was suggested as a possible reason for administering enteral feeds at home via bolus delivery that mimics meal patterns rather than continuous feeding in a survey of 604 patients<sup>21</sup> and this idea is reflected by a response in the present study which described a patient delivering their bolus feed at social activities with food.

Mealtimes have the potential to encourage eating and drinking, even if inadvertently, and may present a risk for patients with an unsafe swallow, particularly if cognitively impaired. Participants acknowledged this risk and described some of their patients' willingness to accept this. Risk of eating and drinking with dysphagia was assessed in a prospective study of 555 patients, including 94 with dysphagia following stroke, who were discharged from hospital and who chose to eat and drink with acknowledged risk (EDAR).<sup>22</sup> A mortality rate of 66% within 3 months of discharge was reported in the subgroup with stroke. Reasons for hospital readmissions included EDAR-related conditions such as choking and chest infections. It was noted that both mortality and readmission rates fell rapidly 3 months after discharge, suggesting that reassessing eating and drinking at this time point might be useful and this is relevant to patients receiving tube feeds in the community. A systematic review examining patient adherence to dysphagia recommendations, including those following stroke but not explicitly describing those receiving tube feeding, identified 12 barriers to adherence including social implications but concluded that little was known or understood about this topic.<sup>23</sup> A better understanding of adherence to eating, drinking and tube-feeding guidance by adults living with stroke might identify how they can be best supported.

Participation in mealtimes and social activities associated with food and drink was described positively by participants but the risks associated with this are noted. Involving patients with meals through use of blended feeds delivered by bolus at mealtimes might address both the advantages of socialisation and inclusivity and the concerns about feeding where swallowing is unsafe. In the present study, all dietitians who participated were aware of blended feeding and, overall, most responses indicated that this could be an option for people receiving tube feeding after stroke. A survey of 188 UK dietitians published in 2017 indicated that 24% of them looked after patients who were receiving blended feeds and these were often in the community and mostly children.<sup>24</sup> Interest in the use and potential benefits and management of risk associated with blended feeding has grown in the last 10 years and is no longer formally opposed.<sup>25</sup> Many blended feeding studies focus on its delivery to children and young adults<sup>26,27</sup> and, although adult studies have been undertaken, these have mostly investigated commercially- or

hospital-prepared blended feeds rather than feeds made at home.<sup>28</sup> No studies of blended feeds have been identified in community-based adults following stroke. Tube feeding is potentially challenging in this group of patients because, compared with younger groups, they include many frail people who may have older carers who are also frail and the time required and physical demands of preparing and administering blended feeds can be time-consuming and hard work.<sup>29</sup> However, the variation in patients' impairment described in the present study and the potentially large number of people requiring tube feeding at home following stroke indicates that assumptions that adults living with stroke lack the capability or interest in blended feeding should not be made. Indeed, most participants in the present study considered blended feeding to be an option for adults requiring tube-feeding following stroke. Their responses indicated an understanding of the potential benefits (e.g., gastrointestinal improvements and QoL) that have been described in other studies,<sup>24,30</sup> as well as the conditions needed for this to be feasible. The potential concerns described by participants in the present study, including nutritional inadequacy, microbial risk and tube-blocking, have been noted previously.<sup>31</sup> These responses were fewer in total number, shorter in length and interpreted as mainly opinion-based (using 'may' or 'would be') rather than the responses about potential benefits which were experience-based or describing a particular patient ('I have seen', 'I've used'). Although the potential risks associated with blended feeding cannot be ignored, evaluation of their extent in published literature does not provide evidence that indicates that blended feeding is extremely risky and should be avoided but considers how risks can be mitigated.<sup>10,25</sup>

The strengths of the present study include the collation of experience from a range of healthcare professionals, predominantly dietitians, who work with adults following stroke who are receiving tube-feeding in the community, and their collective expertise has been drawn from many years of practice. The questionnaire was designed with both open and closed questions to enable quantitative analysis of some key responses and qualitative exploration of free-text responses to gain a rich understanding. The limitations of the study include the collection of data using a tool that had not been piloted or previously used and the small number of health professionals who participated who were not dietitians which may reflect the recruitment techniques or limited interest in this topic. We did not provide definitions of participation in social activities with food and drink and so participants may have interpreted this differently. Investigating experiences and attitudes of healthcare professionals is important but, alone, provides limited information. A wider understanding is also needed from patients receiving enteral feeding at home after stroke and their carers, both family and paid carers. Future studies investigating attitudes could use an analogue scale to quantify the extent of participants' response. Using the findings from the present study as a

basis to investigate patients' and carers' thoughts on enteral feeding, including their involvement in mealtimes and interest in blended feeding, is needed. Although a questionnaire, interview or focus group approach might yield useful information in future studies, 'hands on' opportunities to try making and administering a blended feed, providing this can be done safely, would be insightful.

In conclusion, the findings from the present study show that participants' experiences and attitudes to tube feeding in adults living with stroke in the community in this study sample are varied and focussed on individual patient's needs within a context of professional standards. Most have positive attitudes towards their patients' involvement in their tube feeding and mealtimes and consider that blended feeding is an option for this group at the same time as recognising safety issues and how these can be addressed. These findings provide a basis to inform comparable investigations with patients and carers which are needed to gain an insight into aspects of feeding that are working well for them and areas that need further exploration and potential improvement.

### AUTHOR CONTRIBUTIONS

Both authors were actively involved in the conceptualisation of the investigation, designing the study, seeking funding and ethical approval, collecting and analysing data, and writing the manuscript for dissemination.

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### CONFLICTS OF INTEREST STATEMENT

The authors declare that there are no conflicts of interest.

### DATA AVAILABILITY STATEMENT

The research data are not shared.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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