Title

The experiences and support needs of people living at home with an enteral tube: a qualitative interview study

Name and address of the institution where work performed

University of Southampton, School of Health Sciences, Highfield, Southampton, SO17 1BJ, UK

Author names and affiliations

Sue M Green1, Kay Townsend1, Nikki Jarrett2, Mandy Fader1

1University of Southampton, School of Health Sciences, Highfield, Southampton, SO17 1BJ, UK. k.townsend@soton.ac.uk, m.fader@soton.ac.uk

2University of Portsmouth, School of Health Sciences and Social Work, University of Portsmouth, St Andrew's Court, St Michael's Road, Portsmouth, UK, PO1 2PR. nikki.jarrett@port.ac.uk

Statement of Authorship

SG was responsible for the conceptualization, data curation, formal analysis, funding acquisition, investigation, methodology, project administration, resources, supervision, validation, visualization, and writing (original draft, review and editing). KT and NJ contributed to the formal analysis, validation and writing (review and editing). MF contributed to the conceptualization, funding acquisition and writing (review and editing).

Corresponding author

SM Green, sgreen@bournemouth.ac.uk, Bournemouth University, Faculty of Health and Social Sciences, Room B236, Bournemouth House, 19 Christchurch Road, Bournemouth, BH1 3LH, UK. sgreen@bournemouth.ac.uk

Keywords

Home enteral nutrition, home nutritional support, enteral feeding, enteral nutrition, gastrostomy tube

Acknowledgements

I am grateful to the participants and the members of the Public and Patient Involvement Group for their contribution to the study. I acknowledge the support of PINNT ([www.pinnt.com](http://www.pinnt.com)) in the development of the protocol prior to funding and for support in recruitment for the study. This report is independent research arising from an NIHR/HEE CAT Clinical Lectureship (Sue Green CAT CL-2013-04-014) supported by the National Institute for Health Research and Health Education England. The views expressed in this publication are those of the authors and not necessarily those of the NHS, the National Institute for Health Research, Health Education England or the Department of Health.

**Abstract**

**Background**

The number of people with an enteral tube (ET) living at home is increasing globally and services to support them to manage this complex and life-changing intervention vary across regions. This study aimed to gain an understanding of the experiences of people living at home with an ET and their carers, and explore their views of supporting services and ET related hospital admissions.

**Methodology**

A qualitative inductive descriptive design was employed. Semi-structured, face-to face interviews with a purposive sample of people with an ET living at home and carers were undertaken. Interviews were transcribed, initial codes assigned for salient constructs, grouped and developed into themes and sub-themes.

**Results**

Nineteen people with ETs and 15 carers of people with ETs were interviewed. Five themes were generated: home better than hospital, feelings about the tube, living with the tube, help when you need it and cost for health service. Participants indicated the ET significantly influenced daily life. Participants described becoming used to coping with the ET at home over time and developing strategies to manage problems, avoid hospital admission and reduce resource waste. Variation in supporting services were described.

**Conclusions**

People with ETs and their carers need considerable support from knowledgeable, responsive healthcare practitioners during the weeks following initial placement of the ET. 24 hour services to support people with ETs should be designed in partnership with the aim of reducing burden, negative experience, waste and hospital admissions. National frameworks for home enteral nutrition could set the standard for support for people with ETs.

**Introduction**

Enteral tubes (ETs) enable the delivery of food, fluid and medication for people who are unable to swallow sufficient to meet their needs. The number of people receiving ET feeding at home has increased globally over recent years, although the exact prevalence is difficult to ascertain ([1](#_ENREF_1)). The increase is due to the trend for more complex care needs being managed in primary care as well as increasing numbers of people having ET placed to manage long-term conditions or support a long recovery from illness or surgical intervention. Gastrostomy tubes are commonly placed for long term nutritional support ([2](#_ENREF_2)). In addition people may be discharged from hospital with a jejunostomy and nasoenteric tubes ([2](#_ENREF_2)).

Discharge from hospital of a person receiving ET feeding has enormous implications for both the person and their relatives or carers. It is a complex therapy, requiring development of knowledge and skills and life style adaptations. People with a gastrostomy tube report it to be time-consuming and disruptive to their lives ([3-7](#_ENREF_3)). Further, relatives of people living at home with an ET have described managing the new life situation it presents as a struggle ([8](#_ENREF_8), [9](#_ENREF_9)). Others have described ET feeding as an appreciable burden of treatment ([10](#_ENREF_10)). Appropriate education, training and support is required both to ensure a smooth transition between care settings and safe and effective management within the primary care setting ([11-13](#_ENREF_11)).

Lack of support to manage ET feeding in the community has been reported to lead to complications, such as tube blockage, increased hospital admissions ([14](#_ENREF_14)) and dissatisfaction with care provided ([9](#_ENREF_9)). Acute care hospitalizations has been reported to be common in some groups receiving enteral nutrition ([15](#_ENREF_15)) with many visits to the emergency department being described as potentially avoidable ([16](#_ENREF_16)). Avoiding hospital attendance is important as the cost of hospital care is high and it has the potential to negatively impact on the person with an ET ([10](#_ENREF_10), [16](#_ENREF_16)).

The presence of Nutrition Support Teams in clinical settings varies from country to country and co-ordinated support for people receiving home enteral nutrition (HEN) can be lacking ([2](#_ENREF_2), [17](#_ENREF_17)). A recent systematic review by Majka et al ([18](#_ENREF_18)) highlighted reduction in hospital costs with team interventions to support people with long-term enteral feeding. Interventions were described as multifaceted and included education, auditing and feedback methods ([18](#_ENREF_18)) There are several ways in which services can be organised to support people receiving enteral feeding at home ([18](#_ENREF_18), [19](#_ENREF_19)). Standards or guidelines for HEN services have been developed in some areas ([20](#_ENREF_20)) although lacking in others ([2](#_ENREF_2)). However, there have been few published reports on patients or carers views on what could support them to manage ETs at home and their experiences of admission for tube related problems. This is crucial to inform the design of services to support people to develop confidence and techniques to self-manage ETs and prevent avoidable hospital admissions.

The overall aims of the study were to gain understanding of the experiences of people with ETs and their carers concerning hospital admission for ET related issues and to explore their views of services that could support management of ETs at home and avoid hospital admission. The purpose of this study was to provide the data to underpin the design of patient-focused ET services

**Methods**

Study design

A qualitative inductive descriptive design was employed to allow participants to voice their opinions and share their experience ([21](#_ENREF_21)). Semi-structured, face to face interviews were undertaken with people with ETs and their carers enabling the interviewer to discover the participants own “framework of meanings” ([22](#_ENREF_22)).

Sample size

A purposive sample of people with ETs living at home in UK southern counties and their carers participated. The services provided for people with ETs living at home vary across the region giving a sample with a range of experiences. Sample size was determined during analysis when it was considered data saturation had been achieved, that is, when no new information or themes emerged from the interviews ([23](#_ENREF_23)). Participant characteristics were collected to “ground” the findings ([24](#_ENREF_24)). Carers included unsalaried carers (i.e. family members) or employed carers for the person because both provide support for ET issues.

Eligibility criteria

Eligibility criteria included: adults (over 18 years) with ETs living at home; adult carers of people (over 18 years) with ETs at home; ability to give informed consent; ability to understand and converse in English language.

Recruitment

Participants were recruited though several routes to increase the range and diversity of experience. Methods included:

* Advertisement through a support group (Patients on Intravenous and Nasogastric Nutrition).
* Contact of eligible people in GP practices via a Trust Research Nurse and the local NIHR Clinical Research Network. A researcher contacted those who expressed an interest and supplied a contact number via the Research Nurse or potential participants were invited to contact the lead researcher directly via letter from the practice.
* Three dietitians provided verbal information about the study during planned clinical visits if considered appropriate. People who expressed an interest and provided their contact details were contacted by a researcher.
* Advertisement and Participant Information Sheet (PIS) available at local events for people with ETs.

At first contact with the researcher the study was explained, eligibility checked and, if interest expressed, a PIS sent. A follow-up phone call within a week confirmed receipt of the PIS and arranged an interview date.

Interviews were conducted between October 2015 and March 2018 by two researchers trained in qualitative interview techniques. Thirty-one people were interviewed in their home, two people were interviewed in a private room in a healthcare location (with reimbursement of transport costs) and one person was interviewed at the home of the person for whom they cared. People with ETs and carers who agreed to participate chose to be interviewed together rather than separately. This enabled those who had difficulty in expressing themselves verbally to ‘voice’ their views. Both interviewers were Registered Nurses (RN) but introduced themselves as researchers. However, some participants knew one in her capacity as an RN in a HEN Team.

At the start of the interview, the PIS was reviewed with the participant/s and the Consent Form signed. Interviews were recorded digitally ([21](#_ENREF_21)) and guided by an interview guide ([25](#_ENREF_25)). The guide contained six closed questions about participant characteristics in relation to their ET to allow description of the context of the findings and the main open-ended questions (Table 1) with associated prompts relating to the aim of the study ([22](#_ENREF_22)).

Table 1 here

Participants were informed the interview could be stopped and their consent withdrawn at any point without giving a reason, until the study findings were published. The interviewer explored topics raised by the participant in detail and checked understanding by summarising. At the end of the interview, participants were thanked and asked if they have any further comments. The interview was complete when the participant had nothing further to add.

Interviews were transcribed verbatim by a professional transcription service. The recorded interview was deleted following transcription. Transcription and analysis took place concurrently with the interviews. Initially six transcripts were checked for accuracy against the recording by one researcher. This allowed the researcher to ensure the transcription was verbatim and immerse themselves in the data at the start of data analysis ([26](#_ENREF_26))

Data handling

Research data was managed according to University policy. A unique anonymised number was allocated to individual participants’ audio recordings and electronic files which were stored on a password-protected University system. Paper records containing personal information (e.g. signed consent) were stored in a locked cabinet in a locked University office separately from interview data.

Data analysis

Transcripts were imported into the software package NVivo 12 and analysed according to the phases of thematic analysis outlined by Braun and Clarke ([27](#_ENREF_27)). Transcripts were read and reread to develop a general understanding, initial semantic codes were assigned to key attributes, then expanded, and revised as required. The initial codes described important features of the data of relevance to the broad research question. Codes were then refined by grouping and a thematic list developed ([21](#_ENREF_21), [28](#_ENREF_28)). Themes represented coherent groups of codes. Similar clusters of codes within each theme formed subthemes. Interviews were analysed separately for each person even when the interview of a carer and person with an ET took place together. A proportion of the scripts were independently analysed by two other researchers with the aim of identifying whether the codes and themes generated were robust and unbiased, and disputes resolved by discussion. Potential themes were reviewed and finalised to ensure they presented the main concepts relating common, recurring patterns within interviews ([27](#_ENREF_27)). Subthemes focused on specific elements of the themes and provide a rich description of each theme. Quotations were selected to illustrate the essence of a theme ([29](#_ENREF_29)) and the selection of quotes aimed to give a clear example from a wide range of participants. Quotes are *verbatim* but edited to provide a fluent account (omissions are indicated by (…)) and punctuation added to aid clarity ([30](#_ENREF_30)). Participants were referred to as C (carer) or P (person with ET) followed by an anonymous number.

Credibility

Standards for Reporting Qualitative Research ([31](#_ENREF_31)) were used to ensure transparency. Dependability of the data and analysis were enhanced by conducting the research rigorously by adhering to the protocol to guide the systematic conduct of the study and allow for transparency of methods. An interview topic guide was used to ensure questions were relevant to the research question. The audio recording of the interviews was transcribed verbatim by an experienced transcriber and checked to ensure participants’ views were accurately represented in the dataset. Credibility was enhanced by the use of multiple analysts. The process of identifying participants, data collection and the analysis are reported accurately to enable readers to consider the confirmability and context of the findings ([26](#_ENREF_26)). While the issues described were context-specific, commonalities with other reports are discussed to enable consideration of transferability.

Research governance and ethics

Research ethics approval (15/LO/1359) was obtained via the National Integrated Research Application System (IRAS project ID: 185295). Approval to undertake the study in a Trust was given by the Trust Research Office and NHS Permission/PIC Authorisation was granted by the local CRN to undertake the study in the related primary care region. Informed consent was obtained from all participants.

Results

Nineteen people with ET and 15 carers of people with ET participated. Interview length was between 15 and 82 minutes (mean 43 ±16). People interviewed together described the management of the tube as a joint venture, often with clearly defined roles for each person, as illustrated by the following:

“I look after the tube and she maintains it” to which his wife replied, “You’re the host, aren’t you!” and he replied, “I keep it safe” (PO15 and CO14).

The age of the person that carers supported ranged from three to 83 years (mean 41 ±27). Only one carer was salaried. Four people with ETs lived alone, with the rest living with family (grandchildren, children or spouses). All reported living in their own homes. Table 2 shows the participant characteristics.

Table 2 here

Five themes and ten associated subthemes were generated (Figure 1) and are described with selected quotes to illustrate salient points. There was great similarity between the experience of carers and people with ETs so themes were generated from both groups together.

Figure 1 here

Home better than hospital

This central theme described participants’ experience and views of hospital admission for ET related issues. Almost all participants stated that they preferred management of ET related issues to be undertaken in their own home. Participants with balloon gastrostomy tubes (BGT) expected their tubes to be changed at home rather than hospital. One participant who had had his tube changed at home voiced his opinion about having it changed in hospital:

“I don’t want to have to do that. Go up the [hospital name], are you joking? This way, suits me down to the ground” (P002)

Two subthemes within this theme related to hospital attendance avoidance and experiences of hospital admission.

**Avoid hospital**

A number of participants expressed that they would actively avoid hospital admission, as illustrated by one person with an ET stating:

“If we can avoid hospital we will” (P011)

Reasons for hospital admission avoidance included the time and discomfort taken to travel to hospital and the experience of hospital admission. As one person with a tube stated when describing why she liked to stay at home:

 “Being at home is a hundred times better even if I’m still just as ill (...) because I’ve got the comfy chair that I can be hoisted into - we’ve got all the facilities here” (P004)

Several described strategies used to avoid hospital admission, ranging from replacing displaced BGTs to managing without feed over the weekend until routine community services could be accessed. This is illustrated by one carer describing how she reinserted a tube that had fallen out and then administered only water (contrary to good practice guidelines ([32](#_ENREF_32))) until the ET could be replaced by community staff:

"So, I put it back in and I phoned the helpline (…). But it was a case of if you really want anything done you’ve got to go to hospital. (…) so I thought he isn’t going to go into the hospital, we don’t have good experiences of [hospital name] (…) I said to her ‘well he’s still having fluids so he’ll be alright without his feeds until Monday morning’ ” (C005)

However, a few participants did not have strong views about avoiding attending hospital, as one carer said:

“I don’t mind, I’m quite happy to take her if there was an issue or I’m quite happy for people to come here. I haven’t got a problem either way…” (C009)

If admitted to hospital many participants outlined that they were very keen to be discharged quickly.

**Hospital admission**

Many participants related experiences of hospital admission for ET related issues attributable to a variety of causes, such as ET dislodgement, stoma infection and complications with a routine BGT change. Some participants described the admissions as avoidable, for example, one carer participant who had experienced multiple admissions for tube dislodgement and considered hospital admission could be avoided by more frequent changes stated:

“Yes most of them, nearly all of them I think could be avoided” (C003)

Some participants described how their inability to contact a community healthcare professional able to provide support resulted in admission. This was often described as occurring out of usual office hours, for example one carer stated:

“if it happened to be out of hours you (….) talk to somebody who doesn’t know anything but is just reading a script. Then because it’s always low priority you end up with hours and hours and hours before they get back to you. And then they say take him up to A and E. He doesn’t belong in A and E, we just need some help with this” (C010)

Others had experience of being admitted over one or more nights because the required procedure could not be scheduled in the hospital on the day they attended:

*“When the tube came out and the new one wouldn’t go in we were sent to the hospital about 11am. Went up there, they said they couldn’t refit it until the next day” (C005)*

Experiences of hospital admission ranged from being portrayed as positive to experiences that had left the person with the tube or the carer frustrated and fearful. The positive experiences were described as admissions where the issue was resolved quickly due to the presence of a healthcare professional experienced in tube management or where it was considered the issue was complex and admission inevitable. One carer described how a community professional had arranged for the person they cared for to be seen by the appropriate department which had led to a satisfactory experience:

“We’ve gone up a couple of times. Because you have to check for acid when you put the [type of] button in now, and a couple of times I haven’t been able to get an acid reading. And I phoned [name of nurse] and [name of nurse] arranges for us to go up for an ultrasound to check the PEG is in place and things. But that’s the only time and you’ll just literally go in, have the x-ray and back out again. It’s never been a major problem for us” (C009)

One of the reasons for a poor experience appeared to arise from hospital healthcare practitioners’ lack of knowledge about ET placement and management. Further, variation in the availability of staff able to manage tube problems impacted on the experience of hospital admission. One participant described his view having experienced tube displacement:

“…the thing that I’d like you to note is that you go to Accident and Emergency and I don’t think they are always ready and able to look after a PEG that has fallen out.” (P006)

Another aspect of hospital admission described related to the hospital environment and the detrimental effect this could potentially have on the person with the tube. For some people the busy hospital environment caused confusion and the change in routine affected ET management. Several others described not being supported to self-manage their enteral nutrition, for example, one person with a tube reported:

“I got told off for touching the pump, while I was in hospital. They said I mustn’t do anything even though I do it at home all the time, (…) I thought oh well they can do it then!” (P012)

A few described not being able to meet their care needs. For example one participant with limited mobility stated:

“I was really, really thirsty and I said ‘Excuse me could someone help me to have a drink please?’(…) And I called and I called and I called, and in the end someone came and said ‘what do you want?’, I said ‘Could you please pass me my drink?’. So they passed my drink but they put it rested it on my arm (…) so I couldn’t get it because my arm was still bad (...) So then when the consultant came round and said ‘we’d like you to keep you in and do some surgery to hopefully stop it doing that again’ I said ‘no thank you I want to go home’”. (P004)

Several participants described their journey and hospital experience as time consuming and problematic. For example one carer stated:

“This one time we had to go to the day ward because there was no actual slot for us to get it done. So, obviously the ambulance that we went in couldn’t stay there for hours, so they had to come back (...) We were there at 9am and we didn’t get seen until 2pm that afternoon and then [hospital worker] turned around and said ‘we can’t arrange transfer you’ll have to get a taxi and sort your own way back’” (C004)

A few participants and their carers described how food and drink offered was unsuitable for their dysphagia management. For example, one carer stated:

“That’s what annoyed him as well. ‘What would you like to eat, what would you like to drink?’ He’s nil by mouth!” (C007)

This gave rise to feelings of frustration and anxiety.

Feelings about the tube

All participants described their feelings about the ET, both in terms of both physical sensations and emotional experience, giving rise to the second central theme. Participants described their feelings changing over time as they adapted to living with the tube and coping with issues that arose.

**Feelings at first**

Participants talked about their initial experience and feelings about having an ET inserted and coping in the immediate period following discharge from hospital, as illustrated by one participant:

“It’s a huge shock to the system, when you actually get the tube put in and you stop eating. Immediately you are in a pickle anyway because it all seems very odd, your whole life seems very strange suddenly. That’s bad enough having to deal with that (…) it’s very isolating and very odd, so to have something else go wrong with the tube” (P018)

The decision to have the tube inserted was described as difficult to cope with by several.. This was either because it would impact on their eating habits or, for carers, because they were unable to provide food and drink for the person for whom they cared. As one carer stated:

“It made me feel awful as a mum that I couldn’t even get basic food and medication to her and it was taken out of my hands. It wasn’t great.” C003

The period before initial tube placement was described as frightening by some, due in part to a fear of the unknown. One participant verbalised her feelings waiting for the tube insertion on the day of the procedure:

“I kept thinking, where are my clothes?”, because I was just going to run away and not be there. But obviously I did [stay] in the end and actually having it put in was fine, in the end” P018

The procedure to place the tube was commented on by a few with only one person reporting a distressing experience:

“And I wouldn’t want to go through; I wouldn’t go through it again” P007

However, the need to have the tube placed appeared to be accepted, as one carer participant stated:

“But then to be honest, when we found out that we will have to put the tube in, although it was a scary thing, (…) the way the situation was, I thought, you know what, you can only get better” C011

Many participants reported receiving some training in managing the tube in hospital prior to discharge, although some would have liked more opportunity to learn the procedures required to care for the tube. As one participant indicated:

“I would have preferred someone to say ‘now do you understand?’ and I could have said ‘could you go through that again’. But she did it so quickly and spoke so quickly, which young ones do now, I couldn’t take it all in” C014.

Some participants identified that learning opportunities could be missed in hospital and suggested that they would have like to have been involved in tube management in the acute care setting. One participant stated:

“It would be nice to say ‘well this is what you can do at home’, because there wasn’t really much of that” C002

The complexity of the therapy was recognised, as one participant stated:

“But in the hospital people had come from University and they’d had weeks of training” C012

This lead to feelings of anxiety on discharge, as one participant described:

 “You feel at a loss to begin with, and it’s a bit worrying for family as well” P009

Some felt that they needed more time and support to learn the care required at home:

 “I think it would have been better if she had done it the first time - ‘this is how it’s done’. And then come in another week, the next week, and say ‘right now you do it and I’ll see where you go wrong’ ”. P015

The first few weeks following discharge after initial insertion required people to learn and adapt to life with the ET.

**Gets better with time**

Many described becoming used to the tube and adapting their lifestyle to accommodate the tube. For example, one carer spoke about her initial feelings and how over time, through experience, she became used to managing the tube:

“I was petrified quite frankly. I never said anything but inside I was all tensed up all the time. So, yes it was very, very scary. But I’ve got it off pat now. I’m quite organised and once I knew what I had to do I was fine” CO12

Participants described the process of becoming used to the tube as a learning process that required time, as one indicated:

“It takes time to learn everything” CO15

Some participants stated that they were supported to learn ET management by observing a nurse undertake it and then doing it a few times observed until they felt confident. For many, the learning was described as a process both the person with an ET and their carer went through together. As one participant carer stated:

“We both learnt together, didn’t we?” C013

Over time, the intervention was described as becoming a part of normal lifestyle, as one participant said:

“Like with most things when you start anything complex it is a bit of a worry how to deal with it. When you do it all the time you think everybody else does it.” P015

Participants who had managed their tubes for years described getting to know the system and learning whom to contact when help was needed. As one participant indicated:

“..now I have the confidence that I’ve got enough phone numbers and I know enough contacts, but I know how to get things done and make things happen” (P001)

Further, participants indicated little need for support to manage:

“I’m so used to doing it on my own now; I don’t really know that anyone could give me any help as such” (P008)

And considered themselves experts by experience:

“As our GP will say to other health professionals ‘Mrs X is the expert, talk to her she knows what she’s doing’ ” (C010)

**I can’t do without it**

The final subtheme illustrates how many participants viewed the ET as a positive intervention, reducing the risk of choking and improving nutritional intake, as exemplified by one carer statement:

“….when people ask ‘oh when do you think he’ll get rid of the tube’, I say I don’t worry about the tube at all, the tube is something, it’s like a blessing” C011

However, one participant divulged the presence of the tube was a negative influence on life, stating:

“Living with that it’s like having a ball and chain right. It ruins your life”. P003

A number expressed how they considered the tube crucial to maintain life as without it the person with the ET would be unable to eat and drink sufficient to stay well, as one participant stated:

“Without that tube she’s not going to survive and I don’t think anyone ever sees it as that much of an issue where to us it’s a big issue” C003

Living with the tube

The theme “living with the tube” describes how participants managed day-to-day life to accommodate the tube and associated management and is considered in depth by xxx et al (in press). As one participant indicated:

“It is a huge life changing thing” P018

Participants explained the need to adapt their lifestyle to accommodate the tube and associated interventions.

**Day to day routine**

All participants described the impact of the tube on day-to-day life. Significant changes to activities of daily living were outlined and how participants planned holidays and managed work were described. Social activities were reported to present a challenge. One participant carer explained how she felt when administering enteral feed outside of the home:

“I’m so conscious if I’m outside and if I have to feed him I have to cover everything and do it like I am doing something wrong” CO11

**Managing tube problems**

As well as managing the day-to-day routine with the tube, all participants revealed the need to deal with tube problems and the strategies that they adopted to do this and to avoid a problem arising in the future. The range of tube problems related was wide and included dislodgement, stoma infection and overgranulating tissue. Multiple strategies were described to manage issues. At times strategies did not adhere to practice guidelines, for example, using wire to unblock a tube. Pain was a significant issue for many participants particularly when the tube was pulled.

Two participants identified a solution to the repeated problems of the BGT falling out that they experienced, indicating that a more frequent change could result in less emergency admissions. However, this request was reported to have been refused by their healthcare providers. One participant considered that this was due to the cost of the tube stating:

“It’s expense isn’t it, but it was eight months and then slowly they brought it forward to the seven and then obviously it got to six but then no change other than an emergency” C004

Some participants described not having problems with the tube and managing well with it.

 “Yes, I am quite happy. I don’t have any problems” P002

**Left to manage**

A number of participants related that they felt that they were left to manage their tube, illustrated by one carer stating:

“You are kind of left to it (…) you don’t see anybody” C001

Support from healthcare practitioners was described as very limited by some participants with little contact with healthcare professionals experienced in ET management reported.

Help when you need it

Many participants stated that they wanted help when they considered that they needed it and outlined the type of help they wanted. Others articulated that the support they received was sufficient to address their needs. Support from a variety of healthcare practitioners was described and included Dietitians, Nutrition Nurses (Company and NHS), District Nurses and GPs. The need for routine support was indicated and this was outlined as particularly important in the time period immediately following tube placement. As participants became “experts” in their tube management, less need for routine support was described.

**Routine support**

All participants described the need for regular contact with a healthcare worker with knowledge of ETs, described by one participant as:

“Someone who knew the ins and outs of how that thing works (…) and could organise and arrange, it seems to be all over the place” C004

Some described the routine support they had in positive terms, for example:

“I just have to phone her and say I’ve got a problem and she either comes out or she’ll call me back and we’ll deal with it. She is supportive” C009.

Whilst other indicated they lacked sufficient routine support. One person with a tube talked about how the community nurse provided support when requested but regular visits were not scheduled:

“The district nurse comes out but only, mainly, if you’ve got a problem. Simply because they’ve got other workloads so there is no point coming out and saying hello - it’s not a chat show! This is where you get left and if you’ve got a problem you don’t really know who to speak to because you don’t see these on a regular basis” (P015).

The need to have support to train carers was indicated by some. A few participants considered the use of virtual support rather than face to face or telephone support as potentially helpful but this this did not feature strongly in many interviews.

**Urgent help**

In addition to the need for routine support, a requirement for some to help when urgent issues arose was described. Participants described varying experiences, with some knowing and having access to knowledge healthcare practitioners when an issue arose with the tube and some describing a chaotic and uncoordinated response to urgent issues. As described above, of particular concern for many participants was support out of office hours, as one participant described:

“It’s such a turmoil when it’s out of hours” (C010)

Cost for Health Service

This theme related to some participant’s concern about waste of both time and resource. It was a very prominent theme in a few interviews but, unlike the other themes, did not feature in many interviews. Several participants outlined that the equipment that they received was in excess of that required. As one carer stated:

“And we ended up with boxes and boxes of stuff. I’ve still got some sterile water and syringes” (C013)

At times participants reported that had explicitly stated they did not require a resource but it was still delivered to them. One participant reported that despite indicating no feed was required continued to receive deliveries of feed:

“They just kept on sending it, even though my partner was phoning up saying we don’t need it, can you not send it?” (P014)

One participant described how he had tried to give the excess resource to the local hospital and his pharmacy to avoid waste but they had been unable to accept the excess feed.

Other participants stated that what they considered avoidable hospital admissions used considerable resource, for example, the carer of a person with a tube who had experienced several admissions for problems with their tube stated:

“The amount of money it costs to do out of hours, do the district nurse coming out, do an ambulance call, do the A and E, do the switch to AMU for two days to wait for them to figure out what to do – how much is that costing the NHS? It’s ridiculous, it’s wasteful and it’s not patient centred” (C010)

Other areas participants described as wasteful included the cost of supplying equipment and feed to travel abroad when it was considered local supplies in the country visited could be used.

**Discussion**

This study provides an understanding of the experiences of people with ETs and their carers of hospital admission for ET related issues in one UK region. The findings highlight the potential for some hospital admissions to be prevented by the presence of supportive services in the community. Whilst access to healthcare practitioners or services during traditional office hours was often described, support to manage urgent problems at evenings and weekends was considered particularly limited. Other factors that were strongly considered to avoid hospital admission included changing BGTs according to requirement even if this was more frequently than usual practice.

People with ETs and their carers described varied experiences of hospital admission for ET related issues which were influenced by availability of healthcare personal experienced in ET management. They generally wanted to avoid hospital and, if admitted, wanted to go home as quickly as possible. When people with ETs did attend hospital admission, they believed an overnight stay could potentially be avoided by prompt management in the Emergency Department or Acute Medical Admissions Unit.

The interviews enabled participants to describe their situation and voice their views on issues of particular relevance to them, as well as exploring the topics driven by the interview schedule and study aims. As a result participants all described their feelings about adapting to and living with the ET. Whilst the burden of treatment is recognised ([5](#_ENREF_5), [33-36](#_ENREF_33)), similarly to other studies, many participants in this study described the ET in positive terms emphasizing how important it was for life ([7](#_ENREF_7), [8](#_ENREF_8), [37](#_ENREF_37), [38](#_ENREF_38)). Participants in this study described the tube as part of the context of their life and described how they managed day-to-day, including for some taking a vacation and working.

The findings of this study have also enhanced our understanding of people’s experience of managing an enteral feeding tube at home from the perspective of both the carer and the person with an ET. The insertion and management of an enteral feeding tube has a huge impact on day-to-day life at home. People with ET require much more support in the initial weeks and months following tube insertion to support them to develop confidence and techniques to self-manage. Training on tube management undertaken in the busy hospital environment prior to discharge may be forgotten on discharge. As other studies have highlighted ([8](#_ENREF_8)), the first few days following discharge can be frightening as people learn to manage the tube and complications that can arise. Bjuresater et al ([5](#_ENREF_5)) highlighted that lack of preparation before discharge as support at home results in insecurity and uncertainty. Following the initial period people appear to adapt to the presence of the tube and learn to manage the intervention and common complications, gradually becoming proficient. The findings stress the need for comprehensive preparation and support from health practitioners when the therapy is introduced and to continue with this support. A recent study by Jukic et al ([8](#_ENREF_8)) explored the experience of carers who supported older patients with HEN in Italy and outlined the importance of supporting caregivers. MacDonald et al ([39](#_ENREF_39)) describe the concept of “wayfinding”, whereby carers actively learning and developing over time as a response to their lived experience. This is supported by the findings of this study.

In accordance with other studies ([3](#_ENREF_3), [6](#_ENREF_6), [7](#_ENREF_7), [16](#_ENREF_16), [40](#_ENREF_40), [41](#_ENREF_41)), participants described a variety of problems associated with the ET and strategies that they employed to manage them (see xxx et al ([42](#_ENREF_42))). The qualitative approach of this study enabled participants to freely describe issues with their enteral nutrition, although there are well documented limitations with an interview approach (([43](#_ENREF_43)) Participants with tubes in this study often described managing the tube themselves and most described receiving dietetic input. In contrast, Lim et al ([44](#_ENREF_44)) identified most people with tubes as bed-bound and not receiving dietetic follow-up. One interesting finding is that some participants described how cost savings could potentially be realised. HEN is a costly therapy ([17](#_ENREF_17)) and, in common with a another recent study ([7](#_ENREF_7)), people with ETs at home in this study identified areas of potential cost savings.

This study highlighted variation in local services available to provide support; leading to differences in people’s experiences. The need to review regularly people with ET in the community setting is well recognised ([45](#_ENREF_45)), with the emphasis on a multidisciplinary team approach ([13](#_ENREF_13), [46](#_ENREF_46), [47](#_ENREF_47)). The participants in this study did not express a strong preference for a team approach or the type of healthcare professional that could support them. They described a range of different practitioners from whom they sought advice. Their main requirement appeared to be someone who listened to them and was knowledgeable. Regular support by knowledgeable practitioners has previously been suggested to improve experience and may reduce hospital admission ([5](#_ENREF_5)). Support could be provided by a HEN team or other established community services, such as community nurses or a combination of services. The availability of a HEN team may lead to improved clinical outcomes for people with tubes and can save costs ([17](#_ENREF_17), [48](#_ENREF_48)). Gramlich and colleagues ([2](#_ENREF_2)) have made the case for a standardized approach to HEN and Boland et al ([6](#_ENREF_6)) described the need to develop national guidelines for HEN service provision to inform local policy. A regional or national strategic approach to HEN informed by people with ETs and their carers and similar to that of the national framework for home parenteral nutrition could address some of the unwarranted variation in services and patient experience described in this study.

**Limitations**

The findings of this study may not be transferable to other regions. Regional variations in service delivery are well documented ([45](#_ENREF_45)), however, the findings do generate insights, which have relevance to similar settings. The context of the research has been carefully described to enable others to understand the findings ([26](#_ENREF_26)) and relate them to their practice setting. Participants were self‐selected and may have had views different from those who did not participate. Many of the participants had a BGT, which are more likely to become displaced due to balloon failure than other types of ET ([49](#_ENREF_49)). One of the researchers was a member of a service which supported a few of the participants with their ET management which could have influenced the content of the interview and biased the findings. For example a more in-depth interview could have been achieved because a relationship was already formed with the participant, or an interview less focussed on the research question because the participant expected the researcher to take a therapeutic role ([43](#_ENREF_43)). This was addressed by the inclusion of participants from areas not covered by the service and using analysts independent of the service.

**Conclusion**

Participants in this study emphasised the need for knowledgeable healthcare practitioners to provide routine support, particularly in the initial discharge period when adapting to the tube, and manage urgent issues beyond traditional office hours. Organisation of HEN services should be guided by national standards for the provision of services for people with ETs, informed by people with ETs and their carers and the regional context, to ensure an equitable and supportive experience. The presence of a responsive community service with the knowledge and skills to support people with ETs is likely to reduce hospital admission for ET related problems, particularly if a service is available during the evenings or overnight. Economic evaluation would inform the development and viability of such services.

**Transparency Declaration**

"The lead author affirms that this manuscript is an honest, accurate, and transparent account of the study being reported. The reporting of this work is compliant with SRQR guidelines. The lead author affirms that no important aspects of the study have been omitted and that any discrepancies from the study as planned have been explained.

References

1. Ojo O. The challenges of home enteral tube feeding: a global perspective. Nutrients. 2015;7:2524-38.

2. Gramlich L, Hurt RT, Jin J, Mundi MS. Home Enteral Nutrition: Towards a Standard of Care. Nutrients. 2018;10(8):1020.

3. Rogers SN, Thomson R, O'Toole P, Lowe D. Patients experience with long-term percutaneous endoscopic gastrostomy feeding following primary surgery for oral and oropharyngeal cancer. Oral Oncology. 2007;43(5):499-507.

4. Mayre-Chilton KM, Talwar BP, Goff LM. Different experiences and perspectives between head and neck cancer patients and their care-givers on their daily impact of a gastrostomy tube. JOurnal of Human Nutrition and Dietetics. 2011;24(5):449-59.

5. Bjuresäter K, Larsson M, Athlin E. Patients’ experiences of home enteral tube feeding (HETF) – a qualitative study. Journal of Research in Nursing. 2015;20(7):552-65.

6. Boland K, Maher N, O'Hanlon C, O'Sullivan M, Rice N, Smyth M, et al. Home enteral nutrition recipients: patient perspectives on training, complications and satisfaction. Frontline Gastroenterology. 2017;8(1):79-84.

7. Williams GF, White H, Sen M, Prestwich RJD. Patients' experience of enteral feeding following (chemo) radiotherapy for head and neck cancer: A qualitative study. Clinical Nutrition. 2018;In press:1-8.

8. Jukic NP, Gagliardi C, Fagnani D, Venturini C, Orlandoni P. Home Enteral Nutrition therapy: Difficulties, satisfactions and support needs of caregivers assisting older patients. Clinical Nutrition. 2017;36(4):1062-7.

9. Bjuresäter K, Larsson M, Athlin E. Struggling in an inescapable life situation: being a close relative of a person dependent on home enteral tube feeding. Journal of clinical nursing. 2012;21(7-8):1051-9.

10. Jordan S, Philpin S, Warring J, Cheung WY, Williams J. Percutaneous endoscopic gastrostomies: the burden of treatment from a patient perspective. 2006:270-81.

11. Howard P, Jonkers-Schuitema C, Furniss L, Kyle U, Muehlebach S, Odlund-Olin A, et al. Managing the Patient Journey through Enteral Nutritional Care. 2006:187-95.

12. NICE. Nutrition support in adults. Quality standard [QS24]. Manchester: National Institute for Health and Clinical Excellence; 2012.

13. Boullata JI, Carrera AL, Harvey L, Escuro AA, Hudson L, Mays A, et al. ASPEN Safe Practices for Enteral Nutrition Therapy. Journal of Parenteral and Enteral Nutrition. 2017;41(1):15-103.

14. Kurien M, White S, Simpson G, Grant J, Sanders DS, McAlindon ME. Managing patients with gastrostomy tubes in the community: can a dedicated enteral feed dietetic service reduce hospital readmissions? European Journal Of Clinical Nutrition. 2012;66(6):757-60.

15. Drake R, Ozols A, Nadeau WJ, Braid-Forbes MJ. Hospital Inpatient Admissions With Dehydration and/or Malnutrition in Medicare Beneficiaries Receiving Enteral Nutrition: A Cohort Study. Journal Of Parenteral And Enteral Nutrition. 2017;42(4):730-8.

16. Correa JA, Fallon SC, Murphy KM, Victorian VA, Bisset GS, Vasudevan SA, et al. Resource utilization after gastrostomy tube placement: Defining areas of improvement for future quality improvement projects. Journal of Pediatric Surgery. 2014;49(11):1598-601.

17. Wong A, Goh G, Banks MD, Bauer JD. A systematic review of the cost and economic outcomes of home enteral nutrition. Clinical Nutrition (Edinburgh, Scotland). 2018;37(2):429-42.

18. Majka AJ, Wang Z, Schmitz KR, Niesen CR, Larsen RA, Kinsey GC, et al. Care Coordination to Enhance Management of Long-Term Enteral Tube Feeding: A Systematic Review and Meta-Analysis. Journal of Parenteral and Enteral Nutrition. 2014;38(1):40-52.

19. Green S, Dinenage S, Gower M, Van Wyk J. Home enteral nutrition: organisation of services. Nursing Older People. 2013;25(4):14-8.

20. ACI. ACI Nutrition Network Guidelines for Home Enteral Nutrition (HEN) Services. Chatswood NSW: Agency for Clinical Innovation, 2012 August 2012. Report No.

21. Cresswell J. Qualitative Inquiry and Research Design. Third ed. London: SAGE Publications; 2013.

22. Britten N. Qualitative interviews in healthcare research. In: Pope CM, N, editor. Qualitative research in healthcare. London: BMJ Books; 2000.

23. M S. Sample size in qualitative research. Research in Nursing and Health. 1995;18:179-83.

24. Burr J. ‘On the Shoulder of giants’: Putting the quality into qualitative research. In: Burr JN, P, editor. Researching health care consumers. Basingstoke: Palgrave Macmillan; 2005.

25. Welch A, Jirojwong S. Data collection in qualitative research. In: Jirojwong S, Johnson M, Welch A, editors. Research Methods in Nursing and Midwifery. Melbourne: Oxford University Press; 2014.

26. Holloway I, Wheeler S. Qualitative research in nursing and healthcare. Oxford: Blackwell; 2010.

27. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology. 2006;3(2):77-101.

28. Robson C. Real World Research. Oxford: Blackwell Publishing; 2002.

29. Whitehead L. Qualitative data analysis. In: Jirojwong S, Johnson M, Welch A, editors. Research Methods in Nursing and Midwifery. Second ed. Melbourne: Oxford University Press; 2014.

30. White C WK, Ritchie J, Ormston R. Writing up qualitative research. In: Ritchie J LJ, McNaughton Nicholls C, Ormston R, editor. Qualitative Research Practice. Second ed. London: SAGE; 2014. p. 367-96.

31. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Academic Medicine. 2014;89(9):1245-51.

32. Group NNN. Changing of a Balloon Gastrostomy Tube (BGT) into the Stomach for Adults and Children. Online: 2016.

33. Roberge C, Tran M, Massoud C, Poirée B, Duval N, Damecour E, et al. Quality of life and home enteral tube feeding: A French prospective study in patients with head and neck or oesophageal cancer. British Journal of Cancer. 2000;82(2):263-9.

34. Brotherton AM, Abbott J, Hurley MA, Aggett PJ. Home percutaneous endoscopic gastrostomy feeding: perceptions of patients, carers, nurses and dietitians. Journal of Advanced Nursing 2007;59(4):388-97.

35. Brotherton A, Abbott J. Clinical decision making and the provision of information in PEG feeding: an exploration of patients and their carers' perceptions. 2009;22(4):302-9.

36. Martin L, Blomberg J, Lagergren P. Patients’ perspectives of living with a percutaneous endoscopic gastrostomy (PEG). BMC Gastroenterology. 2012;12(1):126-33.

37. Stavroulakis T, Baird WO, Baxter SK, Walsh T, Shaw PJ, McDermott CJ. The impact of gastrostomy in motor neurone disease: challenges and benefits from a patient and carer perspective. BMJ Supportive & Palliative Care. 2016;6(1):52-9.

38. Kwong JPY, Stokes EJ, Posluns EC, Fitch MI, McAndrew A, Vandenbussche KA. The Experiences of Patients With Advanced Head and Neck Cancer With a Percutaneous Endoscopic Gastrostomy Tube: A Qualitative Descriptive Study. Nutrition in Clinical Practice. 2014;29(4):526-33.

39. McDonald J, McKinlay E, Keeling S, Levack W. The ‘wayfinding’ experience of family carers who learn to manage technical health procedures at home: A grounded theory study. Scandinavian Journal of Caring Sciences. 2017;31(4):850-8.

40. Wei-Kuo C, Ning-Chi W, Wei-Ming W, Jeng-Feng C. Prospective Evaluation of Peristomal Cutaneous Changes among Patients with Long-term Percutaneous Endoscopic Gastrostomy. Advances in Skin & Wound Care. 2014;27(6):260-7.

41. Halliday V, Baker M, Thomas AL, Bowrey D. Patient and Family Caregivers' Experiences of Living With a Jejunostomy Feeding Tube After Surgery for Esophagogastric Cancer. JPEN Journal Of Parenteral And Enteral Nutrition. 2017;41(5):837-43.

42. Green S, Townsend, Jarratt, Foley. 2019.

43. Yeo A LR, Keegan J, Ward K, McNaughton Nicholls C, Lewis J. Qualitative Research Practice Second ed. London: SAGE; 2014.

44. Lim ML, Yong BYP, Mar MQM, Ang SY, Chan MM, Lam M, et al. Caring for patients on home enteral nutrition: Reported complications by home carers and perspectives of community nurses. Journal of clinical nursing. 2018;27:2825-35.

45. Jaafar MH, Mahadeva S, Morgan K, Tan MP. Review: Systematic review of qualitative and quantitative studies on the attitudes and barriers to percutaneous endoscopic gastrostomy feeding. Clinical Nutrition. 2016;35(6):1226-35.

46. BAPEN. Home Enteral Nutrition Redditch: British Association for Parenteral and Enteral Nutrition; 2016 [cited 2018 29/10/10]. Available from: https://[www.bapen.org.uk/nutrition-support/enteral-nutrition/home-enteral-nutrition](http://www.bapen.org.uk/nutrition-support/enteral-nutrition/home-enteral-nutrition).

47. Strollo BP, McClave SA, Miller KR. Complications of Home Enteral Nutrition: Mechanical Complications and Access Issues in the Home Setting. Nutrition in Clinical Practice. 2017;32(6):723-9.

48. Dinenage S, Gower M, Van Wyk J, Blamey A, Ashbolt K, Sutcliffe M, et al. Development and Evaluation of a Home Enteral Nutrition Team. Nutrients. 2015;7(3):1607-17.

49. Ojo O. Balloon gastrostomy tubes for long-term feeding in the community. British Journal Of Nursing (Mark Allen Publishing). 2011;20(1):34-8.