

1 Title

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

4

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14

15 Statement of Authorship

16 SG was responsible for the conceptualization, data curation, formal analysis, funding acquisition,  
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26

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30

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39 of Health.

40 **Abstract**

41

42 **Background**

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

47

48 **Methodology**

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

53

54 **Results**

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

61

62 **Conclusions**

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

68 **Introduction**

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

77

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

86

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

93

94 The presence of Nutrition Support Teams in clinical settings varies from country to country and co-  
95 ordinated support for people receiving home enteral nutrition (HEN) can be lacking (2, 17). A recent  
96 systematic review by Majka et al (18) highlighted reduction in hospital costs with team interventions  
97 to support people with long-term enteral feeding. Interventions were described as multifaceted and  
98 included education, auditing and feedback methods (18) There are several ways in which services  
99 can be organised to support people receiving enteral feeding at home (18, 19). Standards or  
100 guidelines for HEN services have been developed in some areas (20) although lacking in others (2).  
101 However, there have been few published reports on patients or carers views on what could support

102 them to manage ETs at home and their experiences of admission for tube related problems. This is  
103 crucial to inform the design of services to support people to develop confidence and techniques to  
104 self-manage ETs and prevent avoidable hospital admissions.

105

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

110 **Methods**

111

112 Study design

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

117

118 Sample size

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

126

127 Eligibility criteria

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

131

132 Recruitment

133 Participants were recruited through several routes to increase the range and diversity of experience.

134 Methods included:

- 135 • Advertisement through a support group (Patients on Intravenous and Nasogastric Nutrition).
- 136 • Contact of eligible people in GP practices via a Trust Research Nurse and the local NIHR  
137 Clinical Research Network. A researcher contacted those who expressed an interest and  
138 supplied a contact number via the Research Nurse or potential participants were invited to  
139 contact the lead researcher directly via letter from the practice.
- 140 • Three dietitians provided verbal information about the study during planned clinical visits if  
141 considered appropriate. People who expressed an interest and provided their contact  
142 details were contacted by a researcher.

- 143 • Advertisement and Participant Information Sheet (PIS) available at local events for people  
144 with ETs.

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

148  
149 Interviews were conducted between October 2015 and March 2018 by two researchers trained in  
150 qualitative interview techniques. Thirty-one people were interviewed in their home, two people  
151 were interviewed in a private room in a healthcare location (with reimbursement of transport costs)  
152 and one person was interviewed at the home of the person for whom they cared. People with ETs  
153 and carers who agreed to participate chose to be interviewed together rather than separately. This  
154 enabled those who had difficulty in expressing themselves verbally to 'voice' their views. Both  
155 interviewers were Registered Nurses (RN) but introduced themselves as researchers. However,  
156 some participants knew one in her capacity as an RN in a HEN Team.

157  
158 At the start of the interview, the PIS was reviewed with the participant/s and the Consent Form  
159 signed. Interviews were recorded digitally (21) and guided by an interview guide (25). The guide  
160 contained six closed questions about participant characteristics in relation to their ET to allow  
161 description of the context of the findings and the main open-ended questions (Table 1) with  
162 associated prompts relating to the aim of the study (22).

163  
164 Table 1 here

165  
166 Participants were informed the interview could be stopped and their consent withdrawn at any  
167 point without giving a reason, until the study findings were published. The interviewer explored  
168 topics raised by the participant in detail and checked understanding by summarising. At the end of  
169 the interview, participants were thanked and asked if they have any further comments. The  
170 interview was complete when the participant had nothing further to add.

171  
172 Interviews were transcribed verbatim by a professional transcription service. The recorded  
173 interview was deleted following transcription. Transcription and analysis took place concurrently  
174 with the interviews. Initially six transcripts were checked for accuracy against the recording by one  
175 researcher. This allowed the researcher to ensure the transcription was verbatim and immerse  
176 themselves in the data at the start of data analysis (26)

177

#### 178 Data handling

179 Research data was managed according to University policy. A unique anonymised number was  
180 allocated to individual participants' audio recordings and electronic files which were stored on a  
181 password-protected University system. Paper records containing personal information (e.g. signed  
182 consent) were stored in a locked cabinet in a locked University office separately from interview data.  
183

#### 184 Data analysis

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

202

#### 203 Credibility

204 Standards for Reporting Qualitative Research (31) were used to ensure transparency. Dependability  
205 of the data and analysis were enhanced by conducting the research rigorously by adhering to the  
206 protocol to guide the systematic conduct of the study and allow for transparency of methods. An  
207 interview topic guide was used to ensure questions were relevant to the research question. The  
208 audio recording of the interviews was transcribed verbatim by an experienced transcriber and  
209 checked to ensure participants' views were accurately represented in the dataset. Credibility was  
210 enhanced by the use of multiple analysts. The process of identifying participants, data collection and



211 the analysis are reported accurately to enable readers to consider the confirmability and context of  
212 the findings (26). While the issues described were context-specific, commonalities with other  
213 reports are discussed to enable consideration of transferability.

214

215 Research governance and ethics

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

221 Results

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

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

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

232 Table 2 here

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

236

237 Figure 1 here

238

### 239 Home better than hospital

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

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

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

249

250 **Avoid hospital**

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

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

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

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

260 Several described strategies used to avoid hospital admission, ranging from replacing displaced BGTs  
261 to managing without feed over the weekend until routine community services could be accessed.

262 This is illustrated by one carer describing how she reinserted a tube that had fallen out and then  
263 administered only water (contrary to good practice guidelines (32)) until the ET could be replaced by  
264 community staff:

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

270

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

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

275

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

277

278 **Hospital admission**

279 Many participants related experiences of hospital admission for ET related issues attributable to a  
280 variety of causes, such as ET dislodgement, stoma infection and complications with a routine BGT  
281 change. Some participants described the admissions as avoidable, for example, one carer

282 participant who had experienced multiple admissions for tube dislodgement and considered hospital  
283 admission could be avoided by more frequent changes stated:

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

285

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

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

294

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

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

300

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

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

314

315 One of the reasons for a poor experience appeared to arise from hospital healthcare practitioners’  
316 lack of knowledge about ET placement and management. Further, variation in the availability of

317 staff able to manage tube problems impacted on the experience of hospital admission. One  
318 participant described his view having experienced tube displacement:

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

322

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

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

331

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

334 *“I was really, really thirsty and I said ‘Excuse me could someone help me to have a*  
335 *drink please?’(...) And I called and I called and I called, and in the end someone*  
336 *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*  
337 *because my arm was still bad (...) So then when the consultant came round and*  
338 *said ‘we’d like you to keep you in and do some surgery to hopefully stop it doing*  
339 *that again’ I said ‘no thank you I want to go home’”. (P004)*

341

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

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

350

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

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

355 This gave rise to feelings of frustration and anxiety.

356

### 357 Feelings about the tube

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

361

### 362 **Feelings at first**

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

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

370

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

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

376

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

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

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

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

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

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

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

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

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

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

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

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

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

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

407

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

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

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

414

415 **Gets better with time**

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

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

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

424 *“It takes time to learn everything” CO15*

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

429 *“We both learnt together, didn’t we?” CO13*

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

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

434

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

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

440 Further, participants indicated little need for support to manage:

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

443 And considered themselves experts by experience:

444 *“As our GP will say to other health professionals ‘Mrs X is the expert, talk to her*  
445 *she knows what she’s doing’ ” (CO10)*

446

447 **I can’t do without it**



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

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

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

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

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

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

458

#### 459 Living with the tube

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

463 *“It is a huge life changing thing” P018*

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

466

#### 467 **Day to day routine**

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

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

474

#### 475 **Managing tube problems**

476 As well as managing the day-to-day routine with the tube, all participants revealed the need to deal  
477 with tube problems and the strategies that they adopted to do this and to avoid a problem arising in  
478 the future. The range of tube problems related was wide and included dislodgement, stoma

479 infection and overgranulating tissue. Multiple strategies were described to manage issues. At times  
480 strategies did not adhere to practice guidelines, for example, using wire to unblock a tube. Pain was  
481 a significant issue for many participants particularly when the tube was pulled.

482

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

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

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

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

492

#### 493 **Left to manage**

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

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

497

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

500

#### 501 Help when you need it

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

509

#### 510 **Routine support**

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

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

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

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

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

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

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

528

### 529 **Urgent help**

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

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

536

### 537 Cost for Health Service

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

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

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

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

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

551

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

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

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

561

562

563 **Discussion**

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

572

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

579

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

587

588 The findings of this study have also enhanced our understanding of people's experience of managing  
589 an enteral feeding tube at home from the perspective of both the carer and the person with an ET.  
590 The insertion and management of an enteral feeding tube has a huge impact on day-to-day life at  
591 home. People with ET require much more support in the initial weeks and months following tube  
592 insertion to support them to develop confidence and techniques to self-manage. Training on tube  
593 management undertaken in the busy hospital environment prior to discharge may be forgotten on  
594 discharge. As other studies have highlighted (8), the first few days following discharge can be  
595 frightening as people learn to manage the tube and complications that can arise. Bjuresater et al (5)  
596 highlighted that lack of preparation before discharge as support at home results in insecurity and

597 uncertainty. Following the initial period people appear to adapt to the presence of the tube and  
598 learn to manage the intervention and common complications, gradually becoming proficient. The  
599 findings stress the need for comprehensive preparation and support from health practitioners when  
600 the therapy is introduced and to continue with this support. A recent study by Jukic et al (8)  
601 explored the experience of carers who supported older patients with HEN in Italy and outlined the  
602 importance of supporting caregivers. MacDonald et al (39) describe the concept of “wayfinding”,  
603 whereby carers actively learning and developing over time as a response to their lived experience.  
604 This is supported by the findings of this study.

605

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

616

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

631 for home parenteral nutrition could address some of the unwarranted variation in services and  
632 patient experience described in this study.

633

### 634 **Limitations**

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

648

### 649 **Conclusion**

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

659

### 660 **Transparency Declaration**

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





667

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