

1 Title

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

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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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30

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39 **Abstract**

40

41 **Background**

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

46

47 **Methodology**

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

52

53 **Results**

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

60

61 **Conclusions**

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

67 **Introduction**

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

76

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

85

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

92

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

100 However, there have been few published reports on patients or carers views on what could support

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

104

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

109 **Methods**

110

111 Study design

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

116

117 Sample size

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

125

126 Eligibility criteria

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

130

131 Recruitment

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

133 Methods included:

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

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

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

147

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

156

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

162

163 Table 1 here

164

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

170

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

176

177 Data handling

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

182

183 Data analysis

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

201

202 Credibility

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

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

213

214 Research governance and ethics

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

220 Results

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

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

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

231 Table 2 here

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

235

236 Figure 1 here

237

238 Home better than hospital

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

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

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

248

249 **Avoid hospital**

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

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

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

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

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

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

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

269

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

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

274

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

276

277 **Hospital admission**

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

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

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

284

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

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

293

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

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

299

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

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

313

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

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

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

321

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

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

330

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

333 *“I was really, really thirsty and I said ‘Excuse me could someone help me to have a*
334 *drink please?’(...) And I called and I called and I called, and in the end someone*
335 *came and said ‘what do you want?’, I said ‘Could you please pass me my drink?’. So they*
336 *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)*

340

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

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

349

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

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

354 This gave rise to feelings of frustration and anxiety.

355

356 Feelings about the tube

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

360

361 **Feelings at first**

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

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

369

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

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

375

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

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

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

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

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

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

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

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

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

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

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

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

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

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

406

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

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

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

413

414 **Gets better with time**

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

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

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

423 *"It takes time to learn everything"* CO15

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

428 *"We both learnt together, didn't we?"* CO13

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

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

433

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

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

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

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

442 And considered themselves experts by experience:

443 *"As our GP will say to other health professionals 'Mrs X is the expert, talk to her*
444 *she knows what she's doing' "* (CO10)

445

446 **I can't do without it**

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

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

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

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

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

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

457

458 Living with the tube

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

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

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

465

466 **Day to day routine**

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

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

473

474 **Managing tube problems**

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

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

481

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

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

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

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

491

492 **Left to manage**

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

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

496

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

499

500 Help when you need it

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

508

509 **Routine support**

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

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

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

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

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

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

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

527

528 **Urgent help**

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

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

535

536 Cost for Health Service

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

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

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

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

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

550

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

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

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

560

561

562 **Discussion**

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

571

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

578

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

586

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

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

604

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

615

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

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

632

633 **Limitations**

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

647

648 **Conclusion**

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

658

659 **Transparency Declaration**

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

665 References

666

- 667 1. Ojo O. The challenges of home enteral tube feeding: a global perspective. *Nutrients*.
668 2015;7:2524-38.
- 669 2. Gramlich L, Hurt RT, Jin J, Mundi MS. Home Enteral Nutrition: Towards a Standard of Care.
670 *Nutrients*. 2018;10(8):1020.
- 671 3. Rogers SN, Thomson R, O'Toole P, Lowe D. Patients experience with long-term percutaneous
672 endoscopic gastrostomy feeding following primary surgery for oral and oropharyngeal cancer. *Oral*
673 *Oncology*. 2007;43(5):499-507.
- 674 4. Mayre-Chilton KM, Talwar BP, Goff LM. Different experiences and perspectives between
675 head and neck cancer patients and their care-givers on their daily impact of a gastrostomy tube.
676 *Journal of Human Nutrition and Dietetics*. 2011;24(5):449-59.
- 677 5. Bjuresäter K, Larsson M, Athlin E. Patients' experiences of home enteral tube feeding (HETF)
678 – a qualitative study. *Journal of Research in Nursing*. 2015;20(7):552-65.
- 679 6. Boland K, Maher N, O'Hanlon C, O'Sullivan M, Rice N, Smyth M, et al. Home enteral nutrition
680 recipients: patient perspectives on training, complications and satisfaction. *Frontline*
681 *Gastroenterology*. 2017;8(1):79-84.
- 682 7. Williams GF, White H, Sen M, Prestwich RJD. Patients' experience of enteral feeding
683 following (chemo) radiotherapy for head and neck cancer: A qualitative study. *Clinical Nutrition*.
684 2018;In press:1-8.
- 685 8. Jukic NP, Gagliardi C, Fagnani D, Venturini C, Orlandoni P. Home Enteral Nutrition therapy:
686 Difficulties, satisfactions and support needs of caregivers assisting older patients. *Clinical Nutrition*.
687 2017;36(4):1062-7.
- 688 9. Bjuresäter K, Larsson M, Athlin E. Struggling in an inescapable life situation: being a close
689 relative of a person dependent on home enteral tube feeding. *Journal of clinical nursing*. 2012;21(7-
690 8):1051-9.
- 691 10. Jordan S, Philpin S, Warring J, Cheung WY, Williams J. Percutaneous endoscopic
692 gastrostomies: the burden of treatment from a patient perspective. 2006:270-81.
- 693 11. Howard P, Jonkers-Schuitema C, Furniss L, Kyle U, Muehlebach S, Odlund-Olin A, et al.
694 Managing the Patient Journey through Enteral Nutritional Care. 2006:187-95.
- 695 12. NICE. Nutrition support in adults. Quality standard [QS24]. Manchester: National Institute
696 for Health and Clinical Excellence; 2012.
- 697 13. Boullata JI, Carrera AL, Harvey L, Escuro AA, Hudson L, Mays A, et al. ASPEN Safe Practices
698 for Enteral Nutrition Therapy. *Journal of Parenteral and Enteral Nutrition*. 2017;41(1):15-103.
- 699 14. Kurien M, White S, Simpson G, Grant J, Sanders DS, McAlindon ME. Managing patients with
700 gastrostomy tubes in the community: can a dedicated enteral feed dietetic service reduce hospital
701 readmissions? *European Journal Of Clinical Nutrition*. 2012;66(6):757-60.
- 702 15. Drake R, Ozols A, Nadeau WJ, Braid-Forbes MJ. Hospital Inpatient Admissions With
703 Dehydration and/or Malnutrition in Medicare Beneficiaries Receiving Enteral Nutrition: A Cohort
704 Study. *Journal Of Parenteral And Enteral Nutrition*. 2017;42(4):730-8.
- 705 16. Correa JA, Fallon SC, Murphy KM, Victorian VA, Bisset GS, Vasudevan SA, et al. Resource
706 utilization after gastrostomy tube placement: Defining areas of improvement for future quality
707 improvement projects. *Journal of Pediatric Surgery*. 2014;49(11):1598-601.
- 708 17. Wong A, Goh G, Banks MD, Bauer JD. A systematic review of the cost and economic
709 outcomes of home enteral nutrition. *Clinical Nutrition (Edinburgh, Scotland)*. 2018;37(2):429-42.
- 710 18. Majka AJ, Wang Z, Schmitz KR, Niesen CR, Larsen RA, Kinsey GC, et al. Care Coordination to
711 Enhance Management of Long-Term Enteral Tube Feeding: A Systematic Review and Meta-Analysis.
712 *Journal of Parenteral and Enteral Nutrition*. 2014;38(1):40-52.
- 713 19. Green S, Dinenage S, Gower M, Van Wyk J. Home enteral nutrition: organisation of services.
714 *Nursing Older People*. 2013;25(4):14-8.

- 715 20. ACI. ACI Nutrition Network Guidelines for Home Enteral Nutrition (HEN) Services. Chatswood
716 NSW: Agency for Clinical Innovation, 2012 August 2012. Report No.
- 717 21. Cresswell J. Qualitative Inquiry and Research Design. Third ed. London: SAGE Publications;
718 2013.
- 719 22. Britten N. Qualitative interviews in healthcare research. In: Pope CM, N, editor. Qualitative
720 research in healthcare. London: BMJ Books; 2000.
- 721 23. M S. Sample size in qualitative research. *Research in Nursing and Health*. 1995;18:179-83.
- 722 24. Burr J. 'On the Shoulder of giants': Putting the quality into qualitative research. In: Burr JN, P,
723 editor. *Researching health care consumers*. Basingstoke: Palgrave Macmillan; 2005.
- 724 25. Welch A, Jirojwong S. Data collection in qualitative research. In: Jirojwong S, Johnson M,
725 Welch A, editors. *Research Methods in Nursing and Midwifery*. Melbourne: Oxford University Press;
726 2014.
- 727 26. Holloway I, Wheeler S. *Qualitative research in nursing and healthcare*. Oxford: Blackwell;
728 2010.
- 729 27. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*.
730 2006;3(2):77-101.
- 731 28. Robson C. *Real World Research*. Oxford: Blackwell Publishing; 2002.
- 732 29. Whitehead L. Qualitative data analysis. In: Jirojwong S, Johnson M, Welch A, editors.
733 *Research Methods in Nursing and Midwifery*. Second ed. Melbourne: Oxford University Press; 2014.
- 734 30. White C WK, Ritchie J, Ormston R. Writing up qualitative research. In: Ritchie J LJ,
735 McNaughton Nicholls C, Ormston R, editor. *Qualitative Research Practice*. Second ed. London: SAGE;
736 2014. p. 367-96.
- 737 31. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative
738 research: a synthesis of recommendations. *Academic Medicine*. 2014;89(9):1245-51.
- 739 32. Group NNN. Changing of a Balloon Gastrostomy Tube (BGT) into the Stomach for Adults and
740 Children. Online: 2016.
- 741 33. Roberge C, Tran M, Massoud C, Poirée B, Duval N, Damecour E, et al. Quality of life and
742 home enteral tube feeding: A French prospective study in patients with head and neck or
743 oesophageal cancer. *British Journal of Cancer*. 2000;82(2):263-9.
- 744 34. Brotherton AM, Abbott J, Hurley MA, Aggett PJ. Home percutaneous endoscopic
745 gastrostomy feeding: perceptions of patients, carers, nurses and dietitians. *Journal of Advanced*
746 *Nursing* 2007;59(4):388-97.
- 747 35. Brotherton A, Abbott J. Clinical decision making and the provision of information in PEG
748 feeding: an exploration of patients and their carers' perceptions. 2009;22(4):302-9.
- 749 36. Martin L, Blomberg J, Lagergren P. Patients' perspectives of living with a percutaneous
750 endoscopic gastrostomy (PEG). *BMC Gastroenterology*. 2012;12(1):126-33.
- 751 37. Stavroulakis T, Baird WO, Baxter SK, Walsh T, Shaw PJ, McDermott CJ. The impact of
752 gastrostomy in motor neurone disease: challenges and benefits from a patient and carer
753 perspective. *BMJ Supportive & Palliative Care*. 2016;6(1):52-9.
- 754 38. Kwong JPY, Stokes EJ, Posluns EC, Fitch MI, McAndrew A, Vandenbussche KA. The
755 Experiences of Patients With Advanced Head and Neck Cancer With a Percutaneous Endoscopic
756 Gastrostomy Tube: A Qualitative Descriptive Study. *Nutrition in Clinical Practice*. 2014;29(4):526-33.
- 757 39. McDonald J, McKinlay E, Keeling S, Levack W. The 'wayfinding' experience of family carers
758 who learn to manage technical health procedures at home: A grounded theory study. *Scandinavian*
759 *Journal of Caring Sciences*. 2017;31(4):850-8.
- 760 40. Wei-Kuo C, Ning-Chi W, Wei-Ming W, Jeng-Feng C. Prospective Evaluation of Peristomal
761 Cutaneous Changes among Patients with Long-term Percutaneous Endoscopic Gastrostomy.
762 *Advances in Skin & Wound Care*. 2014;27(6):260-7.
- 763 41. Halliday V, Baker M, Thomas AL, Bowrey D. Patient and Family Caregivers' Experiences of
764 Living With a Jejunostomy Feeding Tube After Surgery for Esophagogastric Cancer. *JPEN Journal Of*
765 *Parenteral And Enteral Nutrition*. 2017;41(5):837-43.

- 766 42. Green S, Townsend, Jarratt, Foley. 2019.
767 43. Yeo A LR, Keegan J, Ward K, McNaughton Nicholls C, Lewis J. Qualitative Research Practice
768 Second ed. London: SAGE; 2014.
769 44. Lim ML, Yong BYP, Mar MQM, Ang SY, Chan MM, Lam M, et al. Caring for patients on home
770 enteral nutrition: Reported complications by home carers and perspectives of community nurses.
771 Journal of clinical nursing. 2018;27:2825-35.
772 45. Jaafar MH, Mahadeva S, Morgan K, Tan MP. Review: Systematic review of qualitative and
773 quantitative studies on the attitudes and barriers to percutaneous endoscopic gastrostomy feeding.
774 Clinical Nutrition. 2016;35(6):1226-35.
775 46. BAPEN. Home Enteral Nutrition Redditch: British Association for Parenteral and Enteral
776 Nutrition; 2016 [cited 2018 29/10/10]. Available from: [https://www.bapen.org.uk/nutrition-](https://www.bapen.org.uk/nutrition-support/enteral-nutrition/home-enteral-nutrition)
777 [support/enteral-nutrition/home-enteral-nutrition](https://www.bapen.org.uk/nutrition-support/enteral-nutrition/home-enteral-nutrition).
778 47. Strollo BP, McClave SA, Miller KR. Complications of Home Enteral Nutrition: Mechanical
779 Complications and Access Issues in the Home Setting. Nutrition in Clinical Practice. 2017;32(6):723-9.
780 48. Dinene S, Gower M, Van Wyk J, Blamey A, Ashbolt K, Sutcliffe M, et al. Development and
781 Evaluation of a Home Enteral Nutrition Team. Nutrients. 2015;7(3):1607-17.
782 49. Ojo O. Balloon gastrostomy tubes for long-term feeding in the community. British Journal Of
783 Nursing (Mark Allen Publishing). 2011;20(1):34-8.

784