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1 **Title Page**

2 **Patients' experiences with home parenteral nutrition: a grounded theory study**

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14 Key words (MeSH): Home parenteral nutrition, Intestinal failure, Patient experience,

15 Quality of life

## 16 **Abstract**

### 17 **Background & Aims**

18 Parenteral nutrition (PN) provides nourishment and hydration as an intravenous  
19 infusion to patients with intestinal failure (IF). The aim of the study is to generate  
20 theory that explains the experiences of adult patients living with home parenteral  
21 nutrition (HPN) and complex medication regimens.

### 22 **Methods**

23 A grounded theory methodology was used to explore the experiences of twelve  
24 patients receiving HPN. A semi-structured interview was conducted and recorded in  
25 each participant's home setting. Each interview was transcribed verbatim. The  
26 simultaneous process of data collection and analysis was followed reflecting the  
27 principles of the constant comparative approach.

### 28 **Results**

29 A total of 15 patients gave written consent, with 12 of them agreeing to be  
30 interviewed. All the participants had previously undergone surgery as a result of  
31 chronic ill health or sudden illness. Analysis revealed two core categories: stoma  
32 and HPN, and these were supported by the subcategories: maintaining stoma  
33 output, access to toilets, managing dietary changes, maintaining the HPN infusion  
34 routine, access to technical help to set up an HPN infusion, mobility with HPN  
35 equipment and general health changes. The strategy of living with loss was  
36 demonstrated by all the participants, and this was supported by the action strategies  
37 of maintaining daily activities and social interactions.

38 **Conclusions**

39 This study generates new understanding and insight into the views and experiences  
40 of patients receiving HPN in the UK. The findings from these participants have been  
41 shown to resonate with the Kubler-Ross Model<sup>1</sup> of the five stages of grief. The  
42 theory of living with loss was generated by the use of a grounded theory  
43 methodology. This small scale exploratory study reveals opportunities for  
44 improvements in practice to be considered by the nutrition support teams (NST) and  
45 other healthcare professionals involved in the patient's hospital stay prior to  
46 discharge on HPN.

## 47 Introduction

48 Intestinal failure (IF) is a condition that can lead to a range of health problems  
49 associated with extensive loss of absorptive function and capacity of the small  
50 intestines.<sup>2</sup> The causes for IF include congenital defects, obstruction, abnormal  
51 motility, major surgical resection and severe inflammatory bowel disease. The term  
52 short bowel syndrome (SBS) is used to describe the clinical consequences caused  
53 by IF,<sup>3</sup> whereby the body is unable to absorb nutrients (fat, protein and  
54 carbohydrate), water, minerals and vitamins from the diet to maintain health or  
55 sustain life. Wanten *et al*<sup>4</sup> defined short bowel syndrome when less than 200 cm of  
56 small intestines remain (or 75% is lost) as the result of surgery, bowel disease, or a  
57 congenital defect. Parenteral nutrition (PN) provides optimally balanced  
58 macronutrients, micronutrients and electrolytes by intravenous infusion. PN is a life-  
59 saving therapy for patients with severe IF.<sup>5</sup> In some cases patients with chronic IF  
60 become reliant on PN long term in order to meet nutritional and fluid requirements.  
61 Since the 1970s adults in the USA with chronic IF caused by non-malignant diseases  
62 were offered home parenteral nutrition (HPN).<sup>6</sup> Patients or their main carers learnt  
63 how to set up the infusion, and to connect it to the central venous catheter  
64 aseptically at home. Patients with chronic IF from SBS continued with oral diet and  
65 fluids, and took oral medications to reduce losses from ileostomies or chronic severe  
66 diarrhoea.<sup>7</sup> From the mid-1970s the use of HPN became available in some  
67 European countries. In 1977 St Mark's Hospital, London discharged the first UK  
68 patient on HPN.<sup>8</sup> Between January 1977 and March 1986, 200 adult patients were  
69 registered as receiving HPN in the UK.<sup>9</sup> They were managed by home parenteral

70 nutrition teams in 28 centres, with 7 centres being responsible for 75% of these  
71 patients.  
72 In 1994 the HPN cost in the UK was estimated to be around £55,000 per patient year  
73 in the community.<sup>10</sup> HPN involves a range of non-drug related expenditures, making  
74 the total cost of this treatment modality much higher than those for other chronic  
75 health conditions such as hypertension or diabetes. In 2008 the UK National  
76 Commissioning Group published a report on the 'Strategic framework for intestinal  
77 failure and home parenteral nutrition services for adults in England'.<sup>11</sup> It reported  
78 that 18 adult patients per million populations require prolonged management of IF in  
79 hospitals, and 14.6 adult patients per million population need HPN on discharge from  
80 hospital. They live in local communities and continue to be monitored by HPN teams  
81 at regular out-patient clinics.

82 Since the 1980s there has been increased international research interest to explore  
83 the quality of life (QoL) of patients receiving HPN.<sup>12</sup> In 2005 Winkler<sup>13</sup> reported poor  
84 QoL in patients with HPN dependency compared with healthy populations or patients  
85 with other intestinal diseases not requiring HPN. In 2010 Baxter *et al*<sup>14</sup> published a  
86 validated questionnaire to measure the QoL of patients treated with HPN. A Swiss  
87 multicentre, nationwide, observational study of 33 adult patients receiving HPN found  
88 improvement in anthropometric parameters and QoL at baseline and after a  
89 follow-up of 3 months.<sup>15</sup> Schliefert *et al*<sup>16</sup> conducted a quantitative, cross-  
90 sectional cohort study of 8 Australian adult patients receiving HPN. These  
91 researchers found that the HPN patients' QoL was low compared with Australian  
92 norm values. Dreesen *et al*<sup>17</sup> developed a set of quality of care interventions for  
93 adult patients on home HPN which could be incorporated in quality improvement

94 programmes. A narrative review<sup>18</sup> from 1970 to 2013 did not identify any  
95 published qualitative studies on the experiences of patients receiving HPN in the  
96 UK. The aim of this study was to generate theory that explains the experiences  
97 of adult patients living with HPN and complex medication regimens.

## 98 **Materials and methods**

### 99 **Interviews**

100 The Sheffield HPN team at Royal Hallamshire Hospital (RHH) has been looking after  
101 patients treated with HPN since the early 1990s. Over the years, patients with  
102 severe IF from nearby cities in South Yorkshire (Barnsley, Rotherham, Doncaster  
103 and Bassetlaw) and as far afield as Boston and Mansfield have been referred for  
104 HPN. By 2012 the Sheffield HPN team was looking after twenty-five adult patients  
105 receiving HPN. This study used a qualitative grounded theory approach that involved  
106 simultaneous data collection and analysis, theoretical sampling and the use of  
107 theoretical memos.<sup>19</sup> Ethical approval was obtained from the UK Integrated  
108 Research Application System (IRAS), reference number 12/NW/0554; and from the  
109 Research Department at Sheffield Teaching Hospitals NHS Foundation Trust.  
110 Patients who were receiving HPN feeds alone, home intravenous fluids alone, or a  
111 combination of HPN feeds and intravenous fluids, were included in the study.  
112 Patients treated with HPN, but who were too ill with impaired consciousness, were  
113 excluded as their underlying life-limiting condition imposed different constraints on  
114 their experiences with HPN. The author (CW) was not a member of the Sheffield  
115 HPN team so participants eligible to take part in the study did not know the  
116 researcher.

117 An invitation letter, information pack and informed consent form were sent to patients  
 118 before their next HPN out-patient clinic appointment between October 2012 and  
 119 September 2013. In addition, a recruitment poster was used to advertise the study  
 120 at the hospital's out-patients clinic. Patients who met the inclusion criteria were  
 121 purposefully sampled. 15 out of the 25 patients of diverse social and clinical  
 122 background gave written consent, of whom 12 agreed to be interviewed. As such  
 123 this is a representative sample of patients meeting the inclusion criteria. In  
 124 qualitative research the aim is often not to generalise from a sample, rather ensure  
 125 the sample is representative, (ensuring the range of views held) and this includes  
 126 theoretical sampling as acceptable.<sup>20</sup> Table 1 provides information on the  
 127 participant's underlying disease. All study participants continued with stoma care  
 128 and HPN treatment at home when they were discharged from hospital.

129 **Table 1 Underlying disease of the participants**

<b>Participants with 'Chronic ill health' (n=4)</b>	
Crohn's disease (short bowel & stoma from surgery)	3
Gastroschisis (short bowel & stoma from surgery)	1
<b>Participants with 'Sudden illness' (n=8)</b>	
Mesenteric venous thrombosis (short bowel & stoma from surgery)	5
Bowel fistula (from surgical complication)	1
Rectal cancer (known Crohn's disease with short & stoma from surgery)	1
Encapsulating peritoneal sclerosis (end stage kidney disease with short bowel & stoma from surgery)	1

130 A 60-minute audio recorded semi-structured interview was conducted by the author  
 131 (CW) at each participant's home. Participants were encouraged to describe their  
 132 experiences living with HPN and taking a complex medication regimen. An interview  
 133 guide containing questions and probes was used to guide the conversation, ensuring  
 134 that the conversation stayed focused. The researcher (CW) did not use all the



135 questions, and they were not asked in a specific order when exploring the lived world  
136 of the participants in context of their experiences with HPN. Throughout all the  
137 interviews the researcher maintained a value-neutral approach, making no attempts  
138 to ask leading questions which might favour a particular outcome. The initial  
139 interview guide was developed (a requirement of the ethics application) using  
140 published guidance and information used by other researchers in this field.<sup>21</sup> This  
141 guide contained open-ended questions and probes; however, these were not treated  
142 as structured or prescriptive in their utilisation. Each interview commenced with the  
143 same opening question; *'Tell me about how you came to receive home parenteral*  
144 *nutrition?'* Each interview was fully transcribed verbatim by the author (CW) with all  
145 identifiable names removed.

## 146 **Data analysis**

147 This study followed analytic processes and techniques developed by leading  
148 grounded theorists: Glaser and Strauss,<sup>19</sup> Strauss and Corbin,<sup>22</sup> Charmaz.<sup>23</sup> A  
149 combination of approaches were used which included open, focused and selective  
150 analytic techniques for refining category, linkage and connections. Table 2a provides  
151 the basic methodological information on the grounded theory approach.<sup>19 22 23</sup>

## 152 **Table 2a Key features of Grounded Theory**

• Theoretical sampling (with theoretical saturation) during which the processes of data collection, coding and data analysis are carried out concurrently ;
• Data collection methods are appropriate for the collection of qualitative data;
• Constant comparative method is used throughout data collection and analysis. This Includes the generation and comparison of analytic codes, as well as emergent early categories from data;
• Generating theory from the data;
• Writing of theoretical memos to support all stages of data analysis including coding, identification

153

154 This initial data analysis of the first interview transcript was used to direct data  
155 collection or purposeful sampling.<sup>23</sup> Each interview transcript and the open codes  
156 generated by (CW) were reviewed by co-authors (BL and DW independently).  
157 Theoretical memos were maintained throughout in order to support the generation of  
158 themes, phenomena, early categories and subcategories using a range of coding  
159 techniques.<sup>19 23</sup> The emerging theory was refined and developed with new codes  
160 generated from subsequent interviews, following the principles of constant  
161 comparative analysis.<sup>19 22</sup> This ensured that the participant's experience was  
162 retained during the analytic process, and the generated theory remained connected  
163 to, or grounded in, the data.<sup>19</sup> The pattern of similar focused codes provided clues  
164 on a range of issues associated with physical health, stoma care, HPN routine,  
165 social interactions and emotional responses which were common (or unusual)  
166 amongst the study participants.

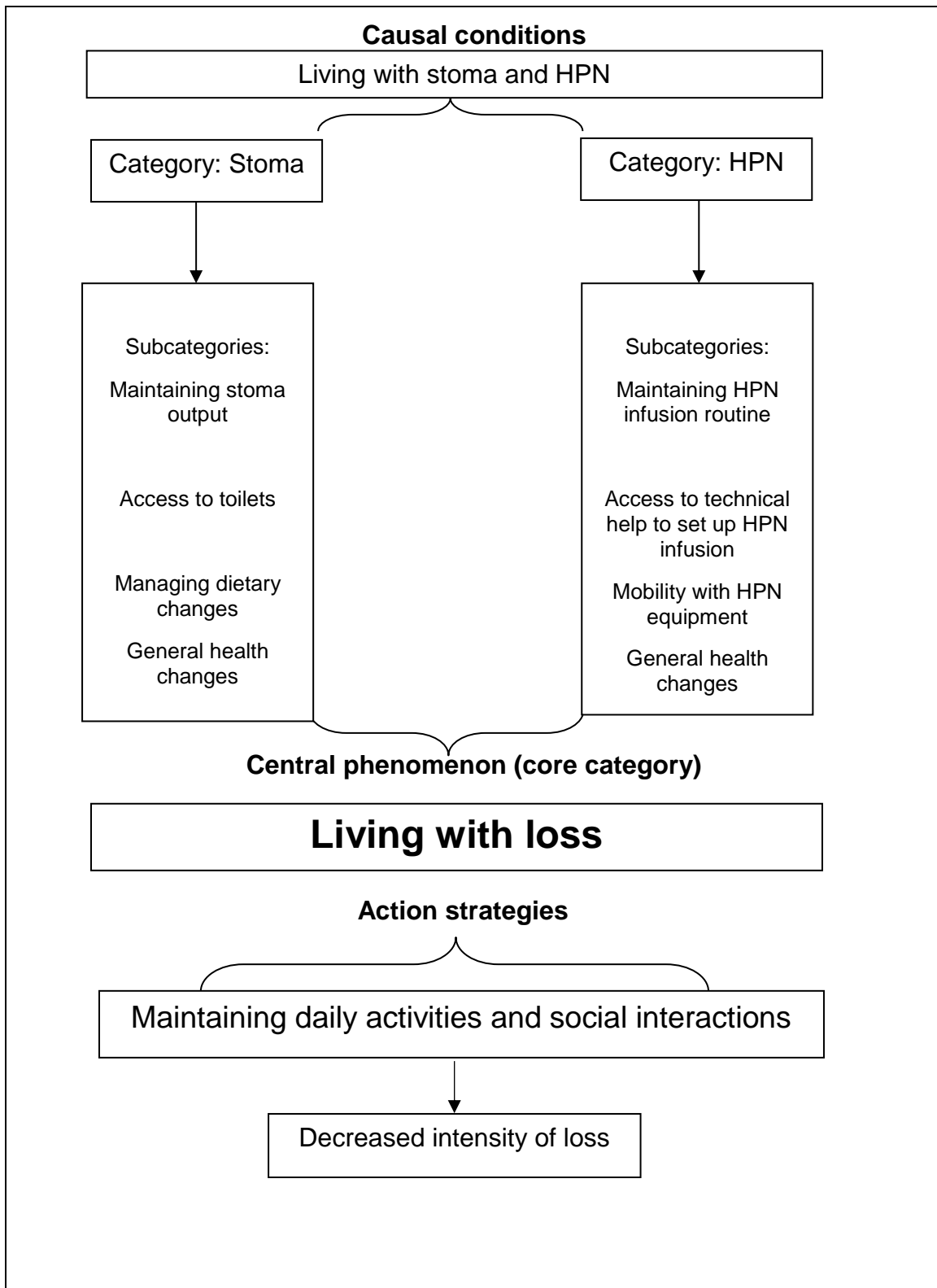
167 Two categories, stoma and HPN, were refined further using the paradigm model<sup>22</sup> to  
168 explore each of the six subcategories generated from data on stoma and on HPN  
169 separately. A paradigm model<sup>22</sup> for the category stoma, and HPN, illustrated the  
170 conditions, strategies and consequences of actions and interactions made by the  
171 participants with stoma and with HPN respectively. These consequences in turn  
172 supported the sense of loss imposed upon these participants in a range of personal,  
173 home and social situations when living with stoma and receiving HPN. Living with  
174 loss was chosen as the core category or central phenomenon after a review of all the

175 theoretical memos. This core category described the main theme of the research  
176 and will now be presented.

## 177 **Results**

178 The 12 participants, 4 male and 8 female, were aged between 29 to 83 years (mean  
179 age 58.9 years, medial age 63.4 years). Each participant had undergone surgery for  
180 one of two clinical conditions: chronic ill health (n=4) or sudden illness (n=8). The  
181 criteria proposed by Strauss and Corbin<sup>22</sup> were used to evaluate the causal  
182 conditions of living with stoma and HPN, and the action strategies in order to refine  
183 and define the central phenomenon (core category) of living with loss. Figure 1  
184 provides a visual representation of the connections between the causal conditions  
185 living with stoma and HPN, central phenomena (core category) living with loss and  
186 the two categories: stoma and HPN, and their corresponding subcategories.

187 **Figure 1** Connections between the causal conditions, central phenomenon  
 188 **(core category) living with loss and the other categories and subcategories**



189 **Category: Stoma**

190 All participants received stoma care training from clinical nurse specialists during  
191 their hospital stay. This included techniques for managing and maintaining stoma  
192 care and dietary advice. Following discharge, they had to incorporate stoma care  
193 into their daily home activities and social situations. Each person learnt about their  
194 stoma characteristics and in particular the high volume of watery stoma losses. The  
195 frequency to empty the stoma bag had a significant impact on the participants' health  
196 and social issues. As a result of high stoma output, participants needed frequent  
197 and easy access for emptying stoma bags. They had to choose carefully where they  
198 would go, to take account of accessibility. All participants on HPN could eat and  
199 drink, however, the loss of small bowel had resulted in loss of ability to digest and  
200 absorb food. The appearance of undigested foods in stoma was recognised. All  
201 participants experienced a range of general health changes caused by the  
202 malabsorption of food and drink associated with the high volume of watery stoma  
203 losses. Table 2b provides evidential quotes on the participants' experience with  
204 stoma.

205 **Table 2b Evidential quotes on the participants' experiences with stoma**

<b>Subcategories</b>	<b>Participants' in vivo quotes</b>
<b>Maintaining stoma output</b>	<p><i>'The outcome of the stoma was such a great amount and I weren't keeping any fluids' #1.</i></p> <p><i>'The stoma fills up quickly and you have to rush upstairs to go to the toilets' #7.</i></p> <p><i>'The bag holds about 300ml and when it gets full, it's heavy so it pulls away from the skin and then it leaks' #8.</i></p> <p><i>'At night it tends to go to water, and then you sleep and your bag fills up, and it's gone... you're swimming in this mess' #4.</i></p>
<b>Access to toilets</b>	<p><i>'I can't go too far from a toilet because you get very little warning when you need to go' #10.</i></p> <p><i>'You're trying to cover up the leak but people are watching you, a bit embarrassing really' #12.</i></p> <p><i>'I have been in a situation when it has leaked and you can just sense that trickling feeling and I have to leave everything and rush off to the toilet' #7.</i></p>
<b>Managing dietary changes</b>	<p><i>'Basically everything I eat goes straight through anyway ... I notice with cheese and fruits that ... down the toilet straight away' #5.</i></p> <p><i>'If I have a drink it comes out straight into my stoma' #8.</i></p>
<b>General health changes</b>	<p><i>'I was always thirsty and had no energy ... I just felt ill ... I couldn't put one foot in front of another' #2</i></p> <p><i>'I wouldn't be able to eat vegs or fruits and only certain ones' #3.</i></p>

207 **Central phenomenon (core category) – Living with loss and its connections**  
208 **with stoma**

209 All participants had to integrate stoma care into their daily activities. They described  
210 a range of experiences from loss of sleep to loss of self-image associated with the  
211 stoma and the embarrassment caused by unpredictable stoma leaks and accidents.  
212 Other issues such as loss of independence and the need to have help from others  
213 varied considerably depending on the participants' underlying health status. Some  
214 of them lost physical ability to carry out a range of daily activities. Participants  
215 refrained from social interactions in case the stoma bag leaked and the need to carry  
216 stoma care products around in case it leaked. Following discharge from hospital, all  
217 of them described the loss of independence to self-care at home after prolonged  
218 hospital stay. Some participants lost jobs whilst others had to change from full to  
219 part time working in view of the changes in their general health. Participants  
220 described increased self-consciousness and loss of confidence with the stoma and  
221 from stoma leaks respectively. This led to loss in social interactions making them  
222 house-bound or becoming socially isolated e.g. avoiding holidays or giving up  
223 hobbies. Participants described the limited choice of places to go unless there is  
224 easy toilet access. All of them accepted the loss of choice in the clothes they wear  
225 in order to disguise the stoma bag or leaks. Table 3 provides evidential quotes on  
226 the participants' experience with stoma and living with loss.

227

228 **Table 3 Evidential quotes on participants living with loss and its connections**  
 229 **with stoma**

<b>Central phenomenon (core category): Living with loss and its connections with stoma</b>	
<b>Subcategory</b> <b>Managing stoma output</b>	<p><i>You feel awful because you've made such a mess. I don't think anybody explained how you would feel and how this would be' #3.</i></p> <p><i>'you got to get up in the middle of the night, take your bed sheets off, get bed cleaned, and get everything and yourself cleaned, run a bath, get a clean nightie ... all these ... it's annoying, it shouldn't happen. This happened last night and half of my clothes are ruined, you got to throw them away, it's no good' #4.</i></p> <p><i>'It's demoralising, it's embarrassing ... if it leaked when you're out' #5.</i></p>
<b>Subcategory</b> <b>Access to toilets</b>	<p><i>'I hardly go anywhere because of my stoma' #5.</i></p> <p><i>'I don't know where the loos were ... I was really anxious I thought this [stoma] is just going to go everywhere' #7.</i></p> <p><i>'You feel that you don't want to go out; you just want to stay at home because you're alright at home' #8.</i></p>
<b>Subcategory</b> <b>Managing dietary changes</b>	<p><i>'I still eat fruit and a curry ...I put up with the consequences' #5.</i></p>
<b>Subcategory</b> <b>General health changes</b>	<p><i>'I just Hoover around and that's it, I'm drained, no energy' #5.</i></p> <p><i>'You can't continue with the activity that you were doing before' #7.</i></p> <p><i>'There is one thing I cannot do which is to dress this [stoma] myself; my wife has to dress it [stoma] for me. I couldn't bend down and see where to put things. I'll have to use a mirror which I have done but it's very, very difficult. If you get it wrong, you get the mess all over so it's much easier for my wife to do it' #9.</i></p> <p><i>'I have accepted the fact that working makes me worse so I know I'm never going to be able to hold down a full time job that is a fact' #10.</i></p>

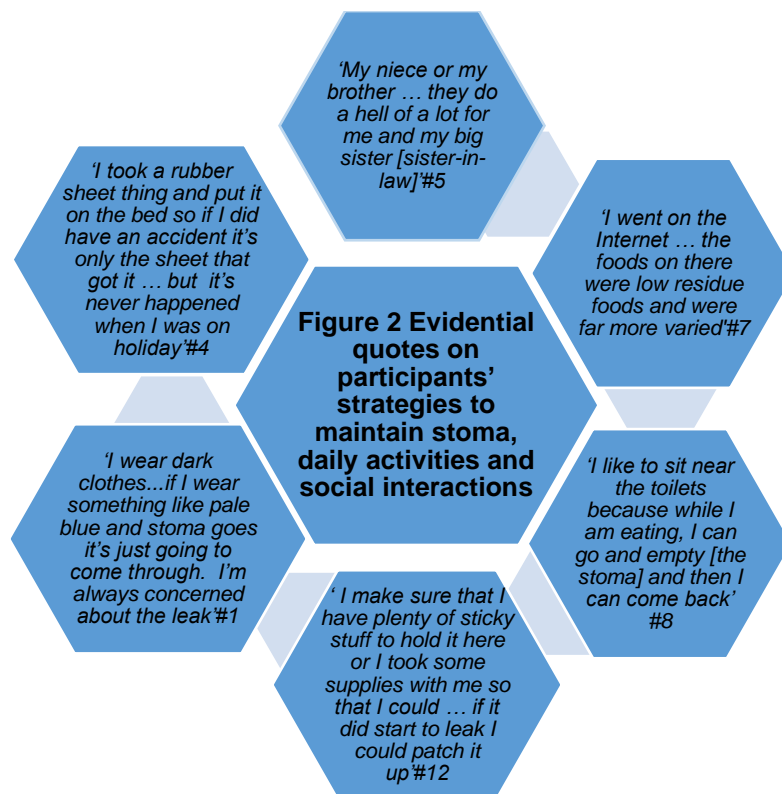
230



231 **Action strategies for maintaining daily activities and social interactions**

232 Prior to hospital admission all were living independently, either alone or with a  
233 spouse or partner. Four participants had a job when they developed the sudden  
234 illness. Six of them were in retirement, but two participants were not in any  
235 employment due to their chronic ill health. During rehabilitation at home all  
236 participants had to learn to integrate stoma care into their daily activities and in social  
237 situations. During this period participants described a range of strategies and  
238 actions taken in order to balance the demands placed upon them from stoma care  
239 against the need to live at home alone, with spouse or partner, and to maintain a  
240 social life. In some cases participants were considering return to work. The study  
241 participants came from a variety of social background and they experienced a range  
242 of general health changes following discharge from hospital. Several participants  
243 received help from their spouse, partner or family members in order to maintain a  
244 range of daily activities at home.

245 Participants who were dissatisfied with the dietary advice received from the HPN  
246 team used the Internet to search for additional information to improve the range of  
247 food choices without increasing stoma losses. They would only visit places which  
248 offered easy toilet access. Participants were resourceful in dealing with unexpected  
249 stoma leaks when in social situations or on holiday. They took medications to  
250 reduce stoma losses and they showed understanding of the need to maintain  
251 medication regimen. Figure 2 provides evidential quotes on participants' strategies  
252 to maintain stoma, daily activities and social interactions.



253

254 During their hospital stay all participants learnt about stoma care from clinical nurse  
 255 specialists. They were competent in changing the bag and emptying the contents  
 256 before it leaked. Following discharge, all the participants had to integrate stoma care  
 257 into their daily activities. All had negative experiences from some aspects of stoma  
 258 care, in particular the unpredictable stoma leaks and accidents. The main focus for  
 259 each participant was to prevent and minimise the risk of stoma leaks or accidents as  
 260 much as possible. In doing so they were living with the loss imposed upon them by  
 261 the need to maintain stoma care.

262 **Category – HPN**

263 By the time participants were discharged from hospital, they were all reliant on HPN  
 264 in order to maintain hydration and nutrition. Each had a different level of reliance on  
 265 HPN depending on how much of the small bowel was resected during surgery.

266 Some needed HPN infusion every night but a few only needed HPN infusion on  
267 three to five nights a week. Several were having intravenous fluids on the nights  
268 when they were not having HPN feeds. The composition of the HPN infusion was  
269 complex. The HPN infusion was prescribed by the HPN team and the volume  
270 ranged from 2000 to 3000ml. Therefore, the infusion time ranged from at least  
271 twelve to fourteen hours a day. The HPN clinical nurse specialists provided  
272 extensive training and supervision to ensure understanding of the HPN infusion  
273 routine. This training covered all aspects of care: the infusion line (Hickman line),  
274 the aseptic technique to connect the administration set to the HPN feed, the  
275 connection of this to the Hickman line, as well as the setting up of the electric  
276 infusion pump. The pump and HPN bag were placed onto an infusion drip stand.  
277 Once this was set up they had to carry the bag, infusion pump and drip stand  
278 around. Most participants managed to set up HPN infusion at home. However, a  
279 few of them needed technical help due to poor vision and very limited hand dexterity.  
280 The HPN equipment was smaller and more compact in size than that used on the  
281 hospital ward setting. But this remained troublesome to older participants. All  
282 participants described a range of positive general health changes from maintaining  
283 HPN. Table 4 provides evidential quotes on the participants' experiences with HPN.  
284

285 **Table 4 Evidential quotes on participants' experiences with HPN**

Subcategories	Participants' in vivo quotes
<b>Maintaining HPN routine</b>	<i>'I'm on [HPN] twelve hours a day every other day, and I just could not go anywhere, completely anywhere' #5.</i>
<b>Access to technical help to set up HPN infusion</b>	<p><i>'I kept having to fetch my daughter because she just lives across from here right next door. She only has a road to cross that's all. I said can you come because I can't do it. I've been at it an hour' #4.</i></p> <p><i>'In my right hand, it's like a claw and I can't grip and I get ulcers on two of my fingers [index and middle fingers] ... and since I am right handed it's very difficult to learn to do things left handed. I have a nurse from [home care company] coming in five days a week. Just to connect me up and disconnect me [from the infusion pump] five days a week, evening and nine o'clock in the morning' #6.</i></p>
<b>Mobility with HPN equipment</b>	<i>'It's quite a heavy bag to carry round with you all the time ... so I tend to sit in the evenings so that's made quite a difference ... it's really restricting, you can't go out in the evening' #3.</i>
<b>General health changes</b>	<p><i>'I'm alive now and I think without it I wouldn't be here ... definitely' #2.</i></p> <p><i>'It stops me from passing out. I mean I was passing out; I was falling over as if I were ... I don't know, you know when you were drunk I suppose ... I was dizzy' #4.</i></p> <p><i>'I am one of the lucky ones because my heart and my lungs aren't affected so as long as I keep on HPN ... I 'm not going to die with it [scleroderma]' #6.</i></p> <p><i>'When I see people that I've not seen for a few weeks they tell me that I've put weight on? You look better in your face' #7.</i></p> <p><i>'I have more energy, I wasn't as tired. It has completely stopped me needing blood transfusion as well' #10.</i></p>

286 **Central phenomenon (core category) – living with loss and its connection with**

287 **HPN**

288 Following hospital discharge, participants had to integrate the HPN treatment into  
289 their daily activities and social interactions. Some of the participants were living with  
290 their spouse or partner, but several of them were living alone. For those who were  
291 living alone some of them had siblings who were living in the same city whilst one  
292 had an older sibling some distance away. Some required help to maintain the HPN  
293 infusion routine. These participants relied on help and had regular visits from family  
294 members. Those who started the HPN infusion in the evening described the loss of  
295 mobility around the house. The weight of the HPN bag and the infusion pump were  
296 problematic to one participant. They had to make time for HPN treatment, and this  
297 would invariably mean that they had to make adjustments or changes in their home  
298 life and social life. The HPN training that they had received at the hospital ward  
299 would not have prepared them for these aspects of reintegration into their own  
300 environment.

301 Participants who received technical help from home care companies to set up HPN  
302 infusion had less flexibility in changing the HPN infusion routine at short notice. One  
303 such participant declined visitors at home in the evening so that it did not interfere  
304 with the technical help to set up HPN infusion provided by nurses from the home  
305 care company. Participants who were maintaining HPN infusion routine  
306 independently described their experiences in the loss of choice in how they spent  
307 their evenings at home. Some said they were unable to go away because of the  
308 need to maintain HPN infusion routine. The amount of HPN infusion equipment

309 which had to be taken on holiday was problematic with a loss of independence and  
 310 choice.

311 Participants disliked the inflexibility with the HPN infusion routine, and the need to  
 312 maintain HPN infusion routine when returning home late from a night out. Several  
 313 described the loss of independence in order to maintain the HPN infusion routine.  
 314 Several also described the loss of self-image caused by the stoma bag, the HPN  
 315 infusion line, and the rucksack which carries the HPN bag. One participant was  
 316 unable to seek employment because of the health condition. Participants continued  
 317 to feel the loss of independence on the basis that they had to maintain HPN  
 318 treatment in order to stay healthy. All participants had to maintain stoma output and  
 319 HPN treatment. Table 5 provides evidential quotes on the participants' experience  
 320 with HPN and living with loss.

321 **Table 5 Evidential quotes on participants living with loss and its connections**  
 322 **with HPN**

<b>Central phenomenon (core category): Living with loss and its connections with HPN</b>	
<b>Subcategory</b> <b>Maintaining HPN infusion routine</b>	<p><i>'So if I'm going out and I get back at half twelve [at night], you've got to put the stuff on at half twelve, it's a bind' #1.</i></p> <p><i>'I can cope with the stoma but there's nothing I can do about the HPN. I've got to be here [at home] to do it. I do miss out somehow... I think the HPN is the worst' #3.</i></p> <p><i>'I haven't got a quality of life no more, compared to what I had before the accident as work, I haven't got a life... and I'm totally dependent on this [HPN] ...my medical condition' #5.</i></p> <p><i>'It rules your life. You've got to live around it. It's a case of you live or you die so everything revolved round it' #7.</i></p> <p><i>'At the end of the day you don't want to die so you've got to have it [HPN]' #8.</i></p>

	<i>The feeling of not being altogether complete ... having to do this [HPN] every night and every morning ... just takes its toll' #9.</i>
<b>Subcategory</b> <b>Access to technical help to set up HPN infusion</b>	<i>'A nurse from X [home care company] comes five days a week, evening to connect and morning to disconnect...seven o'clock in the evening and nine o'clock in the morning. So, I don't go out or have many visitors in the evening' #6.</i>
<b>Subcategory</b> <b>Mobility with HPN equipment</b>	<i>'I have to carry it all night, if I go to the kitchen, I have to carry it, I want go upstairs I got to carry it upstairs. I'm just tired of it...' #1</i>  <i>'I can't go to theatre or cinema or anything that I used to do now and again with a group of friends' #3.</i>  <i>'Once I'm connected, it's quite a heavy bag to carry around with you all the time so I tend to sit in the evenings so that's made quite a difference' #9.</i>

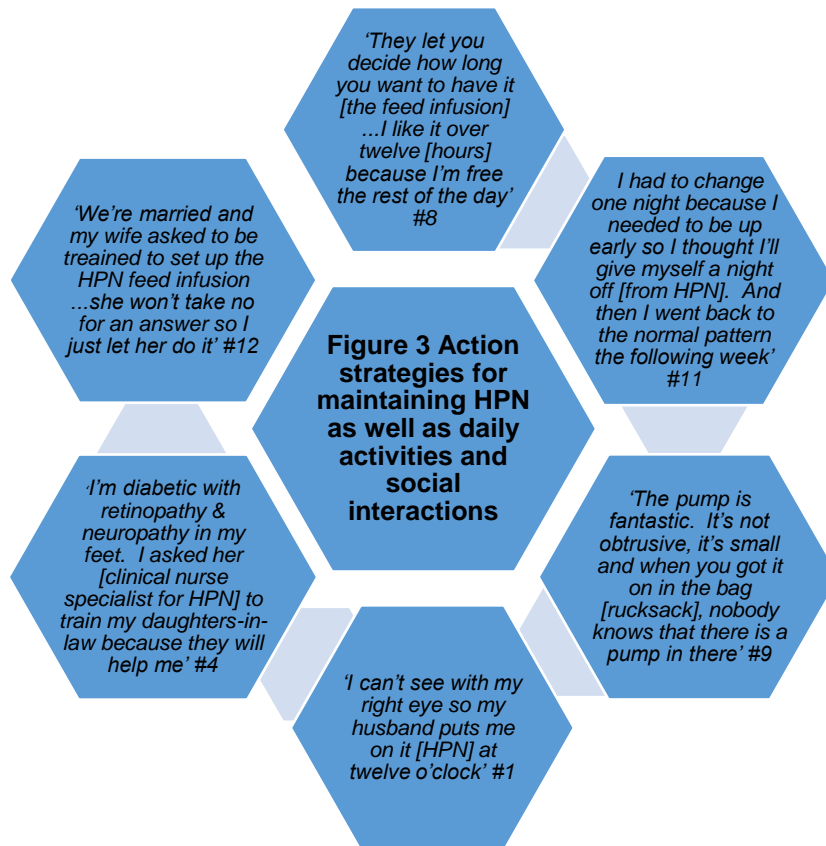
### 323 **Action strategies for maintaining daily activities and social interactions**

324 During discharge planning, written information about the weekly HPN infusion routine  
325 was given. However, all individuals were advised and encouraged to choose when  
326 to set up the HPN infusion in order to fit round their daily activities and social  
327 interactions. The intention was to encourage them to maintain daily activities  
328 gradually during their rehabilitation at home. All were able to maintain HPN  
329 treatment and to gradually integrate this into their daily activities. None of the  
330 participants interviewed had problems with infection from their central venous  
331 catheter used for HPN infusion. In order to encourage mobility at home and when  
332 they were going out, the participants were offered the use of a mobile, portable,  
333 electric infusion pump which would fit inside a standard size rucksack.

334 During the HPN training programme in hospital, each participant was assessed by  
335 the clinical nurse specialist whether the individual was able to self-care and to  
336 maintain HPN treatment safely and competently at home. Three participants were  
337 found to be unsafe to maintain HPN treatment at home due to their concurrent

338 chronic health conditions: impaired eye sight (one participant), poor hand dexterity  
339 (one participant), and a combination of both poor hand dexterity and impaired eye  
340 sight (one participant). One participant was fully dependent on her spouse to  
341 maintain HPN treatment. Another participant was living alone but she had chosen  
342 the option of involving her close family members as main carers in maintaining HPN  
343 infusion routine. For this participant, her family members also received training on  
344 the use and operation of the infusion pump from the home care company. One  
345 participant, who also had a chronic ill health condition, explained that his wife had  
346 made the request to be the main carer for maintaining HPN infusion routine. This  
347 participant's spouse also provided support and help with stoma care at home.  
348 Figure 3 provides evidential quotes on participants' strategies to maintain HPH, daily  
349 activities and social interactions.





350

351 All the participants learnt how to maintain HPN infusion routine from the HPN clinical  
 352 nurse specialists. They were competent in connecting the HPN infusion bag to the  
 353 Hickman line, and then connecting the bag to the infusion pump. Following  
 354 discharge from hospital all had to learn to integrate HPN treatment into their daily  
 355 activities. Some of them were able to maintain HPN infusion routine safely and  
 356 independently. Others were offered technical help to set up the HPN infusion, and  
 357 this was provided by spouses, partners or nurses from the home care company on  
 358 set days of the week.

359 The study participants' experiences during rehabilitation were rich in descriptions of  
 360 what they could and could not do at home and in social situations. Participants  
 361 described a range of positive and negative experiences living with HPN. The  
 362 positive experiences were associated with the general health changes. The negative

363 experiences were related to aspects of the need to maintain HPN infusion routine in  
364 terms of the long infusion time and its frequency, and the issues around mobility with  
365 HPN equipment at home, in social situations and when on holidays.  
366 These findings were demonstrated by participants who had to learn how to integrate  
367 both stoma care and HPN treatment into their daily lives. A couple of the study  
368 participants had described feeling depressed. They referred to the overall impact on  
369 their lives as the result of having a stoma and becoming dependent on HPN  
370 treatment. The issue of depression was not raised by the other participants.  
371 The findings revealed participants experienced a sense of loss in a range of daily  
372 activities and social interactions. Therefore, the central phenomenon living with loss  
373 was closely linked to the participants' need in living with stoma and HPN. The  
374 consequences of using these action strategies successfully would reduce the  
375 intensity of living with loss in daily activities and social interactions.

## 376 **Discussion**

377 The findings supported the lack of control with high stoma output as the main factor  
378 which contributed to a sense of loss of choice. The intensity of this was associated  
379 with restrictions on diet and fluids in order to maintain stoma output. These findings  
380 were consistent with those reported in a Swedish study conducted by Carlsson *et*  
381 *al*<sup>24</sup> who explored patient experience of living with a stoma and SBS associated with  
382 Crohn's disease. All the study participants described the necessity for access to  
383 toilets easily and frequently when emptying stoma bags. Their experiences with  
384 stoma leaks / accidents remained troublesome, despite compliance with restrictions  
385 on diet and oral fluids, and medications to reduce losses.

386 Prior to hospital discharge all received advice from the HPN team about restrictions  
387 on diet and oral fluids. They were offered low residue diet menus to support  
388 maintaining stoma output whilst learning to empty the bag and look after the skin  
389 site. Interviews revealed several had chosen to eat what they really liked, instead of  
390 what they should have eaten once they were at home. They understood the reasons  
391 for dietary advice, but described their dislike for the lack of taste and limited choices  
392 offered by the low residue diets. This sense of loss in choice was similar to that  
393 reported by an American study<sup>25</sup> which surveyed 604 patients with stomas about  
394 food choices and avoidances imposed. Over 200 respondents reported non-  
395 adherence to dietary advice. This probably reflected individuals' desire to have  
396 control over what they could eat and drink. The researcher acknowledged dietary  
397 advice provided by healthcare professionals showed variations and inconsistency.  
398 The availability of reliable dietary information to maintain stoma output has the  
399 potential to reduce the sense of living with loss in patients with stoma receiving HPN.  
400 All 12 participants in this study had a stoma and described tiredness during the day  
401 (caused by disrupted sleep with emptying the stoma bag frequently at night). These  
402 negative changes in general health impacted on daily activities such as house work  
403 and shopping, and were consistent with those reported elsewhere.<sup>24</sup> The patient  
404 self-help group, 'Patients on intravenous and nasogastric therapy' (PINNT) does not  
405 offer dietary advice to patients with stoma receiving HPN and the NHS Choice  
406 website offers limited information on diet and oral fluids for patients with stoma.  
407 The loss of employment due to reduced physical strength and need to maintain  
408 stoma output placed significant burden on participants' physical health and sense of  
409 loss; findings which also concur with Carlsson *et al*<sup>24</sup> Since the 1960s the loss of

410 body image experienced by patients who had undergone stoma surgery has been  
411 studied.<sup>26 27 28</sup> Analysis of data in this grounded theory study revealed that all  
412 described the sense of loss of choice in having to wear loose fitting clothes to  
413 disguise the stoma bag. They were resourceful in adopting measures to lessen the  
414 burden and anxiety from stoma leaks, but experienced increased self-consciousness  
415 in social situations. These findings were consistent with an Australian study<sup>29</sup> of  
416 patients with stoma.

### 417 **Relationships between living with loss and maintaining HPN treatment**

418 All 12 study participants were dependent on HPN treatment in order to overcome the  
419 problems of malabsorption and malnutrition. The data supported the positive  
420 changes in general health associated with HPN treatment, however, there are  
421 currently no published studies that provide a detailed insight into the QoL  
422 experiences of patients with a stoma receiving HPN. The experiences of the current  
423 study participants with the loss in self-image, the increased self-consciousness, and  
424 the loss of mobility were consistent with psychosocial problems reported in a Dutch  
425 study<sup>30</sup> of 48 patients receiving HPN.

426 In 2010 Baxter *et al*<sup>14</sup> published an instrument which assessed the quality of life of  
427 patients receiving HPN (HPN-QOL). This questionnaire used either functional scales  
428 or symptom / problem scales, however, only two questions related to stoma care:  
429 '*the problems in caring for the stoma*' and '*the problems with stoma site*',<sup>14</sup> and this  
430 instrument did not assess the impact of maintaining stoma output on daily activities  
431 and social interactions. It would therefore seem appropriate to consider the practical  
432 and psychosocial aspects of maintaining stoma output and HPN infusion routine

433 when designing items for the assessment of QoL of patients with a stoma receiving  
434 HPN.

### 435 **Model for living with loss**

436 In healthcare settings patients may experience grief in relation to either chronic  
437 illness or sudden ill health. The actions, interactions and emotions displayed by the  
438 participants in the current study resonate with some aspects of the Kubler-Ross's  
439 model,<sup>1</sup> of the five stages of grief. This was described by the American psychiatrist  
440 Elizabeth Kubler-Ross in her book '*On Death and Dying*'<sup>1</sup> when she was working  
441 with terminally ill patients. She later extended her model of grief to any form of  
442 catastrophic personal loss.

443 These five stages of grief do not occur in a specific order and the model is not  
444 intended to be used as a checklist for emotions which could be or are likely to be felt.  
445 Kubler-Ross' hypothesis is based on the premise that an individual who experiences  
446 a life-threatening or life-altering event may not feel all five of the responses because  
447 each individual reacts to personal losses differently.<sup>1</sup> The model provides the  
448 conceptual framework from which the theory of living with loss generated from the  
449 study participants' data could be best described.

### 450 **Living with loss**

451 The theory of living with loss provided by the participants' experiences with stoma  
452 care and HPN treatment mirrored some stages of the Kubler-Ross model. These  
453 revealed participants' feelings of sadness, regret and uncertainty when accepting  
454 their own situations. They accepted that what has happened to their health could  
455 not be undone and the reality was illustrated by involvement in maintaining stoma

456 output and HPN infusion routine. Their effort to reduce stoma output and leaks /  
457 accidents reflected acknowledgement of what had happened and they were  
458 accepting of their own situations. The findings of this study did not demonstrate  
459 denial as the participants had been living with stoma and HPN for some time before  
460 they were interviewed. However, the expression of anger was evident from one  
461 participant who had suffered a sudden and life-threatening illness. These findings  
462 illustrate the patients' physical and social wellbeing when they live with the two  
463 health interventions: stoma care and HPN treatment following hospital discharge.

#### 464 **Implications of findings for professional practice and research**

465 In preparation for discharge, the HPN team reduces the infusion time from 24 to  
466 between 14 and 12 hours depending on the volume. This encourages patients to be  
467 more mobile by taking part in daily activities and social interactions. The patients'  
468 social wellbeing was not assessed by the HPN team as part of the discharge  
469 planning process. There was a general assumption that the patients' competency  
470 with stoma care and HPN treatment implied that the individuals would be able to  
471 incorporate these two health interventions into their daily activities and social  
472 interactions. There were also expectations that the patients' spouse, partner and  
473 close family would provide help. This study has provided new insight on patients  
474 receiving HPN and their sense of living with loss when making adaptations and  
475 adjustments to their lives following discharge from hospital. There are opportunities  
476 to review dietary advice and information at HPN out-patient clinics. Further work is  
477 required to assess other measures e.g. psychological support, and how these would

478 help to reduce the patients' sense of living with loss when they are re-integrated into  
479 their social environment.

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481 We are grateful to the participants in this study, for taking the time to share their  
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