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Title page

Important issues in proposing autonomy training in home parenteral nutrition for short bowel syndrome patients: A qualitative insight from the patients' perspectives.

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Important issues in proposing autonomy training in home parenteral nutrition for short bowel syndrome patients: A qualitative insight from the patients' perspectives.

Abstract

1 **Background/Objectives:** The standard treatment for short bowel syndrome is home
2 parenteral nutrition. Patients' strict adherence to protocols is essential to decrease
3 the risk of complications such as infection or catheter thrombosis. Patient training can
4 even result in complete autonomy in daily care. However, some patients cannot or do
5 not want too much responsibility. However, doctors often encourage them to acquire
6 these skills. Based on qualitative investigations with patients, we wanted to document
7 issues of importance concerning perceptions of autonomy in daily care.

8 **Subjects/Methods:** Semistructured interviews were conducted with 13 adult patients
9 treated by home parenteral nutrition using a maximum variation sampling strategy.
10 We proceeded to a thematic analysis following an inductive approach.

11 **Results:** After achieving clinical management of symptoms, a good quality of life is
12 within the realm of possibility for short bowel syndrome patients with home parenteral
13 nutrition. In this context, achieving autonomy in home parenteral nutrition could be a
14 lever to sustain patients' quality of life by providing better life control. However,
15 counterintuitively, not all patients aim at reducing constraints by reaching autonomy
16 in home parenteral nutrition. First, they appreciate the social contact with the nurses,
17 which is particularly true among patients who live alone. Second, they can feel safer
18 with the nurse's visits. Regaining freedom was the main motivation for patients in the
19 training program and the main benefit for those who were already autonomous.

20 **Conclusions:** Medical teams should consider patients' health locus of control
21 (internal or external) for disease management to support them concerning the choice
22 of autonomy in daily care for parenteral nutrition.

23

24 **Keywords**

25 Short bowel syndrome; autonomy in home parenteral nutrition; health locus of
26 control; patient training program; qualitative research; quality of life

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40 **Introduction**

41 Short bowel syndrome and intestinal failure (SBS-IF) is a rare, chronic,
42 life-threatening condition. By definition, patients with short bowel syndrome (SBS)
43 have a remaining functional postduodenal small bowel length of <200 cm. The true
44 incidence and prevalence of SBS among adults are unknown. In Europe, among
45 adults, the prevalence of SBS varies by region, from 0.4 per million in Poland to
46 approximately 30 per million in Denmark(1) and 34 per million in Germany (2). The
47 standard treatment for intestinal failure due to SBS is home parenteral nutrition
48 (HPN).

49 SBS may result from various causes, such as extensive surgical resection due to
50 Crohn's disease, mesenteric infarction, surgical complications, radiation enteritis and
51 abdominal trauma. Following intestinal resection, if the absorptive capacity of the
52 remaining intestine is not sufficient to provide macronutrients, fluids, electrolytes, and
53 minerals to sustain life, then the patient experiences intestinal failure (IF). Therefore,
54 patients with SBS and IF require parenteral support, which provides nutrition and
55 hydration requirements intravenously. SBS-IF is associated with a decrease in
56 survival due to complications related to SBS and/or parenteral support (PS), such as
57 catheter-related sepsis, kidney disease and liver issues. The main goal of physicians
58 is to reduce PS dependency to reduce complications and increase quality of life.
59 Additionally, it is essential to promote the adaptation of the residual digestive tract by
60 maintaining an oral diet, by carrying out rehabilitative surgery, and possibly by using
61 trophic factors such as GLP-2 analogs (3,4).

62 Studies that document issues of importance from patients' perspectives has been
63 conducted since the early 2010s (5). The first most important observation pointed out

64 the perception of limitations to act spontaneously (6). Adjustments to lifestyle
65 restrictions by way of acquiring new value in life were also highlighted (7). Patients
66 even expressed a strong desire to achieve normalcy in life and sometimes made a
67 positive description of their quality of life (8). Patients underlined that major aspects
68 of need affected by HPN were autonomy, relationships, role fulfilment, socialization,
69 appearance and self-esteem, appetite and perceived vulnerability (9).

70 Patients' strict adherence to protocols and close monitoring of aseptic techniques
71 regarding catheter care are essential to decrease the risk of complications such as
72 infection or catheter thrombosis (10,11). Patient training can even result in increasing
73 patients' participation in self-care up to complete autonomy in daily care for HPN
74 (12). How to disconnect or connect the line from the catheter alone can be an
75 educational objective allowing the patient to be completely independent (13) that
76 could influence their quality of life. However, recent HPN surveys indicated that
77 nearly 50% of patients are autonomous (14). Some patients cannot or do not want to
78 take on too much responsibility. However, doctors often encourage patients to
79 acquire these skills.

80 Several institutions throughout North America and Europe have developed intestinal
81 rehabilitation programs that consist of comprehensive interdisciplinary teams
82 dedicated to the management of patients with IF. A fundamental barrier to the
83 involvement of a team based approach in US is the limited number of IF centers
84 available. Since the mid-1990s many of these programs had been involved with
85 continuity of care from the inpatient to outpatient setting (12). Ensuring patients are
86 competent at catheter care and HPN management is a key component for long-term
87 care with no difference for patients trained in hospital or at home (14).

88 In France self-management for autonomy in HPN are delivered for the adults in
89 approved (reference) hospital centers following a multidisciplinary approach (15). The
90 training stops when patients achieve required skills for HPN that begins only when
91 following a formal pedagogical assessment. After a transition period, there is no
92 regular nurse visit at home except for the implantation of a needle in the port, if
93 necessary. Family caregivers of adult patients can be educated in safety actions but
94 exceptionally, in adults, to disconnect or connect the line.

95 Research findings are clinically relevant for guiding clinicians who are responsible for
96 treating patients (16). Based on qualitative investigations with patients, we wanted to
97 document issues of importance concerning 1) the main determinants of quality of life
98 among patients with HPN in SBS and 2) perceptions of autonomy in daily care.

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111 **Methods**

112 Study design

113 A descriptive qualitative study was undertaken to provide an overview of possible
114 postures for patients concerning autonomy in daily care for HPN. The present study
115 was carried out in compliance with the consolidated criteria for reporting qualitative
116 research (COREQ) (17).

117

118 Sampling and recruitment

119 Semistructured individual interviews were conducted with adult patients with SBS
120 treated by HPN. All patients were cared for at the Transversal Nutrition Unit in Nancy,
121 which is the unique reference center for the whole East quarter of France. The unit
122 treats an active file of 127 in 2021.

123 Sample heterogeneity is considered essential to capture in-depth and large amounts
124 of content in qualitative studies. To maximize variation sampling (18), we identified
125 several dimensions of variations: sex, age, marital status, duration of SBS and HPN
126 and the presence of a stoma.

127 A number of interviews ranging from 11 to 20 corresponds to a satisfactory sample
128 size for qualitative studies to saturate findings (19,20).

129 We selected patients who full-filled our variation criteria (sex, age, marital status,
130 duration of SBS and HPN and the presence of a stoma) among the 127 file active list
131 of patients. Then, we invited the chosen one individually providing a mandatory

132 written information. When a patient refused, we returned to the list to identify another
133 with a similar profile.

134 Data Collection

135 The interview guide was developed based on extensive literature consultation
136 referring particularly to the experience of SBS and HPN from the patients'
137 perspectives. The health psychologist (LR) proposed the first draft, and then a clinical
138 coordinator of a reference center (FJ), member of the team project) refined it. The
139 idea behind the generation of the interview guide was to collect a broad overview of
140 SBS and HPN experiences (Table 1).

141 We also collected demographic and medical information to check the maximal
142 variation strategy previously defined.

143 From September 2020 to December 2021, an experienced female health PhD
144 psychologist (LR) conducted interviews either during a patient's hospitalization, after
145 a medical follow-up consultation or by telephone.

146 Only the participant and the researcher were present during the interview. The
147 researchers did not have any relationship with patients before the start of the study.
148 The interview duration was approximately 1 h. Interviews were integrally
149 audio-recorded and transcribed. Two patients refused to participate in this study. One
150 did not see the point; the second did not give any particular reason.

151

152 Data Analysis and rigor

153 A general inductive approach was followed to identify themes from the patients'
154 perspectives (21). We analyzed the data using NVivo 11 software. After a careful

155 reading of the first three interviews, the health psychologist (LR) developed a coding
156 grid. Then, the grid was refined during a meeting with a clinician (DQ).

157 The health psychologist and an advanced medical student double coded all the
158 interviews. Disagreements were immediately resolved by discussion. Thus, the grid
159 was progressively refined and specified. We applied the same process until the
160 coding grid was completely standardized. In the dataset, Cohen's κ coefficient
161 between the two coders reached a value of .84. A Cohen's κ level $>.80$ is generally
162 considered evidence of reliability (22).

163 The use of triangulation in qualitative research is considered as the best practice
164 (23). We applied an investigator triangulation since content of the themes was
165 discussed during 2 meetings with a health psychologist (LR), and 2 clinicians each of
166 them responsible of a reference center for IF in SBS. In this type of triangulation,
167 researchers provide different insights for a deeper and broader understanding of
168 findings.

169 Interviews were conducted in French but illustrated quotes were translated into
170 English to suit an international audience. Data presented are relevant quotations and
171 ellipsis are used to indicate omitted words/phrases (see Results).

172

173 **Results**

174 **Participants**

175 We recruited males and female for all adult ages. Most of participants were part of a
176 couple. The range of experience with SBS and HPN was from less than 2 years to
177 over 10 years, with a number of days of infusion from one to seven. More than half

178 participants had a stoma bag and underlying diseases of IF due to SBS were
179 classical. Characteristics of our sampling were therefore sufficiently varied for
180 collecting broad perspectives on life with SBS and HPN (see Table 2, for more
181 details).

182 Thematic analysis

183 Six main themes emerged (see Table 2) from the discursive data: 1) installation of
184 the equipment at home, 2) autonomy in daily care for HPN, 3) care and support in the
185 reference center, 4) quality of life determinants, 5) organization in daily life, and 6)
186 impact of SBS on professional life and financial aspects of the disease. In the present
187 paper, we chose to focus on perceptual contents referring to quality of life
188 determinants and to autonomy in daily care for HPN (see Table 3).

189 Table 3 provides an overview of the subthemes related to issues of importance for
190 patients' quality of life and for autonomy in daily care. For each subtheme, we
191 present at least one example below.

192

193 **Quality of life**

194 **Quality of life can be perceived as strongly impacted by:**

195 The need to frequently use the bathroom.

196

197 *"Twice, three times a night, depending (...) Six times, seven times, at the*
198 *beginning it was unbearable, at the beginning it was truly unbearable because*
199 *at the beginning I drank a lot of bottled stuff, now no, now it's fine."* (P5, W)

200

201 *"I don't go to restaurants or even bars anymore because as soon as I swallow*
202 *something I have to go to the bathroom. I don't do that anymore."* (P11, W)

203 *"We don't organize much, well if I go out anyway I mean I have my vehicle if I*
204 *have to go shopping or sometimes to see my family; after that it's a rather sad*
205 *life I would say (...) It's quickly solved, we have to be honest (...). Well it's*
206 *enough that you have diarrhea or something, it's enough that there are no*
207 *toilets or something else, well no it sucks. Sometimes it's all in a hurry, I go*
208 *shopping, it's ta ta ta, thank you, goodbye (...) I see my friends, the people I*
209 *know, I talk a little and then that is it. Yes, no, no, I don't live in a comfortable*
210 *home either. However, now it's not very fun to get drunk either. Inevitably it... It*
211 *transforms you, the desire to laugh has disappeared."* (P9, M)

212

213 The requirement to stay at home.

214

215 *"There was a huge deprivation. Well, I used to go out a lot in the evenings*
216 *(...). Anyway, for me, the arrival of the equipment was a great hardship*
217 *because I could no longer do all that."* (P12, M)

218

219 **A combative posture by setting realistic and achievable goals sustains a**
220 **satisfactory quality of life.**

221 *"I have not changed."* (P4, M)

222 *"I do absolutely everything like other people, I go motorcycling with friends, I*
223 *go everywhere, I take my daughter to the forest, I ride my bike, I do*
224 *everything, I do everything. Frankly, I couldn't tell you that it truly implies*
225 *something in my life, it wouldn't be true!" (P7, M)*

226 *"I had an unattainable goal of 80 kilos and now I'm at 77. It's a dream, even at*
227 *the disease center they told me not to expect so much and I managed to do it.*
228 *I can do sports, I can go on long hikes and everything is more or less in order.*
229 *Of course, I depend on the infusions; if I stop for a day, it is not possible (...) I*
230 *can live quite normally. Of course, I can't go back to work on a construction*
231 *site. Let's just say that I can do the usual things in everyday life, even walking*
232 *15 km in the forest." (P8, M)*

233 *"Since this summer I've taken up sports again, and this summer I tried hiking,*
234 *not like before, but in the middle of the mountains in the Alps, so I was quite*
235 *happy, so now I have taken up tennis again, but in small doses (...). I 've*
236 *always wanted to play music (...). Well, that's it, so it has been a little bit of*
237 *revenge, how can I put it, and so I've signed up for violin lessons." (P13, W)*

238

239 **The team participates in the acceptance process by evoking the**
240 **perspectives of possibilities for the future.**

241 *"It was complicated at the beginning, but the doctors taught me to do it gradually,*
242 *and it was not... Little by little, I discovered that my body was truly modified. That*
243 *was of course a shock, an acceptance. It didn't happen overnight (...). My life was*
244 *going to change completely, and afterward it would be another life so I could*
245 *technically enjoy it again a little bit but... It's true that for me it was a nightmare*

246 *and as the medical staff told me no, no, you 'll see, you'll go back to biking, you'll*
247 *go back to skiing. I didn't believe in it too much (...) and then everything the*
248 *nurses told me became a reality." (P3, M)*

249

250 **Autonomy in daily care for HPN**

251 **Why refuse?**

252 Some patients, although autonomy seems attainable, do not want it:

253

254 For reasons related to contact with the nurse. The need for contact with nurses is most
255 prominent among patients living alone.

256

257 *"I know that she [nurse] would like me to unplug by myself and all that (...).*
258 *Because I don't feel like it, so the nurse comes and we both chat. That's it.*
259 *However, I could do it, but she's there and that's good." (P2, W)*

260 *"Because the nurses tell me, that's what they tell me when they come to the*
261 *house because I prepare everything for them when they arrive (...) And in the*
262 *morning I even take off my perfume, I close everything, they tell me Mrs... you*
263 *are even able to do it by yourself (...) Well actually the fact that the nurses are*
264 *there already gives me someone to talk to (...) Because I'm all alone and in*
265 *fact it gives me a link." (P6, W)*

266

267 For reasons related to the security provided by the nurse's visits.

268

269 Some patients evoked these visits as a kind of safety net to ensure timely referral to
270 health care services if needed.

271 *"That's why I want the nurses to come because I tell myself if I go too far, I can*
272 *tell them that it's not going well, or they can tell me to stop, I have to stop (...).*
273 *That's it and for me the nurses are a guardrail because if they see the moment*
274 *when, if ever there is a moment, because I know that there is always the risk*
275 *of occlusion, which has several risks and all that."* (P6, W)

276 *"They proposed to me to undergo training and to place the bags but I admit*
277 *that I appreciate that it is the nurses for different reasons (...). There are*
278 *periods when indeed, I am not at all in contact with the nutrition service so*
279 *when it is for long periods I see the nurses."* (P13, W)

280

281 **Regaining freedom as the main motivation for patients in the patient**
282 **training program.**

283 In our sample, two patients were following a training program to reach autonomy in
284 HPN and were already trained on disconnection. In other words, they knew that
285 competence from a technical point of view was accessible to them.

286

287 *"I will be able to manage that well if I'm somewhere, if I feel like plugging in at*
288 *9 pm it will flow longer in the morning and I will still gain autonomy."* (P10, W)

289 *"The nurses will always assist me until I feel able to do it myself. Then it is*
290 *going to be a real pleasure, well not a pleasure but an autonomy because I'll*
291 *be more free to move around. They gave me a cooler, I have a backpack*
292 *where I can put my bag and the pump (...) And so with the change of season,*
293 *the arrival of good weather, I can go out even if I'm plugged in, even if I'm on*
294 *parenteral nutrition, I can go out of the house; so that's a freedom." (P3, M)*

295

296 **Freedom regained as the main benefit for patients already autonomous**
297 **in disconnection and connection.**

298 *"Therefore, one year later, I learned how to connect and disconnect my*
299 *infusions so that I have total autonomy (...) I did it for my autonomy, so that*
300 *when we want to leave, we don't have to come back at 1 o'clock because the*
301 *nurse comes to connect." (P1, W)*

302

303 *"We had an almost friendly relationship. Nevertheless, we see the nurses*
304 *more than our own family, it's always complicated (...) I don't have home care*
305 *anymore, I do everything myself, which allows me to live more or less normally*
306 *(...) connection, disconnection, catheter care, injections if there are any. I've*
307 *been trained to do everything, to be prepared for any eventuality (...) I had to*
308 *be at home at 6 pm every day until 9 am the next day. It was like that for 4*
309 *years (...) To find a little autonomy, especially since I have my wife and my son*
310 *and they also need to do things. My current life has no restrictions, whereas*
311 *simply going to eat at a restaurant in the evening was not possible before. To*
312 *be invited in the evening to see family and friends at 6 pm was the end (...) It*

313 *will be more than one year that I am completely free. It changed everything.”*
314 *(P8, M)*

315

316

317 **Patient latitude in the choice of autonomy regarding HPN.**

318 In addition to what patients say is what they do not report. No participant reported
319 elements referring to a refusal for a training pathway for autonomy in HPN that would
320 have been requested by the medical team or of an imposed training that would not
321 have been desired.

322

323 **Discussion**

324 Much of the available literature in the field of SBS tends to be quantitative, with
325 papers measuring the impact of SBS on patients' quality of life and associated
326 influencing factors (16,24,25).

327 If physicians try to prevent and treat the main complications of SBS-IF, it is important
328 to capture in depth the resonance of SBS-IF and treatment with PS for patients by
329 using qualitative methods. As already pointed out in the literature, our results
330 underlined that stool frequency affects quality of life in a major way (26). However,
331 regarding symptomatic control, our findings showed that patients could reach a
332 satisfactory quality of life, particularly when they set attainable goals (i.e.,
333 participating in an activity only if requirements were lowered). The medical team can
334 play a pivotal role by supporting patients' projects (27). After achieving the clinical
335 management of symptoms, a good quality of life is within the realm of possibility for

336 patients with HPN in SBS. In this context, achieving autonomy in HPN could be a
337 lever to sustain patients' quality of life by providing better life control. However,
338 counterintuitively, not all patients aim to reduce constraints by reaching autonomy in
339 HPN. First, they appreciate the social contact with the nurses, which is particularly
340 true among patients who live alone. Second, they can feel safer with the nurse's
341 visits. Finally, for those who have chosen autonomy in HPN, the newfound freedom
342 is key in defining their perceived benefits.

343 In this context of a lack of knowledge among professionals, our results showed that
344 in addition to strict clinical management, teams could contribute to strengthening
345 patients' quality of life by not forcing a choice concerning training for autonomy in
346 HPN. In our sample, no patient reported a forced choice concerning autonomy in
347 HPN in one direction or the other. The health locus of control refers to patients'
348 perception of responsibility for disease management (28). Some patients want more
349 control (internal health locus of control), whereas others prefer to delegate decisions
350 to the medical team (external health locus of control). In summary, the consideration
351 of the health locus of control could help the medical team tailor the support proposed
352 to the patient (29) concerning the choice of training for complete autonomy in HPN.
353 For the European Medicines Agency (EMA), in 2022, patient preferences "refer to
354 how desirable or acceptable is to patients a given alternative or choice among all the
355 outcomes of a given medicine". In a recent systematic review (30), assessing
356 patients health locus of control and control preference was established as a crucial
357 determinant to explain patients preferences on health-related decision. To the best of
358 our knowledge, our study is the first one trying to understand from the SBS patients'
359 perspectives important issues in proposing autonomy in HPN.

360 Although we generated and analyzed our qualitative data according to COREQ
361 criteria, there is a limitation in our study since the results are not generalizable using
362 a maximum variation sampling strategy. In qualitative researches, the notion of
363 transferability to other contexts of understanding (analytic generalization) is preferred
364 to the notion of statistic generalization. Maximum variation sampling strategy is one
365 of the key element to strengthen transferability (31). In France, the support for SBS-
366 IF is usually coordinated by a reference center (15). The all-French territory has less
367 than 10 approved centers and the one from Nancy covers an area of 5.5 million
368 inhabitants. The fact that we did not recruit patients from different reference centers
369 may have affected the analytic generalization even if we multiplied variation criteria
370 for participants' profile. Moreover, we applied a triangulation process for findings
371 interpretation in which a clinician responsible of a second reference center in Paris
372 Beaujon Hospital, Paris was included (150 patients in the file active) (see the part
373 Data Analysis and Rigor).

374 Bias like recall or social desirability are important considerations in quantitative
375 research paradigms. However, these concepts are incompatible with the
376 epistemological concepts underpinnings of qualitative methods (32) in which
377 reliability and validity remain the major criteria for rigor evaluation (33).

378 Our findings could have been strengthened by further collecting health care
379 providers' perspectives on factors that might affect their proposition of autonomy in
380 HPN like socioeconomic determinants underpinnings health inequalities such as
381 income, education, and geographic situation (34,35).

382 The position concerning autonomy in HPN should not be considered definitive, and
383 the team should be able to assess at regular intervals if the mental load required for

384 autonomy does not exceed the patient's resources, i.e., to propose a stop-and-go
385 approach as close as possible to the patients' needs at a given time.

386 Our qualitative results call for complementary studies on medical team adjustment to
387 patient health locus of control in support of a satisfactory quality of life for patients
388 with SBS.

389 Taking into account stratification on for example sex, age, HPN duration, or type of
390 central line, it would be particularly interesting to study the impact of initial health
391 locus of control on successful outcomes for HPN in SBS with patient-
392 reported outcomes measures (PROMs) and patient-reported experience measures
393 (PREMs) or even on complications criteria (infection, catheter thrombosis, and
394 metabolic derangement) (36).

395 **Data Availability Statement**

396 The data that support the findings are available on request from the authors.

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542 LR, FJ and FG contributed to the conception and design of the research.

543 LR, AC and DQ contributed to the acquisition of data.

544 LR, FJ and DQ helped interpret the data.

545 LR wrote the original draft.

546 All authors critically revised the manuscript.

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554 The Comité de Protection des Personnes (CPP (Sud-Ouest et Outre-Mer III))
555 approved the protocol (no. ID-RCB: 2019-A0203453-46). All participants gave their
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Competing interests

The authors declare that they have no conflicts of interest.