



Short bowel syndrome and the impact on patients and their families

DOI:

[10.1111/jhn.12803](https://doi.org/10.1111/jhn.12803)

Document Version

Final published version

[Link to publication record in Manchester Research Explorer](#)

Citation for published version (APA):

Sowerbutts, A. M., Panter, C., Dickie, G., Bennett, B., Burden, S., & Lal, S. (2020). Short bowel syndrome and the impact on patients and their families: a qualitative study. *Journal Human Nutrition and Dietetics*, 33(6), 767-774. <https://doi.org/10.1111/jhn.12803>

Published in:

Journal Human Nutrition and Dietetics

Citing this paper

Please note that where the full-text provided on Manchester Research Explorer is the Author Accepted Manuscript or Proof version this may differ from the final Published version. If citing, it is advised that you check and use the publisher's definitive version.

General rights

Copyright and moral rights for the publications made accessible in the Research Explorer are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.


Takedown policy

If you believe that this document breaches copyright please refer to the University of Manchester's Takedown Procedures [<http://man.ac.uk/04Y6Bo>] or contact uml.scholarlycommunications@manchester.ac.uk providing relevant details, so we can investigate your claim.



GASTROINTESTINAL DISORDERS

Short bowel syndrome and the impact on patients and their families: a qualitative study

A. M. Sowerbutts¹  C. Panter,² G. Dickie,² B. Bennett,³ J. Ablett,⁴ S. Burden¹ & S. Lal⁵

¹Faculty of Biology, Medicine and Health and Manchester Academic Health Science Centre, University of Manchester, Manchester, UK

²Adelphi Values, Bollington, UK

³Formerly Adelphi Values, Bollington, UK

⁴St Helen's and Knowsley NHS Trust, Liverpool, UK

⁵Salford Royal NHS Foundation Trust, Manchester, UK

Keywords

short bowel syndrome, parenteral nutrition, stoma, qualitative.

Correspondence

A. M. Sowerbutts, RM5.328 Jean McFarlane Building, School of Health Sciences, University of Manchester, Oxford Rd, Manchester M13 9PL, UK.

Tel.: +44 161 306 7888

Fax: +44 161 306 7851

Email: annemarie.sowerbutts@manchester.ac.uk

How to cite this article

Sowerbutts A. M., Panter C., Dickie G., Bennett B., Ablett J., Burden S. & Lal S. (2020) Short bowel syndrome and the impact on patients and their families: a qualitative study. *J Hum Nutr Diet.* **33**, 767–774

<https://doi.org/10.1111/jhn.12803>

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

Introduction

Short bowel syndrome (SBS) is a malabsorptive condition caused by surgical resection of the gastrointestinal tract as a result of disease and many patients have a stoma⁽¹⁾. SBS can cause intestinal failure (SBS-IF). These patients need to have parenteral nutrition (PN) to meet their nutritional or fluid requirements⁽²⁾.

The prevalence of SBS-IF is difficult to establish and so a proxy measure of number of patients receiving PN is

Abstract

Background: Short bowel syndrome (SBS) is a malabsorptive condition that can result in intestinal failure (SBS-IF). Many patients with SBS-IF require home parenteral nutrition (PN) for survival. However, PN has profound effects on patients and their family members. The present study aimed to understand the lived experience of SBS-IF for patients and their families.

Methods: In-depth semi-structured qualitative interviews were conducted with 15 patients with SBS-IF and five adult family members living with someone with SBS-IF. A patient-centric approach was taken, with a patient steering group providing input and guidance to develop the interview guide. Key concepts were identified using thematic analysis of interview transcripts.

Results: Patients' lives were dominated by having SBS-IF. They described physical impacts that included patient-reported signs and symptoms and physical restrictions comprising of restrictions on daily life, activities of daily living and physical functioning. In addition, they encountered emotional impacts with a plethora of negative feelings and social impacts, such as difficulties socialising and maintaining relationships. Patients coped by adapting their life around SBS-IF, having support and adopting an attitude of gratitude and acceptance. Family members were also affected and, along with patients, appreciated the respite of a night off from infusions.

Conclusions: Patients and families face many difficulties with SBS-IF. Healthcare professionals can support patients by facilitating them explore what others have found beneficial; adapting their life around PN, viewing PN with acceptance and trying to cultivate gratitude. Further research into the support required for families may be beneficial.

frequently reported. In Europe, this varies by country with approximately 40 per million in the UK to approximately 80 per million in Denmark^(3,4). However, these figures are increasing because both Denmark and the UK have reported increasing numbers of patients in recent years^(3,4). With this expanding patient population, it is essential that patients and family experiences are understood so that appropriate support can be offered.

Much of the available literature tends to be quantitative in nature using generic quality of life patient-reported

outcomes, which lack content validity for specific disease populations⁽⁵⁾, or using quality of life instruments focused on PN rather than on SBS-IF^(6,7). This research indicates that patients on PN have a reduced health-related quality of life compared to matched controls⁽⁵⁾, with psychological symptoms, as well as sexual and social dysfunction^(8–10), and describe an inability to act spontaneously because daily life involves considerable planning around infusions⁽¹¹⁾.

Both family members and patients are impacted by PN, with them experiencing significant psychosocial burdens^(12–15). Families also face imposing financial restraints, including decreased employment, and, more relevant to private or insurance-based health economies, large expenses for non-reimbursed medications⁽¹³⁾.

Qualitative research, in contrast to quantitative, allows for an in-depth exploration of a patient's and family's experience. Currently, qualitative research has explored the experiences of patients with cancer who take PN and their families^(16,17), as well as the experience of patients with mixed benign conditions having PN^(18,19). Patients with cancer and family members are appreciative of the treatment because it is a life line⁽¹⁶⁾, whereas those on long-term PN report impacts on functioning and overall health status⁽¹³⁾. However, the patients' and family members' experiences of SBS-IF involve more than just PN. The present study was to understand the patient and family experience of living with SBS-IF by taking a holistic approach. This will enable the true impact on patients and family members to be explored, adding to the overall knowledge of life on PN with SBS-IF.

Materials and methods

Study design

This was a qualitative, non-interventional interview study involving patients with SBS-IF and family members. Each participant was involved in a 1-h, face-to-face concept elicitation interview at one time-point. To provide rigour and support for a 'patient-centric approach', a separate group of patients provided input in the development of the interview guide⁽²⁰⁾. The interviews from the present study were used in further work to create health utility scores⁽²¹⁾.

Rigour

Rigour was introduced by having a patient steering group, comprising seven members from a support group for individuals receiving home PN, provide input into the development of the interview guide. The steering group were asked whether the questions were easy to understand, relevant to a person with SBS-IF, comprehensive

(captured all relevant concepts) and appropriate. Amendments to the interview guide were made incorporating their feedback. To avoid bias, patients involved in the steering group were excluded as participants in the study sample.

Sample

Patients were recruited via physicians from one specialist intestinal failure unit. Psychological support was provided by multidisciplinary team members with patients referred to a clinical psychologist if required. Eligible patients had to be aged ≥ 18 years, literate, fluent in English, have a diagnosis of SBS-IF and to have received PN for at least 1 year. Eligible patients were asked whether they wanted to nominate a family member to participate in a separate interview about their experience of living with someone with SBS-IF. A purposive sampling approach was taken, with categories determined to ensure a range of clinical and demographic characteristics were captured in the study cohort (see Supporting information, Table S1).

Ethical considerations

The study was submitted for NHS ethical consideration and approved by the National Research Ethics Committee North West (Ref: 15/NW/0576) and received Research & Development approval. Eligible participants were sent written information prior to attending their routine clinic appointment and had the chance to discuss the study with a member of staff before deciding whether they wanted to take part. All participants provided their written informed consent.

Data collection

Face-to-face, semi-structured interviews were conducted by two trained interviewers in the UK with patients and family members; each interviewer conducted 10 interviews. Interviews lasted approximately 1 h, were audio recorded and were conducted using detailed semi-structured interview guides. The interviews were conducted using concept elicitation techniques such that open-ended exploratory questions were asked to facilitate spontaneous content^(22–24), followed by direct, focused questions. The interviews explored symptoms of SBS-IF, the broader impact of the condition and the need for PN, as well as future outlook.

Statistical analysis

Interviews were transcribed verbatim and analysed thematically. A software package, ATLAS.TI⁽²⁵⁾, was used to

aid coding. The coding scheme was devised by discussion between the project leader and project researchers reviewing two interviews. This coding scheme was then used throughout the coding process. As an iterative analytic process, new codes were organically added throughout the coding process. Words, sentences and key phrases were identified from the transcripts and placed within the formulated codes. The themes were generated by reading through the codes and participant quotations. Quotations have been used to illustrate the themes; each quotation has been labelled with a pseudonym and, for patients, age and the number of nights on PN is included (for example, 5PN denotes 5 nights of PN).

Results

Participant sample characteristics

Seventy patients met the inclusion criteria and 37 agreed to be interviewed. From these, 15 patients were chosen to give a diverse sample that most closely matched the purposive sampling criteria. The criteria were not met in three areas because either there were no or very few patients matching the categories who had clinic appointments during the recruitment period. Five family members also took part and there was a maximum of one family member per patient. All patients were Caucasian with a mean age of 53.9 (range 32–76) years and most were living with a partner (67%). Patients had PN between 3–7 nights per week, although most were on 5–7 nights per week (73%). Overall, there was a variety of demographic and clinical characteristics (Tables 1 and 2).

Patient interviews

SBS-IF impacted on all aspects of patients' lives; these have been grouped into physical, emotional and social impacts. Patients also spoke about coping with life having SBS-IF.

Theme 1: Physical impacts

Physical impacts have been grouped into two subthemes, patient-reported signs and symptoms, and physical restrictions, which included physical restrictions on daily life, restrictions on activities of daily living and physical functioning.

Subtheme 1: Patient-reported signs and symptoms

Patients reported a variety of signs and symptoms as a result of SBS-IF, such as dehydration, tiredness and fatigue, and pain (for other signs and symptoms discussed, see Supporting information, Table S2).

Table 1 Patient and family member demographics

| Description | SBS patient sample (n = 15) | Family member sample (n = 5) |
|-------------------------------------|-----------------------------|------------------------------|
| Age (years) | | |
| Mean (range) | 53.9 (32–76) | 53.8 (32–69) |
| Gender, | | |
| Male | 5 | 3 |
| Female | 10 | 2 |
| Living status, | | |
| Live alone | 4 | 0 |
| Live with husband/wife/partner | 10 | 5 |
| Live with parents/family or friends | 1 | 0 |
| Ethnicity, | | |
| Caucasian | 15 | 5 |
| Highest level of education, | | |
| GCSEs (or equivalent) | 6 | 3 |
| A-level (or equivalent) | 2 | 1 |
| Undergraduate degree | 1 | 0 |
| Postgraduate degree | 1 | 0 |
| Other | 2 | 1 |
| Missing data | 3 | 0 |
| Work status, | | |
| Working full time | 2 | 0 |
| Working part-time | 1 | 1 |
| Full-time homemaker | 1 | 0 |
| Not working as a result of SBS | 4 | 1 |
| Retired | 6 | 2 |
| Other | 1 | 1 |

SBS, short bowel syndrome.

Dehydration. Dehydration was a problem for patients; 'Being thirsty is horrendous ... all I want is a glass of water, but I can't have it' (Sally, 52 years, 6PN). A variety of factors triggered dehydration including eating and drinking: 'you have this dreadful thirst. Your body is telling you to drink ... and you do and then it just is that vicious circle that you just can't get out of' (Helen, 44 years, 4PN). Dehydration could be a daily occurrence; 'All the time. Every day' (Julie, 44 years, 6PN). Other patients talked about severe episodes in the past.

Tiredness and fatigue-related symptoms. Patients described tiredness and fatigue, which could leave them unable to carry out their usual activities. 'Sometimes I just can't even get up the stairs' (Dora, 47 years, 7PN). However, for some, the tiredness improved over time. One patient commented that she had it 'quite rarely now' (Helen, 44 years, 4PN).

Pain. Pain was also described by patients particularly stomach pain 'It's like someone's got your insides and knotting them up ... it's horrible, the pain. I mean really bad' (Julie, 44 years, 6PN). Others described burning pain

Table 2 Patient clinical characteristics ($n = 15$)

| Description | |
|---|------------------|
| Total daily volume of PN use (ml) | |
| Mean (range) | 2643 (2000–3500) |
| Time since first on PN (months) | |
| Mean (range) | 100 (11–395) |
| Use of stoma bag, n | |
| Yes | 11 |
| No | 4 |
| Type of bag, $n = 11$ | |
| Colostomy | 1 |
| Ileostomy | 8 |
| Other | 1 |
| Missing data | 1 |
| Cause of SBS, n | |
| Crohns | 6 |
| Surgical complications | 3 |
| Ischaemic bowel | 1 |
| Surgical interventions for ulcerative colitis | 1 |
| Avulsion injury to mesentery | 1 |
| Radiation enteritis | 1 |
| Ischaemic gut | 1 |
| Missing data | 1 |

PN, parenteral nutrition; SBS, short bowel syndrome.

around the stoma, associated with their stoma bag leaking. Generally, the experience of pain was variable and depended on the cause of pain; patients could have pain a few times a year, whereas others had it every week. The length of pain also varied from a few seconds to up to a whole day. 'I think the worst ones are the cramps ... even if it's only just sort of 20 seconds, it's really, really severe' (Sarah, 45 years, 6PN).

Subtheme 2: Physical restrictions

Patients could find that their life was confined as a result of their SBS-IF and the need for PN. Patients described being limited in activities or experiencing a lack of freedom. 'It impacts it a lot when ... I'm having a bad day, because I can't do nothing. And then I go on the TPN and then I'm stuck here' (Dora, 47 years, 7PN).

In addition to restrictions from disease symptoms, the patients had to be at home at a particular time to start the feed 'It's difficult because you need to ... be home at a certain time to get it' (Mark, 31 years, 3PN). The constant need for the stoma bag to be emptied was also limiting.

Patients sleep was curtailed as a result of having to pass urine as a result of the fluid from the PN and needing to empty the stoma bag 'If I am on TPN I don't sleep as well, um, one because I go to toilet a little bit more, um, from weeing ... Unfortunately my bag will leak during the night' (Frank, 35 years, 3PN).

Patients were also restricted in self-care; having a bath instead of a shower, showering every couple of days or showering cautiously. 'I tend to just have baths, so just to try and avoid that – the line getting wet ... You tend not to have any showers because of that ... it's just a risk of infection' (John, 31 years, 3PN). By contrast, one patient showered more often to maintain the sterile conditions required with PN, as she wanted to be 'extremely clean' (Sarah, 45 years, 6PN).

Patients also discussed impacts on physical functioning such as their ability to take part in exercise and their mobility being curtailed. As one patient said 'I've tried ... by walking, by like trying to get yourself like a bit stronger. I, I can't go with it ... it's too exhausting' (Julie, 44 years, 6PN).

Theme 2: Emotional impact

Patients discussed wide ranging emotional and psychological impacts such as feelings of sadness, worry and frustration.

Sadness

Patients expressed sadness due to having SBS-IF. They could feel different from other people 'It makes me feel upset that I'm not just like everybody else' (Sally, 52 years, 6PN) and not understood: 'You're feeling quite low and ... it's almost like nobody else understands what you're going through' (Helen, 45 years, 6PN). As well as sadness for themselves, patients were also sad for their spouses 'makes me feel, uh, upset really, upset for her. And when you've planned all your poor working life to do this, that, and the other' (Bill, 67 years, 5PN).

Worry

Patients commonly worried about getting a central venous catheter infection; one patient described it as 'the only thing that worries me' (Sally, 52 years, 6PN). This concern was heightened for patients responsible for the connection and disconnection of the central venous catheter from the PN and wanted to be 'always doing the right thing ... and were ... frightened of going wrong' (Joan, 70 years, 7PN). The stoma bag was another concern; 'I've just worried about my stoma leaking' (Frank, 35 years, 3PN). Patients could also be worried about being admitted to a non-specialist hospital 'nobody else understands my condition really. So it's that lack of understanding in the, the medical world' (Helen, 44 years, 4PN).

Frustration

Patients discussed feeling frustrated. This could be a result of restrictions of the PN regimen and amount of

equipment; for others, it was the symptoms of the condition or factors relating to their stoma, such as the appearance of it or the bag leaking or needing frequent emptying.

Theme 3: Social impact

Patients experienced impacts on their social relationships as a result of SBS-IF such as difficulties in socialising. This was related to their constant need for the toilet or checking the stoma bag. 'I've always got to know where a loo is and it puts me off going out for a meal' (Paul, 67 years, 5PN). Events involving food and drink were a particular problem because patients could not eat the same quantity of food as prior to their illness and had to be careful about what they ate and drank. This could lead patients to avoid such events. 'It's normal for a person to eat. That's why I avoid going out with friends ... They all sat there eating, drinking beer ... and I can't' (Julie, 44 years, 6PN).

SBS-IF impacted on patient's relationships, in particular with their partner. 'If you're having sort of sex ... I'm embarrassed by it even with him' (Sally, 52 years, 6PN). There were also impacts on other family members with patients being limited to what they could do with children and grandchildren. Friends might not understand the condition and this put strain on the friendship. 'They don't understand ... you try to explain and they don't – one of my friends just doesn't understand ... the problems I have because ... I look normal.' (Dora, 47 years, 7PN).

Patients described hiding elements of their condition from friends or family. Patients could feel embarrassed by having a stoma so did not discuss it. Other patients did not want to worry their family and wanted to be seen as normal by their friends.

Theme 4: Coping with life having short bowel syndrome with intestinal failure

The elements that helped patients cope with their condition were adapting their life around their illness, emotional attitudes, support from others and having a night off from PN.

Adaptation

Patients had adapted their life around their SBS-IF, in particular tailoring their day around the PN regimen 'Sometimes I need a bit longer in the morning to take my feed off ... I've just sort of accommodated it' (Lisa, 45 years, 5PN). They had also adapted to having the stoma bag and learnt to manage it 'It's something I've got, I've got to learn to cope with it and I just get on with it' (Mary, 66 years, 7PN).

Emotional attitudes

The attitudes that helped patients manage with their condition were gratitude and acceptance. Although the PN regimen was restrictive, patients recognised that it was keeping them alive and were grateful for it. 'I'm really, really grateful that there is such a thing as PN because I couldn't survive [without] it, literally' (Sally, 52 years, 6PN). Patients came to a place of acceptance that helped them cope with their life having SBS-IF; 'you either can work with the problem, you know, or you can be against it and it'll just make your life harder ... You have to find that happy medium' (Frank, 35 years, 3PN).

Support

Support was another element which patients cited as helping them cope with SBS-IF. Support came from various sources; friends and family, nurses or specialist hospital staff, and patient support groups. Most patients were satisfied with the support they received.

Night off from parenteral nutrition

Patients who were able to have a night off from PN discussed it as having a positive impact on their well-being. It allowed them to participate in social activities and meant that they could feel free and normal for that one night; 'It just makes me feel that that one day I can be a normal person and just get up.' (Sally, 52 years, 6PN). Although they enjoyed having a night off from PN, some patients acknowledged that it had a detrimental impact the morning or day after in that they felt tired, dehydrated or hungry.

Despite the difficulties, all patients identified that a reduction in nights on PN would make a big difference in their lives. When asked about what they would consider as an ideal treatment, a typical comment was for a reduction in the hours or nights on PN; for example, one patient said 'If I didn't have to be on it 7 nights a week ... just allow me, I suppose to feel normal' (Mary, 66 years, 7PN).

Family member interviews

SBS-IF affected both family members and patients. Family routines and activities could be affected. So, outings needed to be planned around it and could be delayed 'the biggest upset ... is that she may have to go to the toilet. She might be there for quite a while ... it does create a delay then on things' (Andrew).

There were particular impacts on holidays as a result of the amount of equipment and planning needed. One family member commented that when they went away 'literally the whole car [is] taken up with medical equipment ... anything we do has to be planned around it'

(David). This was stressful and could mean that the patient and their family did not go on holiday; 'We haven't been on holidays in a very long time ... it's mainly the [PN]' (Fiona). One family adapted by buying a motorhome and commented 'We're going away more now than we did before' (Martin).

In addition, the patients' SBS-IF could cause financial constraints as a result of family members taking time off work, which one participant described as a 'financial blow' (Martin). Another participant gave up work leading financial problems. 'I don't work anymore. I'm fulltime carer for her now ... [resulting in] mortgage arrears ... that is another massive stress' (David). There were no financial impacts reported by two participants; in one case because they were retired.

Although, it caused problems, relatives expressed gratitude for the availability of PN: 'I prefer that he didn't have to do it, but I'm delighted that it's available, because he would be dead if he didn't have it' (Michelle). Partners would get involved and try to help patients with their PN. 'I actually try and help him out ... maybe shorten the time of the preparation for him ... clean up the kitchen for him just to, to come and set up his trolley, do his med' (Fiona). However, this could sometimes cause friction between them; 'I know that if I try and go and get involved she gets agitated' (David).

Their partner having PN had psychological impacts on family members. Family members could be worried: 'I may be worried ... about his line infections and him feeling bad ... because of course it affects ... me psychologically' (Fiona). Family members could also be irritated by the constraints of PN; 'honestly in the beginning I did feel slightly ... irritated because there's things that I wanted to do that ... didn't happen' (Fiona).

Family members, as well as patients, discussed the benefit of reducing nights on PN. One participant noted that it would improve the mood of them both. Others discussed that they would be less restricted in going out and going on holiday.

Discussion

The present study aimed to understand the impact of SBS-IF on patients and family members. Patients' lives were affected by symptoms from the disease and its consequences; having a stoma and the PN regime. All aspects of patients' lives were affected by their condition; with patients reporting physical symptoms and physical restrictions, as well as effects on emotional wellbeing, their social life and relationships. Family members living with the patient also were affected in multiple ways. Patients described ways of dealing with their condition by adapting their life around the PN, adopting emotional attitudes

of gratitude and acceptance, having support from others, and a night off from PN.

Previous research into patients' perspective of SBS-IF is limited; thus, the present study used qualitative methods to gain an in-depth view of the patients' perspective of SBS-IF, as well as family members living with someone with SBS-IF. Much of the literature has focused on the patient experience of PN rather than considering the effect of SBS-IF in its entirety on patients and their families^(26–28). Quantitative research using patient-reported outcome questionnaires has found that patients have diminished health-related quality of life^(5,29). The data collected from the interviews conducted in the present study illustrate why this might be the case with patients talking about a range of physical symptoms such as diarrhoea and abdominal pain, and the restrictive nature of PN, all of which have a negative impact on quality of life.

Patients' lives were limited as disease symptoms, restrictions from the PN regime and living with a stoma curtailed what they could do. Given the overwhelming nature of the disease and the constraints it imposed, patients had a plethora of negative emotions. This is unsurprising because previous research using a validated questionnaire with patients on PN has shown that belief about lack of personal control leads to emotional distress in these patients⁽³⁰⁾.

The constraints of living with SBS-IF and PN regimen curtailed patients' social lives and impacted on patients' relationships. This is keeping with other research that has demonstrated the impact of home PN on social life^(18,31,32), whereas other studies report that social life is not effected⁽²⁸⁾. It is unclear why there was discrepancy, although it does highlight the need to provide person centred care for all patients.

Both family members and patients are affected by SBS-IF and an important element of the present study was uncovering that impact. Other research using a validated questionnaire has investigated family member experience of PN⁽¹⁴⁾, although the present study is the first to use qualitative interviews so that family members could freely express their views. Family members wanted to help their relative, although they could be worried about them and be irritated with impositions from PN regimen.

As well as considering the impact of SBS-IF, we investigated what helped patients cope. Patients described a number of elements, which could be classified as having a positive outlook – adapting to their situation, seeing the benefit of the PN and being thankful that it was keeping them alive. Patients also cited the support they received from others as a factor that helped them cope. Although other studies have commented on how patients coped with PN, such as trying to integrate it into daily life, they have not drawn strategies together as a coherent theme^(32,33).

Another element having a positive impact on patients' on general well-being was a night off from PN because this gave them more freedom and feelings of normalcy, although they could have an increase in symptoms the following day. With the advent of treatments to improve gastrointestinal absorption, such as glucagon-like peptide (GLP)-2 and GLP-1, number of nights on PN is a potentially modifiable factor^(34–36). Patients' desire for greater freedom and normalcy was further reinforced when discussing a perfect or ideal treatment with a reduction in hours or nights on PN being the most commonly reported theme. This aligns with other research demonstrating that health-related quality of life is related to the number of nights patients receive PN⁽⁶⁾.

Limitations and future research

The family member sample was small and further research into the impact on family members is required; in particular, exploring the adequacy of the support they receive and whether additional support is required.

Conclusions

Patients with SBS-IF and their family members were severely impacted by the condition. Healthcare professionals can help to support patients by facilitating them explore what others have found beneficial; adapting their life around PN, viewing PN with acceptance and trying to cultivate gratitude. Further research into the support required for family members may be beneficial.

Acknowledgments

We thank the patients and family members who took part in these interviews. We also thank NPS Pharma for funding this study

Conflicts of interest, source of funding and authorship

Unrelated to this study, SL and SB have received unrestricted research grant support from Shire/Takeda into their departments, one of which funded a study where AMS was the study researcher. JA, BB, CP and GD declare they have no conflicts of interest.

This study was supported by NPS Pharma.

JA, SB and SL obtained the funding and were involved in the initial conceptualisation of the study. CP and GD conducted the interviews. CP, GD, BB and AMS analysed the data. All authors interpreted the data. AMS wrote a draft of the paper. All authors reviewed, revised and edited the paper. All authors read and approved the final manuscript submitted for publication.

Transparency declaration

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

REFERENCES

1. Tappenden KA (2014) Pathophysiology of Short Bowel Syndrome considerations of resected and residual anatomy. *J Parenter Enteral Nutr* **38**(1 suppl), 14S–22S.
2. Carroll RE, Benedetti E, Schowalter JP *et al.* (2016) Management and complications of short bowel syndrome: an updated review. *Curr Gastroenterol Rep* **18**(7), 40.
3. Brandt CF, Hvistendahl M, Naimi RM *et al.* (2017) Home parenteral nutrition in adult patients with chronic intestinal failure: the evolution over 4 decades in a tertiary referral center. *J Parenter Enteral Nutr* **41**(7), 1178–1187.
4. Smith T, Naghibi M. (2016) BANS Report 2016 Artificial Nutrition Support in the UK 2005–2015 Adult Home Parenteral Nutrition & Home Intravenous Fluids. Available at: <https://www.bapen.org.uk/images/pdfs/reports/bans-report-2016.pdf>
5. Carlsson E, Bosaeus I & Nordgren S (2003) Quality of life and concerns in patients with short bowel syndrome. *Clin Nutr* **22**(5), 445–452.
6. Burden ST, Jones DJ, Gittins M *et al.* (2019) Needs-based quality of life in adults dependent on home parenteral nutrition. *Clin Nutr* **38**(3), 1433–1438.
7. Wilburn J, McKenna SP, Heaney A *et al.* (2018) Development and validation of the Parenteral Nutrition Impact Questionnaire (PNIQ), a patient-centric outcome measure for Home Parenteral Nutrition. *Clin Nutr* **37**(3), 978–983.
8. Ladefoged K (1981) Quality of life in patients on permanent home parenteral nutrition. *J Parenter Enteral Nutr* **5**(2), 132–137.
9. Carls G, Maguire G, Williams N *et al.* (1995) Quality of life on home parenteral nutrition: a single centre study of 37 patients. *Clin Nutr* **14**(4), 219–228.
10. Jeppesen P, Langholz E & Mortensen P (1999) Quality of life in patients receiving home parenteral nutrition. *Gut* **44**(6), 844–852.
11. Carlsson E, Berglund B & Nordgren S (2001) Living with an ostomy and short bowel syndrome: practical aspects and impact on daily life. *J Wound Ostomy Continence Nurs* **28**(2), 96–105.
12. Winkler MF, Ross VM, Piamjariyakul U *et al.* (2006) Technology dependence in home care: impact on patients and their family caregivers. *Nutr Clin Pract* **21**(6), 544–556.

13. Winkler MF & Smith CE (2014) Clinical, social, and economic impacts of home parenteral nutrition dependence in short bowel syndrome. *J Parenter Enteral Nutr* **38**(1_suppl), 32S–37S.
14. Smith CE (1993) Quality of life in long-term total parenteral nutrition patients and their family caregivers. *J Parenter Enteral Nutr* **17**(6), 501–506.
15. Smith CE, Leenerts MH & Gajewski BJ (2003) A systematically tested intervention for managing reactive depression. *Nurs Res* **52**(6), 401–409.
16. Sowerbutts AM, Lal S, Sremanakova J *et al.* (2019) Palliative home parenteral nutrition in patients with ovarian cancer and malignant bowel obstruction: experiences of women and family caregivers. *BMC Palliative Care* **18**, 120.
17. Sowerbutts AM, Lal S, Sremanakova J *et al.* (2020) Discharging women with advanced ovarian cancer on home parenteral nutrition: making and implementing the decision. *Nutrients* **12**(1), 166.
18. Heaney A, McKenna SP, Wilburn J *et al.* (2018) The impact of home parenteral nutrition on the lives of adults with type 3 intestinal failure. *Clin Nutr ESPEN* **24**, 35–40.
19. Huisman-de Waal G, Naber T, Schoonhoven L *et al.* (2006) Problems experienced by patients receiving parenteral nutrition at home: results of an open interview study. *J Parenter Enteral Nutr* **30**(3), 215–221.
20. US Food and Drug Administration (2018) *Patient-Focused Drug Development: Collecting Comprehensive and Representative Input: Guidance for Industry, Food and Drug Administration Staff, and Other Stakeholders*. Rockville, MD: US Department of Health and Human Services Food and Drug.
21. Ballinger R, Macey J, Lloyd A *et al.* (2018) Measurement of utilities associated with parenteral support requirement in patients with short bowel syndrome and intestinal failure. *Clin Ther* **40**(11), 1878–1893.e1.
22. Patrick DL, Burke LB, Powers JH *et al.* (2007) Patient-reported outcomes to support medical product labeling claims: FDA perspective. *Value Health* **10**(Suppl 2), S125–S137.
23. Lasch KE, Marquis P, Vigneux M *et al.* (2010) PRO development: rigorous qualitative research as the crucial foundation. *QualLife Res* **19**(8), 1087–1096.
24. Leidy NK & Vernon M (2008) Perspectives on patient-reported outcomes : content validity and qualitative research in a changing clinical trial environment. *Pharmacoeconomics* **26**(5), 363–370.
25. Atlas.ti software, version 7. ATLAS.ti Scientific Software Development GmbH, Berlin, Germany. 2013. <https://atlas.ti.com/>.
26. Ennis L, Ablett J, Taylor M & *et al.* (2018) The active problem solving of patients dependent on home parenteral nutrition: a qualitative analysis. *Clin Nutr ESPEN* **26**, 77–83.
27. Winkler MF, Wetle T, Smith C *et al.* (2010) The meaning of food and eating among home parenteral nutrition-dependent adults with intestinal failure: a qualitative inquiry. *J Am Diet Assoc* **110**, 1676–1683.
28. Tsang PY & Carey S (2015) Impact of home parenteral nutrition on daily life: a qualitative study of eight patients. *Nutr Dietetics* **72**, 16–21.
29. Kalaitzakis E, Carlsson E, Josefsson A *et al.* (2008) Quality of life in short-bowel syndrome: impact of fatigue and gastrointestinal symptoms. *Scand J Gastroenterol* **43**, 1057–1065.
30. Fortune DG, Varden J, Parker S *et al.* (2005) Illness beliefs of patients on home parenteral nutrition (HPN) and their relation to emotional distress. *Clin Nutr* **24**(6), 896–903.
31. Huisman-de Waal G, Schoonhoven L, Jansen J *et al.* (2007) The impact of home parenteral nutrition on daily life—a review. *Clin Nutr* **26**, 275–88.
32. Winkler MF, Hagan E, Wetle T *et al.* (2010) An exploration of quality of life and the experience of living with home parenteral nutrition. *J Parenter Enteral Nutr* **34**, 395–407.
33. Wong C, Lucas B & Wood D (2018) Patients' experiences with home parenteral nutrition: a grounded theory study. *Clin Nutr ESPEN* **24**, 100–108.
34. Iyer KR, Kunecki M, Boullata JI *et al.* (2016) Independence from parenteral nutrition and intravenous fluid support during treatment with teduglutide among patients with intestinal failure associated with short bowel syndrome. *J Parenter Enteral Nutr* **41**, 946–951.
35. Jeppesen PB, Gilroy R, Pertkiewicz M *et al.* (2011) Randomised placebo-controlled trial of teduglutide in reducing parenteral nutrition and/or intravenous fluid requirements in patients with short bowel syndrome. *Gut* **60**, 902–914.
36. Madsen K, Askov-Hansen C, Naimi R *et al.* (2013) Acute effects of continuous infusions of glucagon-like peptide (GLP)-1, GLP-2 and the combination (GLP-1+ GLP-2) on intestinal absorption in short bowel syndrome (SBS) patients. A placebo-controlled study. *Regul Pept* **184**, 30–39.

Supporting information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Table S1. Sampling quotas for SBS patients and family members.

Table S2. Patient-reported signs or symptoms.