

A Systematic Review of Quality of Life in Patients with Short Bowel Syndrome and Their Caregivers

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Purpose: Understanding the quality of life and the factors that influence it for patients with short bowel syndrome (SBS) and their caregivers is of utmost importance in order to enhance their well-being. Therefore, This study aimed to provide a comprehensive understanding of the impact of SBS on patients and their caregivers, as well as its associated factors, by synthesizing the available evidence.

Methods: A systematic review of the literature was done using PubMed, Embase databases, CNKI, and ISPOR conference papers. Included articles were manually searched to identify any other relevant studies. Quality was assessed using appropriate Joanna Briggs Institute critical appraisal tools.

Results: This review included 16 studies, comprising 15 observational studies and 1 randomized controlled trial. The findings revealed that the QoL of patients with SBS was lower than that of the general population regarding physical functioning and psychological domain. Meanwhile, caregivers experienced challenges in maintaining their QoL. The QoL of SBS patients was found to be influenced by various factors such as treatment, age, sex, stoma, and small intestine length. Among them, the treatment is the most noteworthy factor that can be effectively improved through external interventions.

Conclusion: While numerous studies have provided insights into the compromised QoL experienced by individuals with SBS and their caregivers, there remains a scarcity of large-sample quantitative investigations examining the determinants of QoL. The existing body of literature on caregivers is also notably deficient.

Keywords: caregiver, malabsorption, quality of life, short bowel syndrome, stoma, age

Introduction

Short bowel syndrome (SBS) refers to the malabsorptive condition with a reduction in intestinal length frequently occurring after surgical resection, congenital short bowel, or loss of intestinal function caused by disease and other factors.^{1,2} In individuals with regular intestinal length (275–850 cm), water is absorbed throughout the length of the intestine, and most/major nutrients, B12, bile salts, and magnesium are absorbed in various sections of the intestine at different lengths.³ Patients with SBS have macro and micronutrient malabsorption as a result of reduced absorptive capacity and rely on exogenous nutritional supplements. On the basis of the severity of the disorder, patients can be incapacitated that will adversely affect their quality of life (QoL).¹

Although SBS is relatively a rare disease,^{4,5} the QoL of patients with SBS is an important outcome because SBS can have a detrimental impact on physical and mental health of the patient. In addition to malnutrition, SBS can cause a variety of symptoms, such as diarrhea, bloating, steatorrhea, dehydration, vitamin deficiencies, weight loss, electrolyte imbalance, and intestinal cramping, which can affect the appetite, sleep, and physical strength of the patient, leading to psychosocial challenges to the patient.³ Patients with SBS require intravenous nutritional supplements for an extended period and often experience long-term clinical complications due to the altered intestinal anatomy and physiology. These complications necessitate frequent medical examinations and treatments, inadvertently affecting the patients' daily lives and self-management abilities.^{3,6,7} These patients face the burden of dependency, anxiety, lifestyle alterations, and impaired QoL.⁸

Caregivers of patients with SBS are also under much stress.^{9,10} Caregivers need to take on the tedious responsibility of caring for the patient, such as preparing specialized meal and feeding regularly, administering medication/therapy, and fostering support for the mental and emotional health of the patient. Managing SBS can have significant mental health implications in addition to the potential reduction in QoL for caregivers.¹¹

It is therefore important to assess the QoL of patients with SBS and their caregivers. QoL is a broad concept that encompasses the subjective perceptions, functionality, and experiences of the health and well-being of the patients.¹² Assessing the QoL can help physicians and caregivers understand the physical and mental health of the patient and whether they experience treatment satisfaction.¹³ Improvement in QoL is a common goal for both patients and caregivers, as it promotes the recovery of the patient and improves the QoL of caregivers.^{9,14,15}

Previous studies have explored the QoL of patients with SBS and their caregivers. These studies demonstrate that the QoL of patients with SBS and their caregivers is affected to varying degrees and requires targeted intervention and support.^{9,11,14-16} However, the lack of comparability between studies due to differences in patient populations and measurement tools impedes our comprehensive understanding of common issues. To date, no studies have systematically compiled QoL data for this population nor provided insights into the determinants affecting it. Thus, this systematic literature review aims to synthesize evidence comprehensively on the QoL of patients with SBS and their caregivers, as well as the factors associated with the reduced QoL.

Material and Methods

This systematic review was conducted in accordance with the guidelines from the Preferred Reporting Items for Systematic Reviews and Meta-analyses guidelines and was registered with the International Prospective Register of Systematic Reviews (CRD42023450970).

Search Strategy

We developed search strategies using medical subject headings and text words relevant to patients with SBS, their caregivers, and their health-related quality of life (HRQoL), or QoL from inception till December 5, 2022 across a variety of platforms including PubMed, Embase databases, CNKI, and ISPOR conferences. Detailed search strategies for PubMed, Embase databases, CNKI, and ISPOR are available in [Table S1-S4](#).

Eligibility Criteria

Following the PICOS principle, we included studies that meet the following criteria: (1) Patients with SBS and family carers of these patients. If there were other diseases in the study, the proportion of SBS patients should be more than 95%. (2) all interventions and comparators used for treating SBS, (3) QoL, HRQoL, or utility should be reported without limitation of measurement tools although the use of proven QoL tools was preferred, (4) randomized controlled trials (RCTs), controlled (non-randomized) clinical trials, or cluster trials, as well as prospective and retrospective cohort studies, cross-sectional studies, and case-control studies (with at least ≥ 5 cases), (5) the included articles must be original research published in peer-reviewed journals or internationally recognized conference proceedings, (6) publications published only in English and Chinese languages.

We excluded studies that did not stratify patients with SBS in the presence of other confounding factors. We also excluded qualitative papers that did not provide a specific QoL score. In addition, studies that did not fully reflect the QoL, such as stress index, cognitive function, intelligence, and financial stress, were not included.

Study Selection and Data Extraction

The results of the literature search were imported into Zotero and duplicates were eliminated. Two reviewers independently screened the titles and abstracts of the search results. If eligibility was uncertain, the full text of publication was scrutinized to determine the eligibility. For the studies that were included, the following details were extracted: authors, year of publication, country, language, and study design type. In addition, comprehensive information about the study population, measurement tools, specific scores, control group, treatments, and primary outcomes, was obtained. Details of parenteral treatment, stoma, remnant small bowel and response rate were also noted. One evaluator extracted the data, while another evaluator checked it. Any discrepancies were resolved through discussion.

Synthesis

To derive meaningful outcomes, we intended to combine the results of the studies in a meta-analysis using suitable fixed effects or random effects model. However, due to the differences in the scales used by the studies and the heterogeneous reporting of the results, statistical pooling of the data was not feasible. We conducted a narrative synthesis to elucidate the findings.

The results section was divided into thematic headings of independent factors that affect, or do not affect, the QoL of carers or patients. Themes were identified using an inductive approach, driven by the reported outcomes in the results sections of the included articles. Initially, themes from relevant qualitative studies were extracted.

Two authors (Y.C. and B.W.) reviewed the data independently from the included articles and identified factors that were related or unrelated to carers or patients' QoL. We used literature with quantitative methods at a threshold of $P < 0.05$.

The Quality of Evidence of Individual Studies

The quality of evidence from the studies was assessed using the Joanne Briggs critical appraisal tools.¹⁷ Two authors independently assessed the studies and disagreements were resolved by discussion.

Results

Study Selection and Quality Assessment

A total of 640 articles were identified through the literature search. After removing duplicates, 555 articles remained. Of these, 506 articles were excluded based on the ineligibility of their abstracts, leaving 49 articles for full-text review (Figure 1). Among 6 articles that included caregivers, 1 was a qualitative study,¹⁸ while 2 reported only the caregiver strain index (CSI), which is not a QoL measure and was therefore excluded from this review. Finally, 16 studies that meet inclusion criteria were included in this systematic review.^{9,10,13,18–30} Among these, 13 reported only QoL for patients with SBS,^{9,10,19–22,24–30} 2 reported only QoL data for caregivers,^{18,23} and 1 study reported QoL data for both patients and their caregivers.¹³

The quality of the studies was assessed using the appropriate Joanna Briggs Institute critical appraisal tool for the particular study design (see supplementary material [Table S5–S8](#)). Three of the studies were judged high quality,^{24,28,30} two cohort studies,^{28,30} and one randomized controlled trial.²⁴ Ten cross-sectional studies were judged medium quality.^{9,10,13,18–21,25–27} Three cross-sectional study were judged low quality.^{22,23,29}

Pico

Population Characteristics

We studied the quality of life of 801 SBS patients and another 899 simulated patients. The researchers popularized the situation of SBS patients and the use of PS (Parenteral Support) to them and then used the Time Trade-Off (TTO) and some methods to obtain the health utility from 899 simulated patients. Among 801 SBS patients, all the studies reported the age of the patients. There were 303 males and 353 females. Sex was not reported in 2 studies for 145 patients.^{10,24} In 3 studies that focused on caregivers,^{13,18,23} only 1 study reported carers' number and sex,¹⁸ but the other 2 studies did not.^{13,23} 2 studies reported the relationship between patients and carers.^{18,23} No studies have reported the age of caregivers. The detailed characteristics of patients with SBS and their caregivers are presented in [Table S9–S10](#).

Intervention

Eight studies provided comprehensive details regarding PS and Home Parenteral Nutrition (HPN, a home based method of supplying nutrients directly into the bloodstream, bypassing the digestive system, for individuals who cannot intake or absorb nutrition through the gastrointestinal tract.) for SBS patients who were actively undergoing PS treatment during the research period.^{9,10,13,21,25,26,28,30} Two studies addressed the utilization of Teduglutide (Ted).^{24,25} One study explored the impact on caregiver QoL after children underwent autologous gastrointestinal reconstruction surgery (AGIR).²³

Comparators

Six studies were single-arm with no comparator groups.^{10,13,24,25,29,30} Two studies compared the patients receiving Ted against those receiving placebo,^{9,25} one study compared the patients with SBS with patients with dysmotility, both dysmotility and SBS are the underlying diseases that lead to intestinal failure (IF),¹⁰ and three studies compared the patients with SBS with

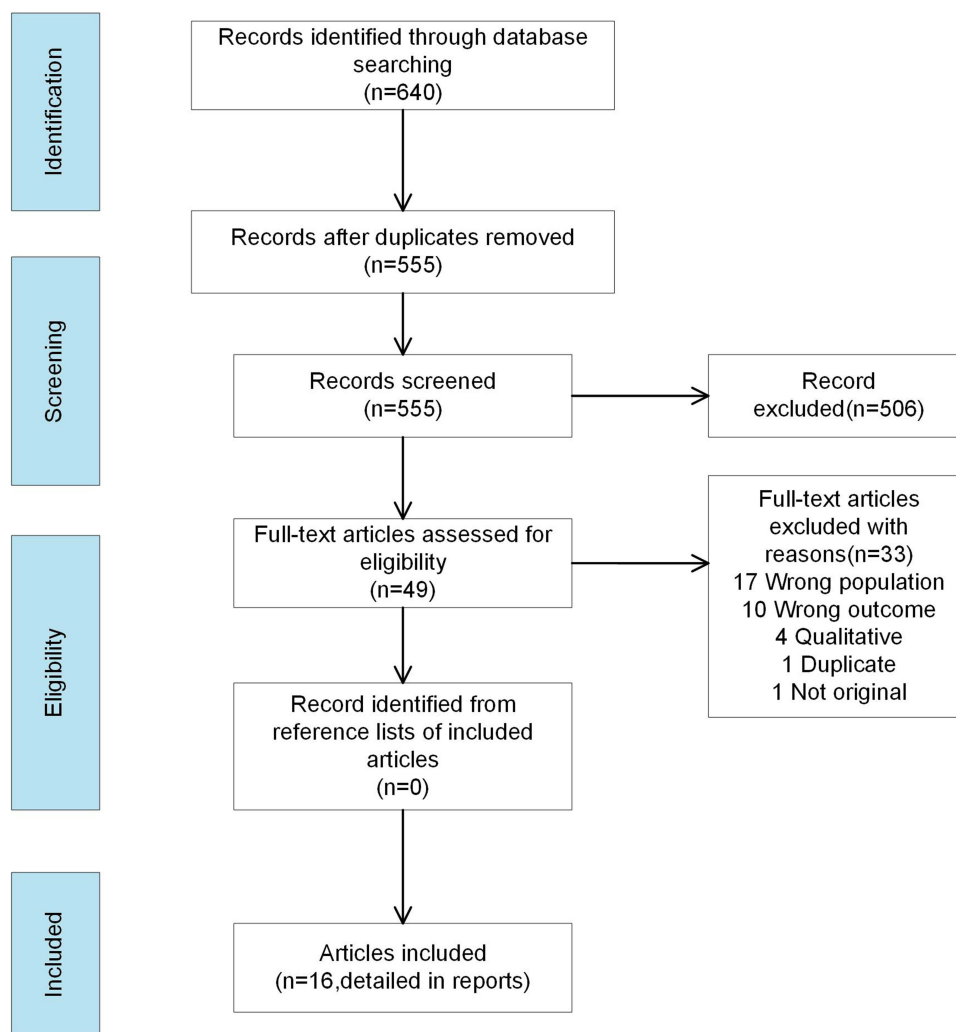


Figure 1 Flow diagram.

normal healthy population.^{13,29,30} Two studies^{21,26} compared the SBS population with two different populations such as one study involving patients with inflammatory bowel disease (IBD) and the normal healthy population.²⁶ Another one compared the patients with SBS with the normal healthy population and made subgroup comparisons.²¹

In the articles presenting data pertaining to caregivers, one study employed self-comparison methodology,²³ while two other studies employed alternative comparative approaches.^{13,18} Among these two investigations, one study juxtaposed caregivers of patients with SBS against the general populace.¹⁸ Another study adopted a dual-comparator strategy, wherein one group encompassed families with children receiving pediatric care at the long-term care facility known as Children's Convalescent Hospital (CCH), whereas the second group comprised caregivers of pediatric patients enrolled in the REACH program tailored for children residing at home with their families.¹³

Outcome

The Instruments for Quality of Life Measurement

The majority of the studies employed validated instruments to assess Quality of Life.^{9,10,13,18,19,21–26,28–30} Two studies,^{20,27} however, employed a TTO survey to gauge health utility. Among the twelve studies evaluating QoL in patients with SBS through various scales,^{9,10,13,19,21,22,24–26,28–30} three studies utilized the Short Form (SF) 36 scale.^{19,21,26} However, meta-analysis was infeasible as only means were provided in two of these studies without accompanying measures of variance.^{21,26} Additionally, two studies employed the Short Bowel Syndrome-Quality of

Life scale (SBS-QoL),^{24,28} while two others employed the Pediatric Quality of Life Inventory (PedsQL).^{13,29} Moreover, two studies implemented the Home Parenteral Nutrition--quality of life (HPN-QoL) scale,^{9,10} and one study employed the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30 (EORTC QLQ-C30).²² Furthermore, two studies adopted multiple scales,^{25,30} with one stratifying QoL by age, using the PedsQL scale for children and the SF-36 scale for adults,³⁰ while the other study employed both the SBS-QoL and SF-12 scale.²⁵ The distribution of scale usage among SBS patients is depicted in Figure 2.

In the assessment of QoL, a greater proportion of studies utilized generic scales such as SF-36,^{19,21,26,30} SF-12,²⁵ EQ-5D-5L,¹⁸ and PedsQL.^{13,29,30} Disease-specific scales, including QLQ-C30,²² SBS-QoL,^{24,25,28} and treatment-specific scales such as HPN-QoL^{9,10} were also employed. Refer to Table 1 for a comprehensive overview of the utilized scales.

Regarding carers' QoL,^{13,18,23} one study concurrently assessed the QoL of individuals with SBS children and their caregivers using the PedsQL scale.¹³ Additionally, one study adapted a questionnaire from O'Neill³¹ to evaluate caregivers' QoL,²³ while another study employed the EQ-5D-5L scale for the same purpose.¹⁸

Quality of Life

The results of QoL for patients and their caregivers have been summarized in Table 2. Four studies using SF-36 concluded that adult patients with SBS have a poor QoL.^{19,21,26,30} One study calculated only the total score and got less optimistic results in SBS patients¹⁹ and one study showed SBS patients' physical and mental component summaries both

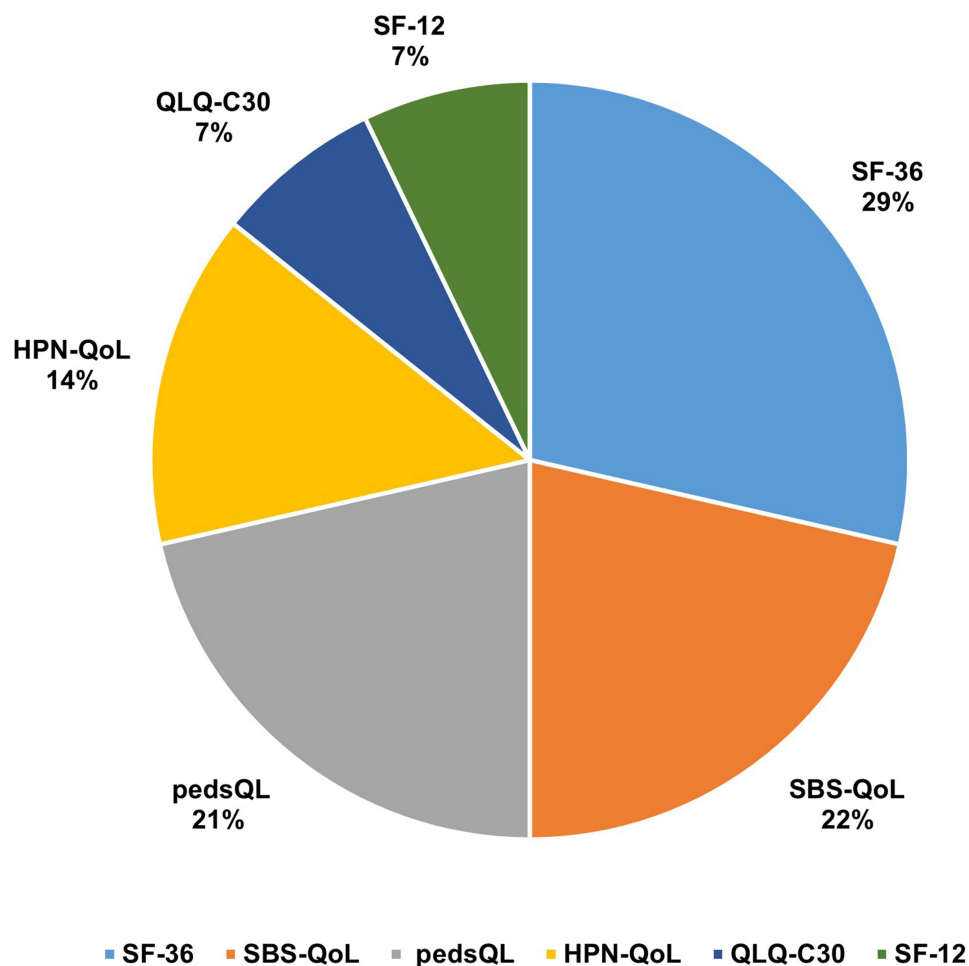


Figure 2 Frequency of scale used in measuring quality of life of SBS patients and their caregivers.

Abbreviations: SF-36, short form 36; SF-12, short form 12; SBS-QoL, Short bowel syndrome-Quality of Life scale; PedsQL, Pediatric Quality of Life Inventory; QLQ-C30, The Core Quality of Life questionnaire; HPN-QoL, home parenteral nutrition-quality of life.

Table 1 Instruments Used in SBS Patients

| QoL instrument | Description | Score |
|-------------------------------|--|--------------------------|
| Generic scale | | |
| SF-36 ³² | 36 items 8 subscales 2 components score(PCS/MCS) | 0–100 (poor to high QoL) |
| SF-12 ³³ | 12 items 2 components score(PCS/MCS) A simplified version of the SF-36 scale | 0–100 (poor to high QoL) |
| PedsQL ³⁴ | 23 items 4 subscales Suitable for children and teenagers aged 2 to 18 | 0–100 (poor to high QoL) |
| Disease-specific scale | | |
| SBS-QoL ³⁵ | 17 items 2 subscales Used to evaluate treatment-induced changes in teduglutide research studies | 0–170 (high to poor QoL) |
| QLQ-C30 ³⁶ | 30 items 5 multi-item function scales 9 symptom scales | 0–100 (poor to high QoL) |
| Treatment scale | | |
| HPN-QoL ³⁷ | 48 questions 8 functional scales 9 symptom scales 2 nutrition support team items 3 global quality of life scales | 0–100 (poor to high QoL) |

Abbreviations: QoL, quality of life; SF-36, short form 36; SF-12, short form 12; SBS-QoL, short bowel syndrome-Quality of Life scale; PedsQL, Pediatric Quality of Life Inventor; QLQ-C30, Core Quality of Life questionnaire; HPN-QoL, home parenteral nutrition quality of life.

lower than the general population ($P < 0.05$),²¹ one study showed SBS patients had lower physical but not mental component summary ($P > 0.05$) when compared with IBD patients,²⁶ and one study showed significantly impaired in physical component scores in SBS patients, while the decline of mental component scores is still within the acceptable range when compared with general population.³⁰ One study used SF-12 to compare SBS patients in Ted with the placebo group, concluding that little improvements were found in Ted and non-Ted patients.²⁵

QoL in children was measured by PedsQL in three studies,^{13,29,30} all the studies scored slightly or significantly lower than healthy controls, and 2/3 of the studies emphasized the disruption of school function.^{13,29,30} The degree of significance varied depending on the control group used in the study; although all three studies used healthy people as controls, their control group scores varied widely (75.6, 82.1, and 82.87). One of the studies found that the QoL of the SBS infant history group scored significantly lower than the control group; in the children's self-reports, the physical and psychosocial differences were not evident with the control group, but in the parent-proxy report, the differences were significant.²⁹

The most frequently used disease-specific scales in SBS patients is SBS-QoL; three of four studies used this scale.^{24,25,28} Two studies used SBS-QoL to compare SBS patients in Ted with the placebo group; both showed patients' QoL had a significant improvement after 24 weeks of medication.^{24,25} It was hard to see the statistically difference between Ted and placebo in 24 weeks, but improvements were found in many scale items.²⁴ One study measured the QoL of SBS patients with different small bowel lengths and found that QoL was the worst in patients with a small bowel length of < 50 cm, the QoL of patients with a small bowel interval of 100–149cm and 150–200 cm did not show a significant QoL improvement with increasing small bowel length.²⁸ Another 1 study using EORTC-QLQ-C30 reported that patients with SBS had moderate QoL but emotional function and symptoms were affected most.²²

HPN is one of the most common treatments for SBS. In our research, two studies used HPN-QoL to measure SBS-IF patients' QoL, and the result was moderate; their subscales have similar results, but the results of emotional function vary widely.^{9,10} They all emphasized that the sexual function, employment, and vacation ability of SBS patients were not optimistic.^{9,10} One study suggested that the negative or positive perception toward PS treatments could influence a patient's QoL.⁹ They compared the satisfaction of patients with SBS and intestinal failure(SBS-IF) with PS treatment and found that those who were satisfied with PS treatment had significantly higher QoL than those who were dissatisfied with PS treatment (17.1 vs 1.69).⁹

Two articles described the effect of PS days on patient HRQoL by using the TTO method, and both showed a downward trend in patient QoL as PS days increase.^{20,27}

Among three studies that measured QoL in carers, all SBS patients were children, and their caregivers were their families.^{13,18,23} One study found that carers' QoL was significantly lower when compared with the general population.¹³ Another study showed their QoL was lower than CCH families but not REACH families.¹⁸ A third study found that QoL improved for parents when measured after 6 months and long-term post-surgery of receiving AGIR.²³

Table 2 Study Characteristics and Quality of Life Scores in Included Studies

| Author, year, country | Number | Age | Trial design | Comparator | QoL assessment tool | QoL scores | Outcome | Quality assessment |
|---|--------|-------|------------------|--|----------------------|--|---|--------------------|
| Ballinger, 2018 Britain²⁰ | 100 | Adult | Cross sectional | General population | TTO | Mean(SD) 0 days on PS: 0.82 (0.22) 1 day on PS: 0.78 (0.23) 2 days on PS: 0.72 (0.23) 3 days on PS: 0.65 (0.27) 4 days on PS: 0.58 (0.31) 5 days on PS: 0.51 (0.33) 6 days on PS: 0.41 (0.34) 7 days on PS: 0.36 (0.35) | The simple linear regression model revealed a significant decrease of 0.07 in utility scores for each additional day of PS ($P < 0.001$). The dummy variable model demonstrated a significant reduction in utility scores for a 2-day duration as opposed to zero days, ranging from -0.10 (2 days) to -0.46 (7 days) ($P < 0.013$). Nevertheless, no statistically significant difference in utility scores was observed between individuals receiving 0 and 1 day of PS ($P = 0.286$). | Medium |
| Beurskens-Meijerink, 2020 Holland¹⁰ | 75 | Adult | Cross sectional | SBS vs Dysmotility | HPN-QoL | Mean(SD) SBS 6 (22.1) vs dysmotility 5.8 (21.3) | The overall QoL was assessed as moderate. There were no significant differences in QoL between patients with SBS and those with Dysmotility. | Medium |
| Carlsson, 2003 Switzerland²¹ | 28 | Adult | Cross sectional | SBS vs general population General population vs HPN vs non-HPN vs stoma | SF-36 | Mean general population 632.8 and SBS 442.2 and SBS-HPN 397.6 and SBS-Stoma 428.5 | In comparison to matched controls, all SBS patients exhibited significantly reduced scores in seven of the eight health dimensions ($P < 0.01$), with the physical dimensions showing lower scores, though not reaching statistical significance ($P > 0.01$). HPN but not stoma affected QoL. | Medium |
| Carvalho, 2012 Brazil²² | 6 | Adult | Cross sectional | NR | EORTC-QLQ -C30 (3.0) | Mean(SD) 70.7 (25.1) | Overall QoL was moderate. Female patients reported a lower QoL compared to males. | Low |
| Jeppesen, 2013 Denmark²⁴ | 70 | Adult | Double blind RCT | Ted vs Placebo | SBS-QoL | Median Baseline and 24 weeks Ted 79.7 and 69 Placebo 73.7 and 78.3 | A decrease in Parenteral Support volume was associated with an improvement in QoL. There was a statistically significant difference within the Ted group between baseline and the 24-week mark ($P < 0.05$). But changes were not significant compared to placebo group at the 24-week point ($P > 0.05$). GI-AE impacted on QoL negatively. | High |
| Jeppesen, 2022 Denmark⁹ | 181 | Adult | Cross sectional | NR | HPN-QoL | Mean(SD) 11.57 (21.77) | Satisfaction with treatment had an impact on QoL. | Medium |

(Continued)

Table 2 (Continued).

| Author, year, country | Number | Age | Trial design | Comparator | QoL assessment tool | QoL scores | Outcome | Quality assessment |
|--|--------|----------|-----------------|---|---------------------|--|---|--------------------|
| Joly, 2021 France²⁵ | 143 | Adult | Cross sectional | Ted vs Placebo | SBS-QoL, SF-12 | Mean(SD) SBS-QoL Ted vs Placebo 48.6(37.3) vs 68.1(44.6), p=0.03 SF-12 Baseline vs 6 months, TED and non-TED 45.2±7.9 vs 42.0±8.9, p=0.06 and 47.3±8.6 vs 44.2±9.8, p=0.17 | Improvements in QoL were observed within the Ted group (P=0.03) using SBS-QoL instruments. The PCS and MCS scores of the SF-12 were not significant (P>0.05). All items improved in both scales. | Medium |
| Kalaitzakis, 2008 Norway²⁶ | 26 | Adult | Cross sectional | SBS vs inflammatory bowel disease(IBD)SBS vs general population | SF-36 | Median SBS PCS 37 and MCS 44 IBD PCS 44 and MCS 51 General population PCS 50 and MCS 54 | The QoL lower than Norway population. The MCS scores for SBS were comparable(P>0.05) but the PCS scores were lower than those of IBD patients (P<0.05) HPN and BMI had an impact on PCS and MCS respectively(P<0.05), but, age, sex, length of remaining small bowel, presence of a stoma, comorbidity, and daily use of analgesics or opiates had no impact on QoL (P>0.05). | Medium |
| Lachaine, 2016 Canada²⁷ | 799 | Adult | Cross sectional | NR | TTO | PS0= 0.74 PS1= 0.70 PS2= 0.65 PS3= 0.61 PS4= 0.57 PS5= 0.52 PS6= 0.48 PS7Low = 0.44 PS7High= 0.39 ^a | The increase in demand for PS was correlated with lower QoL. | Medium |
| Nordsten, 2021 Denmark²⁸ | 60 | Adult | Cross sectional | NR | SBS-QoL | Median(25th percentile and 75th percentile) 0–49 cm 101.2 (84.6, 130.4) 50–99 cm 83.8 (28.3, 100.4) 100–149 cm 38.8 (17.3, 130.2) 150–200 cm 50.3 (27.3, 102.9) ^b | QoL higher in males than in females. HPS, high jejunostomy, and a residual small intestine length of <50cm associated with lower QoL. | High |
| Dai, 2016 China¹⁹ | 137 | Adult | Cross sectional | NR | SF-36 | Mean(SD) 495.15 (85.17) | Treatment, appetite, exercise, monthly income, and sleep duration positively correlated with QoL, whereas intestinal anastomosis pattern, alcohol consumption, age, and place of residence showed negative correlations with QoL. | Medium |
| Olieman, 2012 Holland²⁹ | 31 | Children | Cross sectional | Age-matched control group | PedsQL 4.0 | Mean(SD) child self-report vs controls 75.6 (14.9) vs 82.1 (12.5) Parent-proxy report 74.9 (15.9) vs controls 86.0 (10.9) | QoL was lower in SBS infant history group compared to the control group. physical and psychosocial disparities were significant differences compared with the control group in parent-proxy reports but not prominent in children's self-reports. | Low |

| | | | | | | | | |
|--|--------------------------|---------------------------------------|-----------------|--|----------------------|---|---|--------|
| Silva, 2021 Portugal ³⁰ | 31 | Children (20) Adult (11) | Cross sectional | General population | PedsQL, SF-36 | Mean(SD) Children PedsQL 73.3 Adults SF-36 489.8 PCS 45.8 (11.1) and MCS 47.7(8.9) | Children's QoL slightly lower than Portuguese population. Adults' QoL was notably lower than Portuguese population. PCS but not MCS exhibited clinical significant decrement in adults. | High |
| Ballinger, 2019 Britain ¹⁸ | 36 patients 45 carers | Children (Patients) Adult (Carers) | Cross sectional | General population | EQ-5D-5L | Mean(SD) Carers 0.79 vs control 0.87 | QoL of carers was lower than UK population. | Medium |
| Pederiva, 2019 Germany ¹³ | 30 patientsNR carers | Children (Patients) Adult (Carers) | Cross sectional | SBS vs CCH vs REACH<5 years old vs>5 years old vs general population | PedsQL 4.0 | Mean(SD)>5 years old patients and controls 70.09 (16.65) and 82.87 (13.16) Carers for patients >5 years old and <5 years old 67.12(23.59) and 57.06(22.32) | QoL of SBS children was suboptimal. Caring for younger children with SBS was linked to lower QoL among caregivers. Families with SBS children reported a significantly lower QoL compared to CCH but not REACH. | Medium |
| Edge, 2012 Britain ²³ | 19 patientsNR carers | Children (Patients) Adult (Carers) | Cross sectional | Self-comparison | Adapted from O'Neill | Mean(SD) Carers: 6 months before surgery 1.0(1.000) 6 months after surgery 2.7(1.047) in the last 6 months 3.88(0.332) | Following the autologous gastrointestinal reconstruction procedure in their children, there was a significant improvement in the QoL of parents. | Low |

Notes: ^aAccording to the number of days/hours of PS per week, it is divided into PS0 to PS7, and low and high are defined according to PS liters. ^bQoL scores were based on short-bowel length.

Abbreviations: NR, not recorded; QoL, quality of life; SBS-QoL, Short bowel syndrome-Quality of Life scale; SD, standard deviation; PedsQL, Pediatric Quality of Life Inventor; PCS, physical component score; MCS, mental component score; RCT, randomized controlled trial; SF-12, short form 12; SF-36, short form 36; EORTC-QLQ-C30, The EORTC Core Quality of Life questionnaire; TTO, time trade-off; EQ-5D-5L, five-level EuroQol five-dimensional questionnaire; HPN-QoL, home parenteral nutrition-quality of life; Ted, teduglutide; PS, home parenteral support; GI-AE, Gastrointestinal adverse events; IBD, inflammatory bowel disease; CCH family, the families whose children are at the pediatric residents of the long-term care facility Children's Convalescent Hospital(CCH); REACH family, the carers of pediatric patients enrolled in the REACH program designed for children who resided at home with their families.

Factors

Treatments

A particular study highlighted that treatments exhibit a significant correlation with QoL.¹⁹ This investigation conducted a comparative analysis of four distinct treatment modalities, namely no treatment, surgical intervention, bowel rehabilitation, and nutritional therapy. The findings revealed that individuals who did not undergo any form of treatment or surgery exhibited lower QoL levels and instead leaned towards a preference for nutritional therapy. Additionally, patients who had undergone surgery also demonstrated a comparatively improved QoL.¹⁹ This observation underscores the pivotal role of different treatment approaches in shaping the QoL outcomes of the individuals studied.¹⁹

Four studies examined the impact of HPN/PN (Parenteral Nutrition, a method of supplying nutrients directly into the bloodstream, bypassing the digestive system, for individuals who cannot intake or absorb nutrition through the gastrointestinal tract.) on QoL and consistently reported a negative influence.^{20,21,27,28} Among these, two studies, conducted by Carlsson et al and Nordsten et al, provided comprehensive insights into PS and HPN for SBS patients actively receiving PS treatment during the research period.^{21,28} In one of these two studies, patients had an average HPN treatment duration of almost 6 years (ranging from 4 to 17 years) and a median treatment frequency of 7 days per week.²¹ This study reported a significant adverse impact of HPN on patients' QoL, surpassing the influence of a stoma. The other study recorded a median HPN treatment duration of nearly 4 years, with a frequency of 14 times every 14 days and a volume of 2588 mL/day.²⁸ This study demonstrated that increased PS volume was associated with a decline in QoL among SBS patients ($P < 0.05$). Multiple linear regression analysis revealed that a 1-liter increase in daily volume corresponded to a notable deterioration of 7.91 in the SBS-QoL sum score.²⁸ Furthermore, two articles examined the effect of PS days on patients' HRQoL through the TTO method. Both studies illustrated a declining trend in patient QoL as the duration of PS days increased.^{20,27}

Notably, Ted, a GLP-2 analog, emerged as a particularly noteworthy intervention, exhibiting efficacy in diminishing the reliance on PS, as evidenced in two investigations.^{24,25} After 24 weeks of treatment with Ted, SBS patients achieved an average weekly PS volume reduction of 32% compared to baseline while maintaining constant oral fluid intake throughout their study, and 54% of patients achieved at least 1 day off PS, which may result in a significant improvement in QoL compared with baseline.²⁴ However, the improvement in SBS-QoL at 24 weeks did not reach a statistically significant difference between the Ted and placebo groups.²⁴ Another one study showed that after 6 months of Ted treatments, PCS and MCS scores in SF-12 scale were not different ($P > 0.05$), while the SBS-QoL score was significantly higher in Ted ($P < 0.05$), all the items improved in both scales.²⁵

As for three studies focused on caregivers,^{13,18,23} one study reported that following the autologous gastrointestinal reconstruction procedure in their children, there was a significant improvement in the QoL of parents ($P < 0.05$).²³

Age

Five studies delved into the age demographics of the patients.^{13,19,22,28,29} Among these, one study reported results but did not show data, and reached the consensus that age had a marginal impact on QoL.²⁶ Conversely, two studies asserted that increasing age detrimentally affected QoL in SBS patients.^{19,28} One study stratifying patients into three age groups (15–34, 35–59, ≥ 60 years) discovered a decrement in QoL with advancing age ($P < 0.05$).¹⁹ Similarly, another study involving patients with a median age of 56.3 years demonstrated a negative correlation between age and the total QoL score but did not reach statistical significance ($P > 0.05$).²⁸ One study concerning QoL in children showed that QoL was independent of age, but the QoL of SBS children aged 11 years and older was significantly lower than that of the general population in the corresponding age group ($P < 0.05$).²⁹

Regarding caregivers, a lower QoL was observed among parents of patients below 5 years of age in one study, but no statistically significant differences were found between families with children below and above 5 years of age ($P > 0.05$).¹³

Sex

Four studies reported the effect of QoL on patients' sex.^{19,22,26,28} Two studies claimed that different sexes does little to QoL ($P < 0.05$).^{19,26} Two studies demonstrated that female patients exhibited a lower QoL compared to their male counterparts.^{22,28} In one of these two studies, females obtained the lowest scores in the functional domain and the

highest scores in the symptoms domain.²² However only one of the studies showed a statistically difference,²⁸ and the other one did not do further statistical analysis.²²

Only one paper showed that the percentage of female caregivers was higher than that of male caregivers (69%), but no further analysis was performed.¹⁸

Stoma

Two studies delved into the impact of stoma on patients' QoL.^{19,21} One study comparing three small bowel anastomosis methods—small bowel anastomosis, small bowel colon anastomosis, and high jejunostomy—revealed that patients with high jejunostomy experienced the most compromised QoL due to severe impairment of intestinal absorption.¹⁹ In contrast, patients with small bowel anastomosis exhibited better QoL.¹⁹ The other study suggested that the presence of a patient's stoma might not significantly impact their QoL($P>0.05$).²¹ However, it was observed that SBS patients with stoma had slightly lower QoL scores compared to those without.²¹

Length of Small Bowel

A linear regression analysis adjusted for confounders showed that having a small bowel of less than 50 cm was associated with a significantly poorer QoL($P<0.05$).²⁸ However, another study showed the length of the small bowel did not have any effect on QoL($P>0.05$).²⁶

Other factors like comorbidity and the daily use of analgesics or opiates were found to not affect QoL.²⁶

Discussion

The aim of the present review was to investigate and provide a comprehensive understanding of QoL in patients with SBS and their caregivers. This review of literature spanning across twenty years collected substantial data and showed that the QoL of patients with SBS was lower than that of the general population regarding physical functioning and psychological domain. QoL in SBS patients may be influenced by treatment, age, sex, stoma and small intestine length, however, the influence of these factors has not been fully supported. The treatment received by their children also had an impact on the caregivers' QoL.

The majority of the studies under consideration employed validated questionnaires to assess QoL. According to our findings, a greater prevalence of studies opted for generic, disease-specific, and treatment-specific scales. Nonetheless, it's important to acknowledge that there is no universally applicable scale. Researchers must consider distinct research objectives and the inherent nature of scales when selecting one or more appropriate measurement tools. While general-purpose scales are undoubtedly valuable, they might lack the sensitivity required to effectively capture the nuanced impacts of specific diseases or treatments, particularly in detecting factors that can influence QoL. To address this, the integration of different types of scales can enhance coverage, sensitivity, and specificity. This approach is particularly advantageous for minimizing bias.^{25,38} However, it's important to recognize the limitations inherent to certain scales. Variables such as age, sex, residual length of small bowel, presence of a stoma, comorbidities, and the daily usage of analgesics or opiates might not be adequately differentiated between groups on some scales.^{26,39} Consequently, this variability can lead to divergent study conclusions, even if some results exhibit statistical significance.⁴⁰ Therefore, it's essential for researchers to interpret findings within the context of the chosen measurement tools and the inherent limitations of these tools.

As of now, a comprehensive systematic review encompassing the various factors that may influence the QoL of SBS patients is lacking. However, several studies have honed in on the QoL of patients receiving PN, shedding light on the substantial burden it imposes on both patients and their caregivers, thereby compromising their QoL.^{41–44} Our research aligns with these findings, confirming the negative impact of PN on the QoL of patients but not on caregivers because there is so little literature on caregivers. Interventions aimed at reducing PN have shown promise in enhancing patient QoL in previous studies.^{45–48} For example, drugs such as Ted has been demonstrated to enhance structural and functional integrity of the remaining intestine in SBS, could improve patients' QoL by reducing patients' use or dependence on HPN/PN, thereby relieving patients' chronic state of limitation.^{48,49} Yet, the precise relationship between reduced PN and improved QoL in SBS patients remains enigmatic.⁴⁸ This ambiguity could potentially stem from the cross-sectional

nature and limited time frame of studies measuring QoL.^{24,25} It is not a new finding that QoL decreases with age.⁵⁰ However, it is imperative to also consider the mental health aspects of adolescent SBS patients. The psychological development associated with age may lead to a QoL that is inferior to that of their age-matched peers in the general population, suggesting that factors beyond mere physiological changes warrant consideration.⁵¹ Sex may not serve as a definitive influencing factor, contrary to the concerns raised by Carlsson et al. It is crucial to account for intergroup disparities, such as co-morbidity, among other significant variables.²¹ It is unsurprising that factors such as the presence of a stoma and a shortened residual length of the small intestine contribute to diminished QoL. A stoma can lead to discomfort in the abdominal and stoma areas, skin complications, challenges in managing stoma noises, and issues with leakage and odors,⁵² leading patients to face many challenges in terms of quality of life, including psychological issues, social and family relationships, financial challenges, and more.⁵³ Furthermore, a high colostomy or a reduced remaining length of the small intestine results in a significant impairment of intestinal absorption.

Our study does have several limitations. Firstly, the inclusion of a limited number of studies is a notable constraint, mainly due to the scarcity of large-sample quantitative research focusing on the QoL among individuals with SBS and their caregivers. Given the rare nature of the condition, the heterogeneity in sample sizes across studies also poses a challenge. Moreover, the diversity in measures used across the studies further restricts the feasibility of conducting a comprehensive meta-analysis. The rarity and complexity of SBS contribute to the challenges in assembling a sizable and consistent body of evidence. This scarcity underscores the need for further investigations to unravel the intricate dynamics affecting the QoL of individuals with SBS and their caregivers. As the field evolves, an increased emphasis on standardized measurements and larger study cohorts will be pivotal in facilitating more robust and generalizable conclusions.

Conclusion

In summary, the findings revealed that SBS patients and their caregivers generally had lower QoL and more evidence is needed to support the factors influencing the QoL of patients and carers. The type of treatment is probably the most common factor affecting QoL in both patients and their caregivers. Future studies should continue to confirm this idea and explore more beneficial treatments. The study also highlighted the scarcity of research on caregiver QoL and called for further investigations with standardized measurements and larger cohorts to better understand and address the complex dynamics affecting individuals with SBS and their caregivers.

Acknowledgments

The authors would like to acknowledge Anwasha Mandal, Lakshmi Settu, and Dr. Ramandeep Singh, PhD of Indegene Ltd, for their medical writing and editorial support provided under guidance of authors.

Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

Funding

This publication was funded by Takeda (China) International Trading Co.

Disclosure

Yanan Sheng is employee of Takeda (China) International Trading Co and grants from Takeda Pharmaceutical Company Limited. The authors report no other conflicts of interest in this work.

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