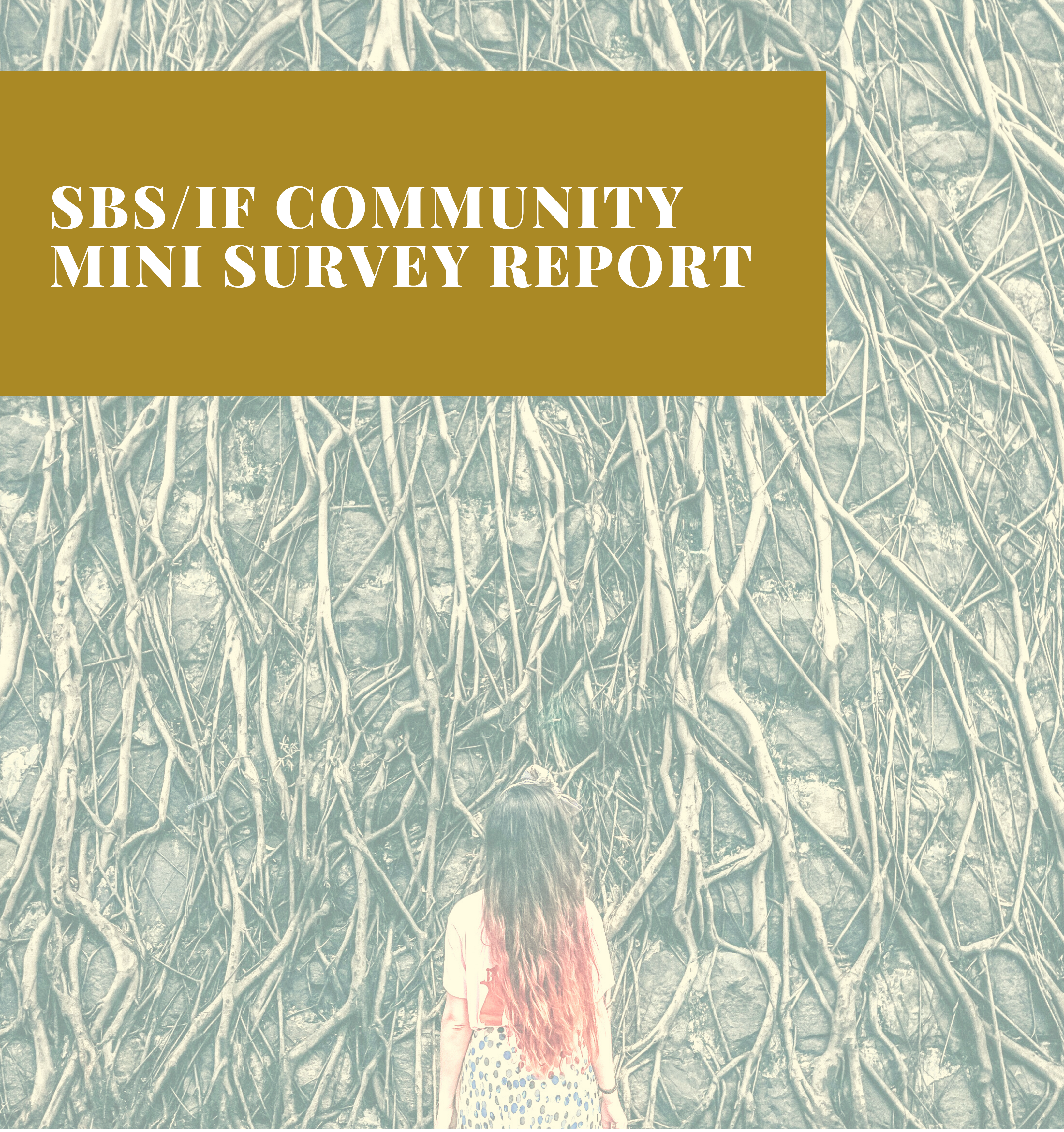


SBS/IF COMMUNITY MINI SURVEY REPORT

the gutsy perspective

COMMUNITY SURVEY: SUMMARY

In December 2021, the gutsy perspective shared a **mini survey** with the short bowel syndrome (SBS) and intestinal failure (IF) community to give community members the opportunity to share their perspectives on **quality of life** and their **priorities for the project**. The survey was open to:

- patients with SBS/IF since childhood
- parents/caregivers of children with SBS/IF

Amazingly, within just a few weeks, **128 patients and parents** completed the survey, providing us with invaluable information which will be used in the development of our SBS quality of life questionnaire. We are so grateful to everyone who took our community survey, and honored you shared your perspectives with us. **Thank you!**

The following pages highlight the survey results, including the items most frequently reported by adult patients and parents of children with SBS/IF to affect quality of life.

Across the board, **support from family members**, **positive relationships with medical providers**, and having **access to high quality medical care** were reported as having a strong positive impact on wellbeing.

On the other hand, **poor sleep**, **negative experiences related to hospitalizations or medical procedures**, and a **lack of energy** were items most commonly reported to have a strong negative impact on adult patient, child, and parent/caregiver wellbeing.

128

survey respondents in total

104 PARENTS
24 ADULT PATIENTS

Many patients and parents also provided information on what they believe should be **priorities for the gutsy perspective** in an open-ended format. Most frequently, respondents highlighted the **need for research, advocacy, and education about quality of life** for patients with SBS/IF and their families. Many respondents expressed the importance of **informing clinicians about what life is like for SBS/IF patients and families**. Another common theme was the need for **information on treatment options** and **finding experienced and knowledgeable providers**; respondents also expressed an interest in information for **improving clinician-patient/family communication**. Research, advocacy, and resources related to **mental health and the experience of trauma in the medical setting** were an additional theme that arose from the open-ended responses to this question. Ultimately, many respondents expressed their desire for the gutsy perspective to be the **voice for patients with SBS/IF and their families.**

We are committed to continuing to amplify your voices and sharing your perspectives widely with the ultimate goal of improving outcomes.

Thank you for being part of the journey!

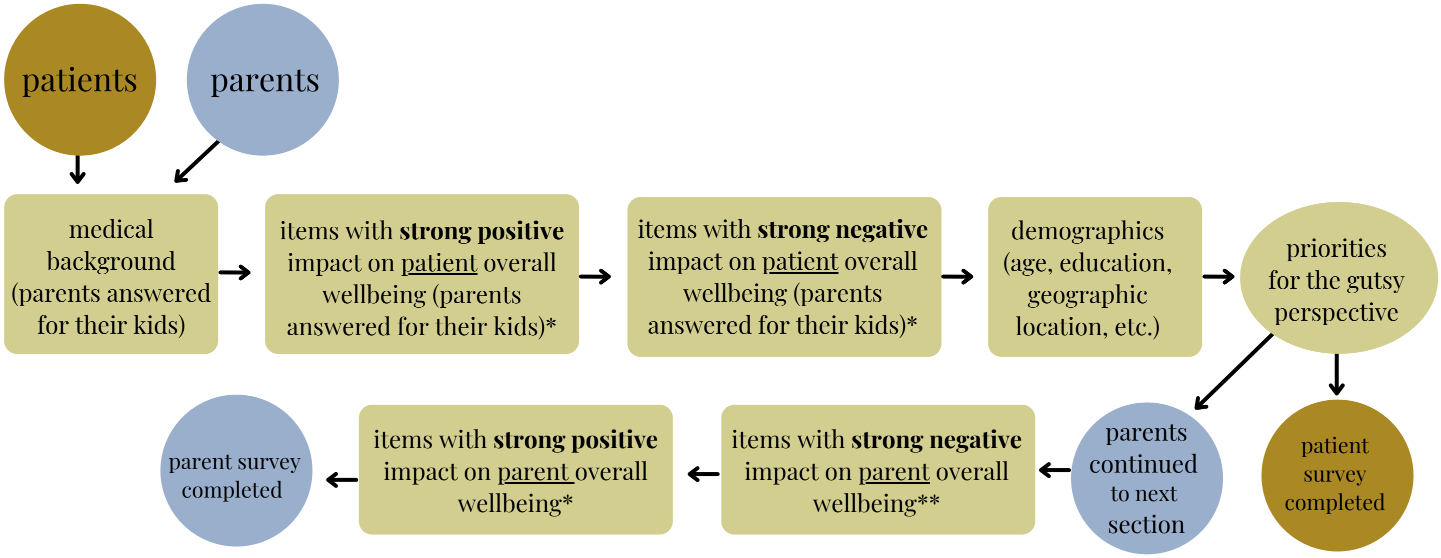
ABOUT THE SURVEY

Who was eligible to participate?

The community survey was open to:

- Patients with short bowel syndrome (SBS) or intestinal failure (IF) since childhood (before the age of 18)
- Parents of children (under the age of 18) with short bowel syndrome (SBS) or intestinal failure (IF)

Survey contents



*Respondents were asked to select items with a strong impact on overall wellbeing. Each list consisted of 20-30 items, with survey respondents able to choose as many items from each list as they liked. Respondents also had the option to describe any additional items not in the list in an open-ended follow up question.

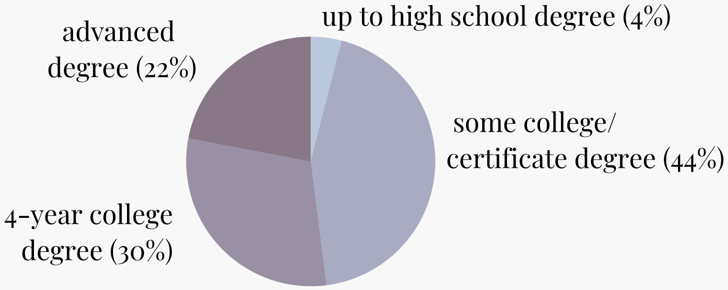
**Because of a survey error, parents were able to select no more than 10 items on this list.

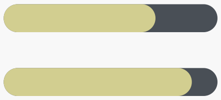
ADULT PATIENTS

with SBS or IF since childhood

Demographic background
Twenty-four (24) adult patients with SBS/IF responded to the survey. A third of respondents were **between 19 and 29 years old**, with an additional third between the **ages of 30 and 39.**

Medical Background
With respect to the medical background of the adult patients responding to the survey, **67% had SBS specifically** (with the remainder having IF more generally), and **58% were managed by an intestinal rehabilitation program (IRP)**.



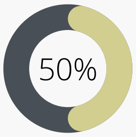


71% female

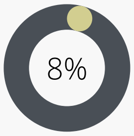
88% non-Hispanic white

67% diagnosis of SBS specifically

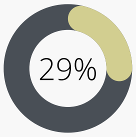
58% IRP management



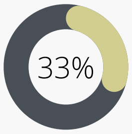
currently on PN/hydration



currently on EN/tube feeds



currently have feeding tube



currently have ostomy

Items most commonly selected as having a **STRONG IMPACT** on **adult patient** overall wellbeing

*strong **positive** impact*

SUPPORT: relationships with family **(83%)**

MEDICAL CARE: having access to high quality medical care, being satisfied with the medical care you are receiving for your SBS/IF **(79%)**

MANAGING YOUR SBS/IF: generally having good control overs symptoms or coping well with symptoms **(71%)**

MEDICAL CARE: having positive relationships with medical providers/staff **(71%)**

ENERGY: having energy to keep up with daily activities as desired **(67%)**

MENTAL HEALTH: coping well with stress and negative emotions, ability to adapt, having positive outlook and self esteem **(67%)**

RECREATION: traveling/going on vacation **(67%)**

SUPPORT: relationships with friends **(67%)**

*strong **negative** impact*

SLEEP: sleeping poorly/interrupted sleep **(79%)**

ENERGY: not having energy to keep up with daily activities as desired **(75%)**

FOOD/EATING: having a negative relationship or association with food/eating **(67%)**

MEDICAL CARE: having negative experiences with hospitalizations or medical procedures **(63%)**

COMMUNICATION: having difficulty explaining or communicating about SBS/IF to others **(58%)**

RECREATION: not being able to travel/go on vacation as you would like **(58%)**

RECREATION: not being able to participate in the activities and/or hobbies you want to **(54%)**

MANAGING YOUR SBS/IF: difficulty with symptoms (e.g., toileting, pain, discomfort, thirst/hunger) **(50%)**

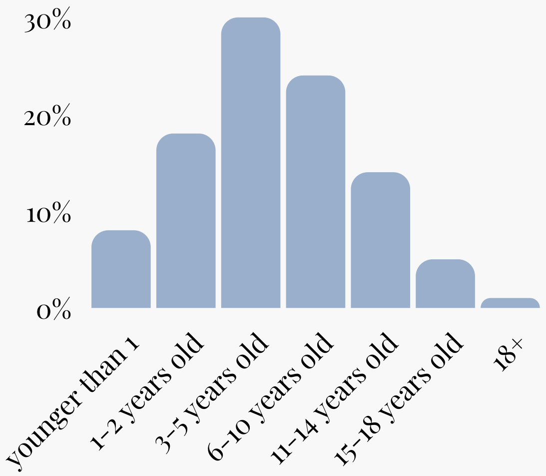
*IRP: intestinal rehabilitation program, PN: parenteral (IV) nutrition, EN: enteral nutrition (nutrition through feeding tube)

PEDIATRIC PATIENTS*

with SBS or IF

**as reported by parents*

Demographic background
Just over 100 parents (104 in total) provided information about their child using the community survey. Over half of the children **(54%) were between the ages of 3 and 10.**



Medical Background
With respect to the medical background of the children with SBS, **91% had SBS specifically** (with the remainder having IF more generally), and almost **74% were managed by an intestinal rehabilitation program (IRP).**

91% diagnosis of SBS specifically

74% IRP management

64% currently on PN*/hydration

65% currently on EN*/tube feeds

73% currently have feeding tube

22% currently have ostomy

Items most commonly selected as having a **STRONG IMPACT** on **child** overall wellbeing*

*strong **positive** impact*

RECREATION: participating in activities or hobbies (82%)

SUPPORT: relationships with family **(81%)**

MEDICAL CARE: having positive relationships with medical providers/staff **(75%)**

FOOD/EATING: having positive relationship or association with food or eating **(74%)**

MEDICAL CARE: having access to high quality medical care, being satisfied with the medical care you are receiving for your SBS/IF **(74%)**

PARTICIPATION: attending school, having positive experiences in educational setting **(73%)**

ENERGY: having energy to keep up with daily activities as desired **(71%)**

*strong **negative** impact*

RECREATION: not being able to participate in the activities and/or hobbies they want to **(56%)**

MEDICAL CARE: negative experiences with hospitalizations or medical procedures **(54%)**

SLEEP: sleeping poorly/interrupted sleep **(52%)**

RECREATION: not being able to travel/go on vacation as they would like **(51%)**

ENERGY: not having energy to keep up with daily activities as desired **(50%)**

FOOD/EATING: having a negative relationship or association with food/eating **(49%)**

PARTICIPATION: not being able to attend school, having poor experiences in school setting **(49%)**

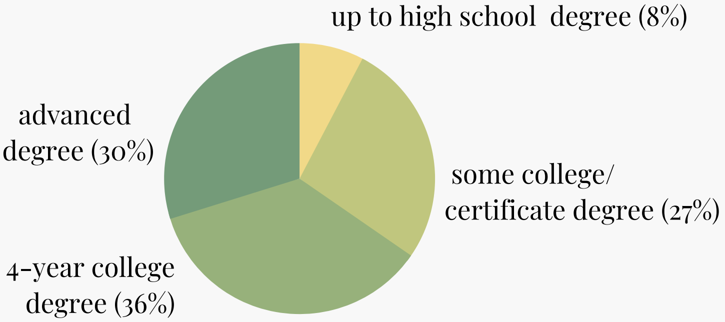
CHILD'S SBS/IF MANAGEMENT: difficulty with symptoms **(48%)**

**as reported by parents*

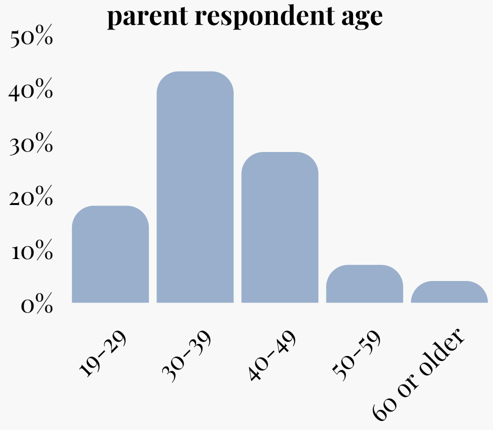
PARENTS

of children with SBS or IF

Demographic background
Parents responding to the survey were **mostly women (95%)**, identifying as **non-Hispanic white (90%).** Close to half **(43%) of respondents was between the ages of 30-39.**



parent respondent age



95% of parent/caregiver respondents were female

Items most commonly selected as having a **STRONG IMPACT** on parent overall wellbeing

*strong **positive** impact*

CHILD: your child's resilience, strength, positive outlook (**85%**)

MEDICAL CARE: having access to high quality medical care, being satisfied with the medical care your child is receiving **(79%)**

MEDICAL CARE: having positive relationships with medical providers/staff **(79%)**

MEDICAL CARE: being able to advocate for your child in the medical setting **(77%)**

CHILD'S SBS/IF MANAGEMENT: having a good understanding of your child's SBS/IF and available therapies **(72%)**

RESOURCES: having health insurance that covers your child's/your family's medical needs (**72%**)

SUPPORT: relationships with family **(69%)**

CHILD'S SBS/IF MANAGEMENT: generally having good control over- or coping well with- your child's symptoms **(67%)**

*strong **negative** impact**

SLEEP: sleeping poorly/interrupted sleep **(76%)**

ENERGY: not having energy to keep up with daily activities as desired **(67%)**

RECREATION: difficulty with travel/going on vacation as desired **(62%)**

MENTAL HEALTH: your difficulty coping with stress and negative emotions, difficulty adapting, lacking a positive outlook/self esteem **(59%)**

MEDICAL CARE: negative experiences with hospitalizations or medical procedures **(54%)**

RECREATION: lack of opportunity to engage in physical activities and/or hobbies as desired **(55%)**

PARTICIPATION: nlack of ability to work, if desired, or having poor experiences in work setting; lack of professional development **(51%)**

**while the survey was designed to allow respondents to select as many items as they wanted from each list, an error occurred on this list. Because of this error, parents were able to select no more than 10 items*

COMMUNITY PRIORITIES

for the gutsy perspective

respondents were asked the following open-ended question:

As a member of the SBS/IF community, what do you think should be the priorities for this research project?

"Raising awareness of the effects of SBS/IF on quality of life!"

quality of life research, education,** and **advocacy

"quality information about clinical options"

"lists of medical professionals who are experienced with SBS/IF"

resources** for **treatment options** & finding **experienced clinicians

"Enhancing and providing education opportunities for health care personnel"

clinician training** and **awareness

be a **voice** for **patients & families**

["forming] an open honest relationship with doctors"

clinician-patient/family communication

"Information dissemination to [clinicians] about Quality of life realities."

"Creating better communication and collaboration between patients and care teams"

"support of the mental health of SBS families/medical trauma"

medical trauma

mental health research & advocacy

"Mental health support for caregivers, specifically for burnout, depression, and anxiety."

"Understanding mental impact of disease and role of clinicians"

This data collection was deemed exempt from full review by the University of Nebraska Medical Center (UNMC) IRB under protocol number 079-21-EX

This report was prepared by Marie Neumann,
project researcher for the gutsy perspective.

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