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Poster Supplementary information

Poster title: Beyond clinical outcomes: using a disease-specific pilot survey to explore parent perceptions of wellbeing for children with short bowel syndrome

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Table 1. Parent respondent characteristics (N=21)

Category	Response	n (%)
Caregiver Characteristics		
Relationship to child with SBS	Biological parent	16 (76.2)
	Adoptive parent	4 (19.0)
	Foster parent	1 (4.8)
Gender	Female	17 (81.0)
	Male	4 (19.0)
Race/ethnicity	non-Hispanic white	20 (95.2)
	Hispanic/Latinx	1 (4.8)
Age	19-29	2 (9.5)
	30-39	6 (28.6)
	40-49	11 (52.4)
	50+	2 (9.5)
Educational background	Some college	3 (14.3)
	Bachelor's degree	9 (42.9)
	Advanced degree	9 (42.9)
Employment status	Working full time	8 (38.1)
	Working part time	5 (23.8)
	Retired/homemaker/disabled	7 (33.3)
	Student	1 (4.8)
Relationship status	Married/cohabiting	19 (90.5)
	Single	1 (4.8)
	divorced	1 (4.8)
Spiritual identity	Christian	13 (61.9)
	Jewish	1 (4.8)
	Not religious	6 (28.6)
	Prefer not to say	1 (4.8)
Number of children in household	1	12 (57.1)
	2-3	9 (42.9)
SBS-related care managed by established IRP	Yes	15 (71.4)
	No/unsure	6 (28.6)

Table 2. SBS child characteristics (N=21)

SBS Child Characteristics		
SBS child's gender	Female	8 (38.1)
	Male	13 (61.9)
Underlying cause of SBS	NEC	6 (28.6)
	Gastroschisis	4 (19.0)
	Hirschsprung's disease	4 (19.0)
	Jejunal atresia	5 (23.8)
	other	2 (9.5)
Age of SBS child now	0-12 months	3 (14.3)
	Between 1 and 6 years	7 (33.3)
	Between 6 and 10 years	7 (33.3)
	Between 10 and 14 years	3 (14.3)
	Between 14 and 17 years	1 (4.8)
Comorbidities secondary to SBS	Yes	12 (57.1)
	No	9 (42.9)
Child TPN status	Currently on TPN	17 (81.0)
	Previously on TPN	4 (19.0)
	Never on TPN	0
Child enteral feeds status	Currently on enteral feeds	12 (57.1)
	Previously on enteral feeds	7 (33.3)
	Never on enteral feeds	2 (9.5)
Child ostomy status	Currently has ostomy	10 (47.6)
	Previously had ostomy	5 (23.8)
	Never had ostomy	5 (23.8)
	Unsure	1 (4.8)

Table 2. Distribution of parent-reported negative impact for select items

Disease-specific item	Negative impact (5-point Likert scale) n (%)					Item not applicable to child n
	1	2	3	4	5	
	Item has little or no negative impact on child's overall wellbeing		Item has some negative impact on child's overall wellbeing		Item has a strong negative impact on child's overall wellbeing	
Daily TPN Management	3 (18)	6 (35)	4 (24)	4 (24)	0	4
CVL care and Management	6 (35)	2 (12)	6 (35)	2 (12)	1 (6)	4
Feeding-related	4 (19)	4 (19)	6 (29)	3 (14)	4 (19)	-
Enteral feeds	2 (13)	4 (27)	3 (20)	2 (13)	4 (27)	6
Medications	8 (40)	5 (25)	3 (15)	2 (10)	2 (10)	1
Toileting	5 (28)	5 (28)	2 (11)	2 (11)	4 (22)	3
Feeding tube/ ostomy care	5 (29)	2 (12)	3 (18)	5 (29)	2 (12)	4
Vomiting*	11 (52)	4 (19)	4 (19)	0	2 (10)	-
Pain or discomfort*	7 (33)	5 (24)	4 (19)	2 (10)	3 (14)	-
Feeling tired*	11 (52)	4 (19)	1 (5)	3 (14)	2 (10)	-
Sleep issues*	10 (48)	2 (10)	1 (5)	3 (14)	5 (24)	-
Procedures	4 (21)	3 (16)	5 (26)	3 (16)	4 (21)	2
Social life**	5 (26)	2 (11)	3 (16)	5 (26)	4 (21)	2

* “n/a” responses for these items were recoded as “no negative impact”

** Social life variable counts include responses referring to impact of COVID-19 pandemic

Table 4. Thematic analysis of select items perceived by parents as having a strong negative impact on child wellbeing

Disease-specific item	Sub-theme	Exemplary quotes selected from parent responses to open-ended follow up questions
PN-related items		
PN use (n=4/17)	Affects mobility/ability to do “normal kid” things (n=4)	<i>“She misses out on some neighborhood play to have to come home and hook up... She misses out in swimming parties in the summer.”</i>
	PN disrupts sleep (n=2)	<i>“Although management has improved dramatically as we decrease TPN time/dose, being connected during sleep disrupts sleep”</i>
Central line care (n=3/17)	Dressing changes (n=2)	<i>“He hates dressing change”</i>
	Infection risk (n=2)	<i>“While the line itself is not complicated or overwhelming, it is the unfortunate infections”</i>
EN-related items		
EN use (n=6/15)	Inability to tolerate feeds, causing physical symptoms for some (n=5)	<i>“Child can't tolerate any enteral feeds without having massive g tube output and vomiting”</i>
	Feeds are disruptive; for some, they impact sleep (n=3)	<i>“She's constantly having to deal with us doing something to her pump, g-tube, and bolus feeds as well as vent her and change her site dressing. This interrupts whatever she may be doing at the time”</i>
Feeding tube* (n=4/15)	Tube placement/replacement (n=2)	<i>“NG tube placement is very difficult and traumatic, happens at least once a week due to tube getting pulled out”</i>
Food and eating		
Feeding (n=7/21)	Child’s inability to tolerate food, leading to increased output or physical symptoms and extreme food restrictions (n=5)	<i>“Feeding intolerance make for miserable time.”</i> <i>“[Child] hasn't been able to eat by mouth [for a half year] and recently is only allowed to eat 2 saltine crackers a day. Child had the opportunity to eat by mouth before... if she did eat by mouth she will have belly pain and vomiting”</i>
	Complicated relationship to with food, characterized by picky eating and/or oral aversions (n=4)	<i>“He is very selective with the food he eats”</i> <i>“He is a picky eater”</i> <i>“Breadth of diet is significantly reduced by limited GI absorption, making overcoming oral aversion difficult. Swallow coordination compounds oral feeding problems and limits diet options.”</i>

Output-related items		
Toileting (n=6/18)	Diarrhea/lack of control impacting mobility, activities, independence, and/or development (n=6)	<i>"[My child is] still in nappies. Bouts of diarrhea, lack of control. Explosive diarrhea She can't always tell when she needs to urinate or have a stool so we have to prompt her to go potty every 3-4 hours during the day"</i>
	Nighttime sleep disruptions caused by frequent toileting (n=4)	<i>"[We] try to get her to agree to get up during the night if she shows signs of needing to go". "[The] frequency of stooling affects our entire family's sleep which is a huge stressor."</i>
	Child's anxiety or embarrassment about odors or accidents (n=5)	<i>"His stool of course is very odorous so that sometimes leads to embarrassment"</i> <i>"He's constantly worried and anxious when he can't make it on time to the toilet"</i>
Ostomy* (n=3/10)	Leaking/frequent bag changes, interrupting child activities (n=2)	<i>"Having to care for and manage a colostomy bag is a burden at times for him - he gets frustrated and doesn't want to take a break to empty but then gets anxiety over a huge bag and potential leaking"</i>
Poor sleep/general fatigue		
Sleep issues (n=8/21)	Frequent sleep interruptions due to toileting, pump alarms, or other care needs (n=7)	<i>"Her sleep is often interrupted by pump alarms, diaper changes and/or getting up to go potty, site dressing changes, connecting & disconnecting the feeds, venting, being pulled up in bed to keep her head elevated to prevent aspiration since she's fed overnight"</i>
	Poor quality sleep, for some due to stomach pain or discomfort (n=4)	<i>"His sleep pattern is not constant, it has never been. His stomach and belly rumble, he wails, moves constantly"</i>
Fatigue (n=5/21)	Fatigue/low energy affects child's participation in activities (n=3)	<i>"She misses some morning activities, zoom meetings due to being tired"</i> <i>"He struggles constantly with hydration which affects his endurance and stamina to keep up with his friends and avoid hospitalization"</i>
Social life		
Social life (n=9/19)	Child perceives themselves as being "different" from other children; feels excluded (n=4)	<i>"She also is very embarrassed about needing to wear diapers at night and pull-ups sometimes during the day as well as accidents, especially away from home. It also frustrates her that she can't do things other kids do or go places others do. Other kids tend to exclude her, and that hurts her feelings immensely"</i> <i>"As he is six children seeing him differently because he wears nappies and his gas smells bad."</i>
Medical procedures		
Procedures (n=7/19)	Child traumatized by medical procedures, some are described as anxious or hypervigilant about possible procedures (n=6)	<i>"Every 2-3 months, she has to get enemas and flushes from the top of her diseased intestine and both of those are very traumatizing to her..."</i> <i>"Because of basically a lifetime of medical trauma, ... if she even hears people talking about anything related to [procedures], she comes running in all anxious & worried that she's about to have to have something done or go somewhere medically related"</i> <i>"I believe both he and I have PTSD from having to hold him down so much as a child."</i>
Note: Analyses based on responses to open-ended follow-up questions on the disease-specific item matrix.		
*While the matrix included one item to measure the negative impact of a feeding tube or ostomy together, parent responses to the open-ended follow-up question for this item allowed for the distinction between ostomies and feeding tubes.		