

**ASPEN Nutrition Science and Clinical Practice Conference**  
**March 2022**  
**Poster Supplementary information**

**Poster title:** Transitioning in and transitioning out: parent and adult patient experiences with healthcare for intestinal failure

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**Disclosures:**

This work was supported by an unrestricted project grant from Zealand Pharma to DFM. DFM received consultant fees from Zealand Pharma. All other authors report no known conflicts of interest. MSW contributed to this work in a private capacity. No official support or endorsement by the U.S. Department of Veterans Affairs is intended, nor should be inferred.

<b>Table 1: select respondent (parent or adult patient) demographic characteristics (N=35)</b>			
<b>Category</b>	<b>Response</b>	<b>n (%)</b>	<b>n (%)</b>
		<b>Parents (n=22)</b>	<b>Adult patient (n=13)</b>
Gender	Female	18 (81.8)	10 (76.9)
	Male	4 (18.2)	3 (23.1)
Age	19-29	2 (9.1)	6 (46.2)
	30-39	6 (27.3)	4 (30.8)
	40-49	12 (54.5)	3 (23.1)
	50+	2 (9.1)	0
Employment status	Working full time	9 (40.9)	6 (46.2)
	Working part time	5 (22.7)	3 (23.1)
	Retired/homemaker/disabled	7 (31.8)	1 (7.7)
	Freelancing/as-needed work	0	2 (15.4)
	Student/other	1 (4.5)	1 (7.7)
Relationship status	Married/cohabiting	20 (90.9)	7 (53.8)
	Single	1 (4.5)	5 (38.5)
	Partnered but not cohabiting	0	1 (7.7)
	divorced	1 (4.5)	0
Spiritual identity	Christian	14 (63.6)	7 (53.8)
	Jewish	1 (4.5)	0
	Not religious	6 (27.3)	2 (15.4)
	Other/prefer not to say	1 (4.5)	4 (30.8)

**Table 3: Thematic analysis of parent and adult patient care priorities**

Theme		n	Exemplary quotes
Parents (n=22)	family-centered approach that recognizes parent expertise	14	<p><i>If I say that something's wrong, the gastroenterologist who has known me for 8 years knows I am right. The student can't tell me 'I don't see anything wrong', and look sad and say 'you don't trust me' when I request to see the head GI doc. Head GI doc always says 'You do what mom tells you'.</i></p> <p><i>Listen to our in-put and don't think they always know better than we do because they likely do not. Do not doubt a "mother's intuition/gut"</i></p> <p><i>Listening to what we say about our child and recognizing us as just another expert that sits at the table with them... That they need to meet families on their level, not try to get the family to meet them on theirs.</i></p>
	Ease of access/ responsiveness of the provider or team	8	<p><i>For the medical team to be easily reachable/available/responsive when things arise is very important</i></p> <p><i>Respond promptly to questions/issues... perhaps requiring more support staff.</i></p> <p><i>I think our current medical team is slightly overwhelmed and stretched thin. Response time and ability to get an appointment is not great.</i></p>
	provision of holistic multidisciplinary care	7	<p><i>Learn about &amp; refer us to community resources we need.</i></p> <p><i>That they recognize the horrible nightmare journey most of us have been through, that they keep that knowledge ever present as they think of paths forward for families... That they remember that our children and their families are more than just their diagnosis and that many things need to be factored in when making choices.</i></p> <p><i>Finding out what is important to the child and their family is so important. Something as simple as being willing to modify a TPN schedule M-F to be unhooked for school can be life-changing for a child. Teams need to do a better job of understanding that and how decisions that seem small in the moment can have reverberations for years.</i></p>
Adult patients (n=13)	recognition of patient expertise	7	<p><i>I like my team and I know they are incredibly smart. I wish they were better at working with me instead of around me. Sometimes it feels like if I bring something up, like a new treatment, they will not consider it.</i></p> <p><i>We know our bodies better than ANYONE else and we know when something is wrong!</i></p>
	knowledgeable & nuanced approach (recognizing the uniqueness of each IF case) that helps patient live their desired lifestyle	7	<p><i>They need to understand that one size does not fit all and I am a very outspoken person and will say what I think. I also have trauma medically from procedures in childhood that still haunt me.</i></p> <p><i>It helps when they... take the time to understand your unique situation.</i></p> <p><i>I think what's worked for me is that I talk to my doctor nurses dieticians about the lifestyle that I live and they work around my nutrition so I can live that lifestyle better.</i></p> <p><i>By listening to their patients and not treating every single patient the same. Treat the patient based on their individual needs</i></p>
<p><i>Note: thematic analyses based on parent and adult patient responses to the following two open-ended survey questions:</i></p> <p><i>1. Follow-up to a closed-ended question asking respondent to indicate how satisfied they are with the care they are/their child is currently receiving</i></p> <p><i>2. How can medical professionals, including doctors, nurses, dieticians, therapists, etc., support your child's overall wellbeing- i.e. your overall sense of being comfortable, healthy, and happy?</i></p>			