

Characterizing the Parental Perspective of Food-Related Quality of Life in Families after Pediatric Inflammatory Bowel Disease Diagnosis

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BACKGROUND

- Quality of life is reduced in pediatric patients with inflammatory bowel disease (IBD) because of the burden of disease management.
- Food-related quality of life (FRQOL), described as achieving adequate nutrition, deriving pleasure, and maintaining social activities through eating and drinking, may be an important mediating factor, but there is limited research in the pediatric population.

Research Question: In parents with a child diagnosed with IBD between 5-18 years of age, what are their perceptions of changes in the eating experiences of their family and family functioning related to eating after diagnosis, and how do they impact FRQOL?

Study Aim: To characterize the parental perspective of changes in the eating experiences and family functioning related to eating in their family after diagnosis of IBD in their child to explore how they may mediate FRQOL.

METHODS

- Inclusion criteria: parent/caregiver of a child diagnosed with IBD at least 6 months prior to the interview; age at diagnosis between 5-18 years; and English speaking.
- Exclusion criteria: co-existing condition which required dietary restriction, such as celiac disease or diabetes.
- Semi-structured interviews <60 minutes were completed at a location chosen by the participant.
- Signed informed consent was obtained from each participant before the interview.
- Recorded interviews were transcribed verbatim, and then reviewed for accuracy.
- Clean transcripts were then loaded into NVivo 12 software (QSR International) to conduct conventional content analysis with steps to maximize trustworthiness.⁶⁻⁷
- Data saturation, the point at which conceptual categories could be described fully and additional interviews were not adding to the overall story, was reached with the 10 interviews.
- The homogenous sample created circumstances to reach data saturation in a smaller number of interviews.⁸

Figure 1. Theoretical Framework Model for the Study:

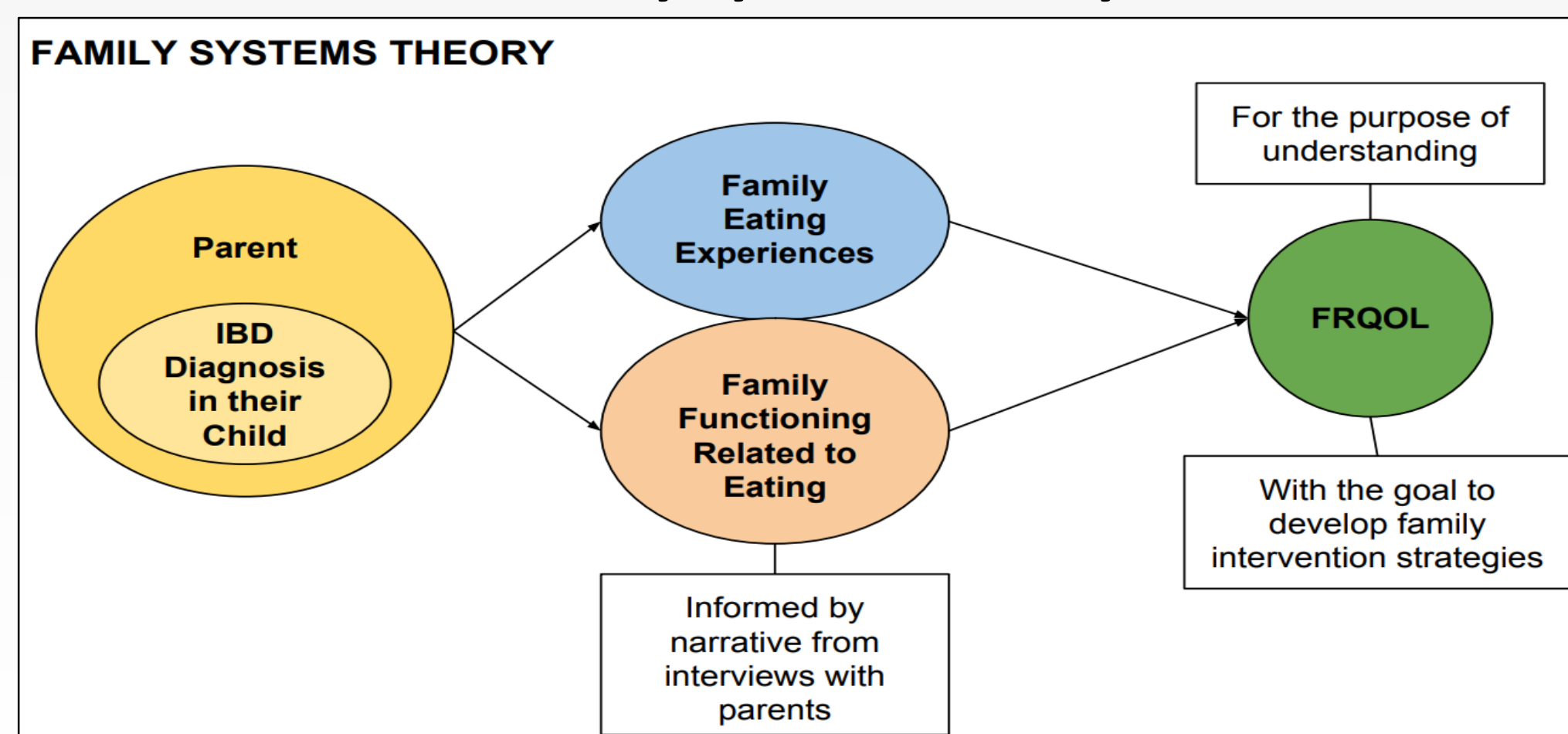


Table 1. Demographic Data of Parent Participants and Their Children With IBD

	Parent Participants (n = 10)	Their Children with IBD (n = 11**)
Sex, n		
Male	1	5
Female	9	6
Age (years), mean (range)	46.2 (36-55)	13.9 (7-20)
Age at IBD diagnosis (years), mean (range)		10.4 (4-15)
Time since IBD diagnosis, mean (range)		3.6 years (7 mos to 8 yrs)
IBD Type, n		
Crohn's disease		10
Ulcerative colitis		1
Disease Activity Level†, n		
Inactive		5
Mild		4
Moderate to severe		2
Race/Ethnicity, n		
White, non-Hispanic	9	
White, Hispanic	1	
Highest degree earned, n		
High school diploma	3	
Bachelor's degree	6	
Master's degree	1	
Annual family income level*, n		
>\$50,000-\$99,000	1	
\$100,000-\$149,000	1	
>\$150,000	7	
Total children in the household, n		
One	2	
Two	5	
Three	3	

IBD, Inflammatory Bowel Disease; mos, months; yrs, years.

*Not reported for one participant.

**One parent participant had two children with IBD.

†Based on Pediatric Crohn's Disease Activity Index (PCDAI) or the Pediatric Ulcerative Colitis Activity Index (PUCAI).

Table 2. Summary of the Reported Diet-Related Experiences of Participants

	Diet Following	Diet Instructed to Follow after Diagnosis (by Gastroenterologist Unless Specified)	Saw RD after Diagnosis?
M1	Low residue, high calorie	Low residue, high calorie	No
M2	Grain and corn free	Low residue	Yes
M3	Regular	Regular	Yes
M4	Low residue	Low residue (oral nutrition supplements for ~1 year)	Unsure
M5	Regular (low residue during flares)	Regular diet (low residue during flares; oral nutrition supplements for ~2 years)	Yes
M6	Grain and sugar free	Regular (low residue during flares)	Yes
J1	Regular	Regular (low residue during flares)	Yes
J2	Paleo (AIP diet during flares)	Regular	Unsure
J3	Low dairy	-Low residue -Dairy, gluten, corn, egg free (by gynecologist)	No
J4	Regular	Low residue, gluten, and dairy free until remission	No

RD, registered dietitian, AIP, autoimmune protocol diet; IgG, immunoglobulin G (food sensitivity testing)

RESULTS

Three main themes emerged and contributed to the parental perspective of FRQOL:

- 1) Ambiguity in the perception of food/eating in IBD
- 2) Challenges related to food/eating after IBD diagnosis
- 3) Resilience when coping with and adapting to challenges

- There were various and conflicting viewpoints regarding the role of diet in pediatric IBD which resulted in confusion and challenges for the families.
- Parents reported frustration regarding the lack of uniform and personalized nutrition guidance from the medical community (Table 2).

It was basically the standard American diet from the government that I was handed to me. It was like there was no consideration made for the fact that she was a Crohn's patient (M6)

- Parents also expressed frustration about the absence of shared decision-making and the fact that diet was not presented as a treatment option.

No one's talking about diet but me, OK. Which is really kind of concerning. (M3)

Why does it have to be, let's just trust the medicine? (M6)

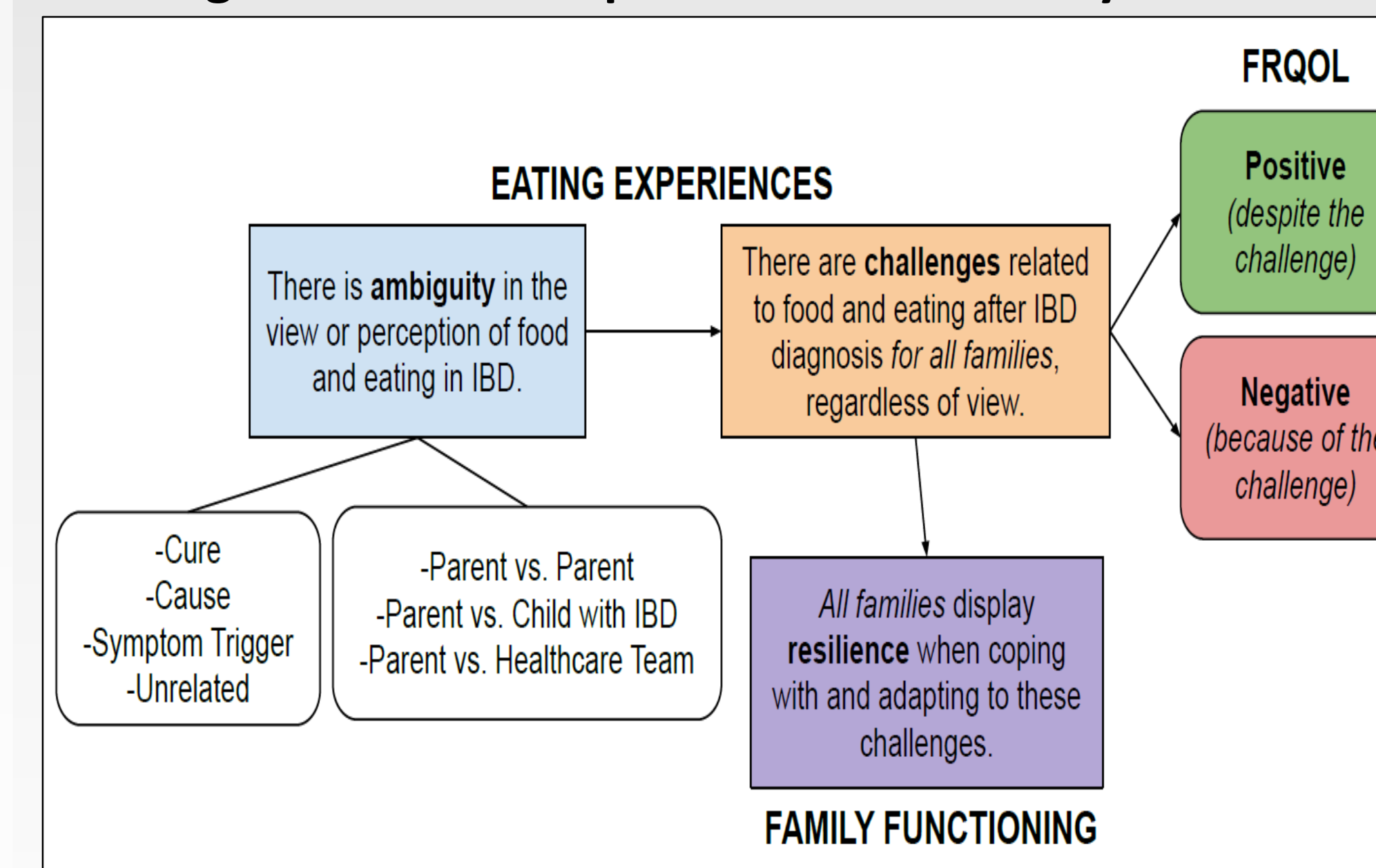
Honestly, I wish I had just known about the diet beforehand or that it could have been so beneficial. I wish that that would have been presented instead of medicate, medicate. (J2)

- All parents described various challenges for their family related to food and eating after IBD diagnosis, but the families displayed resilience when coping with and adapting to these challenges.

Parental perspective of FRQOL

- Both positive and negative FRQOL were reflected in the experiences of the families from the perspective of the parent: either positive despite the challenges, or negative because of the challenges.

Figure 2: Visual Representation of Study Results



LIMITATIONS

- Small, homogeneous sample size.
- Unknown disease severity for children with IBD at diagnosis. Reported experiences may not be reflective of families with a child that has ongoing severe IBD.
- Possible recall bias (3.6 years (range 7 months to 8 years) average time since IBD diagnosis).
- Lack of diversity and high socioeconomic characteristics of study population.

CONCLUSIONS & IMPLICATIONS FOR PRACTICE

Parents of children living with IBD in this study perceived nutrition education and information from health care providers as confusing and ambiguous, which impacted their eating experiences and family functioning, and therefore FRQOL.

- Parents expect their medical provider to acknowledge and address diet after IBD diagnosis and desire shared decision-making related to food and medication.
- It has been shown that patients with IBD and their families will attempt dietary changes regardless of their provider's views or advice, and adequate support assures the intake of the child is still appropriate for growth and prevention of nutrient deficiencies.
- Medical providers need to support the unique dietary goals and needs of each family to promote optimal FRQOL.
- Using the framework of the FST, decisions regarding diet should include all family members, including the child with IBD, to support optimal FRQOL.
- There is a need for consistent, standardized IBD diet and nutrition recommendations.
- Continued research on FRQOL in the pediatric IBD population is warranted.

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