

A patient led, peer-to-peer qualitative study on the psychosocial relationship between patients with Inflammatory Bowel Disease (IBD) and food.

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BACKGROUND

This study is part of an internship within the Patient and Community Engagement Research (PaCER) program at the O'Brien Institute of Public Health, University of Calgary, Canada. The following informed our research project:

- Canada has one of the highest rates of IBD in the world¹.
- No one diet has been identified as effective for disease management or treatment².
- Many patients believe diet affects their symptoms and often make dietary changes early on at diagnosis^{2,3}.
- Food has cultural, social, psychological significance; almost all social events center around food, resulting in patient isolation from their communities due to dietary restrictions⁴.
- Patient experiences with food have not been adequately addressed in the literature, even though 90% of patients with Crohn's Disease in one study changed their diet after receiving an IBD diagnosis^{5,6}.

Our study seeks to understand the psychosocial impact of IBD on nutrition and diet for young adults. We aim to inform healthcare practitioners, members of the IBD community, health policy makers, and others about the complex psychosocial nature of patients' relationship with food, as well as communicate patient perspectives and recommendations to improve outcomes.

METHODOLOGY

- Participants were recruited through social media posts by IMAGINE-SPOR, Crohn's and Colitis Canada, and other personal contacts.
- Inclusion criteria: 1) 18-35 years old, 2) Sufficient fluency in English to participate in interviews/focus groups, 3) Lives in Canada, 4) Self-identify as diagnosed with IBD.
- PaCER methodology was used to engage patients in peer-to-peer co-designed qualitative research (Figure 1):

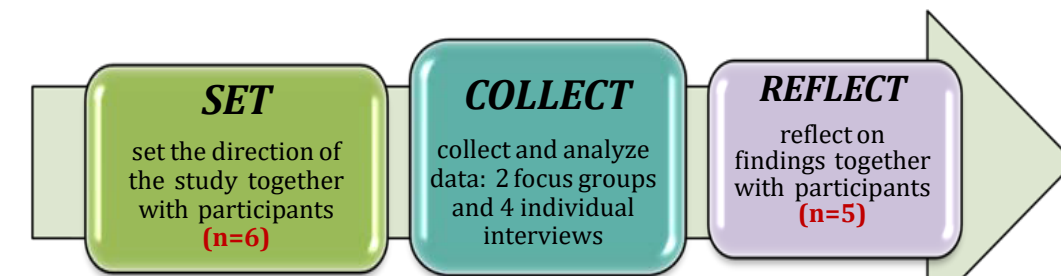


Figure 1

- Data analysis: Iterative questioning, narrative analysis, and open coding elements from grounded theory.
- Narrative interviews and focus groups were held online via encrypted videoconferencing platform.

RESULTS

Iterative analysis revealed four emerging categories (illustrated via numbers on Figure 2):

- 1 Experimenting With Food:** The ways in which people with IBD cope with the challenges of navigating which foods to eat, or the tips and tricks used to lessen food stressors or to regain control. Subcategories: a) *Trial and Error*, b) *Not Black and White*, c) *Weighing Risks and Benefits*, d) *Developing Knowledge and Experience*.
- 2 Evolution Over Time:** How their relationship with food evolves over time. Foods fluctuate between being feared/avoided and being safe, and participants gained knowledge about how certain foods make them feel. Subcategories: a) *Starts with Lack of Professional Guidance*, b) *Experimentation and Independent Research*, c) *Seeking Second Opinions*, and d) *Acceptance and Maintaining Hope*.
- 3 Diet Changes are Emotional:** Experiencing difficult emotions was common as diets changed, especially in relation to not being able to eat foods that bring comfort, attending family gatherings or holiday dinners, and at times not being able to eat at all. Subcategories: a) *Flares Before and After*, b) *Losing Comfort Foods*, c) *Navigating Social/Cultural Gatherings*, d) *Guilt/Burden of Diet Changes on Others*, e) *Reclaiming Joy*.
- 4 Role of Stigma:** Participants' diet changes were judged, thus affecting relationships, causing social isolation, worry, confusion about changing food rules, and frustration. Subcategories: a) *Support System (positive or negative)*, b) *Judgement from Others*, c) *Justifying Your Diet*, d) *Unsolicited "Cures"*, e) *Self-Advocacy*.

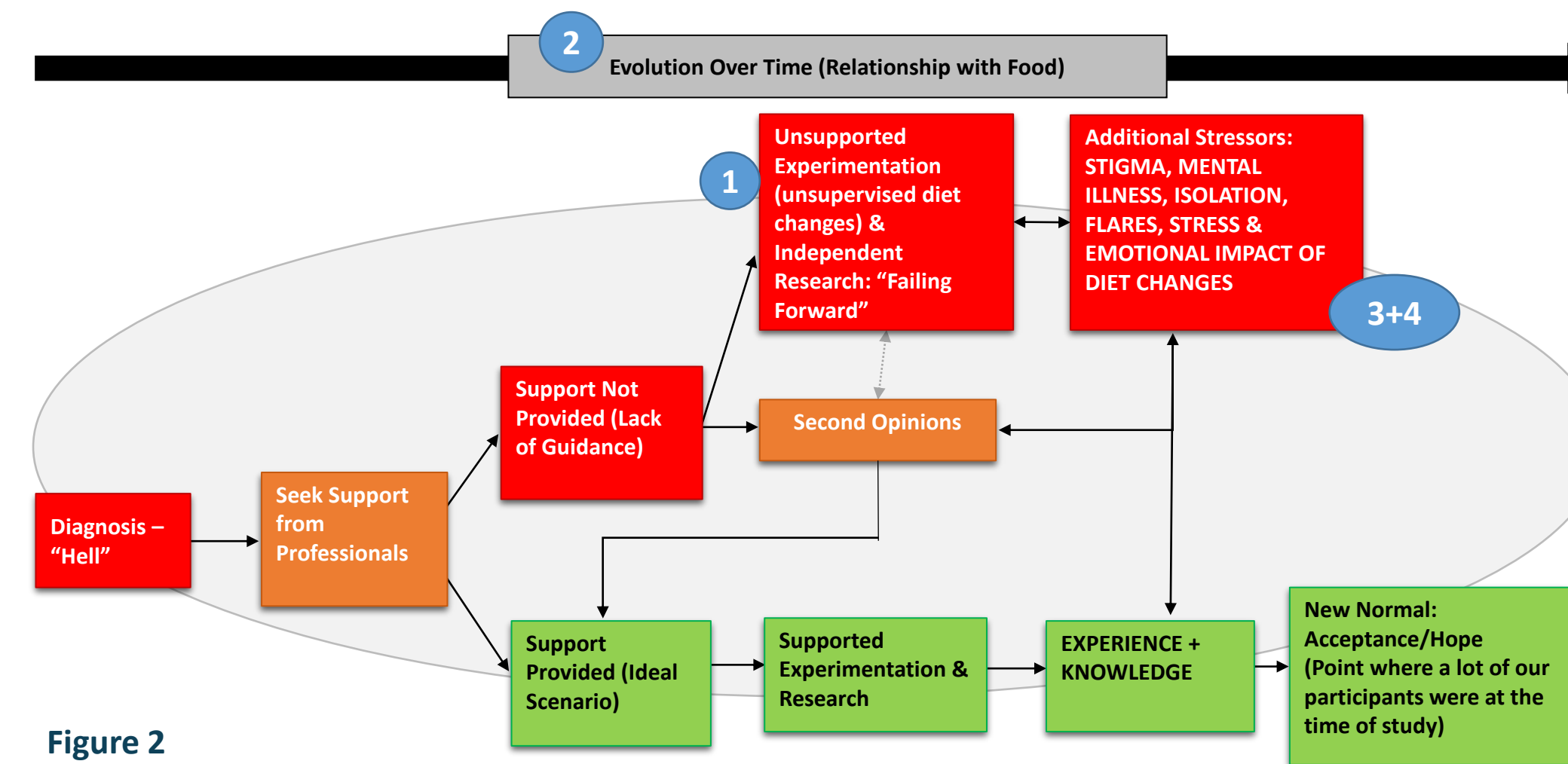


Figure 2

DISCUSSION

Participants described:

- Having a complex psychosocial relationship with food.
- Constantly changing food tolerances and setbacks, emotional distress, social isolation, and stigma.
- Experiencing grief at the realization that their relationship with food had changed forever.
- Perceived gaps in healthcare system and dismissive attitudes (namely from GIs) regarding diet changes.
- Increasing their knowledge and experience about food on their own in order to "survive".

Our findings coincide with existing literature. Participants believed considering diet in the management of their IBD is key, yet Western medical guidelines neglect dietary counselling and resources^{7,8,9}. Our group conceptualizes this journey with food as that of a person white water rafting (see Figure 3 below):

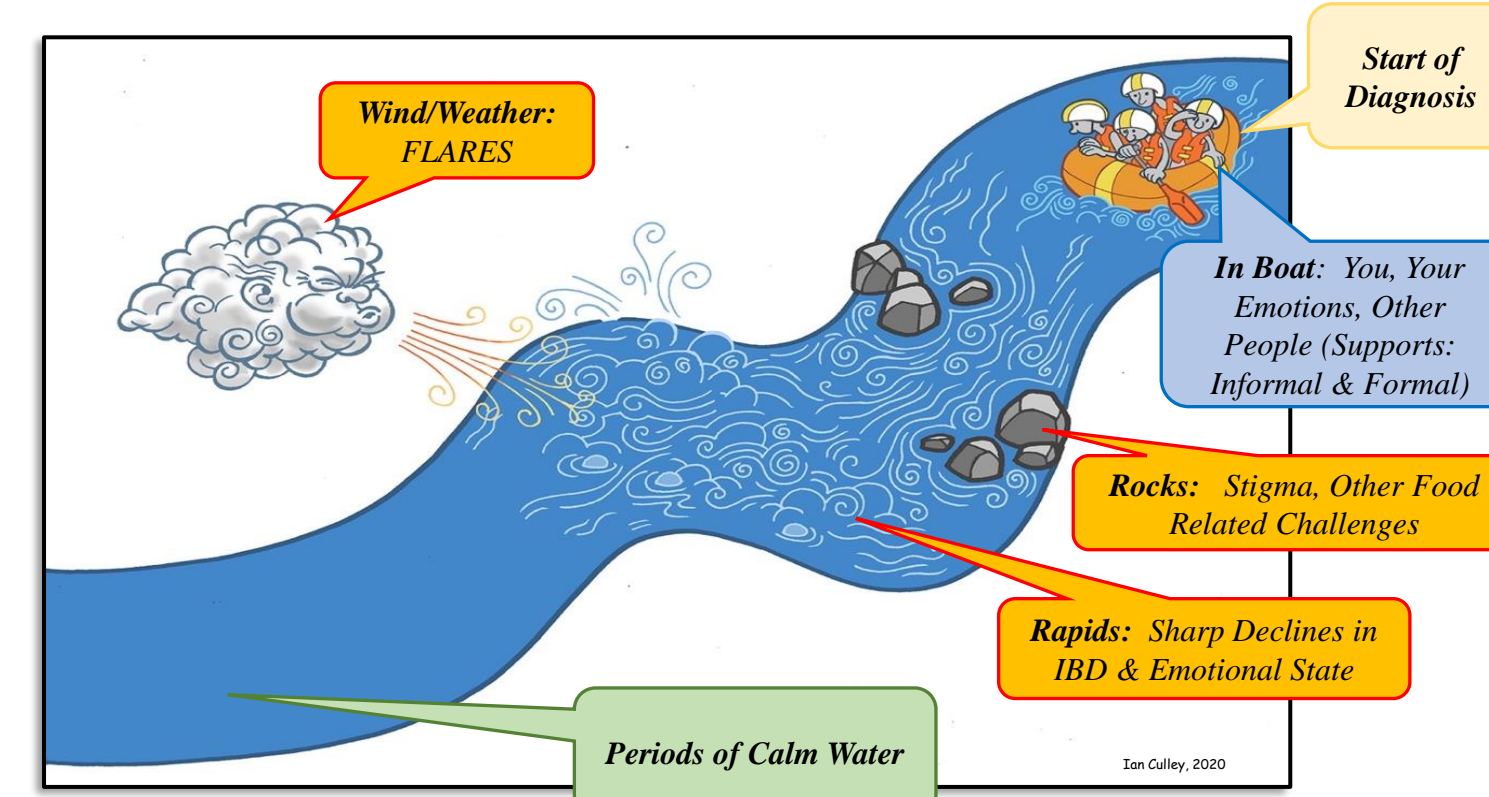


Figure 3

- The people in the raft symbolize the patient and other informal/formal medical supports to assist them.
- The water symbolizes IBD; patients have little control over it and little knowledge about what lies ahead.
- Factors such as weather, rapids, and one's knowledge about white water rafting impact experience.
- The more experience a person has, the more knowledge they accumulate to be able to help them navigate future rocky waters. Acknowledging their own resilience, the person begins to accept their situation, which informs their future behaviour and outlook.

RECOMMENDATIONS

How can IBD healthcare providers challenge outdated assumptions and empower patients to consider ways that they can gather scientifically-informed tools and information to help guide their dietary experimentation?

Recommendations from participants included:

- Create a centralized resource/referral website with facts/contact information of specialized healthcare providers.
- Create a working group of healthcare providers and patients to collaborate and determine clinical guidelines that help patients experiment with diet.
- Additional training for healthcare providers regarding the psychosocial impact of food, and its significance on symptoms and the emotional impact to facilitate referrals to appropriate services and other practitioners.
- Record and share patient stories about their experiences with food widely to encourage increased awareness of issues and messages of hope amongst patients and IBD healthcare providers.
- Utilize telemedicine to reach patients and service areas that may not have access to as many IBD specialists.
- Access to IBD case managers/coordinators that help patients navigate the health care system, make recommendations to improve their situation, and be a non-judgmental person to listen to their story.
- More resources, e.g. support groups and non-judgmental spaces for patients to talk and support each other.

CONCLUSION

- Participants experienced numerous psychosocial challenges as they strived to manage their diet, noting gaps in practical clinical knowledge and structured supports available from IBD healthcare providers.
- Participants noted the lack of supports from their healthcare team as a significant trigger in psychosocial challenges related to coping with changes in their diet, feelings of isolation, and emotional distress.
- Supports Antonovsky's¹⁰ concept of Salutogenesis which describes the origins of **health** and **wellness** in contrast with modern Western medicine's focus on studying the causes and origins of **disease** (Pathogenesis).
- Although participants' experience of illness and distress was discussed, participants also discussed feelings of acceptance, and noted without prompting how they are thriving despite their illness and food challenges.
- Participant recommendations provided were Salutogenic, looking at ways to have productive conversation with healthcare providers and patients alike to implement important guidelines and share stories that seek to educate and advocate to prevent future negative experiences for newly-diagnosed patients.
- Further patient-engaged research in this area is recommended to build a body of practical knowledge and resources that helps patients maintain hope as they navigate food challenges.
- We also suggest specifically examining the psychosocial impact of food on specific IBD patient groups, such as those who have had surgery for their IBD, in order to capture the full range and breadth of experience.

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