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 for Public Health, University of Calgary, Canada. The following informed our research project:

• Canada has one of the highest rates of IBD in the world;¹
• No one diet has been identified as effective for disease management or treatment;²
• Many patients believe diet affects their symptoms and often make dietary changes early on in diagnosis;³
• Food has cultural, social, psychological significance;⁴ almost all social events center around food, resulting in patient isolation from their communities due to dietary restrictions;⁵
• Patient experiences with food have not been adequately addressed in the literature, even though 90% of patients with IBD/Disease have gastrointestinal symptoms;⁶
• Our study seeks to understand the psychosocial impact of IBD on nutrition and diet for young adults. We aim to inform healthcare professionals, members of the IBD community, health policy makers, and others about the complex psychosocial nature of patient/relationship with food, as well as communicate patient perspectives and recommendations to improve outcomes.

METHODS

• 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-identified as diagnosed with IBD.
• PaCER methodology was used to engage patients in peer-to-peer co-designed qualitative research (Figure 1):

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

RESULTS

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

1. EXPERIENCING 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 stress or to regain control.
   Subcategories: a) Trick and Zor; b) Not Black and White; c) Struggling Ribs 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 patients garner knowledge about how certain foods make them feel.
   Subcategories: a) Starts with Good/Professional Guidance; b) Experimentation and Independent Research; c) Seeking Second Opinions; 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) Finding Abridge and After; b) Losing Comfort Foods; c) Navigating Social/Cultural Gatherings; d) Grief/Change of Diet Changes on Others; e) Revisiting Joy
4. ROLE OF SIGMA: 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) Outlining “Cures” and “Self-Advocacy

DISCUSSION

Participants described:• Having a complex psychosocial relationship with food.
• Constantly changing food rules and diets, 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 patient isolation from their communities due to dietary restrictions.
• Patient experiences with food have not being adequately addressed in the literature, even though 90% of patients with IBD/Disease have gastrointestinal symptoms.
• 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.
• The IMAGINE Chronic Disease Network, PaCER Teaching Team, Dr. Maria Santana, Dr. Humberto Ijion, and our participants and IBD community members who contributed to this research. The IMAGINE Network is supported by a grant from the Canadian Institute of Health Research SPOR Chronic Disease Network (Funding Reference Number: 1715-000-001) with funding from several partners.

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 teams that is significant trigger in psychosocial challenges related to coping with changes in their diet, feelings of isolation, and emotional distress.
• Participants recommended providing more focused support to manage IBD.

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 to increase awareness of issues and messages of hope amongst patients and IBD healthcare professionals.
• 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 helps patients navigate the healthcare system, make recommendations to improve their situation, and be a non-judgmental person to listen to their story.

REFERENCES


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