



Phenomenology and IBD: Living with and studying eating with inflammatory bowel disease

Catherine Morley and Heather Bonnell

In Senior Seminar (SS), the capstone course of Acadia University's Bachelor of Science in Nutrition program, Heather Bonnell presented the findings of her Honours research. The project was an exploration of eating experiences while living with Inflammatory Bowel Disease (IBD) for people with or without an ostomy, and implications for nutrition services. Heather had a unique opportunity as a researcher as she lives with IBD and is an ostomate¹. Catherine suggested collaborating on a conversation-style paper integrating Heather's reflection on the research, and her own work on incorporating meanings of eating, nutrition, and food when living with changed health status (CHS).

CM: What a unique opportunity for you to study the experiences of people who also live with IBD. Why did you want to undertake this study?

HB: I have lived with Crohn's disease (CD) for over 20 years, since I was a child. I have had an aggressive disease course, with short periods of remission, and frequent and severe flare-ups. I have had multiple surgeries including a bowel resection, gastrojejunostomy, and ileostomy. And, I have taken just about every available medication to treat my illness. Wanting to become a dietitian and to undertake this study were rooted in my experiences of struggling with eating for symptom control and quality of life.

There is very little published research on the lived experiences of those who live with IBD, and none with a specific dietetics focus. Dietetics is concerned with eating; IBD is a chronic digestive disease with huge implications for eating. While there are quite a few studies and meta-analyses that focus on nutrient absorption and different diet types (like low FODMAP, low fibre, Specific Carbohydrate Diet, etc), they seemed to be missing a vital element. How do humans actually deal with eating these prescribed foods? How have these diets impacted their lives? I wanted to learn what

happens when people return home from the dietitian's office, to understand how their disease has impacted their eating, and how that has impacted their lives. And, in turn, to inform the practice of dietitians and other health care professionals, to see what effects their advice has on people's lives. I was and am excited about the possibility of adding to the literature.

I am curious what interested you about my research ideas. Having not pursued IBD nutrition research in the past, why did you want to support me?

CM: For several reasons: 1) your commitment to doing research that would make a difference in practice, and thereby, the lives of people living with IBD is consistent with my own beliefs about the interrelationships between research and practice. 2) your interest in inquiry into the lived experience of eating aligned with my research on eating with CHS. 3) I saw your potential as a researcher. I believed (epistemologically) that conducting in-depth interviews would yield narratives that would affirm your personal experiences trying to access nutritional care, your desire to see change in care offered to people living with IBD, and how they can access that care.

While I have not studied IBD per se, there was a participant in my doctoral study (Morley, 2016) who lived with Crohn's disease. She told me about her efforts

¹ A colloquial term for a person who lives with an ostomy.

to feed her family while trying to control her own diet (mainly, by fasting) to manage or prevent symptoms, and her minute-to-minute monitoring of gut function. Her attention to 'feeding the family' was consistent with what I had read about (e.g., Devault, 1994) and had observed in clinical practice about family experiences of illness. That is, owing to illness, there are food and eating effects within families beyond what the person living with the condition experiences. She told me of clearing out some papers and finding her eldest's decades-old school project. The report was a 10 year old's view of the effect of Crohn's flare ups on the children in the family, and their efforts (then 7 and 10) to protect their mom. Knowing when to be quiet, when to encourage mommy to have a nap, saying they were not hungry so she did not feel the need to make food, and so on. She was heartbroken to learn about the effort her children had put into caretaking and protecting **her** when she was sick, and their efforts to make everything appear normal, all without her knowledge.

I had this in mind when we discussed your project. I was interested to see how what you learned would contribute; to learn about both the individual and the person in family/social settings. I was excited to think that you would create knowledge that would address the gap you had identified, that would build on my work, that would make an important contribution to the literature, and would set you on your way to becoming a researcher.

HB: The realization that narrative counted as academic research that could influence practice was a game-changer for me. Because of my complicated IBD history and the resistance (and lack of knowledge) I encountered from medical professionals and dietitians about the potential for diet to help manage my symptoms, I was made to believe that my experiences were not real, that what I experienced was "all in my head", and that my perspective was not important. Learning that people's stories have value and have the potential to challenge norms in healthcare was a breakthrough.

Undertaking this project taught me that humans are complicated, and that the 'truth' can be a subjective thing. People report what they consider to be true from their imperfect memories filtered through emotions. There is no right question just as there is no 'right' answer. When asking questions about human experience, the only 'right' thing is human connection. With genuine, unconditional attention, people may choose to open

up their lives to you. And they may not utter a word. Humans are complex. Some questions, especially those that lurk in murky waters of subjective reality, cannot be measured. Quantitative research cannot answer all the questions. Some questions can only be answered by recalling experiences and reflecting on what makes them meaningful.

CM: It was Mezirow (1991) who referred to a 'perspective transformation'. In my view, that is the best possible outcome of participating in research. What you have mentioned reminds me of Schon's (1984) metaphor:

In the varied topography of professional practice, there is a high, hard ground where practitioners can make effective use of research-based theory and technique, and there is a swampy lowland where situations are confusing "messes" incapable of technical solution. The difficulty is that the problems of the high ground, however great their technical interest, are often relatively unimportant to clients or to the larger society, while in the swamp are the problems of greatest human concern. (p. 42)

It puzzles me that given excellent pieces of writing about limits to technical rationality, it continues to dominate what counts as knowledge or evidence in dietetics.

HB: Everything is muddy. The problem is there are not simple answers when working with challenging circumstances. It's hard to get to the bottom of something that is, in its essence, bottomless. This is where there is opportunity for qualitative research. I think when people see the kinds of results that come from rigorous qualitative inquiry, they will see that things are not 'black and white'.

CM: What surprised you about your findings?

HB: One of the most surprising findings was the impact of IBD and interactions with health professionals on mental health. I had not realized how traumatic eating could be for people. Negative eating experiences affected some participants for years. Because IBD is a digestive illness, foods eaten during times of illness that cause symptoms were banished (sometimes for life), to the exclusion of whole food groups in some cases. One participant told me she would not eat in public for years after her IBD diagnosis and ileostomy surgery. I also learned that the literature does not reflect the interest level of dietitians in this topic. There was a lot of interest from dietitians when I spoke about my

project at conferences and meetings this past year. These dietitians confirmed that they had encountered the challenges I had reported in their practice, even though these experiences are not written about in the academic literature.

CM: That speaks to gaps in knowledge generation and mobilization. We return to what counts as knowledge. I am not censuring when I say that dietetic research attention has been focused on figuring out appropriate diet therapy; that was/is needed. It is a recent phenomenon that people's experiences could count as knowledge to inform the practice of dietitians, and to inform ongoing research. This also emphasizes my observation about the value to our profession, and for all people living with IBD, of you, as a person living with IBD, to be in a position to undertake dietetic research.

HB: How did you react to the findings?

CM: There was affirmation of my ontology that CHS changes everything about how people think about food and eating, whether they want to be around other people, dealing with body waste, and their grief about what has gone, wishing they could go back to the carefree way eating had been. The notion of 'gut privilege' that emerged from your findings was intriguing. I was saddened to learn how poorly people had been treated by health professionals, affirming that words can hurt (I am thinking about your report that one participant had a nurse refer to her as "stinky"). People seeking nutritional care are vulnerable, and it is important we recognize our power in all interactions, that we can help/hinder someone for life. People might not remember us as individuals but they will remember how it felt to be helped to learn to live/eat with their new situation. This speaks to our responsibility to work on developing truly supportive/trusting relationships with people who put their trust in us.

HB: When I presented my project to the Senior Seminar class, what did you observe was the class' reaction to the findings (since I was busy presenting)?

CM The class was impressed with what you managed to learn in a short period of time as an undergraduate researcher. There were tears, heads shaking in disbelief, and looks of shock at some of what you reported. Your findings were important to the class' transformational learning. Because of what you presented, those aspiring to be dietitians expressed a resounding communal gulp. Like, holy cow, this job is going to challenge me emotionally and I will be VERY responsible for contributing to the

physical, spiritual, social, and emotional well-being of people living, not only with IBD, but with all conditions that affect what, how, and when people can eat.

What would you like to see happen as a result of having done this thesis, and how do you feel about continuing on as a researcher?

HB: There is substantial evidence that nutrition care for IBD is important. From the literature, my personal illness experiences, and from listening to the stories of others, nutrition care is not seen as important by every treating physician. The focus is on medication, diagnostic imaging/procedures, and bloodwork. While that is an important part of IBD care, the primary function of the digestive tract to digest food/absorb nutrients is all but forgotten. Future research directions are to conduct a mixed methods study in which biochemical and clinical indicators of disease are assessed along with lived-experience accounts to investigate any connections. I would love to explore how mental health is affected by and affects disease activity through a nutritional lens. It is apparent that food availability and perceived safety is a barrier to participating in normal social behaviour which, in turn, affects mental health. I believe that connection is very important to explore further.

Re: continuing with research, I think I found my calling. I knew when I began studying Nutrition and Dietetics that I wanted to do research, but research in a laboratory environment did not feel right to me. It is important that I fulfill my desire to conduct socially-just research, and I love connecting with people. We need to acknowledge that food, nutrition, and eating, in the context of a person's life, are inextricable from IBD care. I am determined to continue to explore that idea and advocate for people with IBD.

CM: How, if at all, did your research experience connect with what you had learned in courses?

A key element from coursework that stands out is the use of EFG² parameters in nutrition assessment (Morley, 2013). Learning about a person's eating experiences and their eating environments (E), and their relationships with and through food (F) were the foundations of my research. The E parameters also include where a person eats, and under what conditions.

2 Anthropometrics (A), Biochemical (B), Clinical (C), and Dietary (D) provide vital information about a person's health; Eating/ Environment (E); Food, Family, and Friends (F); and Gender/ Genetics (G) help us learn how a person lives their life.

The F parameters are about with whom a person eats, and how a person relates to and interacts with food when other people are present. The G parameters (Gender; Genomics) affect every other parameter; experiences vary widely depending on gender identity and genetic makeup. The literature, from a nutrition lens, addresses the ABCDs of IBD, the EFG are missing.

I used the Organizational Framework For Examining Nutrition Narratives (OFFENN)³ that you developed and that we learned about in courses in the analysis of participants' narratives (Morley, 2016). It was useful in organizing and making sense of the material I gathered. How did you come to develop the OFFENN?

CM: The OFFENN is a product of my doctoral research that emerged from analysis of interviews I conducted with women who were living with CHS. I asked about how they managed feeding responsibility for their families while taking care of their own specific nutritional needs (as described above, the minute-by-minute assessment of one's bodily function). Developing a conceptual framework was not what I anticipated producing nor something I had to do for the degree however, the nutrition narratives of the respondents were so similar in terms of types of information provided, the complex nature of feeding within their households, and their views of their roles in taking care of their families despite being very sick, it seemed an obvious step to 'draw a picture' of the ways personal narratives were told. Prior to my doctoral studies, when I worked as a dietitian in a cancer clinic, I witnessed the emotional connections people had with eating or with feeding a loved one who was sick yet these were not covered in my training nor were they addressed in the literature. The eating behaviour change models did not fit with the kind of work I was doing. The premise of these models is that someone consults a dietitian to receive advice and then implements it and changes their eating habits. The people I worked with were trying to cope with challenging barriers to eating, completely altered family eating rituals and routines that lead to the emotional load related to family dynamics around eating and feeding. When I developed the OFFENN framework, I realized I was helping my younger self figure out how to approach challenging counselling scenarios. I have since tested it

with dietitians who have found it useful in making sense of nutrition narratives. And I have found the framework useful in working with students and novice dietitians in helping them acquire counselling skills by learning to 'follow the narrative', to make sense of what they hear in order to form effective relationships with those who seek our advice and then to offer "the kind of help that helps" (Wilbur, 1998).

I recall my defence committee members (PhD dietitians, a nurse, and three psychologists) commenting on the uniqueness of the framework as it specifically relates to eating, rather than generic 'health behaviours'. I have always felt that eating was so much more complex than other health behaviours so that those models were too reductive to be of use to dietitians.

It is a relatively recent phenomena for people living with a chronic condition to become registered dietitians, and a development that is very welcome. I'm wondering as such a person, how do you feel your life experience will influence your work as a dietitian?

HB: There is a trust that comes along with sharing something as life-altering as a serious illness. I understand what it is like to live with IBD and to be lost, in pain, and to feel hopeless and helpless. I hope the people I work with will feel safe in sharing their difficulties with me. Because of living with the illness and receiving little dietary guidance, I hope I am able to use what I have learned to help them manage their symptoms and enhance the recovery process. I am determined to influence nutrition care, and to advocate for the inclusion of lived experiences in health assessments of people with IBD. There is a role for dietitians to advocate for nutrition care, and in advocating, know what the impact of offering care (or not) are to spiritual, emotional, and mental, in addition to physical well-being (Graff, Walker, and Bernstein, 2009; Bryne et al., 2017). Dietitians are uniquely placed in the healthcare team in that they have the opportunity to hear people's stories and they are trained in health science.

CM: You are poised at the right time to make this happen. Others before you have advocated for client-centredness and the importance of acknowledging and respecting a person's story. It is how healing happens. I am excited for you as you continue on your research and practice journey. Thank you for sharing your story.

3 Details from narratives are assessed as being from four domains (Personal, Household, Beyond Household, and Unthoughts); experiences in each domain are conveyed through four filters (Events/Facts, Values/Beliefs, Actions, Emotions/Reflections).

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