CUMMING SCHOOL OF MEDICINE

Living with Inflammatory Bowel Disease

Patient Engagement Research Study Report

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The One Hundred Faces of IBD, Crohn's and Colitis

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Report Index

Inflammatory Bowel Diseases (IBD)

Inflammatory Bowel Diseases(IBD), which include Crohn's disease(CD) and ulcerative colitis(UC), are chronic autoimmune diseases with no cure. Crohn's Colitis Canada estimated the annual cost from IBD in 2012 in Canada was 2.8 billion dollars ($11,900 per/ patient). Direct medical costs exceeded 1.2 billion dollars per year, and the indirect costs to society and patients were estimated at over 1.6 billion dollars, including loss of productivity and patient out of pocket expenses (CCFC, 2012). Canada has one of the highest reported prevalence rates of IBD in the world; approximately 233,000 Canadians, 0.7% of the population, are living with IBD (CCFC, 2012). The reported increase in incidence of these diseases (Molodecky, 2012) is attributed to gene, microbial and environmental factors. Cultural westernization such as the increase in caesarian births, the reduction of breastfeeding rates (reducing the introduction of gut flora 'seeding') and changes in the western diet are also being attributed.

Patients with IBD, Crohn's disease and Ulcerative Colitis experience a wide range of symptoms due to "focal lesions that progress to ulcerations that can extend through the bowel wall and result in the development of fistulas, abscesses, and strictures", (Dalal, & Chang, 2015). IBD, Crohn's and Colitis may actually be up to 200 different and distinct diseases that all affect the GI tract. These are linked by reactions to microbes that are present in the GI tract including "barrier function, wound healing, autophagy, immune balance, and stress responses" Dalal and Chang (2015) Managing symptoms, can impact quality of life, personal relationships, and employment. Patients can require the assistance of multiple health care specialists in managing their health and disease.

Background and Rationale

This project is part of an internship undertaken within the Patient and Community Engagement Research (PaCER) training at the O'Brien Institute for Public Health, Community Health Services, and the Cumming School of Medicine at the University of Calgary. The Inflammatory Bowel Disease Clinic at the University of Calgary has supported this research project, with an assumption that gaining a better understanding of patients and patient experience can contribute to the design of the new centralized IBD Unit. We are working within the context of the development of a centralized IBD Unit, which will provide an innovative approach to the care and management of IBD by housing the services patients require in one central location. This centralized unit would allow patients to access care, medical tests, research and education in a more coordinated and patient centered way, contributing to the overall quality of life for patients, their families and the community.

Over the past decade the IBD Clinic at the University of Calgary has been recognized as an international leader in IBD care and research. The proposed centralized unit would allow patients to access care, medical tests, research and education in a more coordinated and patient centered way and increase the quality of life for patients, their families and community. Current models of chronic disease management suggest patient empowerment leads to better self-management and greater adherence to medications. Baars et al (2010) report that 81% of surveyed IBD patients indicated a strong desire to be actively involved in the decision making process. However, Siegel (2012) cautions that not all patients want to share in decision making. Previously, Husain & Triadafilopoulos reported that the two most significant interventions to dramatically improve quality of life are patient education and appropriate treatment of depression and anxiety (2004). The patient-physician relationship is another important factor in patient care. Lack of encouragement and physician support can create significant barriers to patient engagement, and may result in patients withholding their concerns about medications from their physician (Husain & Triadafilopoulos, 2004).

Methods:

Participant Selection and Recruitment

We recruited adult patients who have IBD: Crohn's disease or Ulcerative colitis and adult family members who have assisted or been affected during the management of the disease. Participant recruitment criteria include:

- Age of 18 years and over,
- Patients with Inflammatory Bowel Disease (IBD), which includes Crohn's disease and ulcerative colitis, or
- Family members self-identifying as having had experience with an IBD patient over the age of 18,
- Speak fluent English,
- Consent to participate in focus groups and/or individual semi-structured interviews.

Efforts were made to obtain a diverse sample regarding age, gender, and type of IBD. The number of patient participants was based on the ability to ensure a diverse cross-section of patient experiences.

During recruitment, participants were informed that PaCER was not affiliated with any health agency. Their decision on whether to participate would not affect their ability to receive services or treatments and would not affect their quality of care. A PaCER researcher described the purpose of the study, and provided a Participant Invitation Letter, Participant Consent Form.

1. We used participant lists from the Inflammatory Bowel Disease Symposium held November 1, 2014. Recruits self-identified their interest in participating in future PaCER research.

2. Personal Contacts of the PaCER Researchers. We identified potential participants from within our personal contacts.
3. Research Project Coordinator at the IBD Clinic assisted in connecting PaCER researchers with participants who communicated an interest in participating in this study. A PaCER Intern facilitated the informed consent process and further explained the procedures.

Methodology

The goal of the study was to explore the lived experiences of people with Inflammatory Bowel Disease (IBD) and their family members in order to gain a deeper understanding of how people manage their disease. The overarching research question guiding the study was: *What is it like to live with IBD?*

The overall approach was one of Participatory Grounded theory wherein iterative data collection and analysis is used to build theory related to new social experiences, relationships and processes. Participants are directly involved in the co design of the study, setting the probable scope of responses and how to best tap rich and diverse data. Data collection methods are chosen to provide opportunities to explore multiple perspectives in order to inform emerging theory and interrogate findings.

The PaCER (Patient and Community Engagement Research) method addresses both the participatory nature of the research and the grounded theory iterative process. The framework below ensures that patients and family members are engaged meaningfully throughout the research process. There are three stages to this method: SET, COLLECT and REFLECT (Marlett & Emes, 2010). The SET and REFLECT phases reinforce the goal of meaningful patient and community involvement and contextual validity.

Set: This initial phase culminates in a day-long co design process where representative participants share experiences and become advisors to help set the study's direction and goals by clarifying protocols (recruitment, locations, alliances), questions and data collection. The SET data is explored to establish the potential scope and focus of the study

We used three data sources from the SET focus group: digital audio recording, flip chart notes, and process notes. During the SET focus group, participants reveiwed the flip chart notes and, as a group, collectively determine the main topics that are important to the study. After the SET focus group, we transcribed the flip chart notes into a text document, listened to the audio recording and supplemented the text document with additional details from the recording. The process notes were typed into a separate text document. We familiarized ourselves with all of the data, identifying major topics, and refining the guiding questions for the Collect phase.

Collect: During this phase, data collection techniques are chosen to best enable consolidation and to challenge previous data and findings. Methods could include field observation, questionnaires, surveys, focus groups, interviews or a combination of methods. We used a combination of focus groups and semi structured interviews.

Semi structured interviews We invited participants to share their thoughts on how their lives have been affected by IBD.. Each interview took between 60 and 90 minutes and were conducted at the participant's home, in a public place of mutual convenience or over the phone. We transcribed data from the interviews, coded each comment, and through constant comparison, our data was added and expanded until we had data saturation. “Data saturation occurs when the researcher is no longer hearing or seeing new information” (Siegle, 2002). When no new information was being heard, no further interviews were conducted.

Participants shared their experiences guided by the following prompts:

1) What is it like to live with IBD?
2) How has IBD affected your life?

   Prompts: Job/Employment
   Lifestyle
   Travel
   Physical Activities
   Family and Relationships
   Dietary Restrictions
3) What is it like when you visit your doctor?

   Prompts: GI, Family Doctor, Healthcare Professional, and Emergency Room Physician
   a. How much information would you like to receive about treatment choices?
   b. What other resources would help you make personal decisions?

      Prompt: How do you make decisions about treatment?
4) Is there anything else that helps you?
5) Is there anything that is missing that you would find useful?
6) What have you learned that may be helpful for others that have been diagnosed with IBD?

Focus groups: Three focus groups were held, each with data soureces: Detailed flip chart notes, process recording and audio recording. Focus groups lasted five hours. In the morning the group shared experiences using the open questions and prompts suggested by the set focus group and the previous data events.

Over lunch the flip charts these were displayed on flip chart paper around the meeting room and the participants were able to indicate which pieces of data resonated with them and for what reasons, identify the data they agreed with, identify the data they disagreed with and were able to freely add comments and additional information.

A PaCER Intern summarizes and records each statement made by participants within each focus group. These comments are then displayed on flip chart paper around the meeting room for both structurally guided and patient-led refinement to obtain further data

We transcribed the digital audio-recordings of the COLLECT focus groups and individual interviews into text documents. Individually, we (PaCER research team members) read and re-read the documents to get a general sense of the data. As a team, we worked together to assign codes to segments of text that corresponded to the themes in the focus groups. The codes were not pre-determined and emerged as we analyzed the data. We then incorporated the interview data into the core categories, looking for new information until we reached data saturation. We grouped the codes together into core and sub categories and compared text segments within the same coding category for similarities and differences. By assessing data and categorizing into core and sub categories using constant comparison, we organized and grouped the data into increasingly refined categories that describe the experiences of patients and families living with Inflammatory

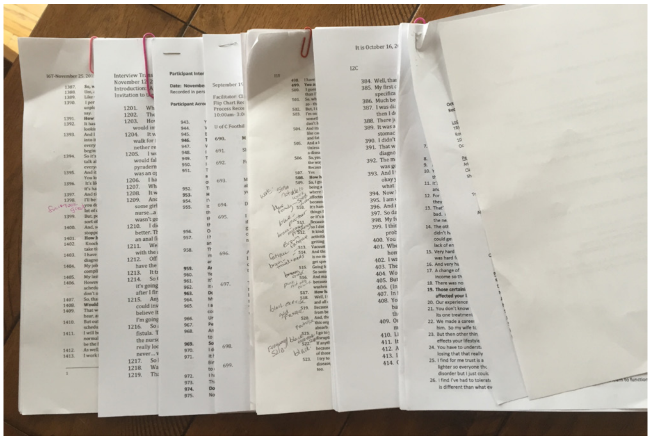
Bowel Disease. This method of analysis is generally consistent with the grounded theory method (Glaser, 1992; Glaser & Strauss, 1967).

Reflect: This final phase invites participants in the SET focus group to review the findings and analysis with the PaCER team and make recommendations regarding information utilization and need for future research.

We presented the main themes from our analysis of the COLLECT phase to original SET focus group participants to seek their reflections. The participants explored whether the COLLECT findings reflected both their individual and collective experiences while respecting differences. They participated in developing the themes and the emerging theory. They were then invited to engage by giving input on how the knowledge gained from the study could best be disseminated and used, and whether further research is necessary. We analyzed the data from the REFLECT focus group using a similar process to the SET analysis and our final findings will incorporate this analysis.

Analysis

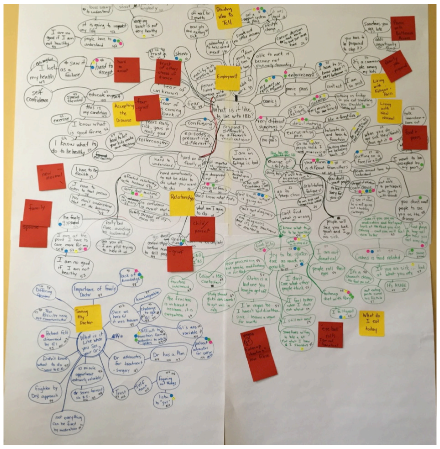
Data was transcribed and open coded and coded. We took the data apart and put it back together into categories. The following photos are samples of the data



Open Coding: the researchers transcribed each data collection event. The data was numbered to allow for open and axial coding.

Each data unit within the transcription was then systematically analyzed and added to the coding paradigm.

We then did axial coding to identify and select reoccurring and core categories. We systematically related these core categories to reoccurring and inter-related categories, adding further exploration and refinement of our findings.



Each data collection event built on the previous analysis.

Study Participants

We had 21 participants in the study. Participants were recruited in three ways. The largest number of participants came from a sign up list at the November 1, 2014 IBD Symposium at the University of Calgary Foothills Campus. We also had participants that came through the U of C IBD Clinic from an email fan-out of our recruitment poster to patients and the third method of recruiting was through word of mouth.

We had 8 male and 13 female participants. The age range of our group was between 25 and 65 years old. We had 3 participants diagnosed with Ulcerative colitis, 14 participants diagnosed with Crohn's Disease and 4 participants who have a family member with an IBD diagnosis. Two of the participants with an IBD diagnosis also had a family member that also had an IBD diagnosis.

Of our 21 participants, 15 participated in at least 1 focus group and 6 had an individual, 1-1 interview.

Code	**Gender**	**Age**	**IBD Connection**	**Year of Symptoms Onset**	**Year of Diagnosis**	**City of Diagnosis**	**City of Care**
S5G	M	45	Crohn’s	2005	2014	Calgary	Calgary
S3M	F	49	Crohn’s	2011	2011	Calgary	Calgary
S2B	F	60	Crohn’s	1974	1975	Calgary	Calgary
S1S	F	54	Crohn’s	1980	2013	Calgary	Calgary
S4S	M	27	Family Member				
C8S2	F	49	UC/Family Member	2013	2013	Calgary	Calgary
C9D2	F	58	UC	1970	2001	Calgary	Calgary
C6S	F	55	Crohn’s/ Family Member	1987	2007	Calgary	Calgary
C1K	M	49	Crohn’s	1977	1977	Winnipeg	Calgary
C3M	F	45	Crohn’s	1982	1986	Vancouver	Calgary
C2D	F	60	Crohn’s	1988	1990	Winnipeg	Calgary
C4A	M	59	Crohn’s	1994 2009	1994 2009	Newcastle Calgary	Newcastle Calgary
C10B	M	65	Family Member				
C5M2	F	57	Family Member				
C7J	M	58	Family Member				

I4R	M	47	UC	2004	2005	Calgary	Calgary
I1Y	F	41	Crohn’s	1990’s	2000	Calgary	Calgary
I2C	F	62	Crohn’s	1994	1994	Calgary	Calgary
I3S	F	54	Crohn’s	2011	2012	Calgary	Calgary
I5L	F	28	Crohn’s	2012	2013	Peace River	Peace River Calgary Grande Prairie
I6T	M	25	Crohn’s	2012	2013	Peace River	Calgary

Participants between ages of 18-65: 21
Participants over age of 65: 0
Participants that withdrew from study: 0
Coding: C / S = Focus Group Participant
Coding: I= Individual Interview

Results Introduction

Participants identified 4 main areas of impact as a result of living with IBD. The disease commences with a wide variety of symptoms and their manifestations and these symptoms lead patients to seek out medical assistance. The medical system presents multiple challenges as the patient moves through diagnosis and treatment. Patients reported that these experiences generated a transformation of their daily life, what they often referred as their ‘new normal’. It stands to reason, this new normal, will effect their family, social situations and employment.
“It’s not completely normal for sure, but it’s is a heck of a lot better than it was.”(1372)

1. The Manifestations of IBD

Inflammatory Bowel Disease can manifest anywhere in the digestive tract, from mouth to anus. Patients seek medical help for a wide range of single or multiple symptoms. Living with the manifestations of these symptoms is often more challenging than the symptom itself. Physical, nutritional, social, and emotional issues are common.

> *"…the problem with this disease, there are so many ways it presents itself in each individual patient. (It) is really hard to say you're going to possibly have this happen when it may not happen at all in the next person. (253)*

Physical Manifestations

Each of the quotes below demonstrates how the manifestation of IBD presented very differently in the individual and to the medical community.

-"(I)…went to the hospital because I couldn't stand or walk properly" (1076)

-If I didn't have to go to emergency with a major blockage I still wouldn't have figured out that I had Crohn's. (712) (I)…had very few symptoms" (731)

-" It wasn't actually in the gut the initial stuff…I had arthritis…sores all over my arms, legs, and in my mouth and in my nether regions…"(1204)

-"(daughter to parent)…should I call 911 now?...I am on the toilet just bawling…I said yeah, I can't move" (723).

The reality of living with IBD is understanding that "…there is no list they can give you as everybody is so different." (71) Therefore, the patients in our study discussed living with a wide range of symptoms with varying degrees of severity. A patient may have one or multiple symptoms at one time that may or may not be present in subsequent flares. "I have had 3 major episodes in my life and they have all presented differently. (9) "It's a chronic condition; it ebbs and flows". (502)

Nutrition Absorption/Dietary Issues

The severity and the location of a patient’s IBD will have specific dietary implications. Patients discussed a wide range of nutritional issues, which had impacted their health or their ability to absorb nutrients.

Patients talked about that “…(they) are not getting all those nutrients from (their) food” (754)”…when you are depleted of vitamin D, vitamin B you can’t get your food in, you’ve been on the toilet all day. How many times do you do that?” (541) Or “…if I eat a large amount of fruit or vegetables, that don’t breakdown quickly, (I) could have a blockage. (748) Still others report “Anemic” (RFG) and “… low iron so I have to go for Venofer infusions.”(572)

Patients therefore have wide-ranging attitudes, views and nutritional complexities that are ultimately viewed as symptoms of IBD. “…Crohn’s is food related big time”.(57)

Social Manifestations

The social reality of living with the symptoms listed for IBD are often as challenging as the actual symptom itself. “Panic Poos” (3) “The first word that comes to mind is panic”(2) It is “…having to know where the washrooms are…” (34)(409) Whether at work “…running to the bathroom…”(705) Shopping… when you know you “have had accidents in the mall…” (706) or with physical activity...”(521) The reality of living with IBD can be challenging. The requirement of frequent bathroom usage and needing to know where the bathrooms are can make it “…difficult to explain to people” (1395) or it can become “...a common joke…” “…After a while you start saying no because you might just have to run to the washroom a million times so I don’t want to go out in public” (511)

Going out in public also presents the challenge of explaining the need for increased bathroom use, bodily function challenges or physical changes... “I don’t want to tell anybody about that, “oh my god that’s uncomfortable…”(1454) One participant even reported that a… “nurse asked do you go to the bathroom a lot?”…my daughter (needed to explain) that I have Crohn’s disease…” (138) Another participant discussed the experience… ”You will be losing weight and people will say you look great and I’m like, I’m sick.” (50)

Fatigue is another symptom that has far reaching manifestations for patients, their families and employment. "…just trying to get through the normal day to day activities,…like getting up, and doing your laundry, and showering and all of those things. Vacuuming, getting groceries some days those are really hard to do, especially if you are working. (512)(513) Sometimes "…I would just like to have the time and energy to do my dishes and not dump everything on my partner." (1169) Or perhaps at "…the end of the day and everybody else is going out after work and (I) just can't" (529) because of fatigue.

Emotional/Psychological Manifestations

The challenge of living with the IBD symptoms, subsequent pain and social issues frequently cause emotional and psychological distress. Like the social challenges, these emotional issues are complex. Many study participants reported that they "…(were) feeling exhausted. You can't help but feel moody." (542) Or that "…the level of irritability was a direct result of being …in the pain I was in." (1451) Another participant stated that, "It's really easy to feel down and depressed when you're very ill and wondering when this is going to end. (536) It was also said "I'm on antidepressants which I needed to be on; (it) is common for people with chronic illness."(779)

We also heard that IBD symptoms can cause "embarrassment" (RFG). "That is the hardest for me, the embarrassment".(4) "And it's really controlled your life…where you don't have the same dignity as before"(706) The symptoms can lead to a loss of control. For example "…those cramps and the pain that goes with it and you go oh-oh there it goes again. It's like it takes over you. (706) One patient shared how they dealt with their personal loss of control. "I didn't have the psychological piece (care), didn't have the coaching…so now I have a coach which helps me take more control." (7790

2. Medical System Challenges

The current medical system and care experienced by patients presented many challenges. Four main issues were identified in this area. These included the variability of care and physician experience, the patient not feeling heard, the physician only seeing one piece of the patient and the patients care plan which includes the relationship needed between the physician and patient to reach the most successful outcomes for patients.

> *"You don't know what to do, you don't know what's going on. You can't get a diagnosis or its one diagnosis and its one treatment or another." (21)*

Doctor and Experience Care Varies

The variability of care and physician experiences covered the spectrum from simply, "I found it variable"(95) to "It was mind blowing how different the experience was."(94). The diversity in the these experiences were quite immense and speak to the radical diversity in education, knowledge and ability for physicians to connect and share information within colleagues and patients. Participants acknowledged that, "It is the best team here in the world. We are lucky to be here and not somewhere else"(713) and yet they also expressed, "…it's exhausting the amount of medical professionals, more like GP's and nurse's and those sort of people, that have zero idea about it…it feels like they have no idea what Crohn's is."(1642). "There are some good health practitioners out there that help us and some that have compassion."(723)

This patient found, "She is very good at addressing concerns or anything she thinks might be a concern."(465). A noted variant in these was the following: "," She has been very thorough. I have made her be very thorough. I am not afraid to ask questions"(464). This patient made a clear and definitive choice to be fully engaged in her care and her physician accepted and met the challenge. Another family spoke of the differences in Edmonton and Calgary, "One of the doctors was very incompetent up there so we have to fly our son home (to Calgary) but those are the challenges of life."

The value and role of the family physician was found to be an absolutely crucial component to patient care and experience. When a foundation of trust and respect is formed and reciprocated, a patient will put great care and effort into maintaining and keeping that relationship: "My GP was not a great support"(121) while for others, when asked "Since you have multi-factorial things that play into your health…who is that one person on your health care team that you respect and depend on most?"(364)

was immediately and unequivocally answered with "my GP"(368) (373). That was validated further with the statement, "The way to make it work best is to go through your GP. They need to know everything, roughly, and get the reports for the specialists. The GP can combine it and make it a little more holistic."(370)(368) although that can take diligence and effort to make it work. Finding that connection is profoundly worthwhile as these patients explained, "My GP is just a walk in clinic doctor and for the first four years, we followed him to all of the clinics he worked at. We had to take control of our health."(372) Another positive experience was shared, "She is very thorough and has helped me through all the crap that I've had…she is really good about getting testing done and stuff. She shares information with my Gastro back and forth. She are really supportive…"(458).

One of the most profound comments provided was "…I don't think GP's have the knowledge or experience or an idea what it's all about when you consider the 100 faces of Crohn's and Colitis."(88) This was reflective to the GP's knowledge, or lack thereof (115), but more importantly captured the very essence of how very different this disease is seen. The "100 Faces of Crohn's and Colitis" (88) covers the spectrum of just how diverse each and every part of this disease can be present for each and every single patient living with it. As one patient so succinctly put it, "…it's a mess; if doctors are having a hard time grasping at it, I know I have a hard time grasping…grasping it" (1631). It can be easy to over focus as much as overlook things, "I stopped and thought, my GI is very thorough and they are awesome but I don't really think past that, he just looks at one area. I discovered my last physical in 2007"(87). This patient was a nurse and admitted that even in her profession, she was so focused on maintaining her care for Colitis, that she forgot to care for the rest of herself. Patients felt that "Physicians need to communicate more"(168) and would be greatly assisted if " GP's were more educated, it would help the GI's a lot too"(214)(215). And while some were pleased with the collaborative sharing between GP and GI (458)(1006), others weren't even sure if their GP was communicating with their GI (1145). There was a repeated theme of lack of knowledge and education of GP's, "I need to for sure advocate for myself as most family physicians don't really understand IBD and leave it up to the GI's, which is probably what they should do.(107) (115) (141)(205) (369). There was also common understanding that, "You can't expect a family physician that has a lot of patients to know everything about a certain disease but if they had the ability to aware"(581). The ability to be aware of the possible issues faced and to collaborate with the patient and other specialists to provide the necessary care.

Every participant found it a challenge to get a GI. "I had moved to Calgary and it took a long time to get a family doctor, someone who would understand and would actually make a referral to a specialist"(553). Add to that, the wait times, and "it was over a year at that time"(555). Other difficulties are faced when the physician leaves (563) or if you are not receiving adequate care. "My GI started me down there…and kept me right there. I'm bleeding and feeling worse so decided I was done and it was time for a transfer (to a new GI)"(103). That is not as easily said as done as "it was difficult to get a GI in the first place".(1331) Participating with studies provided access to nurse practitioners and in one case was how the patient managed to get another GI: "…the nurse practitioner said she would take me on in the meantime as part of the study and then would try to get me back into the clinic under another physician"(569).

The recognition and appreciation of GI's knowledge is prominent; "GI's are brilliant. The amount of knowledge they have is amazing. I feel like they need to share that with their patients"(168). "I will say we are pretty lucky here as a community that we do have the doctors and researchers."(123) Patients sincerely want to understand and hear more from their physicians. From a list of the possible side effects of the disease (245) to "How long I would be on the medication, side effects, would there be something I would be on down the road, like a different medication, along with how long does this medication work for?"(788). Patients wondered if "he (GI) gets that information down to other GI people as well…"(157) and they noted consistently that they "respond differently to different medications"(RFG). How that information is delivered is paramount to how it is received and can alter the acceptance of a treatment plan. One patient felt admonished by his physician, "I got hell from Dr.X for eating popcorn but I like popcorn. He said one of these days you'll end up with a blockage…and end up in hospital and you will be sorry"(422). Understanding the dynamic between the physician and patient is as important as understanding who the patient is. “He was trying really hard to get me to go on Humira by telling me how exciting it was that it was made from mouse proteins. I thought, wow, you are approaching this the wrong way, this is not convincing me.”(459) And there is concern that doctors can “make decisions based on their own belief” (RFG) and that “they have tunnel vision”(RFG) in their choice of treatment and managing of patients. An interesting discussion came down to the financial costs and repercussions of treatment: “Dr. X told me it would cost more for them to put me through this surgery than it would be to take this medication. That helped convince me to take the weekly Humira. I just didn’t want to do that to the public purse if I didn’t have to.”(497) Not only is this patient considering their personal health, they also do not wish to impact our society from a financial standpoint. The physician must be aware of all these things that the patient is considering in those very short appointment times.

Recommended, reliable resources that patients can use before and after appointments for further understanding and support is wanted. “You need to be able to have information at your fingertips, reliable and where you can get that from”(583). There is such a plethora of information on the internet that is can be overwhelming and often incorrect, so to “…have it actually given to me and say these are reliable sites you can look at”(582) would be a welcome resource. “Having that information about what it means to have the disease and how it can affect people differently”(579) because lack of information and the unknown can be frightening and upsetting to patients, “The doctor came in and said, you have colitis and walked away. I mean where was the education for me? There was nothing, nothing and I was sedated too”(148). This was supported as well by “…it was a scary time for me but also they didn’t give a lot of compassion or a lot of information”(556). The information seminars presented by the IBD group were very popular and patients felt they were vital especially for new patients (637) (RFG). They would like more of them and to be emailed of upcoming events (RFG).

“The way to make it work best is to go through your GP. They need to know everything, roughly, and get the reports for the specialists. The GP can combine it and make it a little more holistic.”(370)

What I’m saying is not being heard

“Everything is down to test results….I feel like it doesn’t matter what I say when I see my physician. It’s all just based on test results and that can be frustrating.” (571)

The complex symptoms and conditions that are a part of IBD can often lead to a difficult and long journey for patients to be diagnosed with Crohn’s or Ulcerative Colitis. Patients recognize and acknowledge that it can be a very difficult disease to diagnose (755, 782), but when they feel dismissed and not heard by the physician, it compounds the situation negatively. This can have a profound emotional impact on the patient (1326) and be highly destructive to the patient outcome as well as the patient physician relationship. (1071)

The lack of a proper diagnosis often left patients with feeling of despair and confusion as “You don’t know what to do, you don’t know what’s going on. You can’t get a diagnosis or its one diagnosis and its one treatment or another.” (21) (121). “When I came to her (GP) with painful diarrhea…she said ‘don’t worry about it, if it gets worse, go the hospital.”(713) The remaining choice led them to seek assistance through Hospital Emergency rooms but that too often resulted in further dismissal (1070, 1071) and fear. “…the GI I saw when I came through Emergency, truly frightened me, by be telling me I could try Remicade but if that didn’t work, then I’ve had it.”(99)

The effect of feeling unheard often resulted in the patient being disconnected from the process, from their physician and treatment. “Everything is down to test results….I feel like it doesn’t matter what I say when I see my physician. It’s all just based on test results and that can be frustrating.” (571). “whatever I am going through at the moment….doesn’t really make its way into their consideration of where to go with treatment.” (1492). The very prevalent and dangerous downside presented is the breakdown in the patient physician relationship and compliance with treatment. “She was really quite short with me….it was like pulling teeth to get things out of her (GI)” (1326). The result was non-compliance with further treatment, “I didn’t do anything about it as I was kind of put off by her and her attitude.”(1328) and yet this patient was clearly in need of further treatment. Respectful compassion is a two way street: The patient understands he/she may be the 40th person that physician has treated that day, but this patient is important too, they have value (RFN) and have the greatest understanding of their body and what is going on with it currently.(RFG)

“They only see a piece”

“…those individuals only see a piece, they don’t get to see the whole illness at work”(122). “You have to look at more than just the physical and doctors often get stuck here. There is the social and emotional and how does that all impact the pieces and this person” (352).

One of the most pronounced and significant areas of concern identified focused on the physician seeing beyond symptoms to the whole person (779). There is a desire to be seen in a holistic manner (640) but time, knowledge and specialty often limit the ability of the Physician to do this. The complexities inherent in diseases, such as Crohn’s and Colitis, requires Physicians to focus their abundant and ever growing knowledge, into specific fields of specialty and expertise. This provides immensely focused care that is deeply valued but also results in obstacles to full and complete patient care: “…those individuals only see a piece, they don’t get to see the whole illness at work”(122). “You have to look at more than just the physical and doctors often get stuck here. There is the social and emotional and how does that all impact the pieces and this person” (352).

The care and focus can be found to be too narrow: “…usually appointments are very geared to one thing….very short…but not looking at more of the greater picture of things” (641). As a result, patients often seek additional care separately: “I tend to go see my specialist for each thing”. This points to the problematic dilemma and difficulty presented to both the physician and patient. How can the physician: “…treat the whole person not just the symptoms” (779) when they do not see the patient or have the ability or expertise to treat all possible symptoms experienced by the patient? Patients appreciate the difficulty as well: “…the problem with this disease, there are so many ways it presents itself in each individual patient” (253). But these complexities do not eliminate the requirements patients have identified and are needing further assistance in to attain their level of wellness as "there are other physical/mental concerns impacted by my IBD" (RFG).

A number of very specific areas were identified as clearly missing in patient care:

Gynecological care for IBD patients. It was discussed that: "20% of woman have gynecological effects from Crohn's" (RFG). This speaks to awareness and education, to both the Physician and patient, to understand the connection and possible complications. "…it took 10 Gynecologists before someone made the connection" (RFG). Patients were very forthright and concerned by how their disease affected their sexuality, intimacy and relationships. "We are woman, when we don't feel sexy, we're not intimate." How patients feel about their disease and the impact on their sexuality "should be part of the initial consult" (345). This natural piece of our physicality and identity is often disregarded and, as a whole, not readily discussed due to societal judgement and fear. "And doctors don't talk to you about that (relationships and sexuality) (343). It is an indispensable conversation and fundamental to the design of holistic care and treating the whole patient.

Ophthalmology Care for IBD Patients. Patients identified concerns regarding the impact of the disease on their eyes, "There are eye issues you can get with IBD…" (254). For patients and physicians not familiar with complications of IBD, it becomes a matter of knowledge and education for both. " How is this eye disease impacting….because of the Crohn's…so trying to look at things a little bit more o the broader spectrum now." One patient describes the struggle to have it treated: "…I'm one of the few people that it kind of attacked my cornea and gave me Iritis. It took me 6 physicians to be able to diagnose that…" (578).

Dermatology Care for IBD Patients. Being able to resource dermatological care that has a greater understanding and interest in IBD is of utmost importance. "I have had side effects in the dermatology area and my GP sent me to someone and it was just a disaster. I then contacted my GI and he told me where I should go."(244) To be able to resource this type of focused specialty would be valued asset for IBD patients. Patient's want a "dermatologist who specializes in this"(239) (RFG) as well as "…one who can do skin surveillance for you"(240).

Pharmaceutical Consult for IBD Patients. The Pharmacists knowledge and understanding of the many medications and side effects is a highly underrated resource. “They are professionals, they really help.”(914) They are often the last line of safety, ensuring drugs are coordinated correctly and safely for the patient and a wealth of information and an opportunity for further detailed questions patients may have regarding their treatment medications. “ I can’t see specifically what the drugs are doing to fix the treatment or what actions these drugs are going to take on other parts of my body, and that would be interesting to know”(1548). These individuals become a crucial part of the care plan as: “They are pretty clued in if you go to the same one. They get to know you.”(913) and your disease (914) and support patients with updates and reminders of proper usage and dosage of medications as well as helping at times to coordinate delivery to the patient. “Have more of…a well-informed opinion on the drugs that I’m on.”(1549)

Specific Dietary Education for IBD Patients. Perhaps one of the most controversial and confusing areas patients vigorously identified repeatedly was Dietary Education for IBD (194)(195)(241). And most specifically they requested: “Crohn’s disease related dietary, not the Canada food guide dietary because that’s not going to help.”(197). Many patients have used dieticians, the internet and attempted to figure this out on their own initiative but it often led to further confusion as they didn’t understand which foods could be problematic or why. There is also a social component to food that can play on the emotional wellbeing of the patient as well as some stigma and blame: “That YOU caused it…you must eat poorly…what did you eat today?”(RFG) To have more definitive guidance for IBD patients could greatly alleviate many of these issues for patients, their families and physicians.

Mental Health Care for IBD Patients. Last but certainly not least in the minds of patients and families, in fact, they felt Mental Health Care is “Crucial” (SN) but currently missing. (194)(264)(269)(271)(RFG). “One component that I think has been missing from a lot of appointments is the mental health/psychological” (118). It’s extremely difficult to be at your best, feel confident about decisions that significantly impact their lives, such as medication and treatment: “We are working from a place of fear, we’re scared, what’s our prognosis and we’re feeling stuck. It would be a good thing if there was a therapist…”(143). Every participant agreed unanimously “…you do need support. Someone who is educated who can help you" (219)(RFG) and more specifically, educated care that understands the spectrum of IBD, "There are some in the city that deal specifically with Crohn's and Colitis patients so at least have some education of the disease" (272). Overall wellness includes the gut brain connection (120) and to not address and support it directly has a tangible, detrimental and negative impact on the success of a patient's wellness.

"You have to treat the whole person not just the symptoms. What was missing for me was the psychological treatment. I wasn't getting that piece of it and once I was, I started to get more control of my life around this."(779) Knowledge, support and control foster empowerment and acceptance. The use of a medical coach (RFG) was highly praised and garnered much interest and questions. For this patient, it was the last piece to make her care truly holistic: "That's what I mean by holistic…we've got the GI, we've got the surgeon, we've got the nutrition…but I didn't have the psychological piece, didn't have the coaching…now I have a coach which helps me take more control."(779)(RFG) And as another patient boldly stated, "…visual therapy, group therapy, family therapy. Just give us some therapy." (222) The idea of a "Holistic Approach (Education) Awareness Center: Where you meet with a professional to discuss your medical and psychological needs"(RFG) was offered by one patient and eagerly supported by participants.

Patients have unique insight earned through their personal journeys and strongly connected and supported a model of multidisciplinary faculties team approach (RFG). "The journey could be earlier with a model of multidisciplinary faculty's team approach. Something at the beginning." (RFG) Starting at the top, with medications and treatment, should be applied to every part of patient care to ensure the most powerful and positive outcomes.

My Care Plan

" Tell me everything about this, how does that work, how is it going to affect my disease, what's going to happen if that doesn't work, what's the plan ABCD"(792).

The relationship between the physician and patient needs to be nurtured in order to establish a level of reciprocal respect and trust. “Some are very good at talking to people and some of them are not” (1035). While the physician’s opportunity to foster trust is often limited to the very short time they have with each patient, it can be found and in many cases flourishes. “I find 10 minutes of Dr. X’s time…very good and extremely valuable. Many doctors seem very offhand but Dr. X is very focused and there is no BS in it” (96). “He does an incredibly good job…when I’m in the room with him, I feel like I am today his most important patient”(1490). The awareness that in that moment, the patient has the undivided attention of this physician, their expertise and vast knowledge, develops the initial bond and trust required for a successful partnership. “…He will sit with me for 30 minutes if I need it. I always have to wait for him, but that’s okay because I know he’ll give the time I need”(166). “I actually have his email and cell number so if I really need to reach Dr. X, I can” (1146). There is a delicate balance as many patients also feel like the “doctor doesn’t like me asking questions” (RFG) and many patients concurred with the statement of “I just want them to be okay with me asking questions” (1009) (RFG) which reflects an uncertainty of value felt by the patient and a loss of otherwise valuable time in their appointment.

Patients are often faced with life altering medical decisions that need to be made rapidly and while patients often look to outside resources to do further research (173)(RFG), their decisions are often based on the educated recommendations from their physicians. “I had been steadily going downhill on medications… but the doctor said…I’ll tell you now, the surgery will get you back up there. And as it turned out, he was dead right.”(97). There is trust placed in those decisions that has great value and potential for further growth. “I only had it really because Dr. X said you have no choice, you need it and I wouldn’t question his judgement…I wish I had it years before I did.”(158). So much that the patient wondered “should I have been given that option 2 or 3 years beforehand”(160) but noted that was a different GI providing care at that time. Fear is also a very real factor and deterrent for many patients “Dr. X is really sweet and really persistent and I am someone who is reluctant to take more drugs. It took her a while to convince me to go on injection, because it was a scary thing”(460). “…but once I did, I was like hey…this is like normal. I am much appreciative for that" (461). Once that trust is established, treatment decisions and compliance are more readily accepted. "When he put me on Humira, I didn't even check the side effects because I felt I trust him…"(172). "For every other medication I have taken, I always checked them out. But for him (GI) I just have so much confidence in him, I trust him, there is no question."(174). The patient felt "…I feel the relationship I have with my GI now…he is so on top of everything…I feel totally comfortable that he knows enough of that information (155).

It can feel like a leap of faith on the patients' part, but when the physician takes the time to reassure, to understand the patients concerns and advocate for what they believe to be the best treatment plan for this individual patient, the outcomes are highly positive. Not just on the treatment outcome, but on the overall satisfaction, emotional wellness and lifestyle for the patient. "Now I am on weekly Humira but it took a lot of coaxing from Dr. X." (394) and now "I'm like a normal person again, I just can't believe it!" The patience and kindness demonstrated by the physician made a significant difference for this patient and established an incredibly strong level of respect and trust that this patient can reflect on and confidently use to make future decisions. Patients also often rely on their own beliefs and need the reassurance that even if it conflicts with the physicians recommendations, that it won't destroy the relationship that has been established. The reciprocal respect and understanding was demonstrated when this patient chose to discontinue treatment, "My decision will be we will wait and have surgery if its needed…but since it's my decision, my GI said, 'that's fine, I needed to hear that from you…she was supportive of my decision"(776).

The physician communicating their objectives clearly with patients is vital and valued. "He told me, I'm a hawk, I'm known as a hawk. I don't start medication down there, I start up here. By the time you have the bowel disease, if we start lower, we don't know exactly what's going on and by the time the disease gets worse, it's like an out of control forest fire. So he believes in starting with Humira and biologics first. I really like his philosophy." (102) Patients greatly appreciate that treatment options and protocols have changed in a progressive manner that is benefiting their quality of life and that these opportunities are currently taking place. "…they said they're going to kick this in the ass, right away …we're going to go Remicade right away"(792). "…We are at a lucky time where we can have the discussion and not start at the bottom, we can begin with the better drugs at the top."(124) "I think back to the day when you had to start at the bottom of the pyramid…"(315). There are gaps and different philosophies between physicians however; "My GI started me 'down there' and I wasn't getting any better…she kept me right there" (103) which they felt was about treating the symptoms and not the cause (104)(RFG). Both patience and diligence are required on both side as "it's not just one disease that has one cure…figuring out which kind of medication is going to work for you is going to be different than others" (738)(RFG). There exists a piece of mind and relief felt when the treatment and options are clearly presented to the patient. "…it takes stress away from me….tell me now that this is what happens so I don't panic when it happens. This one might work for a while and then if it stops working then we are going to try this. So that I know he has a plan ABCD, so then I feel reassured that you know what you are doing and that I am in good hands"(791). "They give me warnings about…if we have to go to this…it means it's getting worse"(558). There is a great improvement in the mental outlook of a patient when information is given as it facilitates removing unnecessary worry about the unknown. Some physicians are more forward in their philosophies and the acceptance of such would be predicated on the level of trust between the patient and physician. One patient reported that, "He is assertive with his treatments" (1133). "There is no let's think about this for a while" (1134). "He has a plan" (1135) and the patient is completely confident with this because in her mind, "if he says do this, I do it…because he is THE Crohn's guy"(1140) and he has demonstrated that "you need something, you get it"(1136). Actions show the follow though, the sincere commitment and trust built within those actions.

To know that knowledge and compassionate understanding are being applied to the patients concerns and even more importantly, that the patient is contributing to the framework that will, in fact, become their personalized care plan. Patients want a collaborative approach (RFG), a holistic approach to care (RFG) and one that coordinates with access to other specialties (RFG). " Tell me everything about this, how does that work, how is it going to affect my disease, what's going to happen if that doesn't work, what's the plan ABCD"(792). The conversation questions must flow both directions with the physicians also asking questions of the patient. Patients believed there are basic questions the physician should be asking such as, "Do you need to see a nutritionist, do you need to see a psychologist and how are you dealing with this? (153) and "…if the doctor picks up on anything, using their intuition or the answers you give don't sit right, they should refer you to a therapist."(345) There was a consistent and vigorous conversation throughout the entire process that decisively placed responsibility and ownership on the patient to be educated on their disease, on available treatments, to resource others who have knowledge or experience but most of all to advocate for themselves. (RFG) These patients have seen many positives and negatives through their journey in the health care system and many have become a resource unto themselves as they recognized the strongest voice was but their own. (RFG) They have personally seen the value and benefit of relationships and how things can go wrong when the GP or a physician isn't coordinating everything (RFG) as well as collaboration between physicians, "…I wonder if he gets the information down to other GI people as well, as my sense is maybe not." After seeing how it can work well, "They work together and they worked with my hepatologist as well. They're really working as a team" (777), and having a coordinated and holistic approach was highly sought. "I want to know my options, understand risks and consequences and collaborate on the approach"(RFG)

"*Coming together is a beginning, staying together is progress, and working together is success."*
Henry Ford

3. Their New Normal

The pendulum is a metaphor brilliantly used by patients to describe the ever changing circumstances that IBD presents in their daily lives. It is in constant movement and the momentum and actions of the pendulum often leave the patient feeling a loss of control, but patients also take many actions to bolster and regain that control. Advocating, educating and understanding their disease and identifying their needs were extremely important in assisting them in finding their place of wellness.

> *"I find I've had to tolerate what is going on in your life, in terms of pain, and you learn to function and your norm is different than what everyone else's normal is."(26)*

The Emotional and Physical Pendulum

The common definition of pendulum is: "a body so suspended from a fixed point as to move to and fro by the action of gravity and acquired momentum." Patients described living with IBD as, "Not being on one end of the pendulum or another"(RFG). The changing variables patients encounter daily have an impact on its momentum. "…You take control and then lose control. Back and forth and back and forth"(RFG). The action of that pendulum is just as unique as each patient and that diversity makes it very difficult for those without the disease to appreciate what the patient truly experiences emotionally and physically.

Grief and Loss. These individual experiences that do not have one correct pattern or path, but can be a complicated journey (RFG) that is unique for each person. They are very real and patients are deeply impacted by these emotions. One patient felt the connection to their activities, "My job was gone, my health was gone, my fitness was gone. There was so much loss."(693) We often define ourselves by the activities we do, and to feel they have all been lost at one time is tremendously difficult. "For me, it felt like my life had been taken away from me."(693) It is when grieving a loss that we turn to the things that comfort us, but what if those are many of the things that you have lost as well? "The things that I love to do, I can't do anymore."(753) "And very hard emotionally to not be able to do what you want to do". (16) Common pieces of grief and loss are the feeling of no control and this was very evident with our research group as well. "It's out of your control, the lack of control over this disease."(696) and "I find it controlling me, this disease, instead of me having the control."(705) Loss of control can be very frightening as it quickly pushes the patient into the unknown and fear.

Stigma is one of the most unfortunate and damaging types of behavior shown to patients with any chronic disease and it is certainly present with IBD (275)(276). It was very interesting that a family member asked the question, "Is the issue of whether it's okay to have IBD a psychological issue that a lot of people have to deal with? Is there any stigma with it"(274). This brings up a number of fascinating issues, one being the different ways in which the disease is viewed from the perspective of the patient, the family member and others outside of that frame. There is such a misunderstanding and negative light placed on mental and psychological issues within our current society and health care system that it would be fair to say everyone connected to this framework would give a different answer. The question itself also speaks to the perspective of the family member. Certainly, there are psychological effects of having IBD but they are deeply immersed within the physical ramifications of having the disease. It is something to note for there are a number of disparities found between family member and patient views. This patient clarified it by adding," They might not totally understand what you're going through because they've never been down that path themselves."(653) Additionally, this patient added, "You don't want to look like you have it." Such a heavy statement for a disease that is considered by many to be an invisible chronic disease. There is a need within our society to be accepted by peers, to 'fit in' that we often least desire a characteristic that may make us appear different and this is no different for the IBD patient.

Denial Often an unconscious defense mechanism characterized by the refusal to acknowledge painful realities, thoughts or feelings and it is very much something many IBD patients experience. "But part of me was in denial. I knew what is was but I didn't really want to do down that road."(552) "I was in denial, I did not listen to my body. I refused…I was in denial when I was diagnosed. I said, no goddammit, I'm going to push through this".(702) Another patient has a large family history and received regular physicals for his employment but still questioned, "How could I have missed it, I have siblings with it. I thought that was because of this or this was because of that. I just explained it away."(712) This sentiment was repeated by another patient who watched her father decline and suffer with IBD. "…when you see your loved one going through that and you're having symptoms, you want to keep quiet because…I don't want to have a disease…give me another disease."(667) It's a very frightening reality and for many patients, denial is coping mechanism; "…I would just push it off, ignore the pain, keep going and push through."(729)

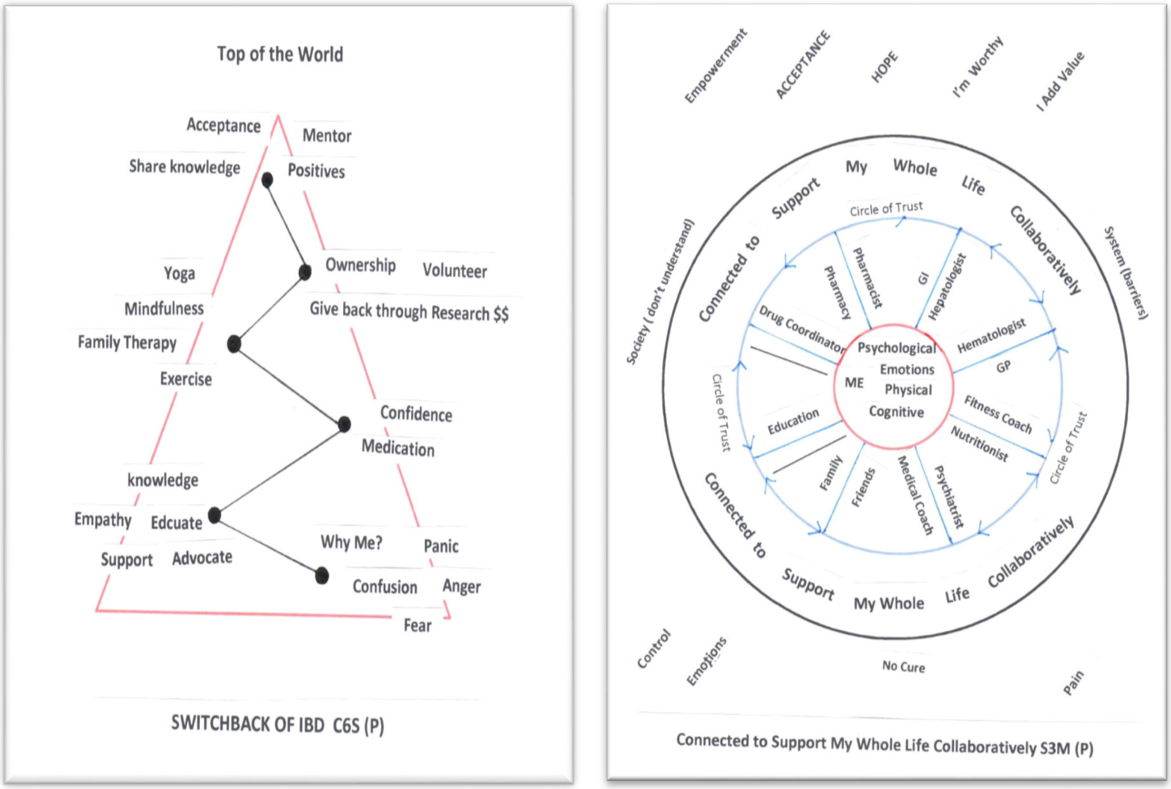
A New Normal Patients found their norm was different from others and that was often a painful realization for many while trying to appear as though they were not different. “It’s difficult because I’m good at putting on a face where I’m normal like everyone else”(27) but this only works while the patient feels well enough. Once feeling sick, that appearance of normal backfired as peers still expected the ‘well’ person the patient is trying to appear to be. “When I do get sick, people are like just take some Imodium and come out drinking with us, but you just can’t do that when you’re sick.”(27) For others, “I find I’ve had to tolerate what is going on in your life, in terms of pain, and you learn to function and your norm is different than what everyone else’s normal is.”(26) This patient stated, “I felt like I have been stripped of my norm.”(33) and yet another patient replied “but you can’t be normal when you are sick all the time(69) and this confirms the many struggles an IBD patient faces. Their norm incorporates how they see themselves, their identity and how they function and relate within society. One patient’s son was encouraged to modify his diet and he said no, “I want to be a normal kid, I want to eat pizza and drink beer (68) which in societies view, is normal 19 year old behavior. Finding that new place of normal can be a difficult transition and it takes time to adjust. “Being diagnosed is a step in itself and then all of the things we have had to access to make ourselves whatever normal we want to be (296) and “…you get into a headspace that becomes normal, you don’t really know what normal is anymore”(396). There were also extraordinary moments of reclaiming that feeling such as when this patient reluctantly began her Humira treatment, “And now I’m like a normal person again, I just can’t believe it!”(396). Another patient discovered pieces of it, “My function is normal but I’m tired, more tired than I should be”(398). Then there is the different view of normal held by the patient and their family members. One patient felt relatively good about where she was at but her family member did not agree, “And now I’m just thinking this is my new normal and my boyfriend is like, he is pissed, this is NOT normal”(756) and this can be very hard on the patient’s self-confidence in terms of how they are managing their disease as well as their personal relationships. Patients supported the belief, “I really think it’s different for everybody”(764)(RFG) and that “It’s not completely normal for sure, but it’s is a heck of a lot better than it was.”(1372) It was also felt that, “That’s what it’s like for me, I generally don’t care. It is what it is.”(961) and that “It doesn’t impact my life too much unless I’m having a full blown flare.”(962) Very much like the pendulum, the feelings and actions are very different and its momentum can be changed by the variables surrounding the patient.

Hiding Their Disease It was also revealed that many people struggle with revealing they have IBD. “…I still don’t want to tell anyone. Right now I am having a really bad flare and I’ve even avoiding telling my husband even though he has picked up on it.”(45) “And I didn’t tell anyone about that at all because that’s weird.”(1453) Both of these comments reflect the difficulty in disclosing the disease to others, even the closest people in our circles and that can lead to isolation and anger (RFG) as this patient described, “I don’t’ want to tell anybody about that, oh my god that’s uncomfortable, so that led to a sort of small amount of irritability towards and the situation and towards what was going on.”(1454) Some patients had experiences that helped them discover the best way to do so. “You have to go through a process. You almost have to grieve first and then go through certain steps before you are ready to tell people”(44). A repeated comment strongly held by all participants, was “I am not the disease”(RFG). This fundamental belief is absolutely instrumental is coming to terms with self-identity, self-acceptance and their confidence in sharing information with others because the reality of a lifelong chronic disease is not always received well by others, “You are like, no one wants to find out that, you know, you have a disease that you are going to have for the rest of your life…and its rather unpleasant.”(1669). It can be difficult for others to be empathetic and understanding to patients yet quite often, these are the first times others have heard of the disease so their initial response can often reflect shock or pity.

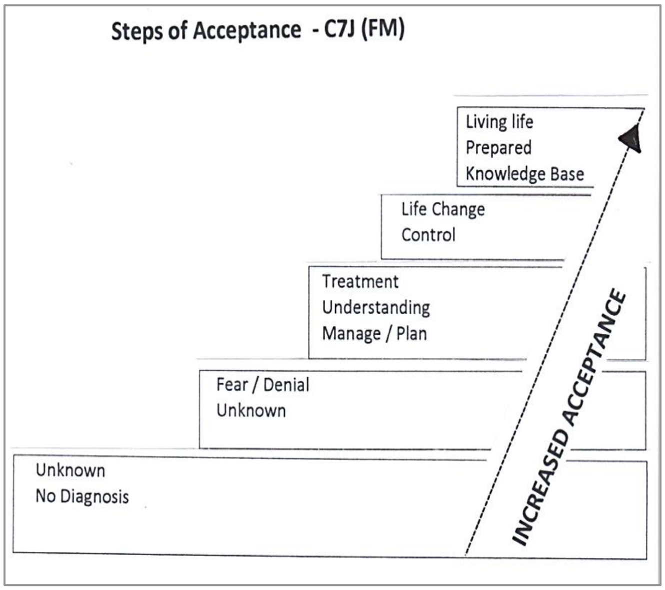
Fear It can be an overwhelming and immobilizing emotion. Fear of the disease, fear of the treatments, fear of the unknown, fear of the disease returning are all common issues IBD patients experience and acknowledge. “We are working from a place of fear, we’re scared, what’s our prognosis and we’re feeling stuck”(143). For some it has an unfortunate early start, “Our son was 12 and the Children’s Hospital wouldn’t accept him so he had to go to the adult GI world immediately…it was scary”(92). Others encounter it through negative and upsetting encounters with physicians lacking empathy, “Another GI I saw when I came through Emergency, truly frightened me and I don’t frighten easily, by telling me I could try Remicade but if that didn’t work, then I’ve had it”(99). While the physicians are extremely busy, they must be cognizant that the words and manner they choose to operate within can have a deep and lasting negative impact on the patient. Fear manifests itself through the mind and body as this patient describes, “It was also very scary because of my symptoms…I had pain in my stomach and I began to pass lots of blood”(389) “I didn’t know what was going on.” The unknown makes it harder to deal with. For this patient pilot, he had to be very careful with his medications as “I can’t fly with certain medications. That was pretty scary”(717). “I was so frightened that it would end my career”(731). Patients are also aware of how it is affecting them as this participant describes, “…it was completely irrational fears, it was like I was going to walk down the street and bang, Crohn’s can jump from behind the corner and get you.”(711) And that it can be with you at all times, “I worry about this”(750) is a very difficult and stressful place to work from. For many patients, “It’s a bit like a rollercoaster because it’s the unknown. You have good times and then all of a sudden it can hit and you don’t know when.(11)(10) “…I will just wake up and I will have all of these symptoms again….I am still fearful of that…”(1364) It’s not just the fear of the physical symptoms returning, there is fear surrounding the treatment and should it stop working effectively, “But I still also have the fear like I am going to have a flare. What if these meds stop working…”(1382). This is particularly worrisome for those patients who do not have another medication available to them to take. Some patients struggled greatly with the symptoms and long diagnosis and one voiced her concern, “I was thinking what if no one knows my story?(1308) “What if I just die and no one knows why?(1309) But for some, it was simply too much, “I just would rather be dead. I did not want to have a bag. I would rather die. I tried to commit suicide. I just couldn’t cope with it.”(1382) Raw situations that patients face, often alone, due to the fears that burden them.

Being stripped of self-esteem and confidence was routinely and commonly found (32)(40)(118). A family member described their son, “…not being able to participate in sports with his friends has stripped him of his self-esteem and confidence.”(31) “He feels almost broken. That he’s not worthwhile having a relationship”(333). Another advised, “Oh my god, I have lost my health. Now what am I going to do?”(47) Many patients felt that having the mental health/psychological effect of the disease being addressed would help immensely, "…really making sure they have the strategies of coping and helping with their confidence and self-esteem as I think that can be just as debilitating as the disease itself."(119)

Acceptance. A word that is simple to understand but is also complex, controversial and loaded with expectation. There was great debate and resulting divide within our group over this word, this concept, just as there was within the participants. The interesting piece observed, however, were the similarities that rose within the patient group and with the family members. Patients did not like the word or the implications it carried whereas the family members seemed perplexed that it was an issue. This was observed within the research team as well, heavily stressing the dynamic of the group, which consisted of two family members and one patient. During the Collect focus group, we asked participants to take part in an art exercise drawing out how they see having this disease, what the journey looks like to them. They were given no limitations or shown any examples prior to beginning and were given the tools to create with. This process was chosen as some family members on the team had drawn a rough sketch as a tool to help them with the work. The sole patient on the team was surprised at the linear process the family members saw the journey as and quickly drew out something very different, that was round, had movement and more complexity. It was a learning moment for both sides as they were just as shocked at the patients' drawing and the decision to have the focus group complete this exercise was just as valuable and interesting. The results showed two types of drawing. Family members saw and drew it as a linear picture whereas patients drew pictures with greater detail, pictures that had movement and meaning.



Two Patient Drawings



Family Member Drawing

The process to understanding and acceptance is just that, a process. There is no set standard, method or time frame that must be met. It's individual and personal. "I learned that it's okay to share that I have a disease and that it's going to impact my life and people around me have to understand that."(42) "This is my condition and educated them on it. Most people had not heard of it, so I started to spread the word and not worry."(43) "So what I have learned over the years is to just accept this. This is me."(697) This is not an easy process as for some patients, "I guess part of it is that I don't really know what it's like to not live with it"(500) and "…there is always something you have to think about…there is never a time that you don't have a break from it, so having IBD is something that's always there"(503). But slowly comes the understanding that, "It is not a reflection of me or who I am. I have a disease, I am not lazy. And that's it."(698) With that comes the ability to share and talk more comfortably about the disease (42)(1394).

Stress One of the most frequently identified triggers for participants was stress (RFG). "It's stress and affects your lifestyle. Its stress but you make choices."(23) This patient managed looking after her extended family well but when that was completed, "then all of a sudden it was back with vengeance. So yeah, it was stress."(719) This was supported by, "…most of my stress comes from when I'm sick"(965) as well as "and high stress…that stress is a real trigger"(749). Many patients agreed that being prepared and coming to their appointments with their question prepared and written down helped significantly, "that also alleviates stress and stress is a major trigger"(268).

Taking back control This was a crucial goal for these participants, "I was going to take control of my life. Of course the disease controls some aspects of my life, I would have no insight if I didn't think it did, but I just feel I am the one who has to live with the consequences of all the decisions, I have to advocate for myself and listen to my intuition. Usually when it's my body, it's usually right."(108) "I am no good if I am not healthy"(53). "I am in control of this body and I only have one, so I want to be able to ask questions and decide what I want to do". (134) These empowering decisions come with the recognition of patients' responsibility as well. "You have to take care of yourself, you can't rely on your doctor to take care of you. You have to realize what is going on. You are responsible".(210) "We had to take control of our own health."(372) Taking that a step further, this patient, "I always do my own follow up research after I leave my appointment"(171) which is incredibly important in both the education and confidence of the patient. "You just have to get on your own bandwagon and start searching."(228) Added to that is the awareness of slowing down and listening to one's body, "I have to pace myself"(699) which can be a challenge as patients often take advantage of feeling well. These patients acknowledged that and "…are trying to find strategies to help us to control, deal with it in a more effective way"(888). Listening to your gut and trusting your intuition are great motivators (RFG) as is being more active "I made a mental decision to be more active"(984). As this patient felt, consciously attending to his attitude made a big difference for him, "You can sit around feeling sorry for yourself or get out and do what everyone else is doing"(985). This included various types of exercise (1621)(323)(825)(616) (971)(615) as well as mindful activities like meditation and yoga (317)(324)(1114).

Part of the process is listening and following through with your intuition, "…intuitively you have to figure out that this is a result of my IBD…"(105) and this is supported by the statement, "…you have to advocate for yourself, advocate for your children and you just need to know intuitively to listen to your gut…"(106). That you "don't have to totally not do anything and be paralyzed by it, but you might have to make some concessions" (632) and that "I think it's important for people to know that everybody's different so what works for me, or what you've read on the internet, might not work for someone else". Taking a realistic and close examination of yourself is useful in identifying your personal health and vitality, "…you have to take account of yourself and say what are my strengths and what are my weakness"(878) and using these to achieve your goals.

Decision Making Participants were clear in wanting further information to aid in the decision making process, to be assured they are making the correct choices, understanding the ramifications of those choices, and looking beyond the current day, to their full futures as well. "I'm looking at the whole picture not just for today"(790). They stated, "I want to know a lot of information. I want to know the whole plan"(132) along with, "how long I would be on the medication, side effects, would there be something I would need down the road, like a different medication and how long does this medication work for?"(788). These conversations also encourage the trust and relationship between the patient and physician as "…sometimes it's good to know what kind of approach your doctor is taking before he send you away"(212) and understanding that can be a leading factor in decision making and compliance with a treatment plan. There are also certain treatments that would push the patient to want to know more information as in this patient's comment, "If I did have to go on biologics though, I would want to know a lot more there."(1015). As this patient explains, removing the unknown from the situation brings a sense of security and trust, "…tell me now that this is what happens so I don't panic when it happens. This one might work for a while and then if it stops working, then we are going to try this. And if that doesn't work, you're going to try this. So that I know he has a plan ABCD so then I feel reassured that you know what you are doing and that I am in good hands."(791)(RFG)

Striving to be healthy is a high priority and patients found a number of strategies to help them obtain this goal. "I just eat healthy and knowing what you can eat is a big advantage"(30) "Exercise is good for me"(52). Food and nutrition were of concern and as this patient stated, "I'm super cautions not to eat certain food because I don't want to deal with that"(731) as did these patients who don't eat apples (732)(733) and the popular use of prune juice to help keep things moving(740). This patient found that, "My self-confidence is at a point where I know this is my disease, this is what I need to do to be healthy. Like I try to be gluten free as much as possible"(54). Noted again was listening to your body (700) as well as simply saying, "sorry, I can't do it"(701). Taking responsibility for your choices and making smarter ones. "It's all about priorities. That is what we have to analyze in our lives, what is the priority. What is really important right now? It gives you a different perspective this disease."(924). Keeping stress managed (1604) because "A. it's exhausting being stressed all of the time and B. because it can have health effects"(1605). Ensuring patients adjust and modify their sleep requirements as without enough patients feel it puts them at risk, "if I don't get my sleep where I need it, I imagine that Crohn's is going to be the first thing that kicks back"(1411). Patients are quite clear they need to be part of the equation for attaining the highest level of health and wellness they can. In not doing so, " I may see, you know flare-ups, if I don't sort of keep an eye on my health and things like that."(1406)

Managing both medications and care can be time consuming and take considerable focus and effort. "…there is a Humira person who arranges your financial thing, there is a person who makes sure your prescription is up to date, there is a pharmacy, there is the lab, and there are just a lot of components involved. There is Progress involved as I get free compassionate shots...I have to confirm every month whether I need them for the next month." Many patients with complex treatment plans found it very time consuming and stressful to manage and wished for one individual that could coordinate and manage this and suggestions were made around the idea of a medical coach (RFG). Being organized and up to date with what medications the patient is taking is essential; "I keep a list of all my meds and dosages in my phone so I can tell you exactly."(910) Getting your medications from one pharmacy is also recommended, "...I only go to one pharmacy. I think you run into risks if you don't get all of your meds coordinated at one spot"(912) and this is a valuable purpose of the pharmacist, to review all medications, possible interactions and correct dosage. Having this professional involved in your care is vital as, "…the drugs I'm on, the things I'm on…its complicated"(1539) Maintaining your health requires that you follow the set procedures and have all required testing and ensuring the results are distributed to all of your physicians. "I go every month for that to be tested and I get copies of that to go to my family physician and GI…"(572). It should also include being aware of research and new treatments, "Look at research being done. If you don't ask, you won't know"(RFG). Sometimes it's outside physical requirements that are a concern, "…now the disease is taken care of, I feel normal, like a normal person. But man, carrying that stuff around is a pain in the butt because Humira has to be kept cold"(446) and another patient found she had to be prepared and carry personal items, "You learn the tricks to get by…I had an extra change of clothes, I always had extra underwear, I have my own toilet paper, I had my own…everything just to get by"(744). Patients have to take responsibility and always advise physicians if they are on any medications and what conditions they are for as they cannot possible always know (909).

A Holistic approach, where the consideration of the complete person, physical and psychological, are taken into the treatment of this disease, is genuinely being sought by patients. “What was missing in the holistic treatment of this, they were treating the symptoms because that’s all they can do, they are not treating the emotional component. This has a significant emotional, psychological component”(777). “That is what I mean by holistic, we got the nutrition piece, we’ve got the GI’s, I’ve got a great surgeon…all of that but I didn’t have the psychological piece, didn’t have the coaching, so now I have a coach which helps me take more control around, get my head wrapped around this. This thing that is so crucial when you can start to accept and start to put plans in place…and that was missing at the beginning”(779). To have that guidance, “…it would be nice, even if it’s not with the GI doc, it could be with someone that can sit down and say I think you need – you need – to do it in this area because we missed here, or we can improve here”(642)(RFG). The idea of a medical coach(RFG) who can support people, help with acceptance and plan strategies and relationships (820)(RFG) was highly praised along with taking a multidisciplinary approach(RFG), that encourages more communication between specialists, and the use of the Complex Chronic Disease Management program (RFG) currently in place. Patients commented that what they felt the average Crohn’s persons’ “general understanding from a medical professional.”(1555) was lacking. Online resources, similar to the Mayo Clinic Site (RFG) and onsite resources like a media room, books and webinars (RFG) that are played in the waiting room to inform and update patients were requested.

4. <u>Living the New Normal</u>

A diagnosis of IBD ripples outward from the personal manifestations to the rest of a patient’s life. Relationships with family and friends are touched. Employer expectations and employment realities may need to be considered. Social situations can be fraught with embarrassment. There is a whole other level of understanding in one’s life with IBD that is required; from patient to other and other to patient.

"I'm at the point where I have to care more for myself and not about my partner. I think he feels gypped but I'm trying to be healthy, but I'm not good if I'm not healthy… not for this relationship, not for me, not for my employer." (53)

"My Family Knows…"

Relationships within the family adjust with a diagnosis. How spouses/partners, parent/child and siblings relate all changes. A patient struggles with symptoms and the reality of a chronic disease. Family members struggle with how to support the patient and as well as to keep their own sense of self with in the family.

The family unit is affected (1430) and there can be immediate stress on the family. (20)(1443)

The relationships of patient to family and family to patient are complex and diverse. Patients recognize their IBD has impacted their family and the family unit requires understanding and flexibility in order to accommodate the physical reality of the patient. The family members learn to be flexible and adapt, "...I have to be ready to do whatever needs to be done at whatever time…It adds a level of uncertainty. (37). "…Let's go out today dad, and I was too tired, so it was hard for them to understand" (15) Study participants reported that the family lifestyle the patient once enjoyed can change. "…We can't go hiking, cancel motor biking, all of the things that we love to do; you're just sitting at home. (756) One participant said that "…my one daughter remembers thinking all mommies laid on the couch…I had no energy." (697)

As the physical symptoms of the patient flare and recess, family members are powerless to impact their loved one's health. "For a family member living with someone who has IBD, it's the inability to be able to do anything for them. "(If) they're in pain, there is nothing you can do to fix it." (12). My family wants to help but they don't know how. (RFG)

IBD may impact the family's ability; to…"make decisions for the future. (It's hard) when we don't know what that's going to look like.(540) For example, "…The types of medication that may be required…."causes birth defects but we don't have anything else at this time to give you, so are you planning to have children?"(539) These types of decisions can completely change the course of a family's future plans.

During interviews and focus groups, participants spoke frequently of the value of family support. Family members learn that: "you have to listen to that person (patient)…you don't understand at the beginning and then you start to listen to them about what they are eating, what they are doing, knowing their routine and where the washrooms are." (38) "They (family members) know when you are not well" (934) so you "listen to what they tell you about you; just as much as listening to your body." (837) We were also told that some family members assist their loved ones not only in medical ways but financially as well when work has been interrupted.(859)

During one focus group, a patient participant said to a family member …"it must be so difficult to watch your family members go through this. I can't imagine what it would be like to be in your shoes. (803) It was suggested "support for the support person (and) support for the family is really important because you can't support somebody if you don't know how or what to do." (216/217) One participant reflected that they … "ended up doing family therapy" (219)

Partner/Spouse

Throughout our focus groups and interviews the impact IBD had on a patient and their spouse was an open and often emotional dialogue about a deeply personal topic. The discussions generally focused around the impact on the relationship when a partner is sick, the supportive and sometimes not supportive spouse. However, the most heartfelt conversations were how the patient feels about themselves and their role as a spouse and intimate partner.

When IBD flares, patients discussed that either…our marriage is best when I am sick" (802) or … "I have to care more for myself and not about my partner, I think he feels gypped…"(53) Either way, the relationship has been affected.

The patient appreciates the support of the spouse. "My husband didn't seem to think it was a particular problem with me being home and sick for 6 months…" (1287) "He (husband) is making all of the meals (1291) Patients talked about how a partner plays a large role with their wellbeing. " He is the one that says "you need to slow down an rest" …he's very understanding" (533) "Sometimes it is good to (hear) “you have had a tough night, it’s okay to stay in bed this morning.”(629) The spouse taking some of the burden of the disease was very helpful in some relationships. “My partner does all of the looking up and research for me. She is my resource” (1017) “I let her worry about things and if she’s not worried, I’m not worried”(977) … “In some ways (IBD) has brought more of an understanding” (1437) to the relationship.

For some people the converse was also true. Some patients spoke about the differences in attitude toward treatment options, especially with surgery. “…my (spouse) was upset I hadn’t pushed for it earlier” (163) My (spouse) is like no way, you’re not going to do that” (776) The disconnect also had social implications “…like turning down invitations to do things …or going out for dinner…(as) I am not feeling well. (528) Even trips posed spousal challenges as one individual discussed. “ my partner wanted me to come (on a trip) but I didn’t see the point in being miserable elsewhere.” (971)

Several patients spoke about hiding pain from their spouses as …(they are) trying to be healthy, but I am no good if I’m not healthy…not for this relationship, not for me….” (53) …Right now I am having a really bad flare and I’m even avoiding telling my husband even though he has picked up on it…. finally he just said are you ok? And even then I am still trying to hide it. “(45) Another patient said “…last night even I was in a lot of pain and trying to hide it from my boyfriend… (he) just doesn’t get it. I feel like I have to hide it when I am in pain.” (727)

However from the focus groups and interview conversations one of the most heartfelt and perhaps personal topics was from the patient’s perspective. Patients talked about how… “it affected my relationship with my husband. Sorry, don’t touch me. No intimacy and no confidence in myself that way. I feel like I have been totally stripped of my norm.” (33) Some of the IBD symptoms and gynecological issues can have a large impact on spousal intimacy. Patients said their “intimacy decreased, sex decreased and they didn’t feel sexy” (RFG). “I thought I guess I am going to be single for the rest of my life because who is going to want someone with (this) disease? (335) One family member said their adult son with IBD “…feels almost broken. That he is not worthwhile having a relationship. Who would want me…”(333) Another individual said that… “going into a new relationship I am still very choosy about when I will have that conversation and it's usually after a bottle of wine. I have to make sure that I feel I can trust this person and they will be accepting. (337).

Clearly IBD affects relationships. As one individual stated "…it hasn't really been detrimental in our relationship in that sense, but I think it's been the biggest negative. (1442) So "…how does my partner help me? I know he's at a loss of words sometimes and doesn't know what to say and asks what can I do, and I'm like nothing and he has started hearing that." (216) "…You can't support somebody if you don't know how or what to do. And maybe you can't physically do a lot but there is probably something you can do. I think that is really important." (217)

Siblings

Even though our group of study participants only included one sibling, several participants in the focus groups and interviews discussed the impact IBD had on their sibling(s). One participant spoke of the time when their teenage son was diagnosed, "we had sibling issues because they are seeing one sibling is getting all this attention although not great attention. They were totally jealous of him." (216)

A patient reported that it "was hard on my brother when I got diagnosed shortly after my (other) sibling (was diagnosed), he was terribly upset. (1431) The hard part was "…just watching my brother and sister and I can do nothing about it. (709) The inability to impact the sibling's health was challenging but it was "not like you were blaming the person for not being able to do stuff…"

An individual receiving an IBD diagnosis when they have siblings can mean the increased potential of the other sibling(s) also receiving a diagnosis of IBD due to the partial genetic nature of the disease. As one participant stated "…everything fell off a cliff after my brother was diagnosed. " …like I was going to be walking down the street and bang Crohn's can jump from behind the corner…I was paranoid all the time. (711) Another participant talked about a sibling who took a long time to join the GEM project. The parent said to her, "…I think she fears if she does that project, she will have Crohn's and that it will show up…"(219) "It feels like a firing squad and I am next. It is a very real thing for me that it very well could be me next. (804) I had a very guilty conscience about it…well it is survivor's guilt; how else do you put it?" (806/808) A patient/sibling relationship may add level of complexity. One participant indicated that their sibling"… want(s) to help but they don't know how. (RFG) "…Even now things will come up that she is always worried about her (sister). It is understood that the patient needs support with their IBD, but a sibling of someone diagnosed with IBD may also need "…someone who is educated who can help…"(219)

"People…Don't Quite Understand"

As we listened to study participants in focus groups and interviews, it became apparent that hiding IBD symptoms and the associated pain and discomfort was a common behavior. However when symptoms are hidden from people in your life and the patient does not let anyone know how they are feeling, it follows that friends are unlikely understand that you are sick.

"People who don't live with this disease…don't quite understand. You can try to be empathetic as possible. But I have the debilitation, excruciating pain and the panic…(27)
"For the rest of the world, you want to put on a face and a façade…"(531)

IBD is a difficult disease for someone's friends to see. There are not any visible signs to be readily identified; "The way you look on the outside isn't really how you are feeling on the inside." (506) …"Everyone says you look fine…even if you don't feel fine." (1398) Living with IBD symptoms and their resulting challenges can leave a patient "…(feeling) totally stripped of (their) norm. (C8S2)(RFG). This new normal can often be difficult to explain to friends. "…When you say you have Crohn's disease, (a lot of people) don't know what that is. So you try to explain it. Unless they know someone, then it's very hard to imagine I think. So, it is kind of isolating in that case." (505) "And it's not like there are a lot of people you can talk to about it. I mean it is a disease …it isn't like cancer. It's not a cool disease to have, talk about bowel movements and bloating and gas…" (504) …semi-annually: if I am having a bad month or week or what have you, that's a tough one for people to understand and it's a tough one that I don't generally go and explain to people. (1399) Patients did find however when they did try to explain IBD "…not everyone wants to talk about it because it's poop.(966) "They are grossed out" (RFG) "They are not sick so they don't understand." (1103) "Very few people care that you are sick"(1168) For example "My (boss) who was touchy about her weight after having 3 babies mentioned she wished she had Crohn’s so she could be skinny too.”(1106) “You will be losing weight and people will say you look great and I’m like, I’m sick. (50)

As IBD impacts the digestive tract, participants spoke about how there was “judgment and blame”. What did you eat today” (RFG)…that could cause your symptoms? One participant noted that “I try to avoid (telling) other people…(because) when you share with other people they often suggest some wacko things. (175) “Have you tried taking this herb? You should try this weird treatment. (176) Other participants concurred. “I agree wholeheartedly, you get a lot of people saying take this, take this as it will make you better…You have to be really careful about what you tell and what you listen to”(182) Someone actually went so far as to inform one participant “…that (Crohn’s) is a disease doctors could cure but don’t as they want to keep you coming back in.” So what can be done about the general ignorance with regard to IBD? “…Maybe (it’s) just sort of trying to breed a community of understanding about it.” (1632) “Then people can be supportive. If you keep it a mystery, they are not going to know.” (281)

Exposure, Education and Empathy Evaluate

(Knowledge, Role Modeling; what does Empathy look like)

Study participants talked about the need for education, not only for our circle of friends but extending as well to the community at large.

We heard the education of friends was able to begin when a patient could finally say… “I find it’s okay to tell people how I am feeling…” (730) or when it could be said that “…I finally came to the point in my life where I educated myself about the disease... (so) I started to spread the word and not worry.” (43) One individual shared with their adult child “…tell people…your good friends… tell them you have a problem. Guaranteed they’re not going to throw you out. Then you don’t have to feel weird when you need to leave or whatever…(484) “If someone is ignorant; I take the opportunity to educate them. Facts, resources, people, they can be in contact with.” (RFG) If someone is ignorant then… give them a little blurb”. (649) Talking and educating friends and peers about IBD is a positive step in the right direction. “It would be a good thing telling someone (who is) looking to learn more about this disease (and it) would be okay that you have this disease and it’s not your fault. (279)

Education and awareness about IBD needs to extend past the personal circle of friends to the community at large. “We need to educate the public about the disease.” (293) As one participant states, “I think our society is becoming more aware but even now you don’t know someone has it until you talk about yourself or family having it. Cancer awareness is everywhere, which is a good thing, but people don’t know about Crohn’s and Colitis” (278) “(Some of us) here are involved with the Crohn’s and Colitis Foundation and I take any opportunity I can to educate people. I don’t talk about myself but do give them statistics, how prevalent the disease is, how it affects your life and many faces. That’s just my rule. It’s a very prevalent disease, it’s not something that’s rare, and it is out there. The more we educate people; they become more comfortable, more trusting and empathetic.” (144) Taking the opportunity to educate whether through school fundraisers (280) or with walks, runs or challenges (657) gives the patient and families the opportunity to teach, and the public the opportunity to learn. The study participants discussed that with education, the public would learn. As one individual stated; “I learned that it’s okay to share that I have a disease and that it’s going to impact my life, and people around me have to understand that. (42) They will learn “you don’t want people to feel sorry for you” (49) “You don’t want people to see you as the disease. You want them to see you as you. (48) “It is not a reflection of me or who I am.”(699) It is a physical problem. It is a disease. People will understand.” (486)

“I hope I Don’t Lose My Job…”

During focus groups and interviews we heard patients talk about how IBD can have an effect on work and school commitments. Job loss, career adjustments as well as time off for sick days and appointments were ways employment was impacted by their disease.

“…There’s not a month that goes by that I don’t have an appointment and sometime I have like, you know six appointments a month with different specialists that I’m having to miss work for.” (611)

One of the most difficult situations to face with IBD is the potential for job loss. “I couldn’t cope with the fact that I had been fired because I been in hospital and had emergency surgery and was off for three months. I got fired the day I got back to work.“ (702) Another patient shared, “when I was first diagnosed, I had just started a new job and was still in my probation period and I got sick and was in hospital - so was off work for three months. And, I just said to my boss, ‘I hope I don’t lose my job, I hope I don’t lose my job’. She had already heard from someone else I had Crohn’s prior to hiring me and it was a concern to her – so, I was blacklisted.” (41a) Work interruption is a reality. Extended periods of time off is a significant reality as one individual said “…it will take six months but we will get you back to work”(716) Another patients said that…I needed 6 ½ months off (and) it used all of my sick pay…thank god I had short term disability” (1248) And another participants said that she “…had to call and tell them I’m in the hospital again and would miss school start up.”

Days Off

Work and school attendance was affected. “Well, sometimes I might be late for work because I couldn’t get out of the washroom on time to leave… and I had to go back home because I had to use the washroom and things like that. “(516) “…There’s not a month that goes by that I don’t have an appointment and sometimes I have like, you know, six appointments a month with different specialists that I’m having to work miss work for.” (610) So, often I will call in sick but on other hand, (I am) trying to find that balance, right? (611) “I have only, like I’ve said, knock on wood, had to take like one or two sick days since being diagnosed, where I was actually sick from something that could have been Crohn’s related.” (1402) The type of position you have could also make a difference to missing work days. One patient shared about a parent who had Crohn’s and “When he was very sick, and my dad never missed work except when he had a Crohn's attack, and they were very, very bad. Usually about once a year, like clockwork, and he was in so much pain, you know. I can remember.”(663-4)

Post-secondary education as well as employment is subject to the challenge of attendance or time commitments. As one family member shared, “My daughter was diagnosed her last year of university, and ended up missing exams as once it would begin she would have to leave and couldn’t come back in.” (282) Another participant agreed as, “that happened with our son. He got sick and just couldn’t write”. (283) Lower levels of schooling are impacted as well as was reported my yet another individual. “My son was given a medical IPP so that he could access the bathroom at all times.”(289)

Career Adjustments

Patients and family members have switched from full to part-time and changed their schedules because of the effects of IBD. “We made a career decision. My wife was teaching and we decided our son needed more time to be there for him. So my wife took a leave and we were able to have a somewhat more normal life. (22) Another participant talked about when “I worked full-time and had to go part-time - because I was single and had no other income so that was a whole lifestyle change for me.” (17) “There was not a support system in place at that time either, so that was hard.”(18) We heard about the lack of understanding with regard to the financial reality of needing to adjust a career because of IBD issues. One person shared“…that aspect because that is a big problem: the financial and economic impact of this disease. I think that is missing.” (894) “Now I can’t hold down a job, so I have gone into consulting that I can manage and have control over my hours. If I do two days, two eight-hour days in a row, I am in trouble by the third day. I am just wiped.” (727) Others communicated, “If I had a more physically demanding job, it would have been very difficult due to a severe lack of energy”. (14) “My job right now is not very physical so that does not have any sort of I guess, you know, complications there.” (1404) “Even at work I have to pace myself.” (725) One person shared that “…it has affected my career …so the jobs that I take. I didn’t go back to school for my graduate degree or anything like that because I wasn’t feeling well. “(509)

Hiding Symptoms at Work

Patients also shared their desire to hide their condition and often the symptoms make this choice impossible. “There’s a time especially when I was younger, when I didn’t disclose, that I didn’t want my employer to know.” (650) “I didn’t want anybody to know because I was afraid that I might lose my job or may not get promoted or this or that.” (651) “… I thought, I’m not telling anybody, this is my secret” (41b) “… I began to cry and later I said to her, look I have Crohn's and I don't want the whole world to know, it's an important thing that people don’t know. I wasn’t ready to share" (41d). "You need to be reliable for that job too. (900) "Nobody knew what I had at work - I just wouldn't tell anybody I was sick. I was hiding it from everybody". (703) Patients communicated that concealing the condition can be a challenge at times because of the symptoms. One person shared that that their washroom "…had only two stalls. You would run around to the different floors to see where there were bathrooms available. You didn't want your co-workers lining up and standing there listening to you. It doesn't sound like much but it's embarrassing."(407/408) "And the pain. I could barely walk when I would come into work. You just try and push through it. And by not accepting it; it just made it worse, I think". (704) "We experience discrimination…it is out there. It happens still." (902)

Conclusion

In conducting the research with our 21 participants, we found that IBD patients are not only strong and resilient, but also insightful and savvy to the complexities surrounding this disease. A new, centralized IBD unit, where a collaborative approach with various specialists would be an ideal resource that would be in great demand. Our study patients want to contribute to the framework that will become their personal care plan. From the physical manifestations of the disease to the social and psychological pieces, patients want to be treated in a holistic manner so that they can truly find peace and their highest level of wellbeing.

Peer support is crucial for patients, as is continuous education in the form of reliable online resources and symposiums. The use of medical coaching is desired whether in the form of patient experts, medical navigators/coaches to help coordinate, review and ensure all areas of each patient is assessed and met. Patients were clear on the aspects of their care that are being missed or lacking and certainly felt that access to a centralized IBD unit would definitely be beneficial to their overall health and wellbeing.

As patients, family members and PaCER interns, we were deeply touched and honored to create a safe space where participants could come together, freely share their stories and further their knowledge. The comradery and connection that we would feel even with one on one interviews, was clearly displayed by the participants in all three focus groups as they connected over this commonly shared bond we call IBD.

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