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Beyond Standard Quality of Life Measures: The Subjective Experiences of Living With Inflammatory Bowel Disease

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Abstract

Introduction: In order to facilitate our understanding of health-related quality of life (HRQoL) for IBD patients, it is critical to explore their subjective experiences with the disease. Research has suggested that current modes of assessing HRQoL (i.e., generic and disease-specific measures) may not fully represent all dimensions of patients' HRQoL. The purpose of this study was to examine IBD patients' subjective experiences of the daily impact of IBD, and categorize dimensions of their HRQoL affected by IBD, as identified by the patients themselves.

Methods: 282 patients with IBD provided answers to the qualitative question "How has IBD affected your daily activities?" A content analysis using NVivo 2.0 was conducted on the participants’ responses to this question to reveal dimensions of their HRQoL.

Results: The analysis yielded six dimensions and several sub-dimensions of HRQoL, including physical (systemic functioning, daily functioning, energy/vitality, pain), emotional, social, cognitive (functioning, attending to disease), self-regulation (taking control, loss of control, and neutral), and practical functioning. Discussion: These results reflect previous findings, but also reveal several dimensions of HRQoL not included in current measures of HRQoL for IBD patients (i.e., cognitive, self-regulation, and practical). The implications of these findings for future measurement of HRQoL and research with IBD patients are discussed.

Key Words: Inflammatory bowel diseases, Quality of life, Measurement, Qualitative research

Introduction

Inflammatory Bowel Disease (IBD) is comprised of three distinct but related medical conditions: Crohn's disease (CD), ulcerative colitis (UC), and indeterminate colitis. A complex disorder of uncertain pathogenesis and etiology, IBD is characterized by chronic inflammation of the gastrointestinal tract in a pattern of alternating periods of remission and relapse. With no known cure, treatment is often typified by attempts to control inflammation through palliative medication, diet, physical activity, and as a last resort, surgery [1,2].

The impact of IBD is felt physically, socially, and emotionally. Physical concerns may include, but are not limited to, abdominal cramps, rectal bleeding, systemic inflammation, diarrhea, nausea, weight loss, constipation, and fatigue. In addition to these physical concerns, IBD patients also contend with the fact that the disease is not well understood. IBD patients are faced with daily stigma, fear, and revulsion, and often describe feelings of embarrassment and helplessness [1,3]. Research has indicated that IBD patients may also experience decreased sexual functioning [4], an impact on their resources due to the expense of medication and visits to the doctor [5], and other costs including refusal of insurance and mortgage [6].

While more emphasis is generally placed on treatment and management of the physical symptoms of IBD, researchers have also acknowledged the need to examine the subjective aspects of IBD patients' health (i.e., health-related quality of life or HRQoL). In many cases, this research has indicated that there can be considerable impairment in HRQoL [7-11]. However, where it was once imperative to determine if HRQoL was impaired as a result of IBD, it is now critical to clarify which dimensions of HRQoL are most impacted, and to what extent this impact is felt [12]. In order to determine these effects, many researchers have focused on the measurement of HRQoL [1,13].

HRQoL is a multi-dimensional construct comprised of physical, social, and psychological functioning, overall satisfaction and well-being, and perceptions of health status, and also includes neuropsychological functioning, personal productivity, intimacy and sexual functioning, sleep disturbance, pain, symptoms, and spirituality [14]. This multi-dimensionality is reflected in the two modes used to measure the construct: generic and disease-specific questionnaires. Generic measures do not offer direct insight into specific conditions, but are able to perform and summarize across conditions [10,15]. Such scales are generally more likely to meet critical standards of reliability and validity [10], but critics often rebuff the value of such measures based on their lack of specificity. Of the many generic HRQoL scales that exist, the Medical Outcomes Study Short-Form 36 (SF-36) [16] is the mostly commonly used measure [17].

Disease-specific measures, meanwhile, generate detailed information related to the disease in question [13]. For IBD in particular, psychosocial concerns are at least as important as physical ones [18]; such factors directly affect the development of the disease, and the patient's perception of their HRQoL [19]. While researchers have argued that some IBD-specific measures only examine the physical impact of the disease [10], more recent scales generally acknowledge the importance of psychosocial concerns, and are seen as more effective than generic ones based on the fact that they have been designed specifically for the disease under study [10]. There are multiple IBD-specific scales available, however the Inflammatory Bowel Disease Questionnaire (IBDQ) [9] is the most commonly used instrument [19].

Researchers have compared generic and disease-specific measures in an attempt to determine which provides the most complete assessment of HRQoL. For IBD in particular, McColl and colleagues [20] compared the SF-36 and IBDQ and found that the IBDQ was better at discriminating between sub-groups categorized by disease-specific variables, whereas the SF-

36 was better at discriminating between sub-groups defined by co-morbidity [20]. They concluded that disease-specific and generic measures are complementary, a finding that has been supported by previous research [9]. The fact that disease-specific and generic measures together offer a more complete picture of HRQoL than either on their own suggests that there may be aspects of HRQoL that are not captured by these measures. We have also recognized the need to include patients' subjective experiences in the process of evaluating HRQoL, and as a result it is then important to critically examine the development of HRQoL measures to determine if and where our understanding of the IBD patients' HRQoL can become more complete. Because the SF-36 and the IBDQ are the most commonly used instruments of their respective type (i.e., generic and disease-specific) to assess HRQoL for IBD patients, and because previous work has compared these two measures with regard to their ability to assess HRQoL, the remainder of this paper will focus on and related new findings to these measures in particular.

Development of the SF-36 and IBDQ. The rationale behind the SF-36 was that the patient's point of view is central to the study of medical care outcomes. Ware and Sherbourne [16] argued that the deficiency in patient input was due to lack of valid and easy methods to collect data related to patient experiences. After reviewing many established instruments [16], items were adapted for their place in the SF-36. The result was a measure that included eight subscales: physical functioning, role physical, bodily pain, general health perceptions, vitality, social functioning, role emotional, and mental health.

The IBDQ, meanwhile, was created out of the need to include details about the IBD patient's subjective emotional and social functioning [9]. An open-ended questionnaire based on IBD-specific problems was sent to both clinicians and IBD patients. The resultant list of problems generated was then sent to another set of IBD patients, who were asked to identify which of these physical, emotional, and social problems they had experienced. The most common and critical problems were included in the IBDQ. The final measure included four subscales: bowel symptoms, systemic symptoms, emotional, and social.

Similarities in the construction of the two questionnaires are evident. The rationale behind each was that there was a need to generate a detailed picture of patients' subjective functioning. Both sets of authors were operating under the assumption that the development of a psychometrically sound instrument would allow for patients' experiences to be illuminated. Both measures were also grounded in the literature; while the SF-36 was developed directly from the literature, the IBDQ was a combination of patient and practitioner input, and supportive research. The main difference between the two questionnaires was that the IBDQ allowed for patient input from the very generation of items, while the SF-36 relied on items that had been generated previously (assuming that these items were inclusive of patients' experiences). Thus, while both scales claim to lobby for the inclusion of patients' subjective experiences, only the IBDQ allowed for this inclusion at the level of generating items. However, the authors of the IBDQ framed the open-ended questions from the position that any issues resulting from living with IBD were inherently 'problems.' In other words, the IBD patients were not able to define for themselves how they experienced the disease. If there had been positive changes in their lives as a result of the IBD, such as a healthier diet, there was no room to describe them in the context of the IBDQ.

The question remains if such measures fully represent patients' experiences. A step towards filling this void is to use qualitative methods to ask the patients themselves how IBD has affected their lives. In the process, the patients can both define their experiences with the disease for themselves (i.e., relate which dimensions of their HRQoL have been most affected by the disease), and explore these experiences without being primed to see them as ‘problems.’ The aim of this research was to explore how the patient’s voice is included in the process of measuring HRQoL. Specifically, the first purpose of this study was to explore IBD patients' subjective experiences of the daily impact of IBD by categorizing dimensions of their HRQoL that had been affected by the disease, as identified by the patients themselves. The second purpose was to compare these experiences with the dimensions utilized in current HRQoL measures (i.e., the SF-36 and IBDQ) in the hope that this work could help to determine if such measures represent IBD patients’ experiences and truly ‘give voice’ to this population.

Methods

The current study involved a secondary analysis of data collected from a larger study examining the well-being of people with living with IBD. Institutional research ethics clearance was received both for the initial data collection and for this secondary analysis. Participants were recruited over a five month period spanning 2002 to 2003 via notices posted in on-line support groups, and in the community at gastroenterologist’s offices in eastern Ontario. The majority of the participants completed the survey on-line, although they were given the option to complete a paper version of the survey by mail. Participants completing the survey on-line read a web page with the letter of information and conveyed their consent to participate by clicking a button which linked to the survey. Surveys were submitted electronically to a secure server and were anonymous as they did not contain any personally identifying information. Electronic data was stored in a secure manner to further maintain confidentiality.

A sample of 291 adults diagnosed with IBD (i.e., CD, UC, or ‘other IBD’) was recruited in the original study. However, only 282 were included in this analysis due to missing data related to the qualitative question being examined. Of the final 282 participants included in the current analysis, 246 individuals participated on-line, and 36 completed paper versions of the survey which were returned by mail. Of the nine participants excluded, eight had completed the survey online.

Participants completed a survey that included demographics questions and questions about their HRQoL, coping, health perceptions, and other aspects of their disease. Following the completion of the IBDQ, multiple questions related to coping, and a single rating scale of how IBD had affected their lives, participants were asked the open-ended question, “How has IBD affected your daily activities?” The question was phrased in this neutral manner to avoid priming positive or negative responses. Because of the unpredictable nature of IBD, the focus of this question was the impact of disease on the daily, lived experiences of people, rather than on the overall impact of IBD. Responses to this open-ended question comprise the data of the current study.

Responses ranged in length from half a page to only a few words, with most participants offering three to four sentences. The transcripts were read multiple times by the researchers, and the textual data (i.e., participants’ responses to the qualitative question) were explored inductively through a content analysis [21]. Using Nvivo 2.0, meaning units (i.e., responses) were inductively tagged for common themes and placed into more general conceptual categories reflecting dimensions of their HRQoL This process was ongoing and required multiple open codings before the final categories were achieved. Two researchers reviewed the coding; when the researchers disagreed about where to place a response, a discussion took place until a consensus was reached.

Although purists will argue that traditional content analysis is quantitative in nature and scope, there are variants to this type of analysis [22]. The type of textual analysis and open coding used in this study allowed for the researchers to identify themes inductively as they emerged from the data, and was thus deemed most appropriate to meet the research goals.

Results

Demographic and disease-specific characteristics of the original and final samples are presented in Table 1. The final sample was largely Caucasian, female, living in North America, and diagnosed with CD. In comparison, the discarded sample had a shorter time since diagnosis, was more likely to be single, and more likely to be diagnosed with UC.

The analysis revealed six broad dimensions of HRQoL, and several sub-dimensions. These dimensions included: physical (systemic functioning, daily functioning, energy/vitality, and pain), emotional, social, cognitive (functioning and attending to disease), a self-regulatory dimension (taking control, loss of control, and neutral), and a practical dimension.

Physical

Participants identified aspects of their physical lives that had been affected by the disease, including systemic functioning, daily functioning, energy/vitality, and pain.

Physical systemic functioning. This sub-dimension was related to the literal physical functioning of the participants' bodies. A well documented concern of IBD patients, systemic functioning was characterized by responses related to bowel and other bodily function. "Due to uncontrollable bowel movements sometimes I cannot even walk across the floor without having an accident. I cannot lift anything heavy due to the same as listed above." (P 1537, female, CD)

Physical daily functioning. These aspects were varied in nature, but dealt with the ability, or inability, to physically participate in daily tasks. The majority of participants identified their career or occupation, including student life, as having been affected, and noted that travel was extremely difficult. Other issues included the inability to participate in physical activity, and in general, difficulty completing daily tasks such as housework, gardening, and other errands.

> I can no longer go to work or school because I'm usually in constant pain/nausea. I cannot trust myself to travel in the car because I get car sick and cannot control my bowels. When I go anywhere, my number one priority is to know where the toilets are. All I do is sit at home and sleep, eat, and watch TV now. (P 1678, female, CD)

While the majority of responses were negative, there did appear to be instances where the effects of the disease were neutral or even positive. "It has also been positive. I definitely eat healthier, no chemical additives, avoid wheat for the most part, no white sugar." (P 1629, male, UC)

Physical energy/vitality. Similar to previous findings, many of the participants were concerned with their energy and/or vitality. Many participants complained of fatigue and the inability to carry out normal tasks due to lack of energy. For some, there was an increased need for sleep. Out of the entire category of responses related to this dimension, not one participant suggested a positive change in their energy as a result of the disease. "I have no energy to get things done. Getting up and making it through the day at work takes all I've got." (P 1623, female, UC)

Physical pain. The pain experienced by participants ranged from cramping and joint pain to pain during sex and physical activity. While this category contained fewer responses than the other physical categories, it was evident that pain often played a large role in the experience of IBD. "Hurts to have sex sometimes, some days I am in a lot of pain and cannot function at all." (P 1670, female, UC)

Emotional

The second category included all responses related to emotional dimensions, ranging from anxiety and depression to fear and loss of passion. An analysis of these responses suggests an intense emotional component resultant of specific physical aspects of the disease, and perceived social repercussions.

> I have anxiety whenever I need to go out of the house for fear of losing bowel control. I don't want to go out with my spouse because I am embarrassed to have to stop on the side of the road to 'go' so I avoid going out with him. I also feel guilt because I have two small boys and I don't always take them all the places I would like to because I am afraid of having to use the bathroom urgently. (P 1611, female, UC)

Social

Many of the participants felt that their social lives had been affected by IBD. In some instances, the participants felt that other people in their lives, including medical professionals, did not understand or value their experiences. Often, the participants noted that they could not participate in their social lives the way they once had. Several participants stated that the real change occurred not in how they participated in life, but rather in how they chose their friends.

> Before going anywhere I worry about whether or not I'm going to have an attack of diarrhea and ruin everybody's plans. I immediately look for a bathroom wherever I am. I don't socialize much anymore because I seem to always be sick and people get tired of inviting me to be with them. (P 1720, female, CD)

Cognitive

The fourth dimension was cognitive in nature, and included two sub-dimensions: functioning and attending to disease.

Cognitive functioning. This sub-dimension was characterized by responses dealing with a perceived reduction in cognitive functioning. Although some of the participants noted that the disease itself required a large portion of mental resources, others stated that the required medication to combat the disease had consequences for their cognitive ability. In many cases, the participants believed that IBD had a negative impact on their motivation, alertness, disposition, and general self image. "I find working more difficult particularly when IBD is active as this takes up a large proportion of mental resources. I feel fatigued and mentally slow compared to my 'normal' self" (P 1657, male, CD)

Cognitive attending to disease. For many of the participants, a significant amount of time was spent thinking or worrying about, and planning around IBD. Although not always perceived as a negative consequence of the disease, for many of the participants, the amount of time spent attending to the disease, and not spent freely on the rest of their daily lives, was a problem. "I spend an inordinate amount of time thinking about how to prevent getting a flare, what to do if I have a flare, and wondering if the blood I saw in my stool means I'm starting a major flare" (P 1593, female, UC)

For other participants, living with IBD meant that they had to manage their disease and time through routines and improved organizational skills.

> Have to be much more organized in terms of eating (what I eat, when I eat, where). I need to know where toilet facilities are at all times. Basically, living with IBD is all about management, creating routines and diets etc. that suit your own needs. (P 1591, female, UC)

Self-Regulation

A fifth dimension was also identified that dealt with self-regulation and control. Although initially perceived by the researchers to be cognitive in nature, it was soon recognized that these concerns were copious and distinct. Within this self-regulation dimension, there were three sub-dimensions: taking control, loss of control, and neutral.

Self-regulation taking control. The ways in which the three sub-dimensions were differentiated were subtle in nature. In most cases, it came down to the type of language used by the participant. In order to be characterized as ‘taking control’ the participants demonstrated that in the face of changes to their life as a result of IBD, they had taken control of disease-related issues. This meant that the participants used language such as, “I do,” “I am,” and “I plan,” and avoided using “I can’t,” and “I don’t.” In general there were fewer responses of this nature than the other two dimensions of self-regulation. “I feel that I have all control over IBD now. Most of the time I can effectively deal with any or all symptoms which I may have today” (P 1719, male, unknown).

> I also feel like I keep control of whatever health issues I do have some control over: e.g., low cholesterol diet, regular cardiovascular exercise, moderate or no use of alcohol, regular sleep patterns, avoidance of pesticide or hormone loaded food the best I can. (P 1544, female, CD)

Self-regulation loss of control. In stark contrast to the ‘taking control’ group, the participants categorized as ‘loss of control’ did use negatively toned language. Responses which fell into this sub-dimension were classified by the perception that as a result of living with IBD, control had been lost in many aspects of their lives. Often, these responses offered the most compelling evidence of changes to HRQoL. “I never leave the house – have not been out in years. Example – My truck is 17 years old and has less than 25000 miles (most of those were in first five years). I'm a hermit." (P 1564, male, CD) "I do not participate in life." (P 1673, male, CD) "I can't work anymore, what office wants a gray haired little old lady that farts uncontrollably?" (P 1740, female, other IBD)

Self-regulation neutral. Although there were clear examples of taking control and losing control, there was also another sub-dimension of responses. For the neutral category, it was evident that some changes had been made in response to the disease, however, they were neither proactive, nor did they appear to be a result of relinquishing control. In contrast to the themes of controlling and managing the disease reflected in the 'taking control' group, these responses reflected themes of making changes as a result of being imposed upon by the disease. The responses in this sub-dimension were characterized by statements such as, "I have to," or "I need to." "I felt I had to leave an extremely high-pressure job (although I enjoyed it) to work in a less stressful environment." (P 1561, female, CD) "I feel that every trip out of the house has to be planned around the bathroom" (P 1572, male, UC)

Practical

The sixth and final dimension was more practical in nature. These responses were related to daily functioning that could not be categorized under any of the other five. Participants' concerns ranged from the inability to get insurance to financial issues and loss of time. "Insurance is another problem. How are we supposed to get insurance if we can barely work part time, let alone full time. Yet we need insurance for our meds." (P 1506, female, UC)

Discussion

In this study, the subjective experiences of a large sample of IBD patients were explored to identify dimensions of their HRQoL, and compare these dimensions with those used in the SF-36 and the IBDQ (i.e., the most commonly used generic and disease-specific measures of

HRQoL for IBD). The participants revealed six dimensions (and sub-dimensions) that had been affected by IBD. In particular, the physical, emotional, and social dimensions illuminated here were included in the HRQoL measures we examined. However, the cognitive, practical, and self-regulation dimensions revealed were not referred to in either measure, and warrant further thought and discussion. A comparison of the current findings to the SF-36 and the IBDQ is provided in Table 2.

The first new finding, related to the cognitive dimension of HRQoL, has not been discussed routinely in the IBD literature. Given that cognitive functioning has been examined in relation to cancer [23], stroke [24], multiple sclerosis [25], and rheumatoid arthritis [26] (i.e., other chronic disease populations), this is a dimension that should be considered relevant for IBD patients. While Loonen and colleagues [27] have suggested that a decrease in cognitive functioning can be an issue for IBD patients, our findings also point to a possible re-conceptualization of the dimension to include excessive attending to the disease. Unfortunately, neither the SF-36 nor the IBDQ examine this dimension in any relevant way. Taken together, these findings emphasize that further research is needed to ensure that the cognitive dimension is acknowledged by researchers and clinicians, and to eventually see that it is included in measures of HRQoL.

Based on the necessity to confront IBD on a daily basis, we were not surprised by our second unique finding that the disease exerted a strain on the participants’ finances, time, and other resources. The practical dimension of HRQoL has been consistently addressed in the literature (see Moody et al. [6]), which brings into question why it is not referred to by either the SF-36 or the IBDQ. For this particular sample of IBD patients, fewer respondents mentioned this dimension than the other five. However, the consequences of changes to this dimension as a result of IBD were often severe and perceived as causing stress in other areas of their lives. As with our first finding, further research will also be needed to ensure that this is a dimension that necessitates inclusion in HRQoL measures for IBD patients.

Although control has been identified previously as a concern for IBD patients [3], our third finding regarding the self-regulation dimension is also an area that is not assessed by the SF-36 or the IBDQ. For the purposes of this analysis, we conceptualized self-regulation along a continuum of control. Perceptions of control are well-known to enhance adjustment to chronic illness, and have been shown to be particularly beneficial when symptom or disease severity is high [28, 29]. In this context control perceptions may serve as a coping resource that can moderate the impact of symptom severity on adjustment [28].

Research has indicated that the perception of control and feelings of self-efficacy can also be extremely adaptive for IBD patients [1], making it an important aspect of HRQoL. However, there has been less emphasis placed on what the patients express about their own self-regulation in response to the disease threatening their perceptions of control. In this study, there was a clear differentiation between those who actively worked to gain control back in their lives, and those who had given up their control to the disease. The third group, those who appeared to neither give up control nor take control, clearly responded to their disease by meeting challenges, yet they seemed to view these responses or changes as being imposed on them by the disease. This intermediate category is consistent with other qualitative research which found that patients with IBD constantly battle to gain a sense of control over their disease but often feel worn down by their attempts [1]. Thus, patients' whose responses reflected neither taking nor relinquishing control may have been struggling to gain control but perceived themselves as less than successful. Although subtle, a separate preliminary analysis of the differences in the way patients express IBD-related control suggests that they may indeed reflect discrete categories of control that are important for understanding HRQoL [30]. Nonetheless, a more complete investigation of patient self-regulation as it relates to HRQoL in people with IBD is warranted.

The differences between these three groups were subtle and were, again, identified through the patients' use of language. Often a limitation of quantitative survey use is that all constructs are pre-defined by the researcher; the rich and contextual differences between participants' narratives are practically indiscernible. Previous qualitative research has demonstrated the need for the inclusion of rich narrative data. In particular, Casati and colleagues [3] found that IBD patient concerns were multifaceted and psychosocial in nature, while Hall and colleagues [1] identified that IBD patients face extreme social burdens which force them to confront their health-related normality on a daily basis. Similarly, we identified multiple dimensions of HRQoL through patients' narratives that would not have been obvious without these methods. Recently it has also been suggested that an excellent way to bridge the realities and ideals of qualitative (i.e. rich data from a smaller sample) and quantitative (i.e. large samples and objective rigor) methodologies is to use text analysis to analyze open-ended narratives quickly [31]. Our study, employing a qualitative method but a large sample size, offers preliminary support for this specific type of analysis. The combined contributions of previous qualitative research and our own findings suggest that researchers should continue to use qualitative methodologies when trying to understand and accurately measure HRQoL.

In addition to our findings regarding the specific dimensions of HRQoL identified by the participants, a secondary issue to consider is how the patients framed the changes in their lives. While changes in HRQoL for IBD patients are often referred to in the literature as 'problems,' there were several cases of participants reporting positive changes in their lives as a result of

IBD. In particular, these participants described better eating and exercise habits, and also discussed how they became more organized in the process of coping with the disease. While it was not our explicit intent to identify positive or negative changes in the patients' lives, these findings are consistent with the positive psychology movement and the greater acknowledgement of the positive experiences of patients with chronic disease [32, 33]. Indeed, researchers have suggested that IBD patients can and do experience a HRQoL similar to 'healthy' individuals [34], and our study also supports the notion that not all people will frame their disease from a negative point of view. This has implications not only for how we research HRQoL, but how we measure it as well. Researchers, many of whom may not have IBD themselves, may unwittingly marginalize the very population they are studying by not keeping their assumptions about the disease in check, and using terminology that may not reflect the participants' experiences. This is certainly an issue to be considered for future work with IBD populations.

One limitation of this study involves researcher bias, which is present in all forms of research but only acknowledged within certain epistemological standards. As with all qualitative research, there is a degree of subjectivity to this analysis which must be acknowledged. However, in qualitative research, trustworthiness is the equivalent of reliability and validity in quantitative work. For this study, trustworthiness was assured in two ways: two researchers reviewed and discussed the themes as a means of data triangulation and peer review, and all emergent themes were eventually referenced against relevant literature.

A second issue involves the method in which the qualitative responses were collected. Participants were only asked one open-ended question about their experiences with IBD via an electronic survey. Although the question was asked after completion of the IBDQ, this measure did not appear to affect participant responses, and rather, many unique dimensions of HRQoL were discussed. Further, a traditional interview may have allowed for additional probing or reflective questions. However, survey methods for obtaining qualitative data have the advantage of eliminating the problems of response effects known to occur in face to face or phone interviews [39]. Moreover, there is mounting evidence that the qualitative responses obtained through electronic surveys may be superior to those obtained through traditional paper surveys completed by mail, with several studies finding that respondents write comments that are lengthier and more self-disclosing in electronic surveys than those written in mail surveys [40-43]. In addition to the large volume of responses that using this sampling method permitted, we believe that using an electronic survey provided an appropriate and valid way to gather qualitative responses to address our research question.

Other possible limitations to be considered when interpreting our findings include the characteristics of the sample. Respondents were predominantly Caucasian and female with CD. Research has indicated that of the three types of IBD, UC is most prevalent, but that in the long term, incidence rates for UC and CD generally match [35]. At least two studies also suggest that IBD patient samples recruited from the Internet tend to have a poorer overall HRQoL than those recruited from clinics [36,37]. Therefore it is possible that, the positive changes in HRQoL we found notwithstanding, our sample may have been worse off with respect to HRQoL than a comparable clinic-based sample. However, given the purpose of our study, to examine the dimensions of HRQoL affected by living with IBD from the patients' perspective, addressing this issue with a sample of IBD patients with poorer quality of life may be preferable, and even desirable. For example, in one qualitative investigation of IBD patients' lived experiences, only patients with the lowest scores on the IBDQ were included in the qualitative analysis as it was reasoned that such individuals would provide the richest range of experiences [1]. It must be acknowledged that participants with potentially poorer HRQoL may not have discussed as many positive changes in their lives as another group of IBD patients. Although our sample characteristics may not be fully representative of the larger IBD population, we generally concur with Vanderheyden and colleagues [38] that the intent of qualitative research is to extend, not test theories. From this perspective the generalizability of our findings, which remain to be verified, is less important than the extensions to existing models of HRQoL that we have proposed.

The results of this study indicate that when participants are asked how IBD has affected their lives, they will largely discuss issues that are already identified in the literature and integrated within measures of HRQoL. Because the point of such measures is to collect data about patients' experiences, this suggests that we, as researchers and practitioners, are on the right track when it comes to understanding how IBD affects a patient's HRQoL. However, our findings have revealed that it is critical to continue examining how the patients themselves live and frame their experiences with IBD. In the process, we can only improve our ability to measure patient HRQoL, and effectively respond through appropriate treatment and intervention.

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Table 1. Demographic characteristics of the three samples

	Total IBD Sample	Group	
		Included in Final Analysis	Not included in Final Analysis
N	291	282	9
Sex (%)			
Female	75.3%	75.2%	77.8%
Male	23.7%	23.8%	22.2%
Age			
Mean	36.2	36.3	33.0
SD	11.92	11.85	14.29
Range	(13-77)	(13-77)	(14-55)
Ethnicity (%)			
Caucasian	96.0%	100%	95.8%
Asian	2.9%	0	3.0%
Hispanic	.7%	0	.8%
Aboriginal	.4%	0	.4%
Country of Residence (%)			
Canada	23.7%	23.4%	33.3%
USA	60.5%	61.7%	22.2%
United Kingdom	8.2%	8.2%	11.1%
Australia/New Zealand	3.7%	3.6%	11.1%
Europe	3.3%	2.9%	22.2%
Other	.3%	.4%	0
Level of Education (%)			
High School	17.5%	17.5%	12.5%
University	57.4%	57.4%	62.5%
Graduate	25.1%	25.1%	25%
Employment Status (%)			
Full time	50.9%	50.4%	66.7%

Part time	18.2%	18.8%	0
Unemployed/Retired	21.4%	21.1%	33.3%
Disabled	9.5%	9.8%	0
Relationship Status (%)			
Married/Living with	58.7%	60.3%	11.1%
Divorced/Separated	10.8%	10.1%	33.3%
Never Married	29.7%	28.9%	55.6%
Widowed	.7%	.7%	0
Type of IBD (%)			
CD	65.2%	66.2%	33.3%
UC	27.9%	26.6%	66.7%
Other IBD	7.0%	7.2%	0
Years Since Diagnosed			
Mean	9.6	9.7	6.3
SD	8.743	8.746	8.733
Range	(0-49)	(0-49)	(1-24)

SD = standard deviations

Table 2. Comparison of current HRQoL dimensions with the SF-36 and IBDQ

SF-36	IBDQ	Current Findings
Physical Functioning	Bowel Symptoms	Physical:
Role Physical	Systemic Symptoms	Systemic Functioning
Bodily Pain		Daily Functioning
General Health		Energy/Vitality
Vitality		Pain
Social Functioning	Social	Social
Role Emotional	Emotional	Emotional
Mental Health		Cognitive:
		Functioning
		Attending to Disease
		Self-Regulation:
		Taking Control
		Loss of Control
		Neutral
		Practical