



Understanding Work Experiences of People with Inflammatory Bowel Disease

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Understanding Work Experiences of People with Inflammatory Bowel Disease

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For Peer Review

Abstract

Background: People with Inflammatory Bowel Disease (IBD) are at increased risk for unemployment and work absenteeism over the course of their adult lives. However, little is known about the firsthand experiences of people living with the disease regarding perceived barriers, facilitators and strategies for navigating work roles.

Methods: In this qualitative study participants were purposefully recruited from two existing IBD cohort study samples. Recruitment strategies aimed for diversity in age, sex, and disease type, duration and symptom activity. In-depth interviews sought perspectives of living with IBD. Data were analyzed using inductive qualitative methods.

Results: Forty-five people currently or previously in the workforce participated; 51% were female. The mean age was 45.4 years (SD = 16.1; range = 21-73 years). Mean IBD duration was 10.9 years (SD = 6.3). Participants had a broad range of experiences in adapting to work roles. IBD symptoms and treatments interacted with other personal and environmental factors to shape the experiences of work. Experiences were shaped by: (1) personal health and wellbeing, (2) personal values, beliefs and knowledge, (3) job characteristics, (4) workplace physical environment, (5) workplace culture, and (6) financial factors. Participants identified personal strategies and environmental supports that assisted them to navigate their work roles.

Conclusions: The perspectives of people with IBD provided in-depth understanding of contextual factors that influence work roles. They identified personal strategies to manage health and choices about work, environmental supports that promote timely workplace accommodations, and appropriate social insurance benefits as facilitators of work retention for people with IBD.

Key Words: employment retention, inflammatory bowel disease, qualitative study, workplace

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adaptation, chronic disease

For Peer Review

Introduction

Inflammatory Bowel Disease (IBD), including Crohn’s disease (CD) and ulcerative colitis (UC), is a chronic disease with intermittent periods of disease symptoms.^{1–3} The fluctuating, unpredictable nature of IBD can cause episodic disability, and consequent barriers to participating fully in employment, or experiencing insufficient income, despite ability and desire to work.⁴

Living with IBD impacts work experiences. A large European survey of 4670 people with IBD reported that 40% of respondents had to make changes to their work life, such as reducing work hours, due to their disease.⁵ The results of a Canadian online survey found that, of 272 people living with IBD, 77% felt that IBD had some to a major impact on pursuing their career of choice, and 82% felt some to a major impact of financial burden related to having IBD; 48% of respondents did not have access to information about how to communicate with employers regarding their IBD.⁶ In a comparison of two population-based data sets, Bernstein et al found that people with IBD were more likely to be unemployed than those in the general population.⁷ More recently, a review of the impact of IBD on work and disability, Büsch et al reported that 9% to 19% of people with IBD experience work absenteeism, and 19% to 22% are not working.⁸

Disability is recognized as a complex phenomenon that results from an intersection of impairments, activity limitations and participation restrictions.⁹ Qualitative research methods address issues of complexity in context.¹⁰ Patients’ perspectives are increasingly sought through qualitative research methods to understand the burden of IBD,¹¹ inform IBD assessment,^{12,13} and improve the quality of treatment¹⁴ and care.^{15,16} However, to our knowledge, no published studies have explored an in-depth understanding of the experiences of living with IBD in the

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context of work. A thorough understanding of navigating work roles from firsthand experiences of living with IBD can provide valuable information to improve clinical management, social policy, and activity and participation of people living with IBD.

In this paper we report on the intersection of people's experiences of work and work disability in the context of living with IBD, and the ways that personal and environmental factors supported or created barriers for them to participate in paid employment. Our goals were to illuminate the commonalities of experience, identify variations, and highlight implications for practice, research and policy, to inform a broader goal of minimizing work disability for people living with IBD.

Methods

As part of a larger study exploring the experiences of people living with IBD, we used a phenomenological approach to explore people's firsthand accounts of their lived experiences¹⁷ with IBD and employment. Through individual face-to-face interviews we explored the experiences and the meanings attributed to those experiences. We chose individual over group interviews because we were interested in obtaining an in-depth understanding of personal experience of living with IBD rather than a blended voice of a group. Individual interviews can yield rich personal experience data without being unduly constricted by others' stated views in group settings. Participants were compensated for their time and any incurred expense with \$80 (CAD). Neither of the interviewers (GR and AS) who obtained consent and conducted interviews were involved in the clinical management of people with IBD. Interviews were held either at the participant's home, the participant's private office, or in a private seminar room at the University of Manitoba, based on the participant's preference. The Health Research Ethics Board at the

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University of Manitoba approved the study. All participants provided written informed consent.

Recruitment

We used a maximum variation sampling approach¹⁸ to purposely select participants with diverse experiences with IBD, between October 2013 and September 2014. Most participants were recruited from the Manitoba IBD Cohort Study, a population-based study that has followed persons with semi-annual surveys over a 12-year period.¹⁹ To ensure representation of early disease experience, remaining participants were sampled from an Inception Cohort study, which recruited individuals in the first six months following IBD diagnosis, and has followed them through annual surveys for up to 5 years. Individuals from these two sources were screened for the following inclusion criteria: adults residing in the province of Manitoba with a diagnosis of IBD for minimum of 6 months, capable of providing informed consent and participating in an interview in English. We purposely selected interested participants with a breadth of characteristics to represent the varied impact and experience of IBD, considering age, sex, disease duration, and long-term symptom activity pattern (Table 1).

Symptomatic activity was assessed using the Manitoba IBD Index (MIBDI). The MIBDI is a validated single-item measure with a 6-level response format that evaluates the frequency of IBD symptoms over the prior 6 month period, to assess disease activity pattern over years. The MIBDI categorizes a period as active for respondents reporting symptoms 1-2 days a month, 1-2 days a week, most days, or daily; respondents reporting symptoms a few days in the past 6 months, or that they were well, are categorized as inactive.²⁰ For this study, participants were identified as having the symptom pattern of *active* if they reported active symptom periods based on the MIBDI, for at least 37.5% or more of the semi-annual measurement periods; otherwise,

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they were categorized as having an *inactive* symptom pattern. Recruitment stopped once participants from all a priori identified categories had been interviewed and data analysis suggested that there was saturation of themes based on the sample characteristics (i.e., no new information was being captured in the later interviews). The sample size of 45 was considerably larger than the size recommended for phenomenological studies ($N=10$),²¹ to account for the variation of characteristics identified in the sampling frame.

Data Collection

Interviews were conducted using an open-ended interview guide with questions designed to explore participants' experiences of living with IBD in the context of activity and participation in their social roles. In keeping with phenomenological interviewing, questioning about work was initiated with a broad invitation to discuss their employment experiences, i.e., "Tell me about work." Subsequent prompts explored challenges with working, accommodations needed or desired at work, experiences with managers, co-workers, and others in the context of work, the processes of seeking workplace accommodations and the meaning of work in the context of living with IBD. Interviews lasted from 25 minutes to 98 minutes and were audio-recorded.

Data Analysis

A professional transcriptionist transcribed audio-recorded interviews verbatim. Transcripts were analyzed by GR and AS using recommended phenomenological approaches.²² GR is an experienced qualitative researcher and clinician, and trained AS in conducting and analyzing interviews specific to this study. AS is a graduate student with 10 years of clinical experience working with people of all ages to manage chronic health conditions. GR and AS reviewed all interview transcripts and field notes to obtain an overall sense of the data in context. An initial coding scheme was developed. Codes were named, added, renamed, merged or

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diverged into clusters, based on iterative analysis of interviews with the goal understanding the meaning of experiences shared by participants in context. All coding was done using NVivo 10.0 qualitative data analysis software.²³ Once all interviews were coded, GR and AS met to identify themes emerging from the data. Themes aimed to reflect shared experience across all participants. Initial themes were agreed upon by GR and AS, and arranged in a model. The themes and model were presented to the research team who provided feedback regarding clarity. Team discussion included reflection of common, typical and unique experiences that emerged from the data, compared with clinical experiences that supported or identified alternate explanations for interpretation of the data. Reflection on the team discussion in consideration of the data, and feedback regarding clarity led to the model presented here, finalized following team consensus through discussion.

Trustworthiness

Multiple approaches were used to support the development of trustworthiness of the findings, guided by Gibbs,²⁴ Dezdin,²⁵ and Creswell and Miller.²⁶ Transcripts were checked for errors by AS who was present for all 45 interviews. Use of meetings, memos and code descriptions during analysis helped improve comparable coding between researchers. An audit trail was kept throughout the study, documenting the research decisions and processes. To reduce the risk of researcher bias, a consistent interview process was followed, including writing of a reflexive field note following each interview. In addition, triangulation of theories and perspectives, including seeking alternate explanations for interpretations, was achieved through meetings to discuss findings with the larger interdisciplinary research team. Member checking was conducted by mailing a summary of findings to participants and asking them to review the summary to ensure their perspectives were included. Two participants responded with additional

comments that we subsequently incorporated into the findings.

Results

Participants

The 45 participants ranged from 21 to 73 years old ($M = 45.4$, $SD = 16.1$); 23 (51%) were women, 26 (58%) had ulcerative colitis (UC). The mean disease duration was 10.9 years ($SD = 6.3$, range = 6 months to 18 years). In the current sample, 31 (69%) had an active IBD symptom pattern and the remainder were categorized as having an inactive symptom pattern. Twenty-eight (62%) participants lived in a mid-sized Canadian city with the remainder living in surrounding small cities and rural communities. Table 2 reports the employment status of participants at the time of their interview. Although not all participants were employed at the time of the study, all participants reported experiences working while having IBD and were included in the results.

IBD and Work

People living with IBD revealed a broad range of experiences that evoked an essence of adapting to major life roles in the face of a chronic disease that was at times fluctuating and unpredictable. The disease and its treatments interacted with other personal and environmental factors to shape the experiences of work. We identified six themes that influenced these experiences: (1) personal health and wellbeing, (2) personal values, beliefs and knowledge (3) job characteristics, (4) workplace physical environment, (5) workplace culture, and (6) financial factors. Two additional themes were identified that assisted participants to cope and navigate work roles: (1) personal strategies, and (2) environmental supports. Figure 1 illustrates these themes and each theme is described below with quotes from participants to exemplify

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perspectives of the themes. Pseudonym initials, followed by their age classification, are used to provide context to the quote while protecting the identity of individual participants. A participant under 35 years has been classified as a *young adult*; 35-55 years is an *adult*; and older than 55 years is an *older adult*.

Influences on Work Experiences

Personal health and wellbeing. Participants identified the impact of the type, frequency and severity of symptoms of IBD on work experiences. Needs could change over the course of the disease and individual experiences varied widely. Some participants experienced an impact on their work prior to diagnosis and the initiation of treatment that then controlled their symptoms; others were impacted throughout their disease course. For example, TJ an older adult male, described retiring seven years earlier than planned, at age 48, because of his IBD. Some participants had more work issues when health interventions were needed, such as physician appointments. JL, a young adult female, remarked, "...when I was at my worst, which was before I actually went to my doctor...I didn't miss a day of work because of being in pain. And then as soon as I got to see a doctor, there were so many appointments...I'd say I probably missed cumulatively about 2 weeks of work." JT, a young adult male, spoke of not being able to work when sick and in hospital for IBD related surgery, but returned to work once he had recovered. Although he has not had any IBD related work issues in years, JT explained: "...I was just looking at my vacation or my like sick [leave] bank if I ever, something did happen...I can go days without thinking about it [IBD], or it just kind of becomes this benign kind of thing that doesn't concern me. But it's like anything, you know, it could strike up again..."

Symptoms of depression, anxiety, addictive disorders, diabetes and cardiovascular

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3 disease were described as increasing challenges to work performance. For example, EA, an older
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5 adult male, spoke about his experience of IBD and depression at a particularly busy and stressful
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7 time in his work year: "...what comes first: depression and then colitis, or colitis and
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9 depression.... I know damn well you'd sink into those times and then it would just make it even
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11 worse.... Just when everything's building up and all of a sudden you, you can't handle it."

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15 ***Personal values, beliefs and knowledge.*** Participants spoke about the ways personal
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17 values and beliefs related to work, and how perceptions of their health condition shaped their
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19 self-identity. Perceptions about entitlements to, and knowledge of, their rights as a worker were
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21 important to seeking accommodations. Some participants, like DM, a young adult male, lacked
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23 knowledge about worker rights and entitlements: "I don't even know if I could ask...I don't
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25 know how I would go about asking for anything like that [accommodations at work]."

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29 GE, an older adult male, explained how guidance from a health professional helped him
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31 communicate with his employer when he was unable to work due to his IBD and depression:
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33 "...[he] was really good at coaching me how to deal with my employer and with the disability
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35 [benefit] people who would be phoning all the time and stuff like that." GE learned from his
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37 health professional that he did not need to disclose his diagnosis to his employer in order to
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39 receive accommodation or benefits.
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44 Participants' beliefs about whether disclosure about the health condition and adaptations
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46 to their jobs or work environments would be helpful, a show of weakness, or result in negative
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48 consequences, affected their approaches to seeking changes that could reduce the burden of
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50 disability in the workplace. At times, it was difficult to find the right words to explain absences
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52 or request changes. MJ, an adult male, said:

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55 ...I just couldn't really say like, this is what it is; this is, you know, when I am
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3 calling in sick this is why. I'm not trying to duck out of work. I'm not trying to
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5 whatever... I guess I never really was able to kind of come up with the right
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7 words....
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10 MJ eventually left this job and found another.
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12 Some participants talked about feeling “worry”, “anxiety”, “shame” and
13
14 “embarrassment” about their IBD at work. KC, a young adult female, said: “...I have to go to the
15 bathroom a lot. Like, yea, it's embarrassing because ... lots of times ... you have no privacy.”
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18 AJ, a young adult female, said: “I go to the bathroom probably 8 or 9 times a day and ... I'm
19 very self-conscious of that. And that's been I guess the only one thing that has really stayed with
20 me since the beginning that I've never gotten over is the whole bathroom thing and like the
21 different smells, different noises.” In contrast, others talked about not being, or learning to not
22 be embarrassed.
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32 **Job characteristics.** Whether participants experienced a good fit with their job was
33 dependent on the demands, flexibility and timing of tasks, and the need for coverage for their job
34 tasks if they were absent for short unscheduled breaks or absent for longer periods such as a day
35 or week. For some, physically demanding work was difficult. EH, a young adult male, said: “It
36 [IBD] kind of limited my options in thinking like what you're going to do for a career type of
37 thing. But, because I didn't know how much manual labor I would be able to take. And I would
38 look for like a job, desk job type of thing than something else.” JF, an older adult female,
39 described IBD related fatigue as interfering with her job that required frequently going up and
40 down stairs.
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53 **Workplace physical environment.** For many participants the physical environment of the
54 workplace was important. The proximity of a toilet was understandably a concern for many
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participants. KC, a young adult female, explained, “Because everywhere you go, you’re looking for a bathroom.” For some participants, working in remote areas raised concerns about whether they could leave the remote area if they became sick. CA, a young adult male, and AM, an older adult female, both frequently had to travel for work and had concerns about sharing a hotel room with co-workers because of embarrassment around the need to frequently use the toilet.

Workplace culture. Workplace culture also influenced participants’ work experiences. Participants spoke about the importance of having workplace policies, practices and education that facilitated participants seeking and obtaining accommodations. Alternatively, a culture that included implicit or explicit expectations to work long hours and to not take time off made it difficult for some participants to have their needs met. A few participants expressed anger about specific incidents in the workplace in which co-workers or supervisors made negative or insensitive remarks or behaviors about their bowel symptoms or overall health status.

Many participants described quitting a job, or believing they were let go because of their IBD symptoms without inquiring about, or being offered accommodation. TB, an adult female, described disclosing her IBD diagnosis to an employer: “And then she let me last a little bit longer and then she said, it’s not going to work. You get sick too much at work where we have to send you home.”

Participants reported that supervisors and managers who were aware of accommodation processes and options, and who had an attitude of willingness to accommodate, facilitated the process. Woven through many participants’ narratives was the importance of trust between themselves and their supervisors and co-workers. An atmosphere of trust and flexibility fostered their ability to seek and obtain changes. ME, an older adult female, described arranging for coverage when needing to go to the bathroom at work: “I told [supervisor] I had the

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3 problem...She said, that's fine...We had a meeting with [coworkers], the ones that I work with
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6 and we all talked about it and they said, fine, no problem."

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8 Alternatively, as GE, an older adult male, described how lack of trust made it difficult to
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10 seek accommodations: "...the work atmosphere there was becoming toxic with all the changes
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12 and everything like that ... most of the staff ended up not liking him (the supervisor). Not
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14 trusting him. So, uh, I couldn't trust him; so I didn't share anything with him." GE was in a
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16 situation in which he had, at one time, a good relationship with his supervisor, but the work
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18 environment changed and trust eroded. Although it may have been helpful for him to disclose
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20 information about his illness, he chose not to out of fear of negative consequences.
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25 Although workplace accommodations were often important for managing symptoms
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27 of IBD, some participants sought and were granted accommodations for other reasons. For
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29 women this decision was sometimes related to parenting. For example, SK, a young adult
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31 female, talked about making arrangements with her employer to work from home once her
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33 baby was born. This arrangement also made it easier to manage the symptoms of her IBD.
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37 "Because after I would have a bowel movement, I, I would have to lay down for
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39 half an hour to regain my strength. And so if I could work from home, I could
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41 just lay down. Then I could go back to it when I needed to. So, yes, flexibility on
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43 the employer part, um, you know, if you do your best at work and you work hard
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45 and you don't take advantage of the company, they treat you well. And not all
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47 companies, but they did. And, yeah, set me up with a home office. So that
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49 allowed me to continue working with having children and being sick which I
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51 really enjoyed"
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55 This quote also calls attention to the perspective of many participants that requests for, and
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granting of, accommodations were often based on a positive reciprocal relationship between an employee and supervisor or employer, rather than on employee rights or workplace policies.

Financial factors. Financial factors were very relevant considerations for many participants. Issues such as whether or not they had paid benefits for leaves from work or disability insurance coverage was emphasized. Other household income and expenses could influence participants' work-related decisions such as their willingness to take unpaid leaves, work part-time, or retire. MJ, an adult male, talked about the importance of his benefit package to cover the costs of medications and how it influenced his decisions about remaining at that job.

"So it's one of the big things why I'm still there. Like it's, like wow, I could maybe go do other things but I will lose this benefit... it just isn't worth it."

Some participants were aware of the health benefits in their workplaces and, like MJ, chose or stayed with jobs that provided benefits. Others were unclear about benefits available to them. TM, an adult female, shared that she was unaware of a government-funded benefit to help cover her medications for years after her diagnosis: "I wish I knew how that worked. If there was some sort of manual...these [drugs] are expensive."

Strategies and Environmental Supports to Navigate Work Roles

Personal strategies. Within the unique and varied experiences at work, participants talked about important strategies they used to navigate work while living with IBD. Key strategies are included in Table 3. Many strategies fostered the ability of participants to remain employed, but could also take a toll on other aspects of their lives. For example, working sometimes meant that participants had to limit participation in social or leisure activities. EA, an older adult male, pointed out: "There's always something you have to give up it seems. You

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know, you can't do it all." CT, an older adult female, explained: "I mean the work at work got done. There was no ifs, buts or maybes about that. But things at home slacked off. So when I came home, you know, I didn't do all the things I wanted to." EA's and CT's comments highlight the ways that a choice to work while living with IBD can result in long term sustained and productive employment, but at the expense of home, leisure and social activities. Women participants, in particular, talked about the challenges of balancing work with parenting and/or providing support to aging parents and managing their IBD. Some found relief in changing from fulltime to part-time work or working from home, which helped them to manage the balance between work and family responsibilities within the context of their disease.

Some participants like DM, a young adult male, and KS, an adult female, expressed regret at lost work and career opportunities. These losses were related to changing career aspirations or jobs because they felt that a more challenging or preferred job or career would be detrimental to their overall health, or not possible while living with IBD.

Environmental supports. Table 4 describes the environmental supports that participants believed facilitated their work participation while living with IBD.

Workplace environments. Participants noted the importance of a workplace that promoted acceptance and facilitated timely accommodations. Supervisors, human resource personnel and co-workers were all important. JL, a young adult female, considered herself fortunate to have an understanding boss: "I'm lucky that, I mean my boss is the kind of person who has always said, family and health...he's been great and very, very much: 'take the time you need. Don't worry about it. You can make up the time'." JL also noted how one of her colleagues was helpful in facilitating her relationships within the workplace: "...she is a really good person to have at the office, because I find that if people are gossipy or trying to figure out

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3 why I'm taking so much time off work, she's really good at diffusing the situation." For JL, these
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5 individuals helped create an environment in which she could manage her illness as well as the
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7 potential negative consequences in the workplace from obtaining needed accommodations.
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11 Workplace accommodation policies that were clear, available, and promoted to
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13 employees helped participants in periods when they needed flexibility in their hours of work and
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15 work schedule, or changes to the physical demands of their job or physical location of their
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17 work. Policies and practices that promoted flexibility and inclusiveness toward people with
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19 chronic health conditions could reduce the need to ask for special consideration that was often
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21 dependent on a good relationship with a supervisor. LS, an adult female, described a quiet room
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23 in her workplace available to all staff: "...we have a sick room at work that I can go and lay
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25 down in for half an hour if I needed to...."
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29 ***Socio-political environments.*** Participants spoke about health and social policies and
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31 public attitudes and knowledge which could be changed to better support people living with IBD.
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33 These included ease of access to medical practitioners, treatments and government benefits for
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35 work interruptions. Participants identified issues with the definition of "disability" contained in
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37 public and private insurance policies that may not allow people living with an episodic disability,
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39 like IBD, to access benefits. In addition, some participants spoke about public attitudes in the
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41 form of stigma associated with IBD and the need for initiatives to address the stigma. For one
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43 participant accepting disability insurance would have been stigmatizing. Participant narratives
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45 also suggested the need for more widespread knowledge about workplace policies and practices
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47 that could accommodate people living with IBD and other health problems, as well as
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49 information about the rights and responsibilities of employers and employees.
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Discussion

Consistent with the International Classification of Functioning, Disability and Health (ICF),²⁷ participants’ narratives supported the importance of considering personal and environmental factors in understanding work experiences. The ICF model depicts disability in context, recognizing the influence of environment and personal factors on body function, activity and participation, in addition to the effects of health condition.²⁷ Although problematic body functions such as bowel disturbance could increase the risk of work disability for people living with IBD,²⁸ the experiences of work and work disability were embedded in a range of personal factors, job characteristics, and work and social environments.

Personal factors that influenced the experiences of work included the symptoms of IBD and other health conditions. Depression, in particular, is recognized as a factor associated with disability in people with IBD.^{29,30} Demanding life roles such as parenting and supporting aging parents can create greater challenges for maintaining work participation and, in the United States and Canada, can disproportionately affect women.^{7,28} Lower health-related quality of life in women with IBD may be related to gender inequalities in social roles.³¹ Our study also suggests that, in many cases, people living with IBD chose work over leisure and other activities. A recent Canadian survey of people living with IBD reported that more respondents identified an impact of IBD on leisure activities than those reporting an impact on work.⁶ Choices to participate in the labor force can result in limited participation in other life areas. Work disability needs to be considered in the context of general disability³² and work ability needs to be considered in the context of other life activities and social participation.

Theoretical perspectives of the person-environment-occupation model³³ suggest that optimum work performance is dependent on a good match between the person, workplace

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environments and the job. Work environments and the availability of accommodations can be important determinants of whether disability is experienced in the workplace. The dominant model of providing accommodations in workplaces is based on addressing the needs of individual employees and requires negotiation between the employee and his or her supervisor.³⁴ Consistent with other literature,^{34,35} participants highlighted the additional importance of workplace culture and policies supportive of accommodations. Disclosure is an important issue for *invisible disabilities* such as IBD because the reasons for needing accommodations are not readily apparent.³⁶ Marri and Buchman³⁷ concluded that most people living with IBD were in favor of disclosure. However, participants in our study highlighted the complexity of decisions about disclosure and requests for accommodations. They had varied experiences that were highly dependent on workplace culture, work relationships, beliefs about whether accommodations could or would be implemented, and perceived stigma anticipated with disclosure.³⁸ Support is needed from health professionals to assist people with IBD with issues such as assessing the relative risks of disclosing the health condition and requesting accommodations in the workplace, understanding the right of workers to not disclose their specific health condition, and communicating requests for accommodations.

Participants in the current study noted the ways that treatments for IBD could be a work-related burden. Attention needs to be paid to the organization of the health system in relation to the distances needed to travel to attend health care appointments and flexibility around appointment scheduling. Further, patients need to be made aware of available funding sources, like government programs, to offset the costs of medication.

Implications

Individual interventions can support people with IBD who are struggling with negotiating

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work and social roles to establish goals and action plans. Assessing the fit between personal factors, job characteristics and work environments and developing strategies for improving the fit by negotiating needed accommodations can improve the experience at work. From a meta-synthesis of qualitative studies on the needs of people living with IBD, Kemp et al³⁹ pointed out the importance of personal control. Participants in our study talked about the ways that they took control in negotiating work roles, which may be helpful for other people living with IBD, especially those who are newly diagnosed. In addition, self-management interventions, including programs designed for managing a range of chronic health conditions,⁴⁰ may be helpful in increasing people’s self-efficacy and sense of control in managing their disease in the context of their work and social lives.

Interventions directed toward work environments are also important.⁴¹ Education of employers on their rights, responsibilities and the need for appropriate workplace accommodations for people with episodic disabilities can help create more supportive work environments. Good accommodation policies, as a foundation for the flexibility that is helpful for retaining employment, can go a long way to reducing work disability. IBD support groups and charitable foundations have a role in enhancing employer awareness about the importance of workplace accommodations in support of employee retention and work productivity.

Social policies that define disability and the extent of coverage for disability-related absences need to take into consideration the needs of people living with episodic diseases such as IBD. These policies vary widely internationally but insurance benefits that respond to the episodic disability experiences of people with IBD and other chronic health conditions can help maintain labor force participation.

Future Directions for Research

Our findings provide a framework for avenues of investigation in future studies. The factors participants identified as influencing work experiences can be included in quantitative studies about work-health-life balance and work retention for people living with IBD. The results can also inform the development of interventions to improve employment outcomes.

Limitations

Although we purposefully selected a diverse sample, we did not sample for socioeconomic indicators or education level, which may have limited the diversity of responses. In addition, participants often provided historical perspectives of their work experiences. Memory and reframing of their responses to these experiences may have influenced their perspectives.

Conclusion

Although several international studies have estimated the extent of work disability among people living with IBD,^{2,5,7,29,42–44} the experiences of work while living with IBD are seldom reported. Exploring these experiences has provided greater understanding of contextual factors that influence work retention, and successful strategies for negotiating work roles and responsibilities. This knowledge has implications for practice in supporting people negotiating work-health-life balance while living with IBD, identifying areas for future research, and for health and social policy that can better support people to maintain work roles.

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Table 1. Sampling Characteristics

Age, y	Disease Duration	Disease Pattern ^a	Women (n=23)	Men (n=22)	Total N=45
≥ 55	≥ 10 y	Active	5	5	10
30-54	≥ 10 y	Active	5	5	10
< 30	≥ 10 y	Active	3	1 ^b	4
< 30	≥ 10 y	Inactive ^c	0	1 ^d	1
≥ 30	≥ 10 y	Inactive	3	3	6
Any age	6-30 mo.	Any	4	4	8
Any age	31 mo. - 9 y	Any	3	3	6
Totals			23	22	45

^aRefer to *Recruitment* in the *Methods* section for details regarding categorization of active and inactive symptom pattern.

^bOnly one participant met the criteria for this category within the cohort sources.

^cThis was not a targeted sampling category; added an interview with participant noted with ^d due to limited number of male participants under 30 years, with 10 years or more disease duration and active disease.

Table 2. Participants' Employment Status at the Time of the Study

Employment Status ^a	No. of Participants (%)
Full time	21 (46.7)
Full time + part time	2 (6.6)
Full time + student part time	1 (2.2)
Part time (1 or more jobs)	5 (11.1)
Student full time	1 (2.2)
Student full time + part time	1 (2.2)
Retired	6 (13.3)
Retired + part time	2 (4.4)
Unemployed	5 (11.1)
Total	45 (99.98)
^a Participants with only unpaid and/or volunteer work counted as unemployed.	

Table 3. Key Personal Strategies Used to Navigate Work Roles

1. Being aware of one’s needs and resources
• For example: awareness of what type of work flexibility is needed and what policies are available in the workplace to facilitate flexibility
2. Self-management of IBD and other health conditions
• For example: looking after diet, exercise and treatment regimes
3. Management of emotional responses and attitudes toward health condition and life situation
• For example: having an accepting attitude toward IBD
4. Making informed choices about careers and job options
• For example: finding a career or job that offers the flexibility, culture and physical environment that eases the burden of IBD
5. Adapting to particular circumstances in the workplace
• For example: getting up earlier in the morning to empty bowels before attending an important meeting or getting a single, rather than shared, room when travelling

Table 4. Environmental Supports and Resources

Organizational Supports

Workplace	<ul style="list-style-type: none"> • Clear, available, and promoted workplace policies related to accessibility and accommodations
Culture and Relationships	<ul style="list-style-type: none"> • All employees have accurate and complete information related to accommodations, benefits and supports regardless of health problems • System in place to get coverage quickly when needed to go to bathroom • Culture of acceptance and support
Time-Based Flexibility	<ul style="list-style-type: none"> • Flexible work hours • Reduced work hours or job share options • Self-directed timing and pacing of tasks and breaks • Regular hours (without shifts or night work) • Timely and customized graduated return to work support post-surgery or after an extended absence
Physical Environment	<ul style="list-style-type: none"> • Access to toilet (preferably private) • Light duties options • Flexibility in body positioning while

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		working
		<ul style="list-style-type: none">Flexibility in where work can be done (e.g., moving a work station closer to a bathroom)
		<ul style="list-style-type: none">Quiet room for rest periods
	Employer	<ul style="list-style-type: none">Paid sick leave
	Benefits	<ul style="list-style-type: none">Health insurance that includes medication coverageShort-term and long-term disability insurance
Socio-political Supports		
	Health and Social Policies and Practices	<ul style="list-style-type: none">Easy access to physician for absence notes, concerns, change in symptoms and prescription refillsEvening and weekend options for biologic medicine infusionsGovernment benefits for episodic disabilities that interrupt work earnings (e.g. employment insurance sick benefits including coverage for graduated return to work)
	Public	<ul style="list-style-type: none">Stigma reduction
	Attitudes and Knowledge	<ul style="list-style-type: none">Widespread knowledge about workplace accommodations and the rights and

responsibilities of employers and
employees

For Peer Review

Understanding Work Experiences of People with Inflammatory Bowel Disease

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For Peer Review

Abstract

Background: People with Inflammatory Bowel Disease (IBD) are at increased risk for unemployment and work absenteeism over the course of their adult lives. However, little is known about the firsthand experiences of people living with the disease regarding perceived barriers, facilitators and strategies for navigating work roles.

Methods: In this qualitative study participants were purposefully recruited from two existing IBD cohort study samples. Recruitment strategies aimed for diversity in age, sex, and disease type, duration and symptom activity. In-depth interviews sought perspectives of living with IBD. Data were analyzed using inductive qualitative methods.

Results: Forty-five people currently or previously in the workforce participated; 51% were female. The mean age was 45.4 years (SD = 16.1; range = 21-73 years). Mean IBD duration was 10.9 years (SD = 6.3). Participants had a broad range of experiences in adapting to work roles. IBD symptoms and treatments interacted with other personal and environmental factors to shape the experiences of work. Experiences were shaped by: (1) personal health and wellbeing, (2) personal values, beliefs and knowledge, (3) job characteristics, (4) workplace physical environment, (5) workplace culture, and (6) financial factors. Participants identified personal strategies and environmental supports that assisted them to navigate their work roles.

Conclusions: The perspectives of people with IBD provided in-depth understanding of contextual factors that influence work roles. They identified personal strategies to manage health and choices about work, environmental supports that promote timely workplace accommodations, and appropriate social insurance benefits as facilitators of work retention for people with IBD.

Key Words: employment retention, inflammatory bowel disease, qualitative study, workplace

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adaptation, chronic disease

For Peer Review

Introduction

Inflammatory Bowel Disease (IBD), including Crohn’s disease (CD) and ulcerative colitis (UC), is a chronic disease with intermittent periods of disease symptoms.^{1–3} The fluctuating, unpredictable nature of IBD can cause episodic disability, and consequent barriers to participating fully in employment, or experiencing insufficient income, despite ability and desire to work.⁴

Living with IBD impacts work experiences. A large European survey of 4670 people with IBD reported that 40% of respondents had to make changes to their work life, such as reducing work hours, due to their disease.⁵ The results of a Canadian online survey found that, of 272 people living with IBD, 77% felt that IBD had some to a major impact on pursuing their career of choice, and 82% felt some to a major impact of financial burden related to having IBD; 48% of respondents did not have access to information about how to communicate with employers regarding their IBD.⁶ In a comparison of two population-based data sets, Bernstein et al found that people with IBD were more likely to be unemployed than those in the general population.⁷ More recently, a review of the impact of IBD on work and disability, Büsch et al reported that 9% to 19% of people with IBD experience work absenteeism, and 19% to 22% are not working.⁸

Disability is recognized as a complex phenomenon that results from an intersection of impairments, activity limitations and participation restrictions.⁹ Qualitative research methods address issues of complexity in context.¹⁰ Patients’ perspectives are increasingly sought through qualitative research methods to understand the burden of IBD,¹¹ inform IBD assessment,^{12,13} and improve the quality of treatment¹⁴ and care.^{15,16} However, to our knowledge, no published studies have explored an in-depth understanding of the experiences of living with IBD in the

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context of work. A thorough understanding of navigating work roles from firsthand experiences of living with IBD can provide valuable information to improve clinical management, social policy, and activity and participation of people living with IBD.

In this paper we report on the intersection of people's experiences of work and work disability in the context of living with IBD, and the ways that personal and environmental factors supported or created barriers for them to participate in paid employment. Our goals were to illuminate the commonalities of experience, identify variations, and highlight implications for practice, research and policy, to inform a broader goal of minimizing work disability for people living with IBD.

Methods

As part of a larger study exploring the experiences of people living with IBD, we used a phenomenological approach to explore people's firsthand accounts of their lived experiences¹⁷ with IBD and employment. Through individual face-to-face interviews we explored the experiences and the meanings attributed to those experiences. We chose individual over group interviews because we were interested in obtaining an in-depth understanding of personal experience of living with IBD rather than a blended voice of a group. Individual interviews can yield rich personal experience data without being unduly constricted by others' stated views in group settings. Participants were compensated for their time and any incurred expense with \$80 (CAD). Neither of the interviewers (GR and AS) who obtained consent and conducted interviews were involved in the clinical management of people with IBD. Interviews were held either at the participant's home, the participant's private office, or in a private seminar room at the University of Manitoba, based on the participant's preference. The Health Research Ethics Board at the

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University of Manitoba approved the study. All participants provided written informed consent.

Recruitment

We used a maximum variation sampling approach¹⁸ to purposely select participants with diverse experiences with IBD, between October 2013 and September 2014. Most participants were recruited from the Manitoba IBD Cohort Study, a population-based study that has followed persons with semi-annual surveys over a 12-year period.¹⁹ To ensure representation of early disease experience, remaining participants were sampled from an Inception Cohort study, which recruited individuals in the first six months following IBD diagnosis, and has followed them through annual surveys for up to 5 years. Individuals from these two sources were screened for the following inclusion criteria: adults residing in the province of Manitoba with a diagnosis of IBD for minimum of 6 months, capable of providing informed consent and participating in an interview in English. We purposely selected interested participants with a breadth of characteristics to represent the varied impact and experience of IBD, considering age, sex, disease duration, and long-term symptom activity pattern (Table 1).

Symptomatic activity was assessed using the Manitoba IBD Index (MIBDI). The MIBDI is a validated single-item measure with a 6-level response format that evaluates the frequency of IBD symptoms over the prior 6 month period, to assess disease activity pattern over years. The MIBDI categorizes a period as active for respondents reporting symptoms 1-2 days a month, 1-2 days a week, most days, or daily; respondents reporting symptoms a few days in the past 6 months, or that they were well, are categorized as inactive.²⁰ For this study, participants were identified as having the symptom pattern of *active* if they reported active symptom periods based on the MIBDI, for at least 37.5% or more of the semi-annual measurement periods; otherwise,

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they were categorized as having an *inactive* symptom pattern. Recruitment stopped once participants from all a priori identified categories had been interviewed and data analysis suggested that there was saturation of themes based on the sample characteristics (i.e., no new information was being captured in the later interviews). The sample size of 45 was considerably larger than the size recommended for phenomenological studies ($N=10$),²¹ to account for the variation of characteristics identified in the sampling frame.

Data Collection

Interviews were conducted using an open-ended interview guide with questions designed to explore participants' experiences of living with IBD in the context of activity and participation in their social roles. In keeping with phenomenological interviewing, questioning about work was initiated with a broad invitation to discuss their employment experiences, i.e., "Tell me about work." Subsequent prompts explored challenges with working, accommodations needed or desired at work, experiences with managers, co-workers, and others in the context of work, the processes of seeking workplace accommodations and the meaning of work in the context of living with IBD. Interviews lasted from 25 minutes to 98 minutes and were audio-recorded.

Data Analysis

A professional transcriptionist transcribed audio-recorded interviews verbatim. Transcripts were analyzed by GR and AS using recommended phenomenological approaches.²² GR is an experienced qualitative researcher and clinician, and trained AS in conducting and analyzing interviews specific to this study. AS is a graduate student with 10 years of clinical experience working with people of all ages to manage chronic health conditions. GR and AS reviewed all interview transcripts and field notes to obtain an overall sense of the data in context. An initial coding scheme was developed. Codes were named, added, renamed, merged or

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diverged into clusters, based on iterative analysis of interviews with the goal understanding the meaning of experiences shared by participants in context. All coding was done using NVivo 10.0 qualitative data analysis software.²³ Once all interviews were coded, GR and AS met to identify themes emerging from the data. Themes aimed to reflect shared experience across all participants. Initial themes were agreed upon by GR and AS, and arranged in a model. The themes and model were presented to the research team who provided feedback regarding clarity. Team discussion included reflection of common, typical and unique experiences that emerged from the data, compared with clinical experiences that supported or identified alternate explanations for interpretation of the data. Reflection on the team discussion in consideration of the data, and feedback regarding clarity led to the model presented here, finalized following team consensus through discussion.

Trustworthiness

Multiple approaches were used to support the development of trustworthiness of the findings, guided by Gibbs,²⁴ Dezdin,²⁵ and Creswell and Miller.²⁶ Transcripts were checked for errors by AS who was present for all 45 interviews. Use of meetings, memos and code descriptions during analysis helped improve comparable coding between researchers. An audit trail was kept throughout the study, documenting the research decisions and processes. To reduce the risk of researcher bias, a consistent interview process was followed, including writing of a reflexive field note following each interview. In addition, triangulation of theories and perspectives, including seeking alternate explanations for interpretations, was achieved through meetings to discuss findings with the larger interdisciplinary research team. Member checking was conducted by mailing a summary of findings to participants and asking them to review the summary to ensure their perspectives were included. Two participants responded with additional

comments that we subsequently incorporated into the findings.

Results

Participants

The 45 participants ranged from 21 to 73 years old ($M = 45.4$, $SD = 16.1$); 23 (51%) were women, 26 (58%) had ulcerative colitis (UC). The mean disease duration was 10.9 years ($SD = 6.3$, range = 6 months to 18 years). In the current sample, 31 (69%) had an active IBD symptom pattern and the remainder were categorized as having an inactive symptom pattern. Twenty-eight (62%) participants lived in a mid-sized Canadian city with the remainder living in surrounding small cities and rural communities. Table 2 reports the employment status of participants at the time of their interview. Although not all participants were employed at the time of the study, all participants reported experiences working while having IBD and were included in the results.

IBD and Work

People living with IBD revealed a broad range of experiences that evoked an essence of adapting to major life roles in the face of a chronic disease that was at times fluctuating and unpredictable. The disease and its treatments interacted with other personal and environmental factors to shape the experiences of work. We identified six themes that influenced these experiences: (1) personal health and wellbeing, (2) personal values, beliefs and knowledge (3) job characteristics, (4) workplace physical environment, (5) workplace culture, and (6) financial factors. Two additional themes were identified that assisted participants to cope and navigate work roles: (1) personal strategies, and (2) environmental supports. Figure 1 illustrates these themes and each theme is described below with quotes from participants to exemplify

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perspectives of the themes. Pseudonym initials, followed by their age classification, are used to provide context to the quote while protecting the identity of individual participants. A participant under 35 years has been classified as a *young adult*; 35-55 years is an *adult*; and older than 55 years is an *older adult*.

Influences on Work Experiences

Personal health and wellbeing. Participants identified the impact of the type, frequency and severity of symptoms of IBD on work experiences. Needs could change over the course of the disease and individual experiences varied widely. Some participants experienced an impact on their work prior to diagnosis and the initiation of treatment that then controlled their symptoms; others were impacted throughout their disease course. For example, TJ an older adult male, described retiring seven years earlier than planned, at age 48, because of his IBD. Some participants had more work issues when health interventions were needed, such as physician appointments. JL, a young adult female, remarked, "...when I was at my worst, which was before I actually went to my doctor...I didn't miss a day of work because of being in pain. And then as soon as I got to see a doctor, there were so many appointments...I'd say I probably missed cumulatively about 2 weeks of work." JT, a young adult male, spoke of not being able to work when sick and in hospital for IBD related surgery, but returned to work once he had recovered. Although he has not had any IBD related work issues in years, JT explained: "...I was just looking at my vacation or my like sick [leave] bank if I ever, something did happen...I can go days without thinking about it [IBD], or it just kind of becomes this benign kind of thing that doesn't concern me. But it's like anything, you know, it could strike up again..."

Symptoms of depression, anxiety, addictive disorders, diabetes and cardiovascular

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2
3 disease were described as increasing challenges to work performance. For example, EA, an older
4
5 adult male, spoke about his experience of IBD and depression at a particularly busy and stressful
6
7 time in his work year: "...what comes first: depression and then colitis, or colitis and
8
9 depression.... I know damn well you'd sink into those times and then it would just make it even
10
11 worse.... Just when everything's building up and all of a sudden you, you can't handle it."

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15 ***Personal values, beliefs and knowledge.*** Participants spoke about the ways personal
16
17 values and beliefs related to work, and how perceptions of their health condition shaped their
18
19 self-identity. Perceptions about entitlements to, and knowledge of, their rights as a worker were
20
21 important to seeking accommodations. Some participants, like DM, a young adult male, lacked
22
23 knowledge about worker rights and entitlements: "I don't even know if I could ask...I don't
24
25 know how I would go about asking for anything like that [accommodations at work]."

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28
29 GE, an older adult male, explained how guidance from a health professional helped him
30
31 communicate with his employer when he was unable to work due to his IBD and depression:
32
33 "...[he] was really good at coaching me how to deal with my employer and with the disability
34
35 [benefit] people who would be phoning all the time and stuff like that." GE learned from his
36
37 health professional that he did not need to disclose his diagnosis to his employer in order to
38
39 receive accommodation or benefits.
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44 Participants' beliefs about whether disclosure about the health condition and adaptations
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46 to their jobs or work environments would be helpful, a show of weakness, or result in negative
47
48 consequences, affected their approaches to seeking changes that could reduce the burden of
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50 disability in the workplace. At times, it was difficult to find the right words to explain absences
51
52 or request changes. MJ, an adult male, said:
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56 ...I just couldn't really say like, this is what it is; this is, you know, when I am
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Work Experiences and IBD

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3 calling in sick this is why. I'm not trying to duck out of work. I'm not trying to
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5 whatever... I guess I never really was able to kind of come up with the right
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7 words....
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9

10 MJ eventually left this job and found another.
11

12 Some participants talked about feeling "worry", "anxiety", "shame" and
13
14 "embarrassment" about their IBD at work. KC, a young adult female, said: "...I have to go to the
15 bathroom a lot. Like, yea, it's embarrassing because ... lots of times ... you have no privacy."
16
17
18 AJ, a young adult female, said: "I go to the bathroom probably 8 or 9 times a day and ... I'm
19
20 very self-conscious of that. And that's been I guess the only one thing that has really stayed with
21
22 me since the beginning that I've never gotten over is the whole bathroom thing and like the
23
24 different smells, different noises." In contrast, others talked about not being, or learning to not
25
26 be embarrassed.
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32 **Job characteristics.** Whether participants experienced a good fit with their job was
33
34 dependent on the demands, flexibility and timing of tasks, and the need for coverage for their job
35
36 tasks if they were absent for short unscheduled breaks or absent for longer periods such as a day
37
38 or week. For some, physically demanding work was difficult. EH, a young adult male, said: "It
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40 [IBD] kind of limited my options in thinking like what you're going to do for a career type of
41
42 thing. But, because I didn't know how much manual labor I would be able to take. And I would
43
44 look for like a job, desk job type of thing than something else." JF, an older adult female,
45
46 described IBD related fatigue as interfering with her job that required frequently going up and
47
48 down stairs.
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53 **Workplace physical environment.** For many participants the physical environment of the
54
55 workplace was important. The proximity of a toilet was understandably a concern for many
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participants. KC, a young adult female, explained, “Because everywhere you go, you’re looking for a bathroom.” For some participants, working in remote areas raised concerns about whether they could leave the remote area if they became sick. CA, a young adult male, and AM, an older adult female, both frequently had to travel for work and had concerns about sharing a hotel room with co-workers because of embarrassment around the need to frequently use the toilet.

Workplace culture. Workplace culture also influenced participants’ work experiences. Participants spoke about the importance of having workplace policies, practices and education that facilitated participants seeking and obtaining accommodations. Alternatively, a culture that included implicit or explicit expectations to work long hours and to not take time off made it difficult for some participants to have their needs met. A few participants expressed anger about specific incidents in the workplace in which co-workers or supervisors made negative or insensitive remarks or behaviors about their bowel symptoms or overall health status.

Many participants described quitting a job, or believing they were let go because of their IBD symptoms without inquiring about, or being offered accommodation. TB, an adult female, described disclosing her IBD diagnosis to an employer: “And then she let me last a little bit longer and then she said, it’s not going to work. You get sick too much at work where we have to send you home.”

Participants reported that supervisors and managers who were aware of accommodation processes and options, and who had an attitude of willingness to accommodate, facilitated the process. Woven through many participants’ narratives was the importance of trust between themselves and their supervisors and co-workers. An atmosphere of trust and flexibility fostered their ability to seek and obtain changes. ME, an older adult female, described arranging for coverage when needing to go to the bathroom at work: “I told [supervisor] I had the

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3 problem...She said, that's fine...We had a meeting with [coworkers], the ones that I work with
4
5 and we all talked about it and they said, fine, no problem."

6
7
8 Alternatively, as GE, an older adult male, described how lack of trust made it difficult to
9
10 seek accommodations: "...the work atmosphere there was becoming toxic with all the changes
11
12 and everything like that ... most of the staff ended up not liking him (the supervisor). Not
13
14 trusting him. So, uh, I couldn't trust him; so I didn't share anything with him." GE was in a
15
16 situation in which he had, at one time, a good relationship with his supervisor, but the work
17
18 environment changed and trust eroded. Although it may have been helpful for him to disclose
19
20 information about his illness, he chose not to out of fear of negative consequences.
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22

23
24 Although workplace accommodations were often important for managing symptoms
25
26 of IBD, some participants sought and were granted accommodations for other reasons. For
27
28 women this decision was sometimes related to parenting. For example, SK, a young adult
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30 female, talked about making arrangements with her employer to work from home once her
31
32 baby was born. This arrangement also made it easier to manage the symptoms of her IBD.
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34

35
36 "Because after I would have a bowel movement, I, I would have to lay down for
37
38 half an hour to regain my strength. And so if I could work from home, I could
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40 just lay down. Then I could go back to it when I needed to. So, yes, flexibility on
41
42 the employer part, um, you know, if you do your best at work and you work hard
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44 and you don't take advantage of the company, they treat you well. And not all
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46 companies, but they did. And, yeah, set me up with a home office. So that
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48 allowed me to continue working with having children and being sick which I
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50 really enjoyed"
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55 This quote also calls attention to the perspective of many participants that requests for, and
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Work Experiences and IBD

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granting of, accommodations were often based on a positive reciprocal relationship between an employee and supervisor or employer, rather than on employee rights or workplace policies.

Financial factors. Financial factors were very relevant considerations for many participants. Issues such as whether or not they had paid benefits for leaves from work or disability insurance coverage was emphasized. Other household income and expenses could influence participants' work-related decisions such as their willingness to take unpaid leaves, work part-time, or retire. MJ, an adult male, talked about the importance of his benefit package to cover the costs of medications and how it influenced his decisions about remaining at that job.

“So it's one of the big things why I'm still there. Like it's, like wow, I could maybe go do other things but I will lose this benefit... it just isn't worth it.”

Some participants were aware of the health benefits in their workplaces and, like MJ, chose or stayed with jobs that provided benefits. Others were unclear about benefits available to them. TM, an adult female, shared that she was unaware of a government-funded benefit to help cover her medications for years after her diagnosis: “I wish I knew how that worked. If there was some sort of manual...these [drugs] are expensive.”

Strategies and Environmental Supports to Navigate Work Roles

Personal strategies. Within the unique and varied experiences at work, participants talked about important strategies they used to navigate work while living with IBD. Key strategies are included in Table 3. Many strategies fostered the ability of participants to remain employed, but could also take a toll on other aspects of their lives. For example, working sometimes meant that participants had to limit participation in social or leisure activities. EA, an older adult male, pointed out: “There's always something you have to give up it seems. You

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know, you can't do it all." CT, an older adult female, explained: "I mean the work at work got done. There was no ifs, buts or maybes about that. But things at home slacked off. So when I came home, you know, I didn't do all the things I wanted to." EA's and CT's comments highlight the ways that a choice to work while living with IBD can result in long term sustained and productive employment, but at the expense of home, leisure and social activities. Women participants, in particular, talked about the challenges of balancing work with parenting and/or providing support to aging parents and managing their IBD. Some found relief in changing from fulltime to part-time work or working from home, which helped them to manage the balance between work and family responsibilities within the context of their disease.

Some participants like DM, a young adult male, and KS, an adult female, expressed regret at lost work and career opportunities. These losses were related to changing career aspirations or jobs because they felt that a more challenging or preferred job or career would be detrimental to their overall health, or not possible while living with IBD.

Environmental supports. Table 4 describes the environmental supports that participants believed facilitated their work participation while living with IBD.

Workplace environments. Participants noted the importance of a workplace that promoted acceptance and facilitated timely accommodations. Supervisors, human resource personnel and co-workers were all important. JL, a young adult female, considered herself fortunate to have an understanding boss: "I'm lucky that, I mean my boss is the kind of person who has always said, family and health...he's been great and very, very much: 'take the time you need. Don't worry about it. You can make up the time'." JL also noted how one of her colleagues was helpful in facilitating her relationships within the workplace: "...she is a really good person to have at the office, because I find that if people are gossipy or trying to figure out

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3 why I'm taking so much time off work, she's really good at diffusing the situation." For JL, these
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5 individuals helped create an environment in which she could manage her illness as well as the
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7 potential negative consequences in the workplace from obtaining needed accommodations.
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11 Workplace accommodation policies that were clear, available, and promoted to
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13 employees helped participants in periods when they needed flexibility in their hours of work and
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15 work schedule, or changes to the physical demands of their job or physical location of their
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17 work. Policies and practices that promoted flexibility and inclusiveness toward people with
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19 chronic health conditions could reduce the need to ask for special consideration that was often
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21 dependent on a good relationship with a supervisor. LS, an adult female, described a quiet room
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23 in her workplace available to all staff: "...we have a sick room at work that I can go and lay
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25 down in for half an hour if I needed to...."
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29 ***Socio-political environments.*** Participants spoke about health and social policies and
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31 public attitudes and knowledge which could be changed to better support people living with IBD.
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33 These included ease of access to medical practitioners, treatments and government benefits for
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35 work interruptions. Participants identified issues with the definition of "disability" contained in
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37 public and private insurance policies that may not allow people living with an episodic disability,
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39 like IBD, to access benefits. In addition, some participants spoke about public attitudes in the
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41 form of stigma associated with IBD and the need for initiatives to address the stigma. For one
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43 participant accepting disability insurance would have been stigmatizing. Participant narratives
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45 also suggested the need for more widespread knowledge about workplace policies and practices
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47 that could accommodate people living with IBD and other health problems, as well as
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49 information about the rights and responsibilities of employers and employees.
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Discussion

Consistent with the International Classification of Functioning, Disability and Health (ICF),²⁷ participants’ narratives supported the importance of considering personal and environmental factors in understanding work experiences. The ICF model depicts disability in context, recognizing the influence of environment and personal factors on body function, activity and participation, in addition to the effects of health condition²⁷. Although problematic body functions such as bowel disturbance could increase the risk of work disability for people living with IBD,²⁸ the experiences of work and work disability were embedded in a range of personal factors, job characteristics, and work and social environments.

Personal factors that influenced the experiences of work included the symptoms of IBD and other health conditions. Depression, in particular, is recognized as a factor associated with disability in people with IBD.^{29,30} Demanding life roles such as parenting and supporting aging parents can create greater challenges for maintaining work participation and, in the United States and Canada, can disproportionately affect women.^{7,28} Lower health-related quality of life in women with IBD may be related to gender inequalities in social roles.³¹ Our study also suggests that, in many cases, people living with IBD chose work over leisure and other activities. A recent Canadian survey of people living with IBD reported that more respondents identified an impact of IBD on leisure activities than those reporting an impact on work.⁶ Choices to participate in the labor force can result in limited participation in other life areas. Work disability needs to be considered in the context of general disability³² and work ability needs to be considered in the context of other life activities and social participation.

Theoretical perspectives of the person-environment-occupation model³³ suggest that optimum work performance is dependent on a good match between the person, workplace

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environments and the job. Work environments and the availability of accommodations can be important determinants of whether disability is experienced in the workplace. The dominant model of providing accommodations in workplaces is based on addressing the needs of individual employees and requires negotiation between the employee and his or her supervisor.³⁴ Consistent with other literature,^{34,35} participants highlighted the additional importance of workplace culture and policies supportive of accommodations. Disclosure is an important issue for *invisible disabilities* such as IBD because the reasons for needing accommodations are not readily apparent.³⁶ Marri and Buchman³⁷ concluded that most people living with IBD were in favor of disclosure. However, participants in our study highlighted the complexity of decisions about disclosure and requests for accommodations. They had varied experiences that were highly dependent on workplace culture, work relationships, beliefs about whether accommodations could or would be implemented, and perceived stigma anticipated with disclosure.³⁸ Support is needed from health professionals to assist people with IBD with issues such as assessing the relative risks of disclosing the health condition and requesting accommodations in the workplace, understanding the right of workers to not disclose their specific health condition, and communicating requests for accommodations.

Participants in the current study noted the ways that treatments for IBD could be a work-related burden. Attention needs to be paid to the organization of the health system in relation to the distances needed to travel to attend health care appointments and flexibility around appointment scheduling. Further, patients need to be made aware of available funding sources, like government programs, to offset the costs of medication.

Implications

Individual interventions can support people with IBD who are struggling with negotiating

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work and social roles to establish goals and action plans. Assessing the fit between personal factors, job characteristics and work environments and developing strategies for improving the fit by negotiating needed accommodations can improve the experience at work. From a meta-synthesis of qualitative studies on the needs of people living with IBD, Kemp et al³⁹ pointed out the importance of personal control. Participants in our study talked about the ways that they took control in negotiating work roles, which may be helpful for other people living with IBD, especially those who are newly diagnosed. In addition, self-management interventions, including programs designed for managing a range of chronic health conditions,⁴⁰ may be helpful in increasing people’s self-efficacy and sense of control in managing their disease in the context of their work and social lives.

Interventions directed toward work environments are also important.⁴¹ Education of employers on their rights, responsibilities and the need for appropriate workplace accommodations for people with episodic disabilities can help create more supportive work environments. Good accommodation policies, as a foundation for the flexibility that is helpful for retaining employment, can go a long way to reducing work disability. IBD support groups and charitable foundations have a role in enhancing employer awareness about the importance of workplace accommodations in support of employee retention and work productivity.

Social policies that define disability and the extent of coverage for disability-related absences need to take into consideration the needs of people living with episodic diseases such as IBD. These policies vary widely internationally but insurance benefits that respond to the episodic disability experiences of people with IBD and other chronic health conditions can help maintain labor force participation.

Future Directions for Research

Our findings provide a framework for avenues of investigation in future studies. The factors participants identified as influencing work experiences can be included in quantitative studies about work-health-life balance and work retention for people living with IBD. The results can also inform the development of interventions to improve employment outcomes.

Limitations

Although we purposefully selected a diverse sample, we did not sample for socioeconomic indicators or education level, which may have limited the diversity of responses. In addition, participants often provided historical perspectives of their work experiences. Memory and reframing of their responses to these experiences may have influenced their perspectives.

Conclusion

Although several international studies have estimated the extent of work disability among people living with IBD,^{2,5,7,29,42–44} the experiences of work while living with IBD are seldom reported. Exploring these experiences has provided greater understanding of contextual factors that influence work retention, and successful strategies for negotiating work roles and responsibilities. This knowledge has implications for practice in supporting people negotiating work-health-life balance while living with IBD, identifying areas for future research, and for health and social policy that can better support people to maintain work roles.

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Table 1. Sampling Characteristics

Age, y	Disease Duration	Disease Pattern ^a	Women (n=23)	Men (n=22)	Total N=45
≥ 55	≥ 10 y	Active	5	5	10
30-54	≥ 10 y	Active	5	5	10
< 30	≥ 10 y	Active	3	1 ^b	4
< 30	≥ 10 y	Inactive ^c	0	1 ^d	1
≥ 30	≥ 10 y	Inactive	3	3	6
Any age	6-30 mo.	Any	4	4	8
Any age	31 mo. - 9 y	Any	3	3	6
Totals			23	22	45

^aRefer to *Recruitment* in the *Methods* section for details regarding categorization of active and inactive symptom pattern.

^bOnly one participant met the criteria for this category within the cohort sources.

^cThis was not a targeted sampling category; added an interview with participant noted with ^d due to limited number of male participants under 30 years, with 10 years or more disease duration and active disease.

Table 2. Participants' Employment Status at the Time of the Study

Employment Status^a	No. of Participants (%)
Full time	21 (46.7)
Full time + part time	2 (6.6)
Full time + student part time	1 (2.2)
Part time (1 or more jobs)	5 (11.1)
Student full time	1 (2.2)
Student full time + part time	1 (2.2)
Retired	6 (13.3)
Retired + part time	2 (4.4)
Unemployed	5 (11.1)
Total	45 (99.98)
^a Participants with only unpaid and/or volunteer work counted as unemployed.	

Table 3. Key Personal Strategies Used to Navigate Work Roles

-
1. Being aware of one’s needs and resources
 - For example: awareness of what type of work flexibility is needed and what policies are available in the workplace to facilitate flexibility
 2. Self-management of IBD and other health conditions
 - For example: looking after diet, exercise and treatment regimes
 3. Management of emotional responses and attitudes toward health condition and life situation
 - For example: having an accepting attitude toward IBD
 4. Making informed choices about careers and job options
 - For example: finding a career or job that offers the flexibility, culture and physical environment that eases the burden of IBD
 5. Adapting to particular circumstances in the workplace
 - For example: getting up earlier in the morning to empty bowels before attending an important meeting or getting a single, rather than shared, room when travelling
-

Table 4. Environmental Supports and Resources

Organizational Supports

Workplace	<ul style="list-style-type: none"> • Clear, available, and promoted workplace policies related to accessibility and accommodations
Culture and Relationships	<ul style="list-style-type: none"> • All employees have accurate and complete information related to accommodations, benefits and supports regardless of health problems • System in place to get coverage quickly when needed to go to bathroom • Culture of acceptance and support
Time-Based Flexibility	<ul style="list-style-type: none"> • Flexible work hours • Reduced work hours or job share options • Self-directed timing and pacing of tasks and breaks • Regular hours (without shifts or night work) • Timely and customized graduated return to work support post-surgery or after an extended absence
Physical Environment	<ul style="list-style-type: none"> • Access to toilet (preferably private) • Light duties options • Flexibility in body positioning while

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		working
		<ul style="list-style-type: none">Flexibility in where work can be done (e.g., moving a work station closer to a bathroom)
		<ul style="list-style-type: none">Quiet room for rest periods
	Employer	<ul style="list-style-type: none">Paid sick leave
	Benefits	<ul style="list-style-type: none">Health insurance that includes medication coverageShort-term and long-term disability insurance
Socio-political Supports		
	Health and Social Policies and Practices	<ul style="list-style-type: none">Easy access to physician for absence notes, concerns, change in symptoms and prescription refillsEvening and weekend options for biologic medicine infusionsGovernment benefits for episodic disabilities that interrupt work earnings (e.g. employment insurance sick benefits including coverage for graduated return to work)
	Public	<ul style="list-style-type: none">Stigma reduction
	Attitudes and Knowledge	<ul style="list-style-type: none">Widespread knowledge about workplace accommodations and the rights and

responsibilities of employers and
employees

For Peer Review

Figure. Influences on work roles while living with IBD



Figure Influences on work roles in persons with IBD
18x13mm (600 x 600 DPI)