


# Understanding Gut Feelings: Transformations in Coping With Inflammatory Bowel Disease Among Young Adults

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## Abstract

Past studies have revealed a dizzying array of coping techniques employed by persons living with inflammatory bowel disease (IBD). Unfortunately, research has provided little insight into when and why individuals adopt or abandon particular coping strategies. Using a retrospective narrative approach, we explored how participants made sense of changes in their approach to coping over time. Shifts in coping strategies were associated with particular illness experiences that wrought new understandings of IBD and novel identity challenges. They followed a common processual form and were marked by a movement away from techniques of purification, normalization, and banalization toward the development of a more communicative body. This was accompanied by notable shifts in identity work. Notably, participants moved from a preoccupation with maintaining continuity and sameness to permitting their extraordinary bodies to occupy a place in their public and personal identities. Implications of this process for theory and practice are discussed.

## Keywords

inflammatory bowel disease; coping; young adults; identity; change; qualitative research; Canada

In Canada, there are approximately 270,000 individuals living with inflammatory bowel disease (IBD), which is among the highest prevalence in the world (Crohn's and Colitis Foundation of Canada [CCFC], 2018). IBD serves as an umbrella term for several distinct but related medical conditions: Crohn's disease (CD), ulcerative colitis (UC), and a cluster of less prevalent gastrointestinal illnesses (Peyrin-Biroulet et al., 2012). The illness affects the small intestine and colon and produces a variety of physiological symptoms, including diarrhea, abdominal pain, reduced immune system functioning, vomiting, intestinal bleeding, weight loss, and chronic fatigue (CCFC, 2018). While adult onset in the third and fourth decades of life is most common, adolescents and young adults are also diagnosed with IBD (Ghorayeb et al., 2018). No cure for IBD currently exists and the course of the illness is unpredictable, typically alternating between periods of relapse and remission of inflammation of the gastrointestinal tract. Accordingly, available treatments are aimed at control and management of inflammation through diet and palliative medication, or, in severe cases, surgical interventions to remove portions of the gastrointestinal tract and re-locate its exit through the abdomen

(known as an ostomy; Wolfe & Sirois, 2008). Managing IBD symptoms renders individuals vulnerable to stigmatization, depression, anxiety, and chronic fatigue, as well as reduced social functioning, self-esteem, and quality of life, which in turn are associated with greater difficulties adhering to an illness treatment regimen (Jäghult et al., 2011; Pihl-Lesnovska et al., 2010; Taft et al., 2011).

Whereas previous research has identified numerous coping strategies employed by individuals with IBD, very little attention has been paid to how coping efforts unfold over time and are influenced by key experiences, realizations, or events. In this article, we examine the evolution of IBD coping using in-depth interviews with six Canadian young adults. We identify four qualitatively distinct (though, at times, overlapping) phases of coping

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and argue that coping efforts have globally shifted from more passive, reactive, detached, and resistant to more active, anticipatory, communicative, and accepting. This shift entailed embracing an extraordinary body and incorporating physical difference into one's identity at the social and personal levels in a manner that proved empowering to participants. Our analysis contributes to the literature in three ways. First, it provides a portrait of coping among young adults, whose unique life circumstances present important challenges, including the necessary transfer of medical responsibility from parent to child, relative instability of life goals and circumstances, and unique institutional contexts. Second, it offers a processual structure of coping among this age group, whereas previous articles have typically examined or compared coping styles at isolated moments. Finally, it contributes to academic understandings of how the body is represented in narratives of IBD by relating changes in coping to alterations in the way the body is understood and stylized.

## Literature Review

Numerous studies have explored how individuals cope with the challenges of IBD and how different coping techniques relate to personal well-being. Coping is defined as "cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 141). Although investigations of coping literature often include research on the effectiveness of pharmaceutical, surgical, or clinical treatments, we focus on forms of coping outside of institutionalized psychological or medical services. We are interested in the everyday coping practices implemented by individuals with IBD. Two types of research designs dominate this field of inquiry: survey-based studies and qualitative research.

Survey research reveals that individuals with IBD utilize a vast array of coping techniques to manage their illnesses and the side effects of various treatments. These can be synthesized as avoidance coping (avoiding situations or thoughts that could aggravate symptoms), emotion-focused coping (focusing on management of distressing emotions evoked by the situation or condition), passive coping (lack of action to manage pain or its accompanying emotions), depressive coping (development of depressive cognitions as a means of coping with illness), and problem-focused coping (dealing directly with stressors by seeking help or changing the stressor or oneself) (Bitton et al., 2008; Crane & Martin, 2004; Drossman et al., 2000; Knowles et al., 2011; Larsson et al., 2008; Mussell et al., 2004; Polidano et al., 2021; Tanaka et al., 2016).

These coping techniques have been further related to a variety of quality of life indicators. Emotion-focused, passive, and depressive coping styles are related to an array of negative outcomes, such as higher levels of depression, poorer health outcomes, psychological distress, poorer health-related quality of life, and somatic complaints (Chao et al., 2019; Crane & Martin, 2004; Drossman et al., 2000; Knowles et al., 2011; Mussell et al., 2004; Petrak et al., 2001). Avoidance coping is also related to increased risk of disease relapse (Bitton et al., 2008). In addition, coping behaviors that are typically considered "adaptive," such as problem-focused coping styles, do not uniformly show benefits among individuals with IBD, possibly because individuals with IBD have little influence over disease course and flare-ups (Knowles et al., 2011; Mussell et al., 2004). Furthermore, while emotion-focused coping is generally considered maladaptive, nuanced analyses reveal that some emotion-focused techniques, such as modulation and acceptance, benefit individuals with IBD (Cohen et al., 2017), while others, such as rumination, escape, and resignation are maladaptive (H. Luo et al., 2018; McCombie et al., 2013).

Survey methods have also been used to explore why individuals with IBD adopt different coping techniques. Perfectionism has been associated with emotional-preoccupation coping, which involves fixating or ruminating about the emotional consequences of a health problem (Flett et al., 2011). Social learning in childhood may also be important, as adults who grew up with parents who reinforced illness behaviors in childhood (e.g., staying home from school, canceling social activities) were more likely to use passive coping techniques in adulthood (Crane & Martin, 2004). Life circumstances and knowledge of the condition also influence coping techniques, as married individuals are more likely to take days off, rest, or see a doctor to cope with symptoms than their single counterparts (Tanaka et al., 2009) and enhanced knowledge about IBD is related to the use of more adaptive coping techniques, such as problem-focused coping, instrumental support, and emotional support (Moradkhani et al., 2011). Disease severity also influences patterns of coping techniques. More severe symptoms are related to an increase in coping behavior generally, higher levels of avoidant coping, and overall poorer coping (Knowles et al., 2011; Lindfred et al., 2012; McCombie et al., 2013). Finally, length of time since IBD onset is related to coping. Pain catastrophizing tends to increase over the first 2 years of illness (Lix et al., 2008) while the number of overall coping techniques decreases within the first 6 months after diagnosis (McCombie et al., 2015). Thus, there is evidence that individual, situational, physiological, and time-related factors are influential in coping with IBD. Nuanced, and occasionally contradictory,

survey findings point to the complexity of IBD coping and the difficulty in assessing the use of particular techniques across contexts and individuals.

Qualitative methodologies have added important knowledge about how individuals cope with IBD by focusing on participant experiences, constructions of successful coping, and the perceived effectiveness of various coping techniques. Participants note the key role of social support, both instrumental and emotional, in coping with IBD (Fletcher et al., 2008; Nicholas et al., 2007; Skrastins & Fletcher, 2016). Whereas survey research has generally focused on the risks of negative emotional coping, qualitative researchers have found that well-being can be promoted through certain emotional coping techniques, such as optimism, social comparison, acceptance of limited control, and personal honesty (Cooper et al., 2010; Fletcher et al., 2008; Larsson et al., 2016; Nicholas et al., 2007; Skrastins & Fletcher, 2016). Qualitative researchers also highlight a range of IBD-specific coping behaviors, such as dietary changes, adjusting and establishing daily routines, pharmaceutical regimes, controlling the situation and surroundings, educating oneself about IBD, and sleeping or resting during flare-ups (Fletcher et al., 2008; Larsson et al., 2016; Skrastins & Fletcher, 2016; Sykes et al., 2015). This research approach has further elucidated which coping techniques individuals with IBD consider helpful or harmful in reducing symptoms (Skrastins & Fletcher, 2016) and how social and environmental factors can influence participants' sense of effective coping (D. Luo et al., 2019; Palant & Himmel, 2019).

Qualitative researchers have also challenged several assumptions derived from survey research. Participant accounts challenged the notion that IBD was solely something to "cope with," as individuals discussed both positive and negative aspects of this condition, such as spiritual growth, improved interpersonal relationships, enhanced meaning in life, making positive lifestyle choices, and finding new life paths (Pihl-Lesnovska et al., 2010; Purc-Stephenson et al., 2015). Findings from qualitative research also question the validity of common measures of coping "success" or personal well-being, as these do not always reflect what matters most to individuals with IBD (Wolfe & Sirois, 2008). Finally, findings from Larsson et al. (2016) showed that participants drew on a *combination* of circumstance-specific coping strategies, highlighting the need to better understand the contextual nature of IBD coping.

Finally, qualitative studies have explored metaphors of coping among individuals with IBD. Participants in one study described coping as a "fight" for normalcy that involved a continued re-assessment and re-definition of "normalcy" to align with emerging circumstances (Hall et al., 2005). This fight metaphor was said to empower

participants, giving them a sense of drive and agency. Alternatively, Delmar et al. (2005) pointed to achieving harmony as a central metaphor of coping with IBD and other chronic illnesses. They proposed that undesirable circumstances brought on by chronic illness violate Western norms of control, linearity, and certainty and that acknowledging and accepting such transgressions provided an opportunity to find meaning in IBD and achieve harmony with oneself and one's surroundings. Interestingly, participants sometimes used conflicting metaphors to express their coping experiences, combining elements of "fight" with "adaption/acceptance" (Hall et al., 2005).

While investigations into coping techniques of individuals with IBD have been numerous, important gaps in the literature remain. First, with few exceptions (Lix et al., 2008; McCombie et al., 2015; Sargeant et al., 2005; Sargeant & Gross, 2011; Sirois & Hirsch, 2017), the vast majority of IBD coping research has been cross-sectional, exploring coping behaviors at a fixed point in time. Such atemporal investigations are ill-suited to explore the dynamism and fluidity of IBD coping over time and are incapable of providing insight into the events, experiences, desires, or fears that might precipitate shifts in IBD coping techniques. Second, very few studies have explored coping with IBD over the lifespan. Although qualitative researchers have produced rich accounts of particular life phases, including adolescence (Sargeant et al., 2005; Sargeant & Gross, 2011) and the transition to motherhood (Ghorayeb et al., 2018), many unanswered questions remain about the nuances of particular phases of life, including the unique challenges, motivations, and supports of young adulthood—typically defined as 18 to 30 or 35 years of age (Furstenberg et al., 2005). Shifts in geographical location, social life, insurance, support services, and health care providers can render the transition from pediatric to adult patient disruptive (Hait et al., 2008). Coping may take on a unique form during this life phase, as individuals renegotiate social/familial roles and responsibility for their health (Plevinsky et al., 2015; Tanner, 2006; Tuchman et al., 2008). Young adults must also contend with the social significance of binge drinking and its effects on illness management (Niland et al., 2013; Saunders, 2011; Weitzman et al., 2015). Third, while various coping metaphors have been identified by those with IBD, previous research has failed to account for differing, and sometimes contradictory, metaphors within this population. Finally, previous research into coping with IBD has failed to clarify the meaning of "adaptive" versus "maladaptive" coping. This suggests a lack of clarity regarding what is at stake in young adults' attempts to cope with IBD and how particular coping techniques impact well-being across the illness trajectory.

## Research Approach

### *Theoretical Framework*

In this article, we approach illness experience from a social constructionist perspective, where the goal is not to approximate a single, objective reality but to interpret the meanings given by actors to significant events within their lives (Geertz, 1973). This necessitates a recognition of the various forces that inform how individuals understand and react to chronic illness in everyday life. As Kleinman (1999) has affirmed, experience is the “medium in which collective and subjective processes interfuse” (p. 359). Experience is framed and articulated through local symbolic forms that are exchanged and negotiated within particular social, political, and historical contexts (Geertz, 1973). It is also shaped by the creative act of interpretation and the particular experiences, understandings, embodied sensations, and moral frameworks of the individual interpreter (D’Andrade, 1984; Mattingly, 1998).

From this perspective, chronic illness is embodied, imbued with intersubjective meaning, and mediated by social practices (Good, 1994). Whereas studies of disease explore how these conditions impact physiological functioning, accounts of illness experience attend to how disordered bodies disrupt people’s experiences of self and world (Becker, 1997; Frank, 1995; Good, 1994). Illness may also undermine personal agency and eschew valued assumptions about the linear, progressive nature of the life course (Becker, 1997; Good, 1994; Ricoeur, 1992/2013). Generally speaking, major illness disrupts the normative flow of everyday experience (Turner, 1986) and one’s relationship to body, identity, and society. Yet illness can also be generative, occasioning reflection on self and society and inaugurating new beginnings, altered life aims, personal transformations, and novel connections to the social order (Becker, 1997; Good, 1994).

### *Methodology*

To explore individuals’ retrospective accounts of coping with IBD, we employed a person-centered ethnographic approach (Hollan, 2001, 2005; Levy & Hollan, 2015). Person-centered ethnography refers to “anthropological attempts to develop experience near ways of describing and analyzing human behavior” (Levy & Hollan, 2015, p. 313). Centering on the interaction between the individual and their sociocultural environment, the researcher explores how sociocultural forces shape experience without losing sight of individual interpretive processes and the creativity, diversity, and complexity that results from the meeting of self and world. Although person-centered ethnography permits the use of various instruments, data types, and analytic approaches, the current investigation

utilized narrative analysis to explore how experiences of coping with IBD are constructed in the stories of young adults.

**Participants.** Recruitment of young adults with IBD was challenging as the condition affects a relatively small portion of Saskatchewan (Canada) residents and onset typically occurs in the third and fourth decade of life. In addition, a certain level of stigma is attached to the illness and certain symptoms can be awkward to discuss. Acquaintance sampling leveraged the relationship of one team member to the local IBD community. Potential participants received letters of invitation which explained the study objectives, interview process, interview topics, time requirements, and voluntariness of participation. Any participants recruited through acquaintance sampling were also asked to forward the contact information of the researcher to any individuals they felt might be interested in participating in the study. Ultimately, six young adults were recruited through acquaintance sampling and one through snowball sampling. This sample consisted of three women and three men between the ages of 21 and 28. Of these, five were living with CD and one with UC. All had been diagnosed with IBD between 3 and 10 years prior to interview. Although a larger sample would have been preferable, common themes and patterns were evident within this limited sample.

**Data collection.** Data were gathered during two separate meetings with each participant held approximately 1 week apart. In the first meeting, participants first provided written consent for participation before completing a life history interview (Flick, 2009), where they were asked to describe their life history as it related to IBD in the past, present, and future. The second meeting utilized a semi-structured interview format (Levy & Hollan, 2015) to allow for a more thorough investigation of particular topics and enable participants to discuss any additional details or experiences they deemed important to the study. Categories of questions were informed by the literature review and theoretical model outlined above. Four main categories of questions provided the basis for the semi-structured interview: (a) experiences of IBD in different contexts (family, school, romance, religion, etc.); (b) the relationship between IBD and social processes (institutional supports, politics, economics, and cultural norms), (c) how experiences with IBD related (or did not relate) to concepts of liminality, marginality, and shifting statuses; and (d) how coping practices influenced, and were influenced by, participants’ identities, bodies, and social relationships. Both interviews were audio-recorded and ranged from 60–180 minutes each. Recordings were subsequently transcribed. During this process, pseudonyms were assigned and identifying

information was removed. This study was granted ethical approval by the University of Saskatchewan Ethical Review Board.

**Analysis.** Data gathered from the life history and semi-structured interviews were analyzed using syntactic analysis, thematic analysis, and deep structure analysis. The purpose of the syntactic analysis was to identify the overall plot structure of the story: how understandings and experiences of IBD shifted across time. The way that the story is told or performed can be defined as its narrative structure or textual structure (i.e., the chronology of the text as it stands within the transcript) (Todorov, 1973/1982). By contrast, the plot structure refers to “the underlying structure of a story” (Good, 1994, p. 144), which integrates the order of events and transformative forces into a meaningful whole. In the life history interview, no participant told their story about IBD from beginning to end in perfect logico-temporal succession; moreover, aspects from the semi-structured interview had to be integrated into an analysis of the underlying plot structure. Thus, the researchers were actively involved in reconstructing the plot based on what participants described in both their life history interviews and semi-structured interviews.

To identify the plot structure, participants’ narratives were examined for states of relative stability (“phases”) and states of relative instability (“turning points”) (Flick, 2009; Todorov, 1973/1982). Participants, for instance, highlighted contrasts across time (“before” versus “now”) and moments of change (e.g., “all of a sudden”), which allowed interpretation of the overall logico-temporal order of events (Good, 1994). Once a provisional plot structure was established for each participant, we compared participants to determine similarities and differences in plot forms. Next, we used a progressive thematic coding process to identify how participants perceived self and world and coped with IBD within each narrative phase and turning point. This process involved labeling segments of text within the transcripts, grouping the labels into higher-order categories, and organizing the higher-order categories into hierarchies of meaning (Braun & Clarke, 2006; Rothe, 2000). Finally, we engaged in deep structure analysis to reflect on how individual accounts of IBD coping were related to local meaning systems, institutions, narrative forms, illness images and metaphors, and sociopolitical forces (Good, 1994; Rothe, 2000). Although progressing according to the order outlined above, analytic procedures were layered, iterative, and mutually-informative. For example, plot structures were often clarified or altered in light of shifting meanings, images, stakes, concerns, and beliefs identified through thematic analysis. Together, syntactic and thematic analysis yielded four phases of IBD marked

by shifts in coping techniques and altered understandings of self, illness, and body.

## Results

The following sections describe participants’ illness and coping trajectories as they progressed through each of four phases (with the exception of one participant, who straddled Phases 3 and 4 at time of interview).

### *Phase 1: A Body Out of Sorts*

Participants’ narratives of life with IBD began by recounting when the illness initially presented in their lives. For the majority of participants, the onset of IBD occurred during high school and early adulthood. Initial symptoms were also diverse, including bloody stool, fatigue, vomiting, abdominal cramping, diarrhea, and a loss of weight and/or appetite. During this initial phase, IBD wrought an unfamiliar and mysterious sense of dis-ease and participants struggled to comprehend and communicate their bodily condition.

Descriptions of early symptoms of IBD reflected an experience of furtive pain and un-wellness, along with a lack of vitality that eluded clear articulation. Participants simply noticed that they “didn’t feel good” during this period. For one participant, the “weird pain” he recounted was accompanied by extreme fatigue; he would show up to his high school in the morning and “be fully exhausted . . . after being up for . . . an hour.” As they struggled to comprehend the state of their bodies, participants also had difficulty communicating their experience to others. As one explained, “I wasn’t very good at identifying what was actually going on. I was like, ‘I have a stomachache.’ It was just hard for me to pinpoint.” Even participants with a close family history of IBD (four) found these early stirrings difficult to comprehend and communicate, a fact they attributed to the rarity with which the condition was discussed in the home. As a participant explained, “it was never anything that was discussed in depth with us . . . what it actually was and how it actually affects you.”

Faced with these mysterious bodily sensations, participants embraced a conservative and dismissive coping style, assuming their illness was transitory and their symptoms would “just go away.” They relied on over-the-counter pain relief medications and “flu pills” intended for the temporary relief of symptoms, including Gravol, Imodium, Tylenol, or Advil. Convinced their bodies would return to a healthy, normal state, participants took no steps to discern the cause of their suffering. Assured they were generally healthy young people, they simply waited for illness to pass. As one participant recalled,

I started getting more symptoms, just more stomach aches and cramping and pain and not really paying attention to them . . . at some points, blood when I was going to the bathroom. But . . . I would just (laughs) kind of ignore it.

In this first phase of the illness experience, participants tried to push through their pain and symptoms, participating in social events and educational activities despite ailing bodies. Those with notable pain in this phase (all but two participants) noted that typical activities—like socializing with friends and attending school—became increasingly difficult. A participant explained that she was always “coming home from school” as a result of her persistent symptoms and another noted that she did not want “to be involved” in other activities because of her symptoms. However, despite the relative flippancy with which participants initially treated their symptoms, concern over the state of the body intensified as symptoms persisted over time and increasingly disrupted daily life. One participant, for example, recalled a growing concern over the “mysterious flu” that he just “couldn’t knock.” He also noted that close acquaintances began to express concern over his persistent symptoms and practices of self-medication: “they’re [his friends] like, ‘aw guy if you gotta take a buncha pills to come hang out with us, don’t . . . you’re probably really sick.’” Even those with relatively less severe symptoms in phase one (two participants) grew concerned about the state of their bodies as time wore on.

In sum, participants began their IBD illness stories by describing a disruption of the taken-for-granted, routinized nature of bodily experience that characterizes everyday life among the “mostly well” (Becker, 1997). Yet, under the assumption that their symptoms were a mark of transient unwellness, participants engaged in temporary remedial efforts focused on alleviating immediate pain and discomfort and controlling symptoms. As a participant noted, “I didn’t really think that I had anything, so I just thought that it would stop and then one day I would . . . not be sick.” Here, IBD was experienced as an inexplicable—yet assumedly transitory—state of bodily disorder. Consequently, it was met largely with patience and endurance as participants awaited the inevitable return of wellness.

### *Phase 2: Becoming “Ill” and Coping With IBD*

Persistent, painful, and increasingly intense symptoms raised questions about the fundamental health status of the body and its capacity to restore itself to a state of well-being. Participants were inevitably forced to confront the possibility that their symptoms reflected the presence of an unknown bodily dysfunction. In short, they began to think of themselves as “ill persons.” In all cases, this shift

in thinking was linked to a sudden increase in the frequency or severity of symptoms and/or the persistence of symptoms beyond what would have been reasonable for a common, acute illness. At this point, participants became increasingly confused and anxious about the nature of their affliction and invariably consulted with medical experts.

Through contact with medical experts, all participants were eventually diagnosed with various forms of IBD (CD in five cases and Ulcerative Colitis in one case). The timing and circumstances of diagnosis varied across participants (from age 12 to 25), with an average diagnostic age of just over 16 years. Participants described the experience of being diagnosed with IBD as emotionally complex, entailing elements of relief, fear, anxiety, and frustration. Diagnoses uniformly revealed that what participants hoped was a transitory illness was, in fact, a persistent health condition. However, the lived implications of IBD remained vague at this point in time and participants tended to under-estimate the challenges of living with IBD, using strategies of purification, normalization, and banalization to cope with the disease.

*Purification.* Armed with a better understanding of the disorder that wrought havoc on their bodies, all participants remained hopeful that their symptoms could be brought under control through biomedical interventions, including regular doctor visits, medication, surgery, and/or diet modification. During this phase, participants happily turned control of illness management over to medical experts and followed their advice regarding medication and surgery. As one participant notes, her own understanding of IBD was limited at the time and deferring to expert authority seemed logical in this phase: “people are just telling you to go on medications and you don’t have, like, you know, [the knowledge to be] an intelligent, like, consumer of that information and, like, whatever they’re giving to you.” In addition, parents were often proponents of deference to medical authority and drivers of the search for a cure during this phase. A participant recalls, “All I remember is [my parents] doping me up and kind of getting me on track. It was my parents doing it for me . . . I was definitely held accountable by them.”

Reliance on medical expertise in this phase sometimes meant embracing unpleasant drug treatments, including a host of immunosuppressants, anti-inflammatories, anti-spasmodics, and steroids (Asacol, Salofalk, Prednisone, Imuran, Remicade, Sulfasalazine). So long as they provided some relief, participants embraced pharmaceutical interventions and the guidance of medical experts. For example, speaking to her “love-hate” relationship with pharmaceuticals, a participant recalled, “at first I was on a really high dose of prednisone, which is just awful. . . I really hated that drug. But it worked so well . . .

to manage it really quickly.” Two others also described continuing to use over-the-counter pain medications during this phase for periods of intense pain. In brief, despite their drawbacks, biomedical expertise and tools provided hope for a full recovery and were eagerly taken up by participants to manage symptoms during this phase.

**Normalization.** Alongside purification efforts aimed at excising illness from the body, participants described trying to live “normally” during this phase. They actively resisted the reshaping of everyday life by the ill body during this phase, continuing to engage in hobbies, professional and academic activities, and social commitments as though they were not living with IBD. For example, five participants signed up for full course loads despite the toll IBD was taking on their bodies. Reflecting on this time, one noted, “I just tried to keep doing everything that I’d been doing before . . . I used to try ‘n push it a lot when I was feeling sick and try to attend everything that was going on.” During this phase, the majority of participants (all but one) also worked to keep their diagnoses and struggles with IBD concealed to varying degrees, preferring to project an image of health and normalcy. One participant described this as “maintaining the façade” or “playing it cool.” The desire for such concealment was particularly notable among female participants, who identified the unpleasant, misunderstood, and taboo nature of the symptoms—which include diarrhea, gas, and rectal bleeding—as central to their desire to hide their illness status from all but close family members. Although two of the male participants stated they were less concerned about their IBD struggles becoming public, both nonetheless noted that few beyond their immediate family were actually aware of their illnesses.

The relative invisibility of IBD allowed participants to keep their condition successfully concealed much of the time. They avoided talking about “embarrassing” symptoms and the pain of IBD and withdrew from social situations where their illness status could not be confidently contained. However, symptom containment and concealment were not always possible, occasionally leading to awkward social situations where others lacked the necessary context to understand participants’ (seemingly odd) behavior. For example, a participant recalled an experience of having to use the bathroom multiple times while out with friends, recalling, “I was so embarrassed.” This secrecy—combined with a desire to avoid stigma and manage IBD alone—also meant that participants were largely isolated from potential social supports during this phase. One participant described being “hesitant to seek out help” during this phase because he felt as though he “needed to be independent.” Although he was often suffering immensely, he noted that he would always assure

people that he was okay during this period: “I was always ‘good.’”

**Banalization.** Although IBD was known to be a potentially chronic and serious illness, participants largely denied the limitations this condition might place on their everyday lives, downplaying its significance and trivializing its seriousness. For example, one participant recalled being convinced that his illness was “never going to get really severe.” Likewise, another described the casual attitude he had toward his body and illness at this phase:

at the time I was like, “Let’s hook up some pills. Uh, gimme some pudding and some Jell-o and let me get home because I need to play some World of Warcraft and the internet in here [the hospital] sucks. I’ve got shit to do.”

This banalization of IBD—that is, attempts to symbolically transform their illness from a notable loss or source of existential suffering to something more neutral (Frank, 1995, 2010)—is not a denial of illness, but rather a euphemistic attempt to managing the threat it poses to everyday life and self. Such banalization was implicit in participants’ increasingly casual attitude toward medical compliance and dietary restrictions after diagnosis, and their marked inconsistency in illness management during this phase. Despite having sought the help of medical experts, four participants recalled shirking medical advice or deviating from pharmaceutical regimes. For instance, one noted that she would often begin a new medication when she was visiting home from university and simply quit taking her pills once her current dose ran out. As an athlete, another similarly noted that he often prioritized his training diet over his recommended IBD diet. Behaviors that pushed the ill body beyond what was comfortable or reasonable are also part of this banalization process. For example, a participant recalled engaging in intense physical activity during this phase despite physical pain and exhaustion: “I started exercising again . . . and went back to work . . . I was not healthy enough to go back to work again, especially physical work like that. But, I just forced myself to do it.”

In sum, the second phase of coping entailed attempts to rid the body of IBD and restore normalcy to everyday life. The desire to *be* normal and *live* normally dominated this phase and largely overshadowed medical compliance and self-care. Consequently, participants frequently ignored medical advice and engaged in behaviors known to exacerbate their symptoms throughout this phase. Participants evidence a strong ambivalence about their illness at this point. Although they recognized that their bodily dysfunction required attention and expert support, they simultaneously downplayed the seriousness of

management activities, refusing to alter their patterns of daily life, and hiding the special status of their bodies from others.

### *Phase 3: A Body That Will Not Mend— Becoming a “Chronically Ill” Person*

Using the coping techniques described in part two, four of the six participants were successful in ridding their bodies of pain and living “like normal” for varying periods of time. For example, one participant described how prednisone had initially allowed him to achieve a state of near remission: “Like I’d just get a minor flare up and we’d go on the prednisone and taper off, and it’d be better again.” Another similarly recounted how she had a period of being “symptom-free” after starting a pharmaceutical regime and a third recalled experiencing significant relief after being prescribed a “saga of different drugs.” For one participant, the reprieve was short, lasting only a few months; by comparison, three others enjoyed a longer return to relative normalcy, lasting approximately 6, 2, and 8 years, respectively. Two participants experienced no reprieve, continuing to live with symptoms of similar intensity from the moment of initial onset.

All participants described entering a third stage of IBD coping after they experienced a particularly bad flare-up of symptoms that cast doubt on the prospects of a medical cure and reinforced the severity and perpetuity of IBD symptoms. For half the participants, this crisis occurred shortly after their symptoms first appeared, within a matter of weeks or months, and was marked by the most intense period of bodily pain and suffering. For the other half, body crisis emerged years after the initial onset of symptoms and was marked by a sudden resurgence of symptoms following years of remission. The duration of crises also varied between participants, lasting anywhere from a few weeks to a full year. For five of the participants, ongoing hospital visits marked this sequence as the peak of bodily distress and loss of control, as participants increasingly came to rely on health care providers to care for them. Crisis was also tied to surgical procedures to remove abscesses (two cases) and/or the threat of requiring surgery to overcome flare symptoms (two cases). Only one participant was in active crisis at the time of interview, having endured his current flare for almost a year and not having fully moved on to the final phase of coping outlined herein.

*The impotence and dangers of biomedicine.* In crisis, participants confronted the impotence of Western medicine. While some found a degree of relief via antibiotics, steroids, anti-inflammatories, and immunosuppressant medications, in all cases, surgical and pharmaceutical interventions failed to fully eliminate participants’ symptoms. One participant noted that certain pharmaceutical

interventions suddenly lost their effectiveness in this phase: “I was doing a couple that worked for a bit and then not.” In addition to experiences of impotence, most participants (five) also identified discreet harms associated with biomedical interventions. One underlined the “really bad side effects” of certain medications; another described the drug Prednisone as “the devil” that makes you “weirdly emotional”; and a third pointed out that “medicine and drugs are good . . . but it’s not ideally what I want in my body all the time.” Following abscess removal surgeries, one participant reported feeling “violated” by the experience and another developed a fistula that had yet to be rectified with medical interventions. Beyond this, two participants described generalized experiences of dehumanization within medical institutions, with one saying “everything’s focused on your disease, not really you as a person.”

*The impossibility of living “like normal.”* Attempts to live “as if” one had a typical body were challenged by a loss of physiological control, the visible manifestation of IBD on the body, the inability to sustain everyday activities, and the contraction of temporality into an intense experience of the present. In crisis, participants described a loss of bodily control that was more severe and jarring than the “unpredictability” of early illness. Intense bouts of vomiting and diarrhea were common throughout crisis, which in turn made nourishing and strengthening the body difficult. This new level of disorder drastically altered the flow of everyday life, demanding participants’ attention and leaving them uncertain about what they would be capable of in both the short and long term.

Four participants reduced their university course loads as a result of heightened IBD symptoms. Although he had originally signed up for a full course load, one participant recalled how he was forced to drop two classes when he could no longer sit through lectures due to extreme exhaustion and gastrointestinal symptoms: “a couple times I told the teacher ‘I’m going to the bathroom’ and I just went to my car and I just went home and just fuckin’ . . . slept for the remainder of the afternoon.” The participant who was still in crisis at the time of interview noted that although he often makes it to social events or his university classes, he is “just there physically”: “I am not into it, everything’s just goin’ over my head and I am not payin’ attention.” Two participants further described how intense symptoms forced them to move back home with her parents to avoid dropping out of university entirely. For two others, changes to work life were also necessary during crisis as their bodies were no longer able to keep up with the physical demands of their positions. For example, one explained that his pain became so severe that he was regularly taking Dilaudid—a potent opioid pain medication that turned him into a “zombie”/“vegetable”—to get through



the day. As a result, he had recently quit his part-time job in an automobile repair shop. Three participants further found the need to cease certain leisure activities (singing, pole-vaulting, and water polo, respectively) due to the extra strain it placed on their bodies.

Moreover, many of the activities, daily routines, and spaces that had previously characterized participants' everyday lives had been supplanted by medical activities, interactions, and institutions during the crisis period. The participant who remained in the midst of crisis stated, "I'm always reminded of it whether it's an actual symptom or physical pain or just the fact that 'oh fuck I gotta go to the doctor' or 'I gotta go for bloodwork.' It's just there every day." Another similarly noted that "you spend every day . . . [thinking] 'Okay my next doctors' appointment,' or you're in the hospital and you're so focused on . . . just getting better."

The flare-up of IBD symptoms in crisis—and the resulting need to stay close to home in case of sudden gastrointestinal difficulties—created widespread challenges to attending social events and maintaining relationships. All participants noted that unfamiliar public spaces—where the location and access of bathrooms was ambiguous—provoked anxiety, leading them to restrict their geographic mobility. Several participants additionally spoke about the anxiety of being trapped in a car, bus, or airplane and unable to access a bathroom. During this phase, social activities and outings were often sacrificed in favor of the desire to remain in safe, comfortable spaces where unpredictable and potentially embarrassing symptoms were easiest to manage. As one simply stated, "you just kinda do what you have to do versus what you want to do."

*Becoming exposed.* As IBD was increasingly felt *within* the body; it also manifested itself *on* the body. Significant weight loss or gain (a result of corticosteroid treatment), acne flare-ups, abscesses that presented as "lumps" on the abdomen, and the presence of medical apparatuses (external surgical drains and collection bags) all marked the presence of IBD. As one participant explained, crisis was "the lamest point of the whole Crohn's debacle because it was the first time that this problem was noticeably external instead of just something inside that I could conquer." Another noted, "I lost like 40 pounds . . . within like a three-month period. I literally wasted away." As participants' bodies became visibly marked by illness, past efforts to conceal IBD became increasingly untenable. As a participant simply stated, "you get to a certain point where you can't keep it secret." In sum, all participants agreed that treating their bodies as "typical" or "normal" and ignoring its special demands proved impossible and unfruitful during crisis. As one noted, there is an evident futility and opportunity for harm implicit in an approach

which involves "suffering for as long as you possibly can and pretending that everything is fine."

#### *Phase 4: Learning to Live With an Extraordinary Body: Becoming a Competent Caregiver*

As the intense symptoms that marked crisis receded, participants critically reflected on their previous coping tactics and how these had failed to serve their bodies, selves, and lives. In this last phase of IBD coping, participants accepted the extraordinary nature of the body and sought to accommodate its special needs through enhanced care, planning, discipline, communication, and personal responsibility, as well as carefully considered moments of indulgence that prevent IBD from becoming overwhelmingly oppressive and alienating. While one participant evidenced some trends typical of this phase, he remained partially in crisis at the moment of interview. His unique case is described near the end of this section.

*Personal responsibility.* Prior to crisis, adherence to medical advice (including special diets or pharmaceutical regimes) was relatively inconsistent and often relied on parental enforcement. However, at the time of interview, all participants took personal responsibility for their care regimes. In the wake of crisis, they appreciated the importance of healthy living and the extent to which their personal actions could influence the course of their illness. Whereas they had initially looked to medical professionals to provide answers and guidance, participants increasingly recognized themselves as the experts of their own bodies and the leaders of their health care efforts. As one participant notes, gaining the confidence necessary to retake control over personal health and wellness developed gradually over time: "at first I felt like I had less control . . . you know, when you don't learn to, like, advocate for yourself, and like stand up for, like, yourself and not be a pushover, you don't feel in control at all." Although medical experts remained important sources of support and information, participants felt much more competent and capable during this phase and positioned themselves as the ultimate arbitrators of what was good for their own bodies. As a participant explained, eventually "you just sort of have to take control of your issues." Two participants were adamant about the need to take control over how and when Western medicine and pharmaceuticals were incorporated into their care regimes, with one emphasizing the importance of informed consent in making choices about treatments: "I have the, like, cognitive ability to understand what they're giving me . . . to look at it and have control over . . . what I'm putting in [to my body] . . . that's really important." Another summarized this ethic, noting that "most twenty, twenty-one-year olds

don't have to worry about their fuckin prescriptions and doctors' appointments and getting their pills in on time . . . It just made me grow up fast, it's made me responsible . . . mature for my age."

**Care.** Whereas the extraordinary needs of participants' bodies had previously been ignored, resisted, or opposed through the stubborn determination to live "like normal," participants now worked to recognize its special demands, protect the body from harm, and support its intrinsic healing capacity. Some participants incorporated new activities to strengthen and nourish the body and improve its ability to cope with the challenges of IBD, initiating exercise plans (two participants) and introducing complimentary, traditional, and alternative medical practices into their care regime (two participants), including chiropractic treatments, naturopathic medicines, and "new age medicine." As they adopted these new practices, two participants noted that their opinions of medical doctors and understanding of the limitations of biomedicine changed. This is not to suggest that biomedicine no longer played a role in coping. Rather, with the realization that biomedicine could not offer any radical cure for their troubled bodies, the role of medical institutions and practitioners shifted within the coping project. As one noted,

a family doctor, y'know, he gives me my anti-inflammatory pills and I see him like, probably once a year and then I get more pills and I say oh yeah I'm fine, everything's okay and get more pills . . . the other doctors I see—my chiropractor and my naturopath—they actually care about me and they want me to be healthy . . . it's different.

Each of the participants identified stress (e.g., work, school, and relationship stressors) as a major trigger for their crises and minor flare-ups and committed themselves to improving their ability to reduce and manage stress in everyday life. While they had previously persisted through stressful times, over-extending themselves and sacrificing their health in the process, participants now described privileging their own psychological well-being as a means of illness management. This involved preemptively limiting or eradicating activities that were likely to prove overly taxing, instead devoting more time to rest and building in moments of calm throughout the day. As one explained, "if there's any family problems or relationship problems I just have to kind of like turf it and do whatever I think chills me out a bit." Since education and work demands threatened their recuperative projects, these taxing activities were described as taking a "back-seat" to the needs of the body in the wake of crisis. This involved reducing university course loads, reducing work hours, avoiding types of work that exacerbate bodily stress, and shifting career goals to obtain better work-life balance.

As they sought to care for their ill bodies, four participants moved back home with their parents for a period of time. Here, they fell back on the care of their parents to obtain the practical support needed to facilitate healing and persist in life goals and responsibilities. One participant described this as a time of restoration wherein she returned to the "super amazing support network" of her parents and hometown allies. Conversely, two others were somewhat reluctant to receive so much support from their parents, but realized the financial, practical, and health benefits outweighed relinquishing some of their independence. One notes,

I had, like, stopped living with my parents when I was 17 until I was, like, almost 22 and then to kind of come back at this point in time, it's weird . . . it's nice to have someone like my cleaning lady . . . not having to buy your own groceries, obviously. And, um, it's nice to be around my family when I'm sick . . . they're very good at taking care of me . . . but in the same breath it's really different than living on your own. It's a lot less freedom.

Having never moved out, one participant felt living at home and accessing parental care and support enabled him to have "more control" over his life and allowed him to be as "healthy" as possible.

In sum, caring for the body meant putting its needs and the pursuit of optimal health and wellness at the forefront of daily life. As one participant explains, he has made a "full-time job of getting healthy again." In addition to healing activities, this meant the pursuit of a more positive, reflective, and simplified existence that balanced wellness with the demands of young adulthood.

**Discipline.** Participants also became intent on protecting the body from known dangers during this phase. Aware that certain foods could aggravate the body, they became hyper-conscious of what they were consuming, limiting or avoiding certain foods and drinks known to irritate their conditions. Often, this resulted in diets that were relatively "bland" and "pretty boring by most people's standards." However, this sacrifice was seen as crucial to protecting the body. As one participant simply stated, "if I'm not careful about how I'm eating and taking care of myself than it definitely leads to, like, really rough days or weeks." Three participants were careful to note that this was an individual process that entailed finding foods that "worked for them." For example, one notes, "in terms of my diet, certain things that I eat might not be technically healthy but they're healthy for me because they work."

All participants further discussed the negative impact alcohol could have on their digestive tract. While one participant rarely drank alcohol before being diagnosed and had no issue with avoiding it during this sequence,

the others described drinking or going out “in moderation.” In this phase, participants simply accepted that they could not drink as much or as frequently as their friends without IBD. To sustain their health and well-being, it was necessary to forgo certain social experiences that were common for their age and circumstances. As a participant simply states, “I’ve become more disciplined in terms of taking care of myself and doing the things I need to do.” However, while participants described a new appreciation for, and commitment to, health discipline and routines, they unanimously affirmed a corresponding need for calculated lapses—moments where they contravened their own health regimes to enjoy typically forbidden elements of everyday life. Participants described, at times, the need to give themselves a break to indulge in “unhealthy” practices for the sake of mental and emotional well-being. Although eating “greasy food,” sleeping in, or having the occasional drink was not necessarily the best thing for participants’ immediate health, these acts were viewed as sometimes necessary to sustain mental health, social connection, and emotional well-being. Although some participants sometimes felt guilty when they let their discipline slide, these occasional deviations from extraordinary discipline allowed participants to feel normal, one “Big Mac” at a time.

**Planning.** Participants recognized that supportive activities, like exercise and eating well, required a degree of planning to be sustained long term. Speaking to the forethought involved in accommodating a special diet, one participant notes, “I have to plan ahead a little more, I have to always have something ready to eat, something healthy.” Likewise, all participants pointed to the importance of anticipating their washroom needs. To counter the threat of their unpredictable bodies (and prevent embarrassing or uncomfortable social experiences), participants described being alert to features of the social and built environment, collecting information about the location of bathrooms, and planning for the possibility of becoming ill in a public place. Some participants also instituted several strategies to combat the threat of experiencing symptoms in public or during a social meal as a result of triggering foods, whether by avoiding eating out with others when feeling ill or suggesting restaurants that would accommodate their dietary restrictions. Self-imposed restrictions of mobility were another step taken to plan for symptom flare-ups. One participant described this as akin to not putting herself “on top of a mountain” during a ski trip with friends. Instead, she says, “I would either . . . not go [on the trip at all], or I would, like, sit in the lodge and chill.” These self-imposed mobility restrictions were not only relevant to the micro-context of staying home, but also to the need to remain in proximity to competent health care: One participant was adamant

about not leaving Canada for more than 8 weeks at a time, noting he could never “live anywhere in the world without healthcare . . . I am grounded here.” While staying close to home was an important coping mechanism, participants noted that they were often disappointed when this meant missing out on social events or experiences.

**Communication.** All participants described becoming more mindful of, and connected to, their bodies in the wake of crisis. They described feeling “more in tune” and skilled at “reading” the body, “listening more” to the body, and “being attuned to what’s happening” in the body. Whereas they had paid little attention to the nuanced signs and states of the body in previous phases, these sensations were now seen as providing important clues to coping well with IBD. As one participant notes, “when I first got sick I did sort of ignore my body . . . and it was a mistake to do so. Now I’m much more aware of what’s happening in me and with me.” Approaching the body as an informant—as capable of providing important information if afforded adequate attention—allowed participants to effectively engage in strategies of caring and discipline. Becoming attuned to one’s body meant discovering the idiosyncrasies of one’s illness. As one explained,

I can’t eat 2,000 calories per day with a strong basis on proteins and vegetables . . . [that is] what’s healthy for women in society . . . finding out . . . [what] helps keep me feeling as well as I can is much more important than what everyone else is doing.

With increased bodily awareness, the mystery of IBD started to dissipate and strategies of care, discipline, and planning became increasingly effective at moderating illness.

Participants also described a pattern of increased interpersonal communication. Being more open about their conditions to friends and acquaintances allowed participants to avoid awkward questions surrounding eating habits or restroom activity. Speaking to the value of disclosing to friends, one participant explained, “you have to disclose to people what’s going on in your life if you want to keep those relationships . . . you’re better off talking about it than not.” Similarly, another stated that “bottling up” one’s IBD struggles often led to social isolation and anxiety. This more communicative approach to coping ultimately allowed friends to become supportive allies, anticipating participants’ needs and providing care during active illness episodes. Illustrating this, one participant highlighted that “people will even cook for me—they’ll make random concoctions of something they’ve Googled and are like ‘well this is supposed to help your stomach.’”

By being open about IBD, participants were also better positioned to take advantage of various accommodations and advocate for their personal health interests at work and school. At the time of interview, all working participants had notified their bosses about their condition. One participant noted that it was important to be “honest and open” with employers and another discussed the value of preemptively discussing the possibility of health-related leaves of absence: “If I tell my boss ‘I can’t come into work’ and she’s like ‘you look perfectly fine.’ I’m like ‘well guess what I’m not.’ Whereas before I would’ve been like, ‘whatever—I’ll just suck it up and go.’” By sharing their illness status with employers, participants limited questions surrounding absences and reduced the number of “uncomfortable situations” they might otherwise encounter in the workplace. However, openness in work settings did not always achieve this intended effect. One participant, for instance, recalled an occasion where her boss had questioned the veracity of IBD-related absences because of her seemingly healthy appearance: “I was definitely challenged on that. It’s like, what would you like for proof? Do you wanna hang around with me for a few days? Do you want a note from my doctor entailing all of my symptoms?”

As students, five participants accessed support from University programs in this phase. One noted,

I had really understanding professors . . . my profs knew—sometimes I just can’t be there . . . if I felt awful and couldn’t get to class, I would just, just stay home and read slides . . . it was good . . . once all my profs knew what I was going through.

Three participants also registered with student services for persons with disabilities. This service reduced the potential anxiety of communicating with professors by legitimizing participants’ need for accommodations, such as access to class notes, extensions for assignments, or additional time for writing exams.

Finally, four participants described reaching out to others with IBD for information and support during this phase. Interestingly, only two participants accessed support from their local Crohn’s and Colitis Foundation of Canada (CCFC) chapter. One participant located a community of people with IBD on the website “Reddit” and another found peers through informal sources. Friends, family members, and acquaintances with IBD offered a level of understanding and insight that was absent among those who had not experienced IBD. Through the sharing of similar experiences in these communities, participants developed a sense of camaraderie with other members of the IBD community. As one participant put it, individuals with IBD recognized one another as “brothers in arms.” Since talking about “poop” is not necessarily socially

acceptable in Canada, participants found that “having people who can relate to your experiences and empathize with you is really important.” In addition to providing participants with understanding and empathy, these communities also provided helpful information about IBD. This information seeking helped participants to further demystify their condition and provided new insights that nourished strategies of care, discipline, and communication. During this phase of coping, participants sacrificed personal privacy in pursuit of enhanced health, transparent relationships, and valuable social accommodations.

*Moments of reprieve.* Generally, the coping techniques described in this phase were driven by the recognition of one’s body as extraordinary and in need of special care. One participant referred to this process as becoming a “more controlled and regimented person . . . more disciplined and responsible”; another described it as a process of maturing and becoming “responsible with how you treat yourself.” However, that is not to say participants lived rigidly. Calculated moments of indulgence and transgression allowed participants to partake of enjoyable activities while also providing an opportunity to reconnect with typical aspects of young adult life from which they often felt alienated—such as a night of heavy drinking. Such acts were symbols of normalcy and belonging and their negative impact was tempered by their infrequency. In this way, a dominant ethic of extraordinary discipline allowed for fleeting moments of normalcy as participants learned to “live in moderation.”

### *Coping as Process*

Although participants’ stories suggest qualitatively different phases of living and coping with IBD, the foregoing analysis is not meant to imply a linear movement through rigid, mutually exclusive stages. Movement between these phases was often gradual, partial, and halting. The case of one participant—who remained to some extent in body crisis at the time of interview and simultaneously exhibited ways of being, thinking, and feeling characteristic of Phases 2, 3, and 4—is illustrative of this point. He was uncertain whether his current flare marked the beginning of a lengthy struggle with intense symptoms or a temporary setback on the path to remission. He continued to hope for a cure and was hesitant to undertake the surgical initiatives or lifestyle changes he suspected might be necessary to improve his well-being. Intent on playing out his track and field career, he continued to push his body to live up to his immediate aspirations. However, he had begun to speak more openly about his illness with teammates and recognized that special care, along with increased health discipline and planning, could prove beneficial to his health.

At the time of interview, he existed in a transitional moment—increasingly recognizing the need to take responsibility for his health and make notable alterations to his everyday life and goals but unable to relate to the competence and proven benefits of such measures described by other participants:

Like, if, if we could get this [current] flare under control and gone, like, that would be amazing. Then I could really focus on my goals again . . . I got sick when I was 13, then I was healthy for, like, eight years. Like, *really healthy* . . . I'm hoping that can happen again. I can get over this flare and be healthy for a while, and not have to worry with this stupid disease for a while. But, at the same time, I know how bad it is, I know it's not getting better, and I know it's dangerous to leave it as active as it is.

Across the four phases identified here, it is evident that participants' attempts to cope with IBD have undergone numerous transformations. Where bodies were once neglected or understood only with confusion, they were now listened to intently and with esteem for the information they could provide. Similarly, by communicating with others about their illnesses in the final phase participants opposed the secrecy of trying to pass in the beginning. In earlier phases, participants strove for normalcy and realignment. At the time of interview, they readily accepted their extraordinary statuses to varying degrees. Finally, though participants struggled with discipline and personal responsibility initially, they developed extraordinary routines and rituals to care for themselves over time. Viewed from a processual perspective, these stories do not speak to an arbitrary accrual or shedding of coping techniques. Rather, these shared phases are the result of key events, realizations, and experiences that are common to the young adults we interviewed. Participants were moved along their coping journey through experiences of becoming "sick"; recognizing the impotence of Western medicine; coming to accept chronic illness; living through the social, psychological, and physical side effects of various ineffective coping strategies; and learning how to best sooth mind and body through trial and error.

Where the ill body is initially construed as an antagonist which stands between participants and their everyday pursuits and future aspirations, it gradually takes the form of an ally, capable of providing vital information to help participants avoid suffering and preserve valued aspects of daily life. This shift provides insight into the use of variable metaphors across the illness experience. Whereas in early phases of illness the fight metaphor was more common, in the last phase of coping, participants began to use metaphors of reading, listening to, and interpreting the body's sensations. In contrast with strategies of denial, banalization, secrecy, and rugged endurance, attempts to

recognize and communicate the body's special needs better facilitated the attainment of personal, social, and academic goals. While IBD remains an important feature of all participants' lives, for most, it no longer inspires the same fear, anxiety, and sense of loss. Importantly, this finding aligns with those identified in numerous studies of chronic illness/injury (see, e.g., Gelech & Desjardins, 2011) and illustrates the human tendency to initially seek continuity and pursue a return to "normalcy" in the face of health crises and other transformative life events (Becker, 1997; Frank, 1995; Good, 1994). Generally speaking, it is only in the clear absence of a "cure," where suffering persists and life crises remain unresolved, that humans are willing to go through the radical reorganization of self, world, and sociality needed to embrace lasting difference.

The four phases outlined herein point not only to a transformation of illness experience and coping approach but also to a transformation of *self-understanding* critical to the establishment of health and a new equilibrium in participants' lives. Importantly, shifts in coping were associated with participants' negotiation of two poles of personal identity: identity as a set of identifiable marks that permit a sense of permanence and continuity over time (one's immutable characteristics or "sameness" over time) and identity as a sense of dynamic agency in context (one's changing sense of continuously emerging or developing) (Ricoeur, 2004/2005). A global view of these four phases permits us to see how participants inscribed themselves into a narrative about *becoming* someone with IBD: a narrative that involved refiguring the relationship between the stable and dynamic dimensions of their identities.

In the first phase, participants encountered a mysterious change to their body, but saw it as minor and inconsequential—a difference that could be treated in the same way as other minor, passing disturbances of the body (over the counter medication, patience, perseverance, etc.) and which posed no real threat to the stable aspects of self. At this phase, participants' styles of coping preserved a sense of continuous identity. In the second phase, intensifying symptoms forced participants to recognize the severity of disturbance they were experiencing but the changed aspects of their selves and bodies remained abstract and disconnected from the qualities they perceived as defining their self-sameness. In the third phase, symptoms intensified to a point where it became impossible for participants to exist as their former selves: Participants felt both alien to themselves (in the sense of being unable to recognize themselves) and unable to take initiatives that would affirm their self-constancy despite bodily transformations. The final phase represented an integration of their difference and change into a new version of self-sameness—a transformation made possible

by their accountability over their illness, their improved understanding of their condition, and their willingness to make sacrifices in some domains to preserve—rather than compromise—their recognition of themselves as the same person over time. Through trial and error, participants incorporated a familiarity with their unique bodies and needs into a new continuity. Participants' changing and stable components of identity were experienced as existing in a new mode of equilibrium—a status that closely resembles Gadamer's (1996) definition of health as "a condition of experienced weightlessness in which different forces balance each other out" (p. 113). As Gadamer points out, such an experience also implies "a condition of being involved, of being in the world, of being together with one's fellow human beings, of active and rewarding engagement in one's everyday tasks" (p. 113) and a readiness to "embark on new enterprises" (p. 112). Certainly, with the exception of one participant who remained in crisis at the time of interview, participants appeared to have found a level of balance that facilitated this type of experience.

Ultimately, the narratives surveyed herein are stories of empowerment—they tell a tale of moving from relative ignorance, impotence, and identity threat to expertise, effective action, and a robust sense of self. Within these stories, participants emerge as "able persons" (Ricoeur, 1992/2013). This recovery of agency, self-efficacy, and esteem in the midst of suffering and confusion is an important accomplishment in itself. Notably, it prevents young adults from collapsing into hopelessness and restores the possibility of a positive future where IBD plays a peripheral (but important) role in personal identity (see Frank, 1995; Good, 1994; Mattingly, 1998; Ricoeur, 1990/1992). Such adaptations refer not just to practical changes and functional adjustments, but to the constitution of a parallel social world, a necessarily restricted way of being (compared with those without IBD) and an alteration of public and personal identity.

## Discussion

The processual approach to IBD coping among young adults employed herein adds to existing literature in several ways. First, it reconstructs how young adults have variably made sense of, and coped with, IBD over the course of their young lives. While past research has presented a dizzying array of discrete coping techniques, the current work highlights qualitative shifts in the employment of various strategies and ties these patterns to key realizations, physical experiences, social contacts, and identity struggles. Second, much existing literature casts young adults with IBD as an at-risk population susceptible to anxiety, depression, and stigmatization (Gray et al., 2012; Kunz et al., 2011). Although those who

experienced IBD onset during their childhood or adolescence highlighted the potential of illness-related anxiety and stigmatization, these risks appear to have diminished over time as young adults learned the benefits of body attentiveness, social openness, and personal care/discipline. Third, the current research helps to make sense of the contradictory metaphors present in past research by placing them within a developmental trajectory. It illustrates that while IBD as "fight" or "battle" might be most salient in moments of intense uncertainty, disorder, pain, alienation, or frustration (illness flares, early symptoms, or instances where the body threatens key goals), the metaphor of communication and the positioning of one's body as an informant/ally becomes more salient as participants learn to more effectively cope with IBD and reconstruct themselves as capable actors. This finding is in line with the Shifting Perspectives Model wherein living with chronic illness entails a dynamic foregrounding and backgrounding of illness over time according to varying situations and circumstances (Paterson, 2003). Finally, this research also underscored that adapting to IBD is a process that unfolds in time and requires complex changes to self and world.

From a clinical perspective, these findings provide insight into supporting young adults with IBD. For example, while observers (medical, parents, etc.) might wish to orchestrate the flow of coping and hasten the movement toward personal responsibility and bodily discipline, each phase seems to consist of necessary experimentations and realizations that perhaps cannot, and should not, be rushed or avoided. Moreover, when young adults are ready to access support from IBD communities, it appears that many are not connecting with institutions like CCFC, but rather locating other young adults in their communities or online. Perhaps outreach programs tailored to the challenges, concerns, and preferences of this unique life stage could increase support for young adults with IBD.

While the current work says a great deal about the specific nature of coping with IBD in young adulthood, it also supports existing research on the nature of coping with chronic illness more generally. In many ways, the trajectory described herein reflects a common approach to living with persistent health struggles whereby individuals initially resist difference and attempt to avoid changes to self, world, and body. They begin by employing techniques broadly conceptualized as "normalization," seeking a cure for IBD and a return to conventionality (Becker, 1997; Brede et al., 2021). This is not surprising given that such techniques are minimally disruptive to participants' worldview and social existence. As Becker (1997), Good (1994), Goodman (1978) and others have noted, customary ways of thinking and being tend to develop a self-perpetuating momentum and grow resistant to change over time. As Goodman (1978) affirmed,

“Reality . . . is largely a matter of habit” (p. 20). Consequently, the pull of continuity is strong and humans tend to shy away from radical change in the face of health crises, instead pursuing conformity, normalcy, and belonging. Young people may be particularly unprepared to make such adjustments given common expectations of health in this period of life (Ghorayeb et al., 2018) and moments of intentional nonadherence—common to many chronic illnesses (Huyard et al., 2017)—might be important for connecting with peers and establishing a sense of normalcy in this stage.

Yet, this is not to suggest that human beings are tied to tradition. When it becomes obvious that a cure is not forthcoming, secrecy risks alienation, and acting “like normal” proves unsatisfying or untenable, people will alter their coping approaches and transcend their previous ways of understanding self and world to consider new possibilities for their lives (Becker, 1997; Brede et al., 2021; Frank, 1995; Good, 1994; Goodman, 1978; Robinson, 2016). Although we might prefer cures and conventionality, we are often forced to adopt new ways of dealing with life crises and imaging self, body, and world. Taking personal responsibility for IBD management appears to be intimately related to the shift away from normalization and more passive coping practices and has previously been identified as an important moment in young adults’ healing trajectories (Auduly et al., 2012; Leung et al., 2020). Coping with unruly bodies and dealing with difference thus entails a dynamic dance between preference and necessity. In this sense, the narratives of young adults with IBD mirror many of the challenges, realizations, and trajectories of individuals and families living with conditions as diverse as brain injury, cancer, heart problems, scleroderma, diabetes, asthma, thoracic outlet syndrome, severe allergies, arthritis, fibromyalgia, epilepsy, multiple sclerosis, and chronic fatigue syndrome (Gelech & Desjardins, 2011; Good, 1994; Robinson, 2016).

The current work is not without its limitations. The small sample size of this study and the social constructionist orientation of the research team preclude any claims of having produced a comprehensive and generalizable understanding of IBD. However, because illness narratives are inherently intersubjective and emerge in shared social, cultural, and institutional contexts, we expect that these stories would resonate, on some level, with the experiences of other young Canadians living with IBD. Moreover, while the current work focuses on the broad contours of the coping process, much remains unsaid about the experience of IBD among this group. Additional work is needed to explore the social contours of IBD in the lives of young adults, including disclosure events and the negotiation of challenges in interpersonal settings. Future research should also attend more closely

to how young adults with IBD negotiate care regimes and advocate for themselves in dialogue with medical professionals, educational institutors, employers, and parents who might delegitimize their agency or bodily distress. How can these supportive actors facilitate an empowering approach to illness management and personal responsibility for health? What value might there be in emerging approaches, such as Recovery Preference Exploration (Kurz et al., 2008) or Unclosed Diary techniques (Sargeant & Gross, 2011), for clarifying individual needs and facilitating dialogues across interested parties in cases of young adult IBD? Future research could examine these nuances by investigating coping patterns among individuals of different severity of illness, time since diagnosis or symptom presentation, nature of physical interventions (permanent ostomy bag, etc.), and type of supports accessed (social, institutional, governmental, private, etc.). As our data suggest, individuals with life aspirations that are heavily embodied and require consistent presence without disruption might be uniquely impacted by IBD, including actors, athletes, or pilots. It would also be interesting to learn more about caregivers’, employers’, and medical professionals’ perspectives and understandings on supporting young adults with IBD. What challenges exist in supporting young adults along their coping journeys?

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