

Stress coping, distress, and health perceptions in inflammatory bowel disease and community controls

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Abbreviations:

CCHS=Canadian Community Health Survey; Crohn's disease = CD; inflammatory bowel disease=IBD; ulcerative colitis =UC

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Background: This study compares a community IBD sample with a matched non-IBD community sample on psychological functioning and health perceptions.

Methods: Participants in the population-based Manitoba IBD Cohort Study (n=388) were directly compared with sex, age, and region-matched controls from a national random-sample health survey on aspects of psychological health, coping, and perceived general health.

Results: The IBD sample overall had lower psychological wellbeing and mastery, and higher distress than the non-IBD controls ($p \leq 0.02$). Those with IBD used avoidant coping significantly more often, and active coping modestly more often than the non-IBD sample; both had similar levels of 'self-soothing' behaviors. Crohn's disease and ulcerative colitis participants had similarly poor levels of functioning along these dimensions compared to the non-IBD sample, as did those with active disease ($p < 0.01$). However, those with inactive disease were similar to the non-IBD sample, and had modestly higher mastery levels. While nearly half of the non-IBD group reported chronic health conditions, those with IBD were three-fold more likely to report poorer health (OR 3.07, 95% CI 2.10-4.47). Psychological factors explained a greater amount of variance in perceived health for the IBD than the non-IBD sample.

Conclusions: Those with IBD have significantly poorer psychological health than those without IBD and view their general health status more negatively, although adaptive stress coping strategies were similar. However, when disease is quiescent there is little detriment to functioning. Active disease should be a flag to consider psychological needs in the care of the IBD patient.

Introduction

Living with a chronic illness can be very challenging. Studies that have assessed psychological functioning in chronic diseases such as arthritis and multiple sclerosis suggest that patients experience high levels of distress, greater psychiatric comorbidity, and poorer quality of life¹⁻⁷. Inflammatory bowel disease (IBD), a chronic condition with fluctuating symptoms, an unpredictable course, and high rates of surgery, is thought to have similar negative repercussions⁸⁻¹⁵. Quality of life has been found to decline in parallel with increased disease severity¹⁶. Some studies have reported poorer functioning of IBD patients and disruption in quality of life even when the disease was in remission^{17,18}. However, much of the work assessing the impact of IBD is based on outpatient specialty clinic samples, which can provide a fairly narrow range of disease experience. Clinic samples can also over-represent those with a higher level of emotional distress, as distress is often a determinant of health service utilization¹⁹⁻²¹.

Research involving community-based IBD samples has produced mixed conclusions regarding the negative impact of the disease on psychological functioning²²⁻²⁴. A study that used health records to identify 400 cases, concluded that those with IBD had only minor impairment overall in quality of life domains including general physical symptoms, social functioning, and emotional wellbeing²². This study found more pronounced difficulties for women and those with Crohn's disease (CD) within the sample. However, disease activity was not accounted for, and a comparative sample without IBD was not available. Two other studies drawing from community samples, one using a population-based cohort and one using volunteers from a self-help IBD organization, reported clinically significant reductions in quality of life across several domains

relative to normative values in the general population^{23,24}. None of these studies had a community comparison group without IBD to control for differences that might be attributable to life stage or other factors unrelated to IBD.

In previous research, using a community-based IBD sample and a broad assessment of psychological functioning, our team found that those with active IBD managed more poorly in multiple domains, experiencing higher levels of distress, health anxiety, and perceived stress, and lower psychological wellbeing and mastery, relative to those with inactive disease, both cross-sectionally and across a two-year period^{25,26}. Once disease activity was accounted for, there were no differences in these aspects of functioning between those with ulcerative colitis (UC) and CD. Poorer disease-specific quality of life was also found for those with active disease compared to IBD participants whose disease was inactive. Of note, the IBD respondents had lower scores on a widely-used general quality of life scale (the SF-36) relative to normative data, even when they had inactive disease over the previous 6 months. These findings provide important information regarding the relationship with disease activity. Nevertheless, the comparisons were within a chronic disease sample, and only indirect comparisons with previously published data from non-IBD samples were possible to consider disease burden, which does not take into account differences in sample composition (age and gender for example), regional variation, and cohort effects.

Coping has been described as encompassing the cognitive and behavioral efforts to manage stress or demand, and varies from person to person²⁷. Coping approaches to deal with the stress of an illness have the potential to mitigate the impact of disease, including IBD^{28,29}. Those

studies relying on IBD clinic samples have found IBD patients are more likely to use maladaptive stress coping strategies than those without IBD¹². These approaches, which can include withdrawal and catastrophic thinking, have been associated with greater distress in IBD patients, adverse health outcomes, and poorer outcome after surgery³⁰⁻³². In a community-based IBD sample, recruited through online IBD groups and GI specialist offices, avoidant coping was associated with poorer outcomes, however a comparison group was not included³³.

Mastery is another factor that can potentially mitigate disease impact. Mastery, the sense that one has control of one's life, has had little attention in IBD research, despite its relevance in chronic illness³⁴⁻³⁶, and its importance to patients³⁷. A person's sense of mastery or perceived control is understood to be a powerful psychological resource, with a lower sense of control negatively affecting health outcomes³⁸ and higher mastery associated with good mental and physical health outcomes even in the context of significant stress or health problems³⁹⁻⁴¹.

To understand whether IBD is uniquely associated with poorer psychological functioning, appropriate comparison groups of those without IBD are needed. That is, are persons with IBD that much different from their peers without IBD in their spectrum of functioning; further, is there a residual negative impact even when the disease is not symptomatic? Few studies have looked at direct comparisons of general functioning for those with and without IBD, or considered psychological factors beyond domains of problematic functioning.

Building on previous work, the aim of the current study was to directly compare the general psychological functioning, specific stress coping, and perceived health of a community sample of

individuals with clearly-established IBD to a matched sample of individuals from the community without IBD. The sex and age-matched controls were obtained from the same region in a nationally-representative random-sample community health study. The comparison with a matched sample allows for a more confident determination of ways in which those with IBD might differ from those without the disease, in order to better understand any unique level of challenge and coping for those with this chronic disease.

Methods

IBD community sample

The Manitoba IBD Cohort Study is a prospective longitudinal project started in 2002, following a population-based cohort of adults, diagnosed within the previous 7 years. Participants were recruited from a province-wide IBD research registry established in 1995 which includes more than half of those diagnosed with IBD in the province. Detailed descriptions of the methods used to establish the Registry⁴² and the Cohort²⁵ have been published previously so a concise description is provided here. The Cohort Study was approved by the University of Manitoba Health Research Ethics Board, and participants provided written informed consent to participate.

At the time of study recruitment, there were 3192 participants in the Research Registry. Contact was initiated with all those in the Registry who met the age and recent onset criteria (n=606) for the Cohort Study. Approximately 12% could not be located, 5% had moved out of province, were deceased or were found to be too young, and 14% directly declined to participate.

A total of 418 were enrolled for the study, and complete data through interview and survey were obtained in the first contact from 388 who subsequently served as the Cohort. To assess representativeness of the Cohort, participants were compared to all other IBD cases diagnosed in the same time period (1995-2002), using the University of Manitoba IBD Epidemiology Database, a comprehensive validated data set which includes all those in the province with IBD. They were compared on demographic characteristics including mean age, age distribution, sex distribution, urban vs rural residence and on mean duration of disease. There were no significant differences between the IBD Cohort and the population of Manitobans with IBD, suggesting excellent representativeness of the sample⁴³.

IBD diagnosis was verified through chart review at physician offices by study staff, to confirm both the IBD diagnosis and disease subtype of CD or UC. Disease activity was determined by the respondent's report of IBD symptom persistence over the previous six months, using the Manitoba IBD Index (MIBDI). This measure was developed for the longitudinal cohort project to better represent disease status for a broader time frame than the brief 24-hour or week period that other disease activity measures provide. It uses symptom frequency anchors with a six-level response format to facilitate more consistent reporting. Active disease was defined as experiencing symptoms constantly to occasionally (levels 1-4), and inactive disease was defined as experiencing infrequent symptoms or feeling well (level 5 or 6). The measure was validated using other clinical indices of disease activity, including the Harvey-Bradshaw Index, the Powell Tuck Index, and the Inflammatory Bowel Disease Questionnaire (IBDQ) total scale and subscales, and was found to have strong test-retest reliability, sensitivity, and convergent validity⁴⁴.

Non-IBD community controls

In order to allow for a comparison to a random community control sample, key measures of psychological functioning used in the Canadian Community Health Survey (CCHS)⁴⁵ were used in the Cohort Study. The CCHS is a nationally-representative random-sample survey conducted by Statistics Canada⁴⁶. The CCHS has a two-year data collection cycle, with the second year of each cycle typically utilizing a smaller sample and a more in-depth focus on particular topics. Cycles 1.1 and 1.2 were conducted during the same time period as the Cohort Study. The large sample size (Cycle 1.1 n=130,880; Cycle 1.2 n=36,984), excellent response rates (Cycle 1.1: 85%; Cycle 1.2: 77%), and rigorous methodology including stratified sampling and standardized in-person interviews make it a valuable source of health information.

To develop the matched comparison group, Manitoba respondents from the Statistics Canada CCHS Cycles 1.1 and 1.2 datasets were randomly selected. Sampling was done from both cycles as not all of the measures of interest were included in the same cycle. Cases were excluded if they reported that they had IBD or a related bowel condition or were of Aboriginal (First Nations) descent, as IBD is rare for those from this ethnic group. Cases were also excluded if they were residents of northern health regions of Manitoba, as these regions are sparsely populated and have a high proportion of Aboriginal peoples. Matching was according to gender and age (collapsed into 5-year groupings). For Cycle 1.1, case matching of 5 controls to 1 IBD participant was used, and for Cycle 1.2, case matching of 2 controls to 1 IBD participant was used, the latter because of the smaller sample size of that survey cycle. This resulted in a total of 1971 individuals from Cycle 1.1, and a sample of 728 individuals from Cycle 1.2.

Assessment of General Psychological Functioning and Health Status

Mastery (Cycle 1.1), psychological wellbeing (Cycle 1.2) distress (Cycle 1.2) and stress coping (Cycle 1.2) were assessed using validated interview scales from the CCHS. The Mastery Scale is a measure of a person's sense of control in their life, involving their perception that their efforts and abilities can affect their life situation⁴⁷. It has 7 items, and uses 5 response categories from 'strongly agree' to 'strongly disagree', with higher scores reflecting a greater sense of ability to control or manage one's circumstances. The Psychological Wellbeing Manifestations Scale (PWB) is a 25-item measure of one's positive sense of their psychological functioning (positive feeling states, being active and useful) in their daily lives⁴⁸. The five level response format ranges from 'almost always' to 'never'. Higher scores indicate a greater experience of wellbeing and positive functioning.

Distress was measured using the Kessler Psychological Distress Scale⁴⁹ (K-10), which was developed for use in epidemiological surveys to screen for level of anxiety and depressive symptoms⁵⁰. The scale consists of 10 questions using 5 response categories from 'all of the time' to 'none of the time'; higher scores reflect greater distress.

Stress coping was assessed to determine approach to coping, using a scale developed by Statistics Canada for the CCHS Cycle 1.2 that was based on the Coping Strategy Indicator⁵¹ and the COPE scale⁵². This 14-item scale measures a variety of behavioral approaches to handling stress, using a 4 level response format of 'often' to 'never'. As it was a hybrid scale, an exploratory factor analysis was performed on the 14 items, using an oblimin factor rotation to account for correlated factors, and an eigenvalue-greater-than-1 rule for factor extraction⁵³. This

analysis yielded a three-factor solution that accounted for a total of 39% of the variance in the items: factor I Avoidant (eigenvalue = 2.36; 16.89% of the variance), factor II Active (eigenvalue = 1.90; 13.55% of the variance), and factor III Self-soothing (eigenvalue = 1.21; 8.61% of the variance). Avoidant strategies include withdrawing from others, sleeping more or wishing the problem would go away. Active strategies include trying to solve the problem, shift perspective, or talk to others. Self-soothing strategies include smoking or drinking to feel better. The strategies are not mutually exclusive so that one could use approaches from all three types. Higher scores on a subscale indicate greater use of those types of strategies, with one exception. On the self-soothing subscale, the item 'praying or spiritual help' loaded negatively onto the factor, so it was coded to reflect that a higher score meant less use of this strategy. Therefore, a higher score on the self-soothing subscale indicates greater use of alcohol, smoking or drugs and less use of prayer to cope with stress.

Overall perception of health status was measured using a single-item question with 5 response options: "In general, would you say your health is... excellent, very good, good, fair, or poor". This measure has been used regularly in the National Population Health Survey (www.statcan.ca) as well as in the Canadian Community Health Survey since inception, and is a core question in the SF-36 quality of life survey⁵⁴. Higher scores indicate perception of poorer health. When used as a categorical variable, the response categories were collapsed into two groups to characterize health perception, with poor health including fair to poor responses and good health including excellent to good responses^{55,56}.

For all of the measures, the responses of the matched community sample were directly compared to IBD participants, as well as with IBD subgroup comparisons of CD/UC, and active/inactive disease over the prior six months.

Statistical Analyses

Univariate comparisons of the IBD sample and the non-IBD community sample, as well as comparisons of subgroups of IBD disease type (CD/UC) and disease status (active/inactive) with the community sample were performed using 2 tailed independent samples t tests for continuous variables and χ^2 tests of association for categorical variables. In order to control for error rates, a Bonferroni adjustment was used for family-wise comparisons (subgroup comparisons on each key measure); comparisons were reported as significantly different when $p \leq 0.02$.

Associations among the psychological functioning and health status variables were assessed using Pearson or Spearman correlations for both the IBD and non-IBD community samples, as appropriate, and Fisher's z -test was used to compare correlations for the two samples. Logistic regression was used to compare the IBD and community samples on perceived health, controlling for other chronic health conditions.

Finally, multivariate regression analyses were used to consider the relationship between psychological factors and health perception for both the IBD and non-IBD community groups. A global model was first used to assess main effects and any interaction effects of the psychological variables with sample type (i.e., IBD and non-IBD community sample) on health perception. If any of the interaction terms in the global model were significant, then the Baron

and Kenny⁵⁷ procedure for a continuous and categorical variable was used to probe the interaction.

Results

The IBD community sample ranged in age from 17-83 years old, with a mean age of 38.5 years for CD participants and 43.0 years for UC participants; 59% were women. A quarter of the sample were university educated (27%) and over half were married or in a common law relationship (67%). The non-IBD community samples (CCHS 1.1 and 1.2) were matched to the IBD sample by age and sex, and they had similar education levels and marital status⁵⁸. For both the IBD and community samples, over half reported other chronic health conditions diagnosed by a physician (IBD 61%; non-IBD 51%), with the five most common conditions including back problems, arthritis, migraine headache, asthma, and thyroid dysfunction for both samples.

For the IBD participants, chart review confirmed that 187 (48.2%) had CD and 169 (43.6%) had UC. Another 18 (4.6%) were identified as having indeterminate colitis, and 14 (3.6%) did not have definitive IBD. The latter two groups were excluded from the analyses, leaving 356 participants for subsequent analyses. Average disease duration was 4.3 years (SD=2.1). The majority of the IBD participants (CD 74%; UC 66%) experienced active disease in the previous 6-month period, and 14% had been hospitalized at some point in the previous year.

The scores for the psychological functioning measures comparing the IBD and non-IBD community samples are shown in Table 1. Distress levels were significantly higher for those with IBD than without IBD. Using the non-IBD community sample as the reference group, both CD and UC subgroups reported significantly higher distress. Similarly, those with active disease

had higher distress levels than the community sample. However, those with inactive disease did not report any more distress than the community sample.

Mastery and psychological wellbeing showed a different pattern. The IBD sample overall had a significantly lower sense of mastery and lower wellbeing than the community sample. When the subgroups were examined, mastery and psychological wellbeing were significantly lower than the community sample for those with CD or with active disease. Mastery was significantly higher for those with inactive disease compared to the community, and there was a similar trend for wellbeing to be higher for those with inactive disease relative to the non-IBD sample ($t=1.9$, $p=0.06$).

As can be seen in Table 1, coping approaches were utilized differently by the IBD and non-IBD samples to some extent. Overall, those with IBD reported using avoidant coping significantly more often than the non-IBD community sample. These differences held across disease subtype, but not disease activity. That is, those with active disease used avoidant strategies more often than the community sample, whereas those with quiescent disease were similar to the community. Active coping approaches were used significantly albeit modestly more often by the IBD sample overall; the difference did not reach significance for the CD subgroup, or the active disease subgroup (CD: $t_{(901)} = 0.94$, $p = 0.35$; Active: $t_{(962)} = 1.35$, $p = 0.18$). The IBD and non-IBD community samples were not significantly different in their use of self-soothing approaches. Self-soothing strategies were used at low levels across both groups.

The coping subscales of active coping, avoidant coping, and self-soothing include a range of behaviors that could be experienced as more or less beneficial, depending on the situation and stressors. In order to explore differences in coping strategies more closely between the non-IBD community sample and those with active or inactive IBD, mean ratings of the frequency of use for each coping strategy within each subscale were compared. These results are shown in Table 2. *Active* coping strategies were used most commonly by respondents in all groups and to a similar degree, with a few exceptions. IBD participants were significantly more likely to engage in exercise to deal with stress than the non-IBD participants, regardless of whether disease was active or not. Those with active disease were less likely to hold an optimistic view of their situation relative to the community sample, and those with inactive disease were more likely to engage in enjoyable activities. With regard to *avoidant* coping, those with active IBD used each one of the avoidant coping strategies significantly more often than the non-IBD group, in contrast to those with inactive IBD who were much more similar to their non-IBD community peers. Finally, the active IBD group was much less likely to drink alcohol. They were also more likely to use medication as a coping strategy when stressed compared to the non-IBD community controls, which may well have been appropriate in the context of their disease.

The relationships among the psychological characteristics and stress coping in both the community IBD and community non-IBD samples are presented in Table 3a and 3b respectively. For both IBD and non-IBD samples, individuals who were more distressed were more likely to use avoidant coping and less likely to use active coping. As well, a greater sense of control or mastery was associated with less use of maladaptive coping approaches (avoidance) and more use of active, adaptive approaches. While there are similar patterns for both the IBD and non-

IBD samples, some of the associations were significantly stronger in the IBD group. For example, perceived health was strongly correlated with psychological wellbeing and distress for IBD patients ($r=-0.55, 0.51$), and only moderately correlated with those same variables in the community sample ($r=-0.21, 0.21$).

The IBD and non-IBD groups had disparate views of their health, although IBD activity status appeared to be an important qualifier. Logistic regression, controlling for other chronic illness comorbidity, indicated that overall those with IBD were three times more likely to view their health as poor than the community sample (adjusted OR 3.1; CI 95% 2.1-4.5). When comparing the subgroups of those with active or inactive disease to the non-IBD community sample however, there was no difference between those with inactive disease and the non-IBD sample, as less than 10% of those with inactive disease saw themselves as being in poor health, similar to the non-IBD sample (Table 1).

An initial multivariate regression analysis of perceived health examined the association of all the psychological variables and their interactions with sample type (IBD and non-IBD). The global model had a significant association with perceived health ($F_{(11,1035)} = 29.35, p < 0.01, R^2 = 0.23$), and indicated a significant interaction effect for sample type and distress ($B= 0.17, t = 2.24, p = .02$).

Given that the global model was significant, multivariate regressions were then done separately for the IBD and non-IBD groups in order to probe the interaction with sample type. As shown in Table 4, these models found that the level of psychological wellbeing, distress, and active coping

behaviors was associated with a poorer view of health. The psychological variables explained a greater amount of the variance in health perception for the IBD than the non-IBD community sample (33% versus 7%). A secondary analysis of the IBD submodel, first controlling for disease activity found that these psychological factors still explained significant variance in perceived health (Table 5).

Discussion

The results of this study support and extend the findings of previous work concerning psychological functioning and IBD²⁵. This is the first study to use both community-based IBD participants and a matched community control sample to determine how those with IBD are managing psychologically and to consider the impact on health perceptions. The findings clearly emphasize the importance of considering disease status when interpreting IBD outcomes. While there were differences overall between the IBD and non-IBD samples, this study confirmed, using direct comparison, that those who have inactive disease over an extended period (i.e., six months) are similar in important areas of psychological functioning and health perception to those in the general community. In contrast, those with active disease over the previous six months are more likely to experience psychological challenges including higher distress, lower psychological wellbeing, and less sense of life control (mastery).

It has recently been questioned whether there is any relationship between psychological functioning and disease status⁵⁹. However, studies that were more adequately powered to detect differences have found that distress levels change in parallel with disease activity^{11,16,60}, and those in relapse have poorer quality of life than those in remission^{61,62}. The findings from this

study, showing clear differences in distress between a matched community non-IBD sample and those with active IBD, add further support to the understanding that it is not having the disease per se that relates to psychological difficulties, but rather that disease activity is pivotal.

The early period around disease diagnosis has been associated with higher rates of anxiety and depression symptoms⁶³, raising the possibility that distress levels were somewhat heightened in this IBD sample given the truncated range of disease onset (i.e., within 7 years). Significant fluctuation in disease activity and greater psychological distress have been found to be most prominent, however, around the time of diagnosis and within the first 1-2 years⁶⁴⁻⁶⁶. In this study, the IBD participants had been diagnosed for at least 4 years on average, and distress was assessed for recent weeks, suggesting it was less likely that distress levels were unusually elevated or that the findings would be less generalizable.

Mastery, or a sense of personal effectiveness and control, has not been widely examined in IBD. In this study, the lower sense of perceived control found for those with active IBD relative to those without IBD may be related to the sudden and unpredictable onset of symptoms as well as the interfering nature of the symptoms many IBD patients experience. This uncertainty about symptom flare and symptom resolution can permeate a person's sense of their ability to be an effective force in their own life. In psychological terms, the intermittent and unpredictable nature of the disease can create a view that important aspects of life cannot be controlled, generating for some a sense of helplessness. A low sense of control has also been found to decrease the likelihood of engaging in healthy behaviors, which in turn can negatively affect illness⁶⁷.

Mastery is not only affected by but can moderate the impact of stressors, playing a role in adaptation to adversity^{34,68}. Our finding that those with prolonged inactive disease had a higher level of mastery than the non-IBD community sample suggests some preliminary support for positive disease adaptation occurring in IBD. The participants in the cohort had lived with IBD for an average of four years; those who had been relatively well for at least the last six months did not just return to a comparable 'community' baseline but were reporting modestly higher levels of mastery, suggesting some possible strengthening of their sense of mastery as they 'weathered' the illness. Longitudinal tracking of mastery has also found modest increases over time in an IBD population²⁶, with mastery levels highest for those with inactive disease. Certainly more information on change over time relative to disease change would better delineate the durability and protective versus reactive nature of mastery in the context of IBD.

This study found that the use of more adaptive, active coping strategies to deal with stress was fairly similar regardless of whether one had IBD or not, and these strategies were the most commonly used by those with and without IBD. This suggests that IBD patients may be receptive to disease management recommendations that support active coping. The IBD sample appeared to be more invested in healthy lifestyle approaches than the general population since they were more likely to exercise and less likely to drink alcohol in response to stress. However, those with IBD, particularly when the disease was active, were more likely to use avoidant coping approaches, which are typically defined as maladaptive. On closer examination, some of the avoidant strategies used frequently may be reasonable to cope with a chronic illness (e.g. sleeping more, eating more or less, and wishing that the situation would go away) while

others are more problematic regardless of the context (e.g. avoiding people and blaming oneself). Notably for those with inactive disease for an extended period (at least 6 months), coping strategies in response to stress were, on balance, similar to the general population. These findings suggest that there are some differences in coping approach used, depending on whether the IBD is active or in remission. This finding is in contrast to a recent report, where IBD patients used similar approaches regardless of disease status⁶⁹. Disease activity in that study was defined by a very brief, immediate time period (i.e., “Are you at this moment experiencing active disease”), which may not allow for any adjustment in coping.

Self-perceived health status has been found to robustly predict health care utilization⁷⁰. In a study on chronic pain, it was the only variable that predicted health care utilization rates after adjusting for prior usage levels⁷¹. So it is valuable to understand the individual’s view of their health and what, in addition to health circumstances, may affect health perception. The IBD participants clearly had a more negative view of their health than the community comparison group, although this was limited to those with active disease. The strong association between psychological variables and perceived health that persisted even after disease activity was controlled for in IBD participants, with half of the explained variance accounted for by distress, wellbeing and avoidant coping, certainly bolsters the understanding that the view of one’s health is based on more than the presence of illness. Maladaptive coping has previously been found to be associated with poorer perceived health⁷², lending further support. However this study could not clarify the direction of that relationship; a poorer view of health could contribute to greater distress, for example, or vice versa.

The strengths of this study include the use of a population-based IBD cohort and matched community controls, as well as measurement of broader aspects of psychological functioning than in previous research. The Manitoba IBD Cohort Study draws participants from a large geographic area with a diverse demographic profile, and the population-based design helps to ensure the sample is representative of a wide range of individuals with IBD. The use of the same measurement tools utilized in a national health survey (CCHS) allowed for direct comparison of appropriate matched controls. The use of a representative population sample to establish the matched control group also adds to the confidence that the controls were reasonably representative of the population at large.

A potential limitation of the study is the reliance on self-report of disease activity. However, previous large-scale studies of IBD patients in the community have successfully used self-report disease activity measures²⁴. The nature of the measure used here, with symptom frequency anchors across time, has been validated in both community and clinic samples⁴⁴. The patient's experience of their disease across a time frame of six months was purposely chosen to provide a more naturalistic time frame. Other disease activity measures that assess disease in the last 24 hours or week do not characterize the patient's experience over an extended period and the impact of disease activity over time. While this study did not differentiate levels of severity in the active disease subgroup, future work will aim to determine if either severity gradation or subtypes of disease severity (e.g., mild chronic symptoms, intermittent severe symptoms, perineal fistulizing disease) are related to differences in psychological functioning and quality of life. Finally, the cross-sectional design does not allow for causal conclusions regarding relationships among disease activity and coping, distress, or health perception.

The “clinician’s illusion” is the discrepancy between what is observed directly in clinic with patients and the experience in the general population⁷³. The findings from this study are relevant for both clinicians and IBD patients, as they provide information on a broader spectrum of the IBD population than just those who present to clinic. The findings emphasize the importance of considering disease activity when assessing patients’ overall functioning and quality of life, and suggest the value of attending to psychological needs when disease has been active for some time. The results are also encouraging, in that they suggest that despite having a chronic disease, once the disease is inactive for a prolonged period, many with IBD manage well and hold a positive view of their health. The findings further raise the possibility of enhanced coping skills when the disease moves to remission.

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What we know

- Distress and quality of life can be worse for those with IBD
- There is mixed evidence regarding negative psychological effects of IBD during remission
- Population-based community control samples have not been used to date to provide a context for comparison of psychological functioning in IBD

What is new

- A community-based IBD sample is directly compared to a matched community-based non-IBD sample
- Disease activity is assessed for an extended period of six months to provide a more naturalistic time frame of disease experience and relationship with psychological functioning.
- Those with inactive disease are similar in important areas of functioning to those in the general community.
- There is preliminary evidence suggesting positive disease adaptation for those with extended inactive disease, with modestly higher levels of mastery (sense of life control) than the community controls
- Adaptive, active coping strategies are used to a similar degree by those with and without IBD, but when disease is active, those with IBD are more likely to use maladaptive, avoidant coping approaches.

- Psychological factors are strongly associated with perceived health in IBD, even when disease activity is controlled for.

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Table 1. Psychological functioning and health perceptions comparing non-IBD community controls to an IBD community sample

	Community Sample	Total IBD n=356	Crohn's Disease n=187	Ulcerative Colitis n=169	Active Disease n=244	Inactive Disease n=104
	Mean (SD)					
CCHS Cycle 1.1 Survey	n=1971					
Mastery	19.9 (3.8)	19.3* (4.4)	18.9* (4.7)	19.8 (4.0)	18.6** (4.5)	20.9* (3.6)
CCHS Cycle 1.2 Survey	n=728					
Psychological wellbeing	81.7 (14.2)	77.5** (16.5)	76.1** (16.3)	79.0 (16.8)	74.5** (16.9)	84.5 (13.5)
Distress	15.1 (5.3)	18.0** (5.8)	18.9** (6.1)	17.1** (5.4)	19.1** (6.1)	15.4 (4.4)
Stress coping						
Avoidant	11.2 (3.0)	12.5** (2.7)	12.6** (2.8)	12.5** (2.6)	12.8** (2.7)	11.8 (2.6)
Active	16.2 (2.3)	16.6** (2.2)	16.4 (2.2)	16.9** (2.1)	16.4 (2.2)	17.0 ** (2.1)
Self-soothing	6.7 (2.2)	6.7 (1.9)	7.0 (2.1)	6.4* (1.7)	6.9 (2.0)	6.5 (1.8)
% Poor perceived health	7.7%	23.6%*	27.7%*	19.0%*	30.3%*	7.7%

Note: Numbers in table are reported as means and standard deviations unless otherwise indicated; higher scores relate to more of that characteristic or condition; statistical comparisons are with community sample (CCHS- Canadian Community Health Survey) as the reference category.

** p ≤ .001; * p ≤ .02

Table 2: Frequency of use of specific stress coping strategies comparing the non-IBD community sample and the IBD community sample with active or inactive IBD

	Community Sample		Active IBD		Inactive IBD	
	Mean (SD)	% Often	Mean (SD)	% Often	Mean (SD)	% Often
Active						
Problem solving	3.76 (0.51)	80	3.75 (0.47)	76	3.78 (0.44)	79
Talk to others	3.31 (0.84)	52	3.38 (0.80)	56	3.35 (0.71)	48
Jog/exercise	2.20 (1.09)	14	2.43* (1.10)	21	2.80* (1.06)	31
Do something enjoyable	3.30 (0.78)	46	3.37 (0.64)	44	3.49* (0.58)	52
Look on bright side	3.60 (0.62)	65	3.48* (0.60)	53	3.58 (0.55)	61
Avoidant						
Avoid people	2.00 (0.93)	5	2.53* (0.90)	12	2.44* (0.81)	6
Sleep more	1.77 (0.89)	5	2.11* (1.00)	11	1.78 (0.85)	3
Eat more/less	1.99 (1.02)	10	2.23* (1.02)	12	2.09 (0.98)	8
Blame self	2.41 (0.96)	12	2.62* (0.88)	16	2.48 (0.78)	8
Wishing situation would go away	3.02 (0.96)	36	3.36* (0.83)	55	2.99 (0.89)	32
Self-soothing						
Smoke more	1.44 (1.31)	8	1.37 (0.89)	7	1.21* (0.60)	1
Drink alcohol	1.45 (0.75)	2	1.31* (0.62)	1	1.55 (0.65)	0
Use drugs, medication	1.16 (0.55)	2	1.33* (0.79)	5	1.12 (0.51)	2
Praying, spiritual help	2.33 (1.21)	25	2.16 (1.14)	17	2.30 (1.17)	22

Note: Coping strategies were rated for frequency of use “when dealing with stress” from 1=never to 4=often, and reported as means and standard deviations. Percentages are reported for those who indicate that they used a strategy often. Statistical comparisons of the mean frequency of use ratings are with the community sample (CCHS Canadian Community Health Survey) as the reference category.

* $p \leq 0.02$.

Table 3a: Correlations among psychological functioning and perceived health for IBD community sample

	Psychological wellbeing	Distress	Perceived health ¹	Coping: avoidant	Coping: active	Coping: self-soothing
Mastery	.53**	-.51**	-.41**	-.38**	.33**	.08
Psychological wellbeing		-.74**a	-.55**a	-.49**	.37**	-.21*
Distress			.51**a	.53**	-.28**	.23**
Perceived health ¹				.25**	-.34**a	.14

¹ higher score indicates poorer perceived health

** p ≤ .001; * p ≤ .02

^a significantly different than the parallel correlation in the non-IBD sample; p ≤ .02

Table 3b: Correlations among psychological functioning and perceived health for non-IBD community sample

	Psychological wellbeing	Distress	Perceived health ²	Coping: avoidant	Coping: active	Coping: self-soothing
Mastery ¹	n/a	n/a	-.30**	n/a	n/a	n/a
Psychological wellbeing		-.60**a	-.21**a	-.47**	.26**	-.27**
Distress			.21**a	.49**	-.16**	.26**
Perceived health ²				.13**	-.16* a	.09*

¹ mastery not utilized in CCHS cycle 1.2; correlations not available with all variables for this sample

² higher score indicates poorer perceived health

** p ≤ .001; * p ≤ .02

^a significantly different than the parallel correlation in the IBD sample; p ≤ .02

Table 4: Psychological factors contributing to perceived health for IBD and non-IBD community samples

	F	p	adjusted R ²	beta	p
<i>IBD submodel</i>	35.07	< 0.001	.33		
Psychological wellbeing				-.31	<0.001
Distress				.30	<0.001
Coping: avoidant				-.12	ns
Coping: active				-.16	<0.001
Coping: self-soothing				-.01	ns
<i>Non-IBD community submodel</i>	12.05	<0.001	.07		
Psychological wellbeing				-.16	<0.001
Distress				.11	0.02
Coping: avoidant				-.01	ns
Coping: active				-.09	0.02
Coping: self-soothing				.02	ns

Note: For perceived health, a higher value indicates poorer perceived health

Table 5: Psychological factors contributing to perceived health for the IBD sample, controlling for disease activity

	F	p	adjusted R ²	beta	p
<i>Step 1</i>	96.81	<0.001	.22		
Disease activity				-.47	<0.001
<i>Step 2</i>	40.25	<0.001	.41		
Disease activity				-.31	<0.001
Psychological wellbeing				-.23	<0.001
Distress				.24	<0.001
Coping: avoidant				-.07	.ns
Coping: active				-.15	<0.002
Coping: self-soothing				-.04	ns