A population-based controlled study of social support, self perceived stress, activity and work issues and access to health care in IBD

Linda Rogala[1,2], Norine Miller[1,2*], Lesley A Graff[1,3], Patricia Rawsthorne[1,2], Ian Clara[1,3], John R Walker[1,3], Lisa Lix[1,4] Jason P Ediger [1,3], Cory McPhail[1,3], and Charles N. Bernstein[1,2]

University of Manitoba IBD Clinical & Research Centre[1], Departments of Internal Medicine[2], Clinical Health Psychology[3], and Community Health Sciences[4], University of Manitoba, Winnipeg, Manitoba, Canada

*Linda Rogala and Norine Miller participated equally as first authors

Address correspondence to:

Charles N. Bernstein, MD

University of Manitoba

804F-715 McDermot Avenue

Winnipeg, Manitoba, Canada R3E 3P4

Telephone: 204 789 3369

FAX: 204 789 3972

E mail: cbernst@cc.umanitoba.ca

Abstract

Background: The Manitoba IBD Cohort Study is a longitudinal, population-based study of multiple determinants of health outcomes in persons with IBD diagnosed within 7 years at enrollment. In this cross-sectional sub-study we compared IBD participants' levels of social supports, self-perceived stress, disability, and access to health care with those of a matched community sample.

Methods: IBD participants (n=388) were interviewed using the Canadian Community Health Surveys (CCHS) 1.1 and 1.2 to assess for psychosocial variables. The national CCHS data were accessed to extract a community comparison group, matched on age, sex and geographic residence.

Results: Compared to the community sample, IBD participants received more tangible, affective, or emotional support in the past year and were more likely to have experienced a positive social interaction. Those with IBD were as likely to be employed as those in the community sample, although they reported greater rates of reduced activity and days missed. Work was not identified as a significant source of stress, but physical health was more likely to be identified as a main stressor by those with active IBD, compared to the non IBD sample. Individuals with IBD were twice as likely to report unmet health care needs than the community sample, however there was agreement across both groups regarding common barriers including long waits and availability.

Conclusions: While the disease may contribute to greater interference with work quality and daily activities, IBD patients have similar levels of stress and appear to have enhanced social supports relative to those in the community without IBD.

Introduction

IBD is a chronic illness that, when active, presents with symptoms including fatigue, diarrhea and abdominal pain. These often unpredictable symptoms can have a profound effect on the individual's quality of life (QOL) (1). Having the disease can be stressful in itself and potentially contribute to difficulty in coping with other demands as they arise, and conversely, psychological stress can affect disease course (2-5). A strong social support network in persons with chronic diseases can facilitate effective coping with stressors, improving physical and psychological health status, and improving overall health outcomes (6-9). Disease activity, perceived stress, and social support all influence an individual's sense of well being (10,11).

Typically, when IBD becomes acutely active, access to health care is important to initiate interventions that can settle the flare. Timely access to care continues to be a major concern of consumers in Canada's health care system (12, 13) as it is in the US and other developed countries (14). It is unclear whether those with IBD experience any particular difficulty with access, although over a third of Canadians and one quarter of Americans with chronic illnesses have reported having to wait more than 6 days to get an appointment to see their doctor when ill (15). An examination of patients' perceptions of their ability to access health care can provide an understanding of how this issue affects them. Access delays or other barriers may increase stress, and further affect self-perceived health and well being.

Work is another area of functioning that can be affected by IBD. Several studies have addressed work disability in IBD. A Norwegian study reported equal numbers of IBD patients on disability pensions compared to a community sample (16). However they noted that women with Crohn's disease had higher use of disability pensions. Sick leave for all causes was also higher in the Crohn's disease group. Not surprisingly there was a noted reduction in QOL with more IBD-related sick leave (16). Feagan et al reported lower employment and higher disability rates in Crohn's disease (17). Bernstein et al, found that persons with IBD at some point after being diagnosed were less likely to be working when compared to those in the general population (18). However, all of these studies generally considered employment impact dichotomously in terms of working or not working. There has been less attention to the quality of work for those with IBD who are employed, such as absenteeism or effectiveness. That is, do those with IBD have more days off from work and is their level of activity reduced in comparison to the general population?

Finally, while much is known about smoking habits of those with IBD, there is little information on alcohol consumption and whether alcohol use is similar or different for those with IBD compared to those who do not have IBD. Many patients have noted anecdotally that alcohol exacerbates their symptoms. The few studies that have assessed alcohol use in IBD have more typically looked at influence on relapse rates (19-21), but have not assessed level of use including excessive use in this population. We aimed to examine the differences between a community sample of persons with recently diagnosed IBD and a community sample without IBD, on several sociodemographic and psychosocial variables, utilizing the Canadian Community Health Surveys (CCHS) (22).

All were assessed regarding perceived stress, social supports, perceived barriers to care, activity restrictions, employment status, and alcohol use.

Methods

IBD Cohort Participants

The Manitoba IBD Cohort Study was initiated in 2002, drawing on subjects from the University of Manitoba IBD Research Registry. This population-based registry was established in 1995 and its creation is reported in detail elsewhere (23). In brief, residents of the province of Manitoba, Canada (population approximately 1 100 000), identified as having IBD through the administrative health database of Manitoba Health (the government agency that provides comprehensive health coverage to all residents), were eligible for inclusion in the registry. ICD 9 codes of 555 (Crohn's disease) and 556 (ulcerative colitis, UC) in the provincial administrative database were used to flag eligible individuals, who were subsequently invited to participate in the Registry. This methodology was repeated in 2000 to enhance the numbers in the Registry. Approximately half of the IBD population in Manitoba participates in the IBD Research Registry (23).

At the time the Cohort Study was established, there were 3192 individuals in the Research Registry. Individuals diagnosed within 7 years, that is, still relatively early in their diagnosis, and in their 18th year or older (n=606) were identified from the Registry and contacted by research staff. Approximately 13% of individuals could not be located, 6% had moved out of province, were deceased, or too young, and 14% declined to take part. Four hundred and eighteen agreed to participate. The University of Manitoba Health Research Ethics Board approved the Manitoba IBD Cohort Study.

Participants completed a mailed survey package, and were then seen for a face-to-face interview by project staff. Of the initial 418 individuals who had consented to participate in the study, a total of 30 subsequently did not proceed, including 19 who did not complete the survey and/or interview, 4 who withdrew, and 7 who were found to be ineligible, leaving 388 study participants. **All 388 responded to the measures that are included in this study.**

IBD participant diagnoses were verified and specific disease phenotype was identified through chart review, which was undertaken by study staff at physicians' offices. Disease activity was assessed by patient report of symptom persistence for the previous six months, using a 6-level response format. The measure was developed for the longitudinal Cohort project (1) to better characterize patients' experience of their disease activity for a broader time frame than the brief 24 hour or week snapshot that other activity measures provide. Participants were asked "In the past six months my disease has been (a) constantly active, giving me symptoms every day (b) often active, giving me symptoms most days (c) sometimes active, giving me symptoms on some days (for instance 1-2 days/week) (d) occasionally active, giving me symptoms 1-2 days/month (e) rarely active, giving me symptoms on a few days in the past six months and (f) I was well in the past 6 months, what I consider a remission or absence of symptoms." Active disease was defined as experiencing symptoms constantly to occasionally (responses a to d), and inactive disease was defined as experiencing infrequent symptoms or feeling well (responses e or f). Standardized clinical indices for disease activity, the Harvey Bradshaw Index for Crohn's disease (24) and Powell Tuck Index for UC (25) were

obtained during the clinical interview and were compared to self-reported disease activity.

Community Sample

A matched comparison group of individuals in the community was drawn from national data obtained through the CCHS cycles 1.1 and 1.2. The CCHS is a large Canadian health survey that provides population estimates of health determinants, health status, and health system utilization. There is extensive consultation by Statistics Canada to identify topics as well as measurement tools for the surveys. A rigorous methodology is applied that ensures standardized interviews, and randomized stratified sampling. The CCHS has a two-year collection cycle, with the second year of each cycle designed to focus in more depth on a particular area. Mental health was the focus for cycle 1.2. Data for these surveys are obtained by in person interviews. The large sample size (cycle 1.1: n=130,880; cycle 1.2: n=36,984, ages 15 years and older), excellent response rate of 85% and 77% respectively, (26) sampling approach, as well as the standardized in-person interview process make the surveys reliable sources of information about the health of Canadians.

Samples of Manitoba residents matched to the IBD cohort were chosen from both the CCHS cycle 1.1 and 1.2 data sets. Control subjects were selected from both cycles to obtain response information for all the measures of interest, as not all of the scales were included in both cycles. For both cycles, control subjects were selected if they resided in Manitoba. They were then excluded if they reported having IBD, if they were of Aboriginal (First Nations) descent, or if they were residents of Norman, Brentwood, or Churchill health regions of Manitoba. These northern regions are scarcely populated and

would have an over representation of Aboriginal (First Nation) peoples; notably IBD is

rare in this population. The control subjects were then matched according to gender and

age (collapsed into 5-year groupings) distributions in the IBD sample. For the CCHS

cycle 1.1, a 5-to-1 matching procedure was used (CCHS cycle 1.1, 5 individuals for every

1 IBD cohort individual from a total Manitoba sample size of 8,470), and for CCHS cycle

1.2, a 2-to-1 matching procedure was used (total Manitoba sample size of 2,230) due to

the smaller sample size of the CCHS 1.2. This resulted in a total sample of 1971

individuals from CCHS cycle 1.1, and a sample of 728 individuals from CCHS cycle 1.2.

Measures

The same questions used in the CCHS interviews were used with the IBD participants to

assess the following areas, allowing for direct comparisons of the IBD cohort responses

to the matched community sample.

Stress

Stress was measured in CCHS cycle 1.2, using questions derived and modified by

Statistics Canada from the General Health Module CCHS Cycle 1.2, Mental Health and

Well-being-Public Use Microdata File Documentation (27). Respondents were asked

questions regarding general stress levels and sources of stress. They rated the amount of

daily stress in their life, using a 5-level response scale from 'not at all stressful' to

'extremely stressful'. Similarly, those who were working were asked about their level of

work stress in the past 12 months. To determine work stress more specifically,

respondents were asked, thinking about your main job or business in the past 12 months,

would you say that most days at work were: 'not at all stressful' to 'extremely stressful?'

(28). Finally, participants were asked to identify their primary source of stress: "Thinking

about the stress in your day to day life, what would you say is the most important thing

contributing to feelings of stress you may have?"

Social support

Examination of social support was used to determine the level of coping resources

available. Assessment was based on the Social Support Measures (SSM) questionnaire.

These are questions that the CCHS 1.2 cycle utilized from the Medical Outcomes Study

social support survey (29). The scale used nineteen functional support items to assess six

support dimensions including: a) emotional support involving expression of positive

affect, b) empathic understanding, and encouragement of expressions of feelings; c)

informational support -the offering of advice, information, guidance or feedback; d)

tangible support -the provision of material aid or behavioral assistance; e) positive social

interaction-the availability of other persons to do fun things with, and f) affection,

involving expressions of love and affection. Each item was rated using a 5 level

response format for support available from 'none of the time' to 'all of the time', and the

IBD and community groups were compared on their percentage responses in each

category.

Health care access and barriers

Cycle 1.1 of the CCHS assessed concerns regarding access to care using questions that

had been previously developed for the Health Access Survey (30). Access was assessed

by the following: "During the past 12 months was there ever a time when you felt you

needed health care but you did not receive it?" If the response was yes, they were asked

to identify the barrier. Barriers to care were assessed by the question: "Thinking of the

most recent time, why didn't you get care?" with a list of several options, including 'the wait was too long', 'was too busy to receive care', 'not available when required.

Reduction in Activity/Disability

Cycle 1.1 of the CCHS assessed recent work history, restriction of activities, and two-week disability, the latter using questions initially derived from the General Social Survey Health Cycle 6, (28). Participants were asked whether they had worked at a job or business at any time in the past 12 months. Two week disability was measured based on 3 questions: in the last 14 days did you a) *stay in bed* for all or most of the day due to illness or injury; b) not counting any days spent in bed, were there any days that you *cut down* on things you normally do because of illness or injury; c) not counting days spent in bed or days where you cut down on normal activity were there any days when it took *extra effort* to perform up to your usual level at work or at your other daily activities. To determine current restrictions in daily activities caused by health problems, participants were asked whether a long term health condition (defined as one lasting longer than 6 months) reduced the amount or kind of activity in their usual daily activities, including (a) at home (b) at work (c) in transportation or leisure, (d) with meal preparation and so on. By asking about disability in the prior two weeks a brief picture of health interference was assessed. Conversely, inquiring about current limitations in daily activities caused by a long-term health condition provides further information on the level of impact on the range of daily activities.

Alcohol consumption

Alcohol use questions were assessed in the CCHS cycle 1.2; they were originally developed for the General Social Survey Health Cycle 6, 1991 (28). Questions assessed current and past alcohol consumption.

Statistical Methods

Univariate comparisons of total IBD, CD, UC, those with active disease and inactive disease against the matched community samples (cycle 1.1 and 1.2) were carried out for a variety of patient characteristics, using χ2 tests of association for categorical variables. All comparisons reported as significantly different were at $p \leq 0.01$.

Results

Participant Characteristics

The IBD sample ranged in age from 17 to 83 years. As can be seen in Table 1, the average age was around 40, and just over half were women. The sample was predominantly Caucasian, with small numbers having self-described backgrounds as East Indian, Hispanic, or European-Aboriginal (Métis). The community sample from the national survey was age and gender-matched. For the cycle 1.1 sample, over half (59%) were married or in a common-law relationship, with 28% single, and 13% widowed or divorced. Fifty-one percent had no post-secondary education. The cycle 1.2 sample had similar marital status and education level rates.

Chi square analyses were used to compare the IBD and community samples on these sociodemographics. In comparison to the cycle 1.1 sample, the IBD sample was more likely to have higher levels of education ($\chi^2(2) = 29.17$, $p < 0.01$) and more likely to be married ($\chi^2(2) = 9.16$, $p < 0.05$). In comparison to the cycle 1.2 sample, the IBD sample

showed no differences with respect to education ($\chi^2(2) = 0.67$, p $= 0.71$) but was more

likely to be married ($\chi^2(2) = 10.55$, p < 0.01).

With respect to chronic health issues, approximately half of those in the community

samples (CCHS 1.1 47.9%; CCHS 1.2 50.9%) reported having one of the following

chronic health concerns: arthritis, asthma, back problems, bronchitis, cancer, cataracts,

diabetes, epilepsy, fibromyalgia, glaucoma, heart disease, migraine, stroke, thyroid

problems. Nevertheless, there was a higher proportion of those in the IBD sample

reporting at least one of these other chronic conditions (excluding IBD or GI –related

diagnoses for all samples) compared to the community groups (CCHS 1.1 χ^2 (1) $= 19.92$,

$p < 0.01$; CCHS 1.2 χ^2 (1) $= 10.49$, $p < 0.01$).

Disease subtype for the IBD sample was confirmed through chart review with 187 found

to have Crohn's disease, and 169 to have ulcerative colitis (UC), the latter category

including UC and ulcerative proctitis. Fourteen participants were found to not have

definite IBD, and 18 were classified as having indeterminate colitis. Mean duration of

disease was 4.3 years (standard deviation 2.1 years). Respondents with Crohn's disease

were significantly younger and more likely to be single than those with UC.

Almost three-quarters of the CD patients and two-thirds of the UC patients, respectively,

experienced active disease over the previous six-month period, and less than one-quarter

of them had been recently hospitalized. Those with Crohn's disease who reported active

disease in the previous six months had a higher mean score on the Harvey Bradshaw

Index than those with inactive disease (6.84 vs3.62; t=5.76; p <.001), with a similar

pattern found for UC participants, using the Powell Tuck Index (6.72 vs 2.47; t=6.16; p <.001).

Stress

There was no significant difference in the level of daily stress or work stress between the IBD participants and the community sample, with about one-quarter of both groups reporting high stress in those areas. Interestingly, when only those with inactive disease were compared to the community sample, the inactive IBD subset experienced significantly less daily stress. Not surprisingly, the IBD participants with active disease were more likely than the non IBD sample to identify their own physical problem as a main stressor (16.2% vs 4.6%), however the subset with inactive disease did not (3.9%). All other sources of stress, including work and family stress, were comparable to the non-IBD community sample (Table 2).

Social supports

The IBD participants were less likely to report that they had someone who understands problems than the community sample 44.4% vs. 52.3% (p<0.01). Those with active disease felt particularly isolated in that regard compared to the community sample, with 25% reporting they rarely had someone who understood their problems, compared to 17% of the non IBD group. However, significantly more IBD participants, regardless of whether they had CD or UC, or active or inactive disease, reported receiving tangible, affective, and emotional support in the past year compared to the community sample, with a strikingly high number endorsing these types of support (Table 3). IBD participants were also more likely to have experienced positive social interactions.

Overall, the findings suggest that those with IBD have good social supports compared to those in the community without IBD.

Access and Barriers to health care

The IBD sample identified significantly more problems with unmet health care needs in the past year (Table 4). One-quarter of the IBD sample reported not receiving care when needed, in contrast to the community sample, where only 12% reported the same concern. The IBD sub-group with inactive disease had a similar rate of unmet needs as the community sample. For those who reported unmet health care needs in the previous year, both the community and the IBD sample identified a long wait for service as the most common barrier. Both groups also reported similar concerns about availability of needed care. However, the IBD participants had less concern than the community participants regarding adequacy of their care, with only 7-8% citing that as a barrier, compared to 21% of those in the community. **The IBD group** also seemed to be less motivated to pursue needed care, with almost a quarter of the sample reporting they didn't get around to it.

Reduction in Activity

With regard to impact on daily activity, three times the number of IBD participants reported having reduced activity (often or sometimes) at work and at home, compared to the non-IBD community sample.   Half of those with IBD reported significantly greater interference in other activities as well. Even those with inactive IBD reported significantly greater interference (reduction of activity) across several domains compared to the community sample. Considering recent disability, significantly more of the IBD

sample reported having been confined to bed, and requiring extra effort due to illness, in the previous two weeks than those in the community sample. However, those with IBD were just as likely to be employed, with almost all of the IBD and non IBD sample reporting some work experience in the previous year (81.3% vs 84.4%) (Table 5).

Alcohol Use

When examining alcohol consumption, recent excess alcohol use (that is, in the past 12 months) was similar for the IBD participants compared to the non-IBD community sample. However, when asked about their alcohol consumption at any time prior to that, a significantly higher percentage of the IBD participants reported having some previous period when they "regularly drank 12 drinks or more per week". Similarly, they reported greater alcohol consumption, as defined by "drank 5 drinks or more on one occasion, at least once a month" in some prior period, again prior to the past 12 months at almost double the rate of the community sample (Table 6).

Discussion

Overall, this population-based IBD sample had similar levels of general and work stress, and similar if not higher levels of social support compared to those without IBD in the general community. Work rates were comparable, however the IBD sample had greater interference in their daily functioning, reporting reduced activity and more short-term disability. In this study, it was found that the level of stress and the nature of what was stressful was very similar for the IBD and non-IBD samples alike. Certainly, those without a chronic disease like IBD are still affected by stress. Both the IBD and community participants shared common areas of concern, with work and family

identified as the main sources of stress. The finding that those with quiescent IBD reported lower levels of daily stress compared to the general community may even reflect a positive rebound effect of having some relief from the disease.

Many studies have reinforced the importance of social support on QOL and how an abundance or lack thereof affects physical health and emotional well being (31). There is mounting evidence that strong self-perceived social support has a positive effect on health status and serves as a buffer of psychological and physical stress for the emotional and physical well being of individuals (32-36). Studies have reported lower levels of coronary artery disease with high levels of social support (34). Similarly, Mookadam et al identified a relationship between a lack of social support with an increase in mortality and morbidity after acute myocardial infarction (36). Strating and colleagues, in their long-term study of arthritis patients, concluded "Social support may have a direct beneficial effect: patients who are supported feel more warmth and affection, and can better cope with the disease than patients who have less social support." (31 p. 736).

There is however a paucity of data regarding support levels for IBD patients, particularly comparing directly to the general community to understand what is normative.   Studies that have assessed those with IBD found that improved social support impacts favorably on psychological distress, improving health outcomes overall (37). While our study did not consider health outcomes per se, it was able to directly compare levels of support, and found that the IBD patients felt well supported in a number of ways by those around them, and to a greater extent than those in the community. It may be that despite the chronicity of the disease, given that the participants were in the relatively early stage of

the disease, they were relatively young, and the majority was in a stable relationship, they were able to facilitate the needed support because of their health condition. An advantage of our study is the access to population-based samples of both IBD participants as well non-IBD controls, minimizing the bias inherent in comparing IBD patients presenting to a tertiary referral centre. Hence, on balance, IBD participants have good social supports compared to a matched population based sample. It is therefore, less likely that adverse outcomes or pronounced psychological dysfunction (9) could be attributed to a lack of social support.

A Norwegian study found that IBD patients utilized more sick leave and had higher rates of unemployment than their general population (16). In this study we found that IBD participants were as likely to be working as the community sample. While work was identified as the major stressor by the IBD group, it was also the major source of stress for the community group. Not surprisingly, personal physical problems were more commonly reported as a source of stress for IBD patients compared to the community sample, but even still this was a source of stress in less than one quarter of patients. What was more striking was the sense those with IBD had that they were not 'keeping up' at home or work, and had to reduce their activities. While this was based on general perception, the two-week assessment of days missed and extra effort required provided further support for a tangible difference between those with IBD and the general community.

Little is known about alcohol use for those with a chronic inflammatory disease such as IBD, although smoking habits have had close attention because of the differential rates

and impact on UC and CD. While patients anecdotally report that alcohol can exacerbate the IBD, and some avoid it altogether, alcohol use, particularly in excess, can be a maladaptive coping mechanism for stress (38, 39) Over the prior year, excess alcohol consumption was similar and relatively low for both the IBD and non-IBD groups. However, the IBD sample had a significantly greater percentage that acknowledged regular excess drinking (regularly drank 12 drinks or more per week) at some point in the past. Furthermore, they also reported higher binge drinking (5 drinks or more on one occasion, at least once a month) at almost double the rate of the matched community sample, again at some point in the past.

This difference in previous drinking habits is unexpected. Although the information was not collected systematically, IBD participants generally identified to the interviewers a time in their late teens and early adult years when this type of drinking occurred. It is possible that the IBD sample was more willing to share information about their past alcohol use due to the comprehensive nature of the Manitoba IBD Cohort Study, relative to the CCHS study. Another possibility is that excess alcohol consumption may have occurred during a period of greater stress or disease activity for the chronic disease sample (40-42), however we are not able to assess that relationship with the available data. Nevertheless, excess alcohol use was comparable in the recent past, during a period in which both the IBD and community samples also had comparable stress levels and social supports.

IBD respondents reported higher rates of unmet health care needs compared to community controls, with the most common problem being timely access. Most reports

on "access to care" focus on minority groups such as the mentally ill, youth, women, seniors and low-income families (40- check which ref this is). Ours is among the first to assess the access to care for a representative community-based patient group (IBD) and compare it to a general community group. The Canadian health system is based on a model of universal care and access, and as such these findings regarding IBD patients may not apply as readily to some other health care systems. Recent comparative studies of American and Canadian systems, for example, reported that Canadians overall have fewer unmet health care needs, with the primary barrier to access being reported differentially as wait time (Canadians) and cost (Americans) (43, 44). Nevertheless, in the context of a universal access system, it is disconcerting that a large proportion (1/4) of those with a diagnosed chronic disease did not feel they were getting the care they needed when they needed it.

For those who reported they didn't receive health care when needed, regardless of whether they had IBD or not, there were similar perceptions of barriers, including availability and long waits. There was a clear difference, though, regarding adequacy or quality of care, with a greater number in the community expressing concern that the care would be inadequate. This difference may reflect the likelihood that those with a diagnosed chronic illness already have linked with a specialist or knowledgeable family physician to help manage the disease. Furthermore, since IBD patients do access health care more than the general public their views may be more based on their realities while the views of healthy community controls may be more based on their perceptions.

In conclusion, the findings suggest that despite the impact of the physical aspects of the disease on daily activities, those with IBD can manage reasonably well along several psychosocial dimensions, even when the disease is in an active phase. This study is assessing a broader spectrum of IBD participants than those usually seen through clinical samples, as they were drawn from a population-based registry. As the IBD participants in this study were recently diagnosed with their IBD (within 7 years) it will be important to determine if they continue to manage well along social dimensions, the longer they have been living with IBD, and to assess what changes occur if their disease worsens.

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Table 1: IBD and Community Participant Characteristics

	Crohn's Disease n = 187	Ulcerative Colitis n = 169	Community Cycle 1.1 n=1971	Community Cycle 1.2 n=728
Mean age in years (SD)	38.5 (14.6)	43.0 (14.7)	40.0 (16.1)	40.0 (14.5)
% Female	61	58	59	59
Marital Status (%)				
Married or common-law	64	71	59	57
Single, never married	28	17	28	29
Separated, divorced, widowed	8	12	13	14
Education (%)				
No postsecondary	43	35	51	41
Trade school, diploma	32	34	33	39
University	25	31	16	20
Work Status (%)				
Working full or part time	68	63	n/a[a]	n/a[a]
Home or student	23	21		
Retired	5	10		
Disabled	3	7		
Ethnic Background(%)				
Caucasian	93	88	n/a[a]	n/a[a]
Chronic health condition (% with 1 or more nonGI)	**63.8[b]**	**59.1[b]**	**47.9[c]**	**50.9[c]**
Active disease 6 months (%)	74	66		
			not applicable	not applicable
Ever hospitalized for IBD (%)	61	33	not applicable	not applicable
Hospitalized in past year?	17	11		

[a] n/a = not available in comparable categories for direct comparison [b] most common other health conditions for IBD sample: arthritis, back problems, migraine, asthma, thyroid
[c] most common health conditions community sample: back problems, arthritis, migraine, asthma, thyroid

Table 2. Levels and sources of stress comparing community and IBD

	Community CCHS 1.2 n=728	Total IBD n=356	CD n=187	UC n=169	Active n=244	Inactive n=104
Self Perceived Daily Stress						
Not at all/not very	29.5	32.3	29.9	38.1	27.6	**44.0***
A Bit	47.3	44.5	43.5	44.0	45.9	**41.4***
Quite a bit/ extremely	23.2	23.2	26.6	17.9	26.5	**14.7***
Self Perceived Work Stress						
Not at all/not very	27.6	25.2	26.5	28.8	22.8	32.0
A bit	42.8	43.3	41.9	44.7	43.3	43.0
Quite a bit/Extremely	29.6	31.2	31.6	26.5	34.0	25.0
Ability to handle demands						
Excellent/very good	71.8	64.6	62.5	70.2	**61.6***	70.7
Good	23.2	30.3	29.3	27.4	**31.7***	27.6
Fair/Poor	5.0	5.1	8.2	2.4	**6.7***	1.7
Sources of Stress						
Time pressures	16.3	**9.8***	**11.2***	**9.9***	**6.5***	18.4
Own physical problem	4.6	**16.2***	**17.6***	**17.2***	**21.5***	3.9
Nothing	10.5	**5.9***	**5.9***	7.3	**3.6***	10.7
Work sources	44.5	41.5	40.6	37.7	42.1	40.8
Family sources	24.1	26.6	24.7	27.8	26.3	26.2

Numbers in table are reported as %; statistical comparisons are with CCHS sample.
* p < .01

Table 3: Social support comparing community and IBD

	Community CCHS 1.2 n=728	Total IBD n=356	CD n=187	UC n=169	Active n=244	Inactive n=104
Social Support						
Someone who gives information/ helps you to understand situation						
None or little of time	16.3	18.4	18.0	17.9	19.5	15.5
Some or most of the time	31.4	37.2	33.3	40.5	35.2	39.7
All of the time	52.3	**44.4***	48.6	41.7	45.3	44.8
Someone who prepares meals						
None, little or some of the time	21.4	15.5	13.6	16.1	16.4	12.1
Most of the time	20.9	23.7	25.0	24.4	24.3	21.6
All of the time	57.7	60.8	61.4	59.5	59.3	66.4
Someone who understands your problems						
None, little or some of the time	17.5	**23.5***	24.6	22.6	**25.7***	18.3
Most of the time	29.8	**34.4***	33.9	33.3	**33.2***	37.4
All of the time	52.7	**42.1****	41.5	44.0	**41.0***	44.3
Received tangible support in the last year	28.9	**51.5***	**58.2***	**45.2***	**57.1***	39.1
Received affective support in last year	93.8	**99.5***	**100.0***	**98.8***	**100.0***	**98.3***
Received positive social interaction in last year	94.3	**99.5***	**99.5***	**99.4***	**99.6***	99.1
Received emotional support last year	92.6	**99.0***	**100.0***	**98.2***	**98.9***	**99.1***

Numbers in table are reported as %; statistical comparisons are with CCHS sample.
*Significant to p value < .01

Table 4. Access to health care and reported barriers comparing community and IBD

	Community CCHS 1.1 n=1971	Total IBD n=356	CD n=187	UC n=169	Active n=244	Inactive n=104
Unmet health care needs	12.8	**25.0***	**25.7***	**25.0***	**31.1***	13.8
Barriers to health care needs**						
Not available when required	19.0	12.7	14.9	**7.1***	13.7	0.0
Wait too long	35.6	31.4	25.5	40.0	31.5	35.7
Felt that care would be inadequate	21.3	**7.8***	8.5	7.1	**8.2***	7.1
Too busy to receive care	10.7	12.7	14.9	11.9	13.7	14.3
Didn't get around to it	11.1	**25.5***	19.1	**28.6***	**23.3***	28.6

Numbers in table are reported as %; statistical comparisons are with CCHS sample.
* p < .01 ; **reflect subset of those who reported unmet health care needs

Table 5: Two week disability and reduction in activity comparing community and IBD

	Community n=1971	Total IBD n=356	CD n=187	UC n=169	Active n=244	Inactive n=104
Two week Disability						
Stay in bed because of illness or injury	7.6	**17.8***	**20.7***	12.5	**22.8***	6.0
Reduced activity due to illness or injury	12.8	**39.1***	**44.8***	**30.5***	**46.6***	**23.3***
Took extra effort due to illness/ or injury	13.2	**45.6***	**51.2***	**40.0***	**54.7***	**26.1***
Reduced Activity						
… at home (often/ sometimes)	15.4	**44.2***	**47.0***	**36.9***	**48.3***	**34.5***
… at work (often/ sometimes)	10.4	**34.7***	**33.6***	**29.6***	**38.6***	**24.2***
… in other activities (often/sometimes)	13.3	**51.8***	**56.3***	**44.6***	**57.7***	**38.8***
Worked at a job last year	84.4	81.3	84.2	77.7	80.1	85.2

Numbers in table are reported as %; statistical comparisons are with CCHS sample.
* p < .01

Table 6 Excess alcohol use comparing community and IBD

	Community CCHS 1.2 n=728	Total IBD n=356
During the past 12 months, regularly drank > 12 drinks/week?	8.1	7.9
In the past 12 months, had 5 drinks or more on one occasion, at least once a month?	26.4	25.7
Prior to the past 12 months, ever regularly drank>12 drinks/week?	14.9	**26.0 ***
Prior to the past 12 months, ever a 12-month period when, at least once a month, had 5 drinks or more on one occasion?	27.6	**55.4 ***

Numbers in table are reported as %; statistical comparisons are with CCHS sample.
* p < 0.01