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Manuscripts

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3 The Manitoba IBD Cohort Study: A prospective longitudinal evaluation of the use of
4 complementary and alternative medicine services and products
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6
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20 of the manuscript for important intellectual content; statistical analysis
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23 revision of the manuscript for important intellectual content; statistical analysis
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32 revision of the manuscript for important intellectual content; statistical analysis; study
33 supervision
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36 important intellectual content
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39 intellectual content; technical, or material support
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42 intellectual content; technical, or material support
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45 interpretation of data; critical revision of the manuscript for important intellectual
46 content; statistical analysis; obtained funding; technical, or material support; study
47 supervision
48

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Abstract

Background: We aimed to determine the prevalence of complementary and alternative medicine (CAM) use over time in a population-based cohort of IBD patients.

Methods: The Manitoba IBD Cohort Study is a longitudinal, population-based study of multiple determinants of health outcomes in persons with IBD. Participants completed semi-annual surveys, and annual in-person interviews. Inquiries about use of 12 types of CAM service providers and 13 CAM products, based on items from a national survey, were included at month 0, 12, 30 and 54.

Results: Overall, 74% of respondents used a CAM service or product in the 4.5 year period, with approximately 40% using some type of CAM at each time point, and 14% using CAM consistently at every time point. There was a trend for females to use CAM more than males; there was no difference in CAM use between Crohn's disease and UC groups. The most often used CAM services (on average) were massage therapy (29.8%) and chiropractic (13.6%), physiotherapy (3.7%), acupuncture (3.5%) and Naturopath /Homeopath (3.5%). There was a wide range of CAM products used, with Lactobacillus/acidophilus (7.6%), fish and other oils (5.5%), glucosamine (3.7%) and chamomile (3.5%) as the most common. On average only 18% of consumers used CAM for their IBD, so the majority chose it for other issues. There were no differences between CAM users and non-users on psychological variables. **Conclusions:** Those with IBD commonly try CAM, although very few use these approaches regularly over years. CAM is not usually used by IBD patients for disease management, but clinicians should be aware that many will trial the services and products.

Keywords: Complementary and alternative medicine, cohort study, inflammatory bowel
disease

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3 Summary box
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6 What is already known about this subject
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8 1. Complementary and alternative medicine use is common and its use has also been
9 reported as common in patients with inflammatory bowel disease
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15 What are the new findings
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17 1. This was a prospective longitudinal study of a population based cohort of persons with
18 IBD where CAM use could be tracked across 54 months and was measured at four
19 distinct points in time
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22 2. Overall, 74% of respondents used a CAM service or product in the 4.5 year period,
23 with approximately 40% using some type of CAM at each time point, and 14% using
24 CAM consistently at every time point.
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27 3. There was a trend for females to use CAM more than males; there was no difference in
28 CAM use between Crohn's disease and UC. There were no differences between CAM
29 users and non-users on psychological variables.
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32 4. The most often used CAM services (on average) were massage therapy (30%) and
33 chiropractic (14%), physiotherapy (4%), acupuncture (4%) and Naturopath /Homeopath
34 (4%). There was a wide range of CAM products used, with Lactobacillus/acidophilus
35 (8%), fish and other oils (6%), glucosamine (4%) and chamomile (4%) as the most
36 common.
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39 5. On average only 18% of consumers used CAM for their IBD, so the majority chose it
40 for other issues.
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3 How might it impact on clinical practice in the foreseeable future?
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6 1. Clinicians should be aware that while patients with IBD are not usually using CAM for
7
8 disease management, CAM is commonly tried among this group. Hence, clinicians
9
10 should be familiar with the many services and products available and be open to
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12 discussing their use.
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Introduction

Complementary and alternative medicine (CAM) has been reportedly used by 40 to 50% of patients with inflammatory bowel disease (IBD) (1-6). All of the studies to date have been cross sectional, and hence it is unknown whether the single sampling reflects more regular long-term use. It is worth further exploring CAM use in IBD since physicians have little knowledge of how these agents may interact with conventional therapies. There has been some attention to reasons for choosing CAM, including dissatisfaction with conventional medication or practitioners (5, 7, 8), however it has not been established in previous research whether IBD patients are using the CAM products and services specifically for IBD or for other health concerns.

In this longitudinal study, we aimed to establish the prevalence of CAM use over time, considering both services and products. Participants in the Manitoba IBD Cohort Study, a population-based sample of individuals with Crohn's disease (CD) and ulcerative colitis (UC) early in the disease course, were surveyed at four different time points over a 54 month period. The types of CAM used, the persistence of use, the degree to which CAM was used specifically for IBD related symptoms, and personal variables associated with greater CAM use were all examined.

Methods

Participants

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3 The Manitoba IBD Cohort Study was initiated in 2002, with participating individuals in
4 their 18th year or older and diagnosed with IBD within the previous 7 years (mean of 4
5 years). Participants are surveyed every 6 months and interviewed annually. They were
6 recruited from a validated population-based research registry that has been previously
7 described (9). The Registry identifies and recruits participants based on an administrative
8 definition of IBD from the comprehensive health data base of Manitoba Health, the single
9 insurer that provides health care to all residents in the province. Of all those with IBD in
10 the province, just over half participated in the Registry. The Manitoba IBD Cohort Study
11 was approved by the University of Manitoba Health Research Ethics Board and
12 participants provided written informed consent.
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29 At the time of the Cohort study recruitment, there were 3192 participants in the Research
30 Registry, of which 606 were eligible for this study, given the age and recent disease onset
31 criteria. Approximately 17% could not be reached and 14% directly declined to take part.
32 Complete data were obtained in the first contact from 388 of those enrolled, and they
33 have subsequently served as the Cohort, described elsewhere in detail (10). To assess
34 representativeness, cohort participants were compared to all other IBD cases diagnosed in
35 the same time period, using a comprehensive validated data set which includes all those
36 in the province with IBD (the University of Manitoba IBD Epidemiology Database).
37 There were no significant differences on standard demographic comparisons including
38 mean age, age distribution, sex, urban vs rural residence, and mean duration of disease,
39 suggesting excellent representativeness (11).
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3 Participants were surveyed at four time points; baseline (Month 0), and Months 12, 30,
4 and 54. CAM use, disease activity, quality of life, perceived stress, and general distress
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6 were measured in all four periods. Other factors were measured 1-2 times in the period
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8 to reduce participant burden. Demographics and personality factors were assessed at
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10 Month 0. Lifetime history of psychiatric diagnoses was assessed at Month 24. Two
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12 additional measures of psychological functioning, mastery and health anxiety were
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14 assessed at Months 0 and 12, and medication adherence and beliefs were assessed as
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20 Month 12.

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24 For this substudy on CAM, 330 of the 388 initial enrollees completed data collection at
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26 all 4 survey points of Months 0, 12, 30 and 54. Of those 330 participants, 309 provided
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28 data on CAM use at all four time points, so they served as the final sample. At Month 0,
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30 participants completed demographic questions regarding marital status, income,
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32 education, surgery prior to enrolment and duration of disease diagnosis.
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38 *Assessment of CAM use:* Questions regarding use of CAM were drawn from a national
39
40 health survey, the Canadian Community Health Survey (12). Following a series of
41
42 questions concerning the use of conventional health service providers (e.g., physicians,
43
44 dentists), participants completed questions about their use of specific alternative medicine
45
46 services based on the list from the national study, and were also asked whether the use of
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48 each was specifically in relation to the IBD or for other reasons. The following
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50 questions assessed CAM use: “People may also use alternative or complementary
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3 emotional or mental health?”. Twelve categories of CAM service providers were listed
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5 and included: massage therapist, acupuncturist, homeopath or naturopath, Feldenkrais or
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8 Alexander teacher, relaxation therapist, biofeedback teacher, Rolfer, herbalist,
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10 reflexologist, spiritual healer, religious healer, and other. Physiotherapists and
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12 chiropractors were some of the more commonly identified providers in the ‘other’
13
14 category. Following a detailed inquiry about conventional prescription and non-
15
16 prescription medication use, participants were also asked about their use of “other health
17
18 products such as herbs, minerals or homeopathic products in the past 12 months”, and
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20 provided with a list of 13 categories of CAM products. These included St. John’s
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22 Wort/millepertuis, valerian, chamomile, ginseng, Kava Kava/Kava root/ piper
23
24 methysticum, lavender, chasteberry/chaste tree berries/vitex agnus-castus, black vohash,
25
26 ginkgo biloba, New Recover-DA, lactobacillus acidophilus, vitamins, and other, where
27
28 additional products could be listed (e.g., herbal tea, fish and other oils, echinacea,
29
30 glucosamine).
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39 *Disease activity.* The *Manitoba Inflammatory Bowel Disease Index* (MIBDI)
40
41 characterizes symptomatic disease activity over the prior six months, based on 6 levels of
42
43 symptom frequency in that time period. It has been validated with other clinical indices
44
45 for CD and UC (13). Participant responses are classified as ‘active disease’ if any of
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47 levels 1-4 were endorsed (e.g. daily to occasional symptoms over six months) and as
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49 ‘inactive disease’ if levels 5-6 were endorsed (e.g., symptoms rare or was completely
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51 well).
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Quality of life. The *Inflammatory Bowel Disease Questionnaire* (IBDQ) is the most widely-used health-related quality of life measure in adult patients with UC and CD. It is a valid and reliable tool, and correlates highly with disease activity (14). The questionnaire consists of 32 questions scored in four domains: bowel symptoms, emotional health, systemic systems, and social function.

Psychological variables. Personality characteristics were assessed using the *NEO Five-Factor Inventory* (NEO-FFI) (15). The NEO-FFI is a well-validated 60-item scale designed to give quick and reliable measures of the five major domains of adult personality. The domains include Neuroticism, Extraversion, Openness to Experience, Agreeableness, and Conscientiousness.

Validated and standardized measures were used to assess psychological functioning related to stress, health anxiety, mastery and general distress. The *Cohen Perceived Stress Scale* (CPSS) is a 14-item scale used to examine the role of stress in disease, assessing the individual's perception of their stress level rather than particular stressful events (16). Higher scores correspond to higher levels of perceived stress. The *Health Anxiety Questionnaire* (HAQ) identifies individuals with high levels of concern about their health (17). The scale evaluates worry and health preoccupation, fear of illness and death, reassurance-seeking behaviour, and symptom interference. A total score is typically reported, with higher scores reflecting higher health anxiety. The 7-item *Mastery Scale* (18) assesses an individual's sense of their ability to effect change in their life. This scale has been used in health-related studies and has reasonable internal

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3 reliability and good construct validity (18, 19). *General distress* was measured using the
4
5 K-10, a ten-item scale evaluating level of emotional distress used widely in
6
7 epidemiological studies (20).
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12 Psychiatric diagnoses were determined through a semi-structured clinical interview, the
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14 *Comprehensive International Diagnostic Interview* (CIDI), which identified lifetime
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16 prevalence of anxiety, mood disorders and phobias (21, 22).
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22 Self-description of usual medication adherence was assessed with a validated self-report
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24 measure, the *Medication Adherence Report Scale* (MARS; 23, 25), while the *Beliefs*
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26 *About Medication Questionnaire* (BMQ, 24, 25) was used to assess beliefs. The BMQ is
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28 a 17-item standardized scale with four subscales assessing specific concerns about the
29
30 medication the person is taking for their disease (Concerns subscale) and beliefs about
31
32 the importance of that medication to the person's health (Necessity subscale). It also
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34 assesses beliefs in general about the potential of medication to produce harm (Harm
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36 subscale) and overuse of medications (Overuse subscale). Psychometric data suggest that
37
38 this measure is both reliable and valid in a variety of medical populations including those
39
40 being treated for asthma, diabetes, cardiac problems, and psychiatric disorders (32).
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48 Use of prescription medications was assessed for the 6 months prior to each evaluated
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50 period, including non-prescription medications such as aspirin, acetaminophen, vitamins
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52 and over-the-counter medications, herbal remedies, or dietary supplements.
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Statistical analysis

In the first set of analyses, respondents were classified as CAM users and CAM non-users. The CAM user group included those respondents who reported using any CAM service or product across any of the four assessment points; the CAM non-user group were those who did not use any CAM service or product across any of the four assessment points. Cross-tabulations and chi-square statistics were used to compare group differences for categorical variables. The second set of analyses examined the associations of being a CAM user or non-user with psychological, quality of life, and select demographic variables, at each assessment point individually. To categorize respondents into either a current CAM user or non-user at each respective assessment point, their response on the use of CAM services or products at that assessment point was used. For this analysis, independent-group t-tests comparing current CAM users and nonusers were utilized to assess mean differences of CAM use groups with the continuous psychological and medication adherence at each assessment point. Note that not every psychological measure was administered at each assessment point.

In the final set of analyses, respondents were classified at baseline and again at the end of this study (Month 54) according to their current CAM use at that point (i.e., CAM user / non-user), with a further breakdown of use into one of four mutually exclusive categories: (a) did not use any CAM service or product, (b) used a CAM service only (c) used a CAM product only, and (d) used both CAM services and products. A series of bivariate logistic and multinomial logistic regressions were used to assess the association of type of CAM usage with background (sex, age, education level, disease activity,

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3 history of surgery), psychological (distress, personality, quality of life, and perceived
4 stress), and medication (prednisone, remicade, immunosuppressants, 5-ASA) variables.
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8 Separate regression models were run for each of the two assessment points.
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10 11 12 13 **Results**

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15 In this sample, 59% were female, and the mean age was 40.1 years (range 17-83 yrs).
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17 The majority of participants were Caucasian (89%), 66% were working full or part-time,
18 and 68% were married or living common law. Disease type was verified through chart
19 review, and 52% had Crohn's disease.
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24 25 26 27 *Overall Characteristics of CAM Users and Non-Users*

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29 Overall, 74% (n=229) reported using any type of CAM product or service at some point
30 across the four assessment periods; 26% (n=80) reported not using any CAM services or
31 products, and 14% were persistent users across all 4 time points. Table 1 provides
32 demographic information on CAM users and non-users. Comparing the two groups, the
33 non-users were somewhat older at diagnosis, with 25.3% vs 14.5% being over 50 years of
34 age respectively. There were no significant differences in background characteristics or
35 baseline clinical variables between the two groups, including disease type, prior
36 hospitalization, or disease activity. Women were significantly more likely to use CAM
37 services or products than men at a ratio of 2:1 at almost all the assessment periods
38 (Month 12 (χ^2 (1) = 4.9, $p < 0.05$), 30 (χ^2 (1) = 12.6, $p < 0.01$), and 54 (χ^2 (1) = 7.3, $p <$
39 0.01).
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3 A separate analysis compared the CAM users and non-users for the presence of a lifetime
4 psychiatric diagnosis for the following disorders: specific phobia, social anxiety disorder,
5 agoraphobia, generalized anxiety disorder and major depression. The only significant
6 association between use of CAM and the presence of a lifetime disorder was for lifetime
7 major depression ($\chi^2 (1) = 5.4, p < 0.05$), with 32% of CAM users meeting criteria for
8 major depression (versus 18% of CAM non-users).
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20 *CAM service and product use*

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22 Table 2 provides an examination of CAM usage across the four assessment points. At
23 any one time there were at least 40% of the IBD cohort using some form of CAM
24 services or products, with similar proportions of UC and CD participants using CAM at
25 each time point. Respondents were significantly more likely to use CAM services than
26 CAM products at each of the four assessment points (Month 0: $\chi^2 (1) = 12.9, p < 0.01$;
27 Month 12: $\chi^2 (1) = 10.8, p < 0.01$; Month 30: $\chi^2 (1) = 4.4, p < 0.05$; Month 54: $\chi^2 (1) =$
28 12.5, $p < 0.01$). There were no significant differences between CD and UC groups on
29 CAM usage across the four assessment points.
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43 Table 3 describes the most commonly used CAM services and products. The most
44 frequently used CAM services across the four survey periods were: massage therapy
45 (30%), chiropractor (14%), and physiotherapy (4%). While none of the CAM products
46 were used commonly overall, the most frequently used products in this sample were
47 Lactobacillus/acidophilus (8%), fish and other oils (6%), and glucosamine (4%).
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3 Those who identified any use of CAM services or products (n=229) were asked to
4 indicate whether CAM was used specifically for IBD or for other reasons. Across the
5
6 four assessment points the prevalence of CAM usage (either services or products) for
7
8 IBD ranged from 14 to 21%. Considering the small subset which just used CAM services
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10 (and no CAM products) at any point in the 4.5 years (average n= 19), the average
11
12 prevalence of use for IBD was 20% (range from 15 to 24%); for the subset which just
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14 used CAM products (and no CAM services) (average n= 24) the average prevalence of
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16 use for IBD was 46% (range from 41-52%).
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24 *Mean Comparisons on Psychological and Quality of Life Variables*

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26 Table 4 presents mean comparisons of psychosocial variables and medication adherence
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28 and beliefs for current CAM users and current CAM nonusers, with current users and
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30 nonusers defined as those using any CAM product or service at each assessment point.
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32 For example, participants were categorized as current CAM users or non-users
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34 specifically at month 12 and then compared on variables collected at month 12. These
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36 more time-specific categorizations as a current CAM user or nonuser were used to help
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38 determine more immediate temporal relations since CAM use was variable across time
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40 for participants.
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48 Considering CAM use across the four assessment points, there were almost no significant
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50 differences across the psychological and quality of life variables between CAM users
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52 and non-users. The only exception to this was a slightly lower level of concern about
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3 overuse of medications among those with no CAM use at Month 12 ($p < 0.03$), although
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5 this finding should be interpreted with caution given the multiple comparisons.
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8 9 10 *Predicting CAM Usage Type at baseline and Month 54*

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12 The final set of analyses involved both logistic and multinomial logistic regression
13
14 models to determine the predictive associations of any of the sociodemographic and
15
16 psychological variables with CAM usage. The first set of models, utilizing logistic
17
18 regression, had Month 54 current CAM user / non-user as the outcome variable. For
19
20 predicting Month 54 current CAM users and non-users, all Month 0 sociodemographics
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22 and medication variables were used as predictors. As well medication information and
23
24 disease activity information from the Month 54 assessment was included. In this model,
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26 CAM usage at Month 54 was significantly associated with being a CAM User at Month 0
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28 (OR: 2.6, 95% CI: 1.4-5.1), as was being employed full time (vs not working, OR: 2.6,
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30 1.2-6.1) or being a student (vs not working, OR: 6.0, 1.5-23.7).
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39 A final model examined was a multinomial logistic regression with CAM usage at Month
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41 54, considering four levels of use (current CAM non-user, used CAM services only, used
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43 CAM products only, used both CAM services and products) as the outcome variable.
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45 Baseline sociodemographic and clinical variables as well as the Medications Beliefs
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47 Overuse subscale were included as predictors (the latter as it was the only significant
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49 psychological variable in univariate comparisons between current CAM users and non-
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51 users (see Table 4). The following predictors were significant for the following
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53 comparisons with 'current CAM non-user' as the reference group: Both CAM services
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3 and products: CAM user at Month 0 (OR 9.1, 2.9-28.3), being female (4.2, 1.3-13.9),
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5 being a student (13.1, 1.6-108.7); CAM services only: active disease at Month 0 (2.5,
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7 1.0-6.0); CAM products only: no variables emerged as significant.
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10 11 12 **Discussion**

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14 While CAM use in IBD has been previously studied in our centre and in several other
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16 centres worldwide there are a number of unique aspects to this study that help to frame an
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18 understanding of the type of person with IBD most likely to use CAM. The current study
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20 is population based and encompasses a homogeneous group of IBD patients, in that they
21
22 have all been diagnosed within 7 years at study entry. They were not specifically
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24 recruited through presentation at a referral clinic, reflecting more of a community IBD
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26 sample. A major advantage of this study is the longitudinal tracking of CAM use over
27
28 time, providing insight into the variability or stability of CAM use. Few studies have
29
30 done this in general, and none with an IBD sample. This is of particular interest in the
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32 area of CAM, since some types of CAM may be considered fads and clinicians may have
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34 concerns when patients either mix conventional and CAM therapy or exclusively choose
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36 CAM (26, 27). Finally, this study included a comprehensive assessment of predictors of
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38 CAM use including background, clinical and psychological variables.
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48 As part of an international (Winnipeg, Los Angeles, Cork, Stockholm) assessment of
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50 CAM use in IBD, prior work by our group found that on average 51% used some form of
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52 CAM. (1). Those more likely to use CAM tended to be single, have a higher income and
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54 live in urban areas. A subsequent study considering CAM use and use of conventional
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3 health care resources (28) found that CAM use was not predicted by either greater or less
4 hospitalizations, physician visits, or gastroenterology-specific physician visits. CAM use
5 was described as primarily to palliate pain (64%) or diarrhea (60%). However, in that
6 study more general health behaviors such as exercise, diet and prayer were included
7 among the types of CAM, and accounted for the greatest CAM use. There has been some
8 question whether those types of self-care are appropriate to include in CAM definitions
9 (29). In the current study, we used a more focussed CAM definition, based on the range
10 of CAM services and products investigated by the Canadian Community Health Survey
11 requiring that one obtain particular services or products, rather than just engage in
12 different behaviors (12). Using this more specific definition of CAM, we found that most
13 individuals were using CAM for non-IBD related reasons. This may be particularly
14 relevant in clinical practice, as the IBD patient may not think to discuss CAM products
15 they are using with their family physician or gastroenterologist since they are not
16 typically taking them for the IBD, even though they may have an effect on their disease.

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39 Using a different study methodology, another Canadian research group undertook a
40 postal survey of 2847 IBD patient members of the Crohn's and Colitis Foundation of
41 Canada (2). Current or past use of CAM was reported by 47%, of whom 50% continued
42 their use of CAM (23% of overall respondents had persistent CAM use). CAM Services
43 were used by 34%, while the most common CAM products used were herbal therapies
44 (41%). There was a much larger proportion reporting use of CAM products in this
45 community survey than for the current study. It is possible that the differences in
46 findings reflect differences in recruitment between these surveys. The postal survey
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3 focused primarily on CAM use, which may have drawn those who with an interest in or
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5 experience with CAM. In our cohort study, CAM use was embedded in a broader
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7 measurement of a range of experiences with IBD.
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11 Similar to previous findings, in our study the majority of those with IBD try CAM (74%)
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13 at some time, but very few, only 14%, were found to use the products and/or services
14
15 consistently over several years. In considering personal and disease characteristics that
16
17 might be associated with CAM use, women were more likely to use CAM, as sex
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19 differences were found at 3 of 4 assessment points. Three other Canadian studies have
20
21 reported that CAM use is greater among those with higher education and higher incomes,
22
23 both for those with and without IBD (31-33). Being female (8, 34, 35), higher education
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25 (30, 31-37), higher income (34-36) and being employed (36) have also correlated with
26
27 CAM use in the US (31, 35, 37), Germany (4) and Australia (36). Similar to our findings
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29 with a community-based IBD sample, others also have not found CAM use to be
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31 associated with disease activity, disease duration, health care utilization or treatments in
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33 IBD (31).
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41 Psychological functioning has not typically been assessed in IBD studies of CAM use so
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43 there is little known about any relationships. An American study did report a strong
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45 correlation with CAM use when anxiety was present (OR= 3.1; 95% CI, 1.6-6.0) and for
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47 patients with higher depression and distress scores (29). We found an association
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49 between a lifetime diagnosis of major depression and CAM use. Beliefs and attitudes
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51 toward CAM have been examined as predictors of use, and views such as contribution to
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3 personal control of the disease and concerns about conventional therapies have been
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5 found to be quite relevant (7).
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10 No single CAM product was used very commonly in this community-based study. The
11
12 most often used CAM services were massage therapy (29.8%) and chiropractor (13.6%).
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14 Certainly the distribution of CAM services and products differs widely internationally.
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16 Herbal therapies were the most common CAM used by gastroenterology patients
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18 attending a UK clinic (43%) (3). In the German postal survey study of IBD patients,
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20 homeopathy (52.9%) and herbal medicine (43.6%) were the most commonly used types
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22 of CAM (4). In a French postal survey of IBD patients, only 21% reported using CAM
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24 and the most frequently used CAM were homeopathy (40.6%), magnetism (34.8%) and
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26 acupuncture (33.3%) (8). In a Swiss study of 144 patients, 47% reported using CAM (5)
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28 where the most common CAM used were homeopathy, acupuncture and traditional
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30 Chinese medicine (5). In an Australian general population phone survey the most
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32 popular CAM were nutritional supplements, massage therapy, meditation, herbal therapy
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34 and aromatherapy (33). These variations likely reflect local cultural influences of CAM
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36 in different jurisdictions, suggesting that a uniform profile of CAM service or product use
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38 worldwide is unlikely. As well, accessibility and availability can vary significantly
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40 depending on rural or urban locale, and financial considerations such as extended health
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42 insurance coverage. More direct comparisons of population usage and availability of
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44 these types of CAM products and services within particular regions would help to
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46 provide a context for the level of usage in the IBD community sample.
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3 While the community-based IBD sample, and the longitudinal tracking of CAM use were
4 particular strengths of the study, there were limitations as well. There was reliance on
5 recall of CAM use for the prior 12 month period. The list of services and products from
6 the Canadian census survey provided some recognition prompts for CAM, but it was not
7 an exhaustive list and participants may not have realized other products or services they
8 were using could also be included. As well, the time points where use was assessed were
9 snapshots in time, and there is no way of knowing the frequency or duration of use,
10 except as an approximation across time. Finally, we recognize as discussed about there
11 may be geographic and cultural aspects that impact on what types of CAM services or
12 products are used and hence these data may not be applicable outside of Manitoba or
13 perhaps Canada.
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32 *Conclusions*

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34 Almost three-quarters of those with IBD in a community sample tried some form of
35 CAM over a 4.5 year time span, with only 14% remaining consistent users in that time
36 period.. The minority, around 18%, used any of the products or services specifically for
37 IBD, so 4 out of 5 with IBD are using the products for other reasons. Since its use is so
38 common, clinicians need to make an effort to understand why their patients may choose
39 CAM, where they feel it benefits them, and work with their patients to consider whether
40 there may be any adverse interactions with the management they are prescribing.
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50 However, as few patients remain persistent users over time, clinicians need to be aware
51 that CAM use by patients whether a service or a product, will likely be transient.
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Table 1. Comparison of CAM users (at any of the assessment points) and CAM non--users on demographic and baseline clinical information

		CAM users	CAM non-users
Sex	Male	35%	45%
	Female	65%	55%
Age distribution	<30 years	31%	25%
	31-50 years	46%	41%
	>51 years	24%	34%
Age in years	Mean years (standard deviation)	40.1(14.3)	43.4 (15.7)
Employment	Full / part time	68%	58%
	Student	11%	14%
	Not working (homemaker/retired)	14%	25%
	Other	7%	3%
Education	No post secondary	36%	41%
	Some post-secondary (trade/diploma)	41%	34%
	University	24%	24%
Income (dollars per year)	Less than \$40,000	25%	29%

	\$40-59,000	29%	22%
	\$60-79,000	22%	24%
	\$80,000 or more	24%	24%
Disease type	Crohn's disease	51%	57%
	Ulcerative colitis	49%	43%
Hospitalized for IBD	Yes	57%	51%
Prior surgery	Yes	25%	30%

Note: Chi-square comparisons indicated that none of the variables were significantly different between CAM users and non-users (except for sex (female) at 3 of 4 assessment time points-see text for details).

Table 2. Percentage of complementary and alternative medicine (CAM) usage across time for the total sample, disease subtypes, and gender.

	Month 0	Month 12	Month 30	Month 54
Total sample use n=309				
CAM services only	21%	25%	18%	25%
CAM products only	11%	10%	11%	9%
Both CAM services and products	10%	14%	11%	13%
Any CAM service/product	42%	49%	43%	49%
Disease subtypes and any CAM use				
Crohn's disease n=151	20%	26%	25%	27%
Ulcerative colitis n=136	22%	24%	20%	23%
Gender and any CAM use				
Males n=116	15%	15%	11%	15%
Females n=193	27%	34%	32%	34%

Table 3: Proportion of CAM users (n=229) using five most frequently used CAM services and products across the four contact points

	Month 0	Month 12	Month 30	Month 54
CAM services				
Massage therapy	19%	35%	27%	38%
Chiropractor	19%	22%	5%	9%
Physiotherapy	8%	0%	3%	4%
Acupuncture	1%	6%	2%	5%
Homeopath/naturopath	2%	6%	3%	4%
CAM products				
Lactobacillus acidophilus	4%	6%	12%	8%
Chamomile	0%	2%	7%	6%
Fish and other oils	6%	8%	4%	4%
Glucosamine	4%	5%	2%	4%
Echinacea	3%	4%	0%	0%
IBD-related use:				
Any CAM service/product	N/A ¹	14%	21%	18%

¹ Reason for CAM use (for IBD or for nonIBD condition) was not asked at Month 0

Table 4. Mean scores on psychological and quality of life variables comparing current CAM users and nonusers at each contact point

	CAM Current User Mean (SD)	CAM Current Non-user Mean (SD)	<i>p</i> -value (<i>t</i> -test)
Years since diagnosis	4.3 (2.2)	4.3 (2.0)	0.95
Month 0	Users (n=132)	Nonusers (n=198)	
¹ Neuroticism	20.7 (7.4)	20.1 (7.8)	0.50
¹ Openness	26.0 (5.8)	25.0 (5.0)	0.12
¹ Extraversion	25.4 (5.7)	24.7 (5.4)	0.27
¹ Agreeableness	32.7 (5.1)	31.9 (5.7)	0.23
¹ Conscientiousness	33.0 (5.8)	32.5 (5.9)	0.51
Perceived stress	22.2 (7.6)	22.3 (8.6)	0.89
Health anxiety	15.3 (9.5)	14.0 (9.2)	0.23
Mastery	19.2 (4.5)	19.3 (4.4)	0.86
IBD Quality of life	164.1 (30.0)	167.1 (32.9)	0.41
Month 12	Users (n=155)	Nonusers (n=175)	
Perceived stress	21.0 (8.2)	21.1 (8.3)	0.93
Health anxiety	12.4 (8.5)	13.0 (9.3)	0.52
Mastery	19.4 (4.9)	19.1 (4.6)	0.53
Medication adherence	20.7 (3.9)	21.0 (4.0)	0.63
Medication beliefs: Concerns	13.7 (4.1)	13.1 (4.3)	0.26
Medication beliefs: Necessity	15.9 (4.8)	16.4 (5.4)	0.49

Medication beliefs: Overuse	9.4 (2.4)	8.8 (2.4)	0.03
Medication beliefs: Harm	9.5 (2.6)	9.9 (2.5)	0.22
IBD Quality of life	172.0 (29.8)	172.5 (33.2)	0.90
Month 30	Users (n=159)	Nonusers (n=171)	
Perceived stress	20.7 (8.2)	20.5 (8.8)	0.91
IBD Quality of life	178.0 (26.5)	177.3 (27.8)	0.84
Month 54	Users (n=172)	Users (n=158)	
Perceived stress	19.4 (9.2)	19.8 (9.2)	0.71
IBD Quality of life	176.7 (28.7)	177.3 (28.4)	0.73

[†]subscales of NEO-Five Factor Inventory (FFI) personality measure

The NEO-FFI was administered at Month 0. Medication adherence and beliefs about medication were assessed at Month 12. Health anxiety and mastery were assessed at Months 0 and 12.

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