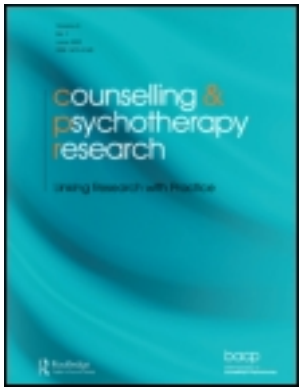

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RESEARCH ARTICLE

'*Just to get it off my chest*': Patients' views on psychotherapy in inflammatory bowel disease

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Abstract
Objective: This study aimed to explore patients' experiences and views on psychotherapy in relation to inflammatory bowel disease (IBD), and Crohn's disease (CD) in particular. *Method*: This descriptive survey study used semi-structured in-depth interviews with open-ended questions and a qualitative content analysis to summarise responses of 12 CD patients with mental health problems undergoing treatment with antidepressants. *Results*: Of 12 interviewed CD sufferers, only four received any form of psychotherapy. Two psychotherapy users considered it useful and beneficial. Patients who used psychotherapy with good results reported it improved their disease course, most likely due to improving patients' skills in reducing stress and thus, delaying relapse of the disease. *Conclusion*: Psychotherapy seems to be under used in IBD patients with mental health problems. Psychotherapy may act as a preventer of disease relapse in some patients and this observation needs to be tested with further quantitative studies. Online therapies may be the answer to limited psychotherapeutic resources in gastroenterology clinics.

Keywords: antidepressants; content analysis; inflammatory bowel disease; psychotherapy

Introduction

Inflammatory bowel disease (IBD) is a chronic relapsing inflammatory condition of the gastrointestinal tract of an unknown aetiology and unpredictable course. Two main types of IBD are: Crohn's disease (CD); and ulcerative colitis (UC). IBD has a significant impact on the mental health of its sufferers, with studies showing a 30% rate of co-morbid depression during remission of IBD (Mittermaier et al., 2004). During relapse of the disease, up to 80% of patients report anxiety and depression (Addolorato, Capristo, Stefanini, & Gasbarrini, 1997). Moreover, a recent large prospective study ($N = 704$) (Bernstein et al., 2011) showed that, of a number of factors studied, only high 'perceived stress' was associated with an increased risk of relapse of IBD symptoms. Other studies have shown a relationship between depression and disease course (Mittermaier et al., 2004), as well as between highly prevalent fatigue and disease-related worries reported by patients (Jelsness-Jorgensen, Bernklev, Henriksen, Torp, & Moum, 2012). Poor quality of life in IBD has been commonly linked to fatigue (Minderhoud, Oldenburg, van Dam, & van Berge Henegouwen, 2003) as have perceived stress and psychological problems (Graff et al., 2011). Impaired body image, relationships and sexuality are also significant contributors to the burden of disease in IBD (Muller, Prosser, Bampton, Mountifield, & Andrews, 2010).

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In light of the psychological impact of the disease and the high prevalence of mental health problems studies have been recommending stress management and psychotherapy to support IBD management (Goodhand et al., in press). However, when traditional psychotherapies were examined in quantitative studies they were shown to be largely ineffective in managing somatic side effects of the disease, although they seemed to work, to some extent, for anxiety and depression (von Wietersheim & Kessler, 2006). Cognitive-behavioural therapy (CBT), although only examined in a few studies, has been shown to be effective for anxiety and depression (Mikocka-Walus, 2010), and potentially impact on disease course (Keefer, Doerfler, & Artz, 2011). The most recent comprehensive Cochrane systematic review has shown that there is no evidence for psychotherapy in general to be effective in the general adult IBD population and that psychotherapeutic interventions should target groups in need (Timmer et al., 2011); however, there are insufficient data specifically on CBT to rule out its effectiveness. Yet, a recent study from the Netherlands shows that psychological illness remains largely undertreated in IBD (Bennebroek Evertsz et al., 2012). In this study with 231 IBD sufferers, in patients with high levels of anxiety and/or depression, only 17.9% received psychological or psychiatric help while 10.5% received antidepressants, 7.4% received anxiolytics and 3% received both antidepressants and anxiolytics. Other studies show that anxiety and psychological distress are associated with poor treatment adherence in IBD (Jackson, Clatworthy, Robinson, & Horne, 2010; Nahon et al., 2012) and thus there is a clear need to identify psychological interventions to manage psychological and possibly somatic symptoms in IBD. Reassuringly, a recent small interventional study focused on particular problems such as fatigue has shown solution-focused psychotherapy to be effective and acceptable to IBD patients (Vogelaar et al., 2011).

Qualitative studies incorporating patients' perspectives on issues relevant to IBD have explored the problem of coping with the disease (Fletcher, Schneider, van Ravenswaay, & Leon, 2008), the role of diet (Fletcher, Jamieson, Schneider, & Harry, 2008; Fletcher & Schneider, 2006), personal control and self-management (Cooper, Collier, James, & Hawkey, 2010), factors influencing quality of life (Pihl-Lesnovska, Hjortswang, Ek, & Frisman, 2010), living with ostomy (Savard & Woodgate, 2009), treatment adherence (Moshkovska, Stone, Baker, & Mayberry, 2008) and experience of colonoscopy (Hafeez et al., 2011; Mikocka-Walus, Moulds, Rollbusch, & Andrews, 2012 (in press)). Self-management of IBD has also been explored qualitatively via a meta-synthesis demonstrating the need for a shift in the patient-doctor relationship to involve greater clinician involvement in providing disease-specific information for the benefit of patients (Protheroe, Rogers, Kennedy, Macdonald, & Lee, 2008). Yet, no studies have specifically qualitatively explored patients' views on psychotherapy in IBD. Thus, the present study aimed to explore patients' experiences and views on psychotherapy in relation to IBD. The study was focused on patients with mental health problems as evidenced by current therapy with an antidepressant and thus potentially a target group for psychotherapeutic interventions, as recommended by the recent systematic review (Timmer et al., 2011).

Method

Setting

South Australia is the fourth largest of Australia's six states and two territories, with >1.6 million inhabitants. The Royal Adelaide Hospital (RAH) is the largest public tertiary teaching hospital in South Australia (SA). The RAH IBD Service currently serves approximately 600 IBD patients offering access to IBD nurses and psychologists with an interest in IBD.

Design and participants

This study was a descriptive survey design using semi-structured in-depth interviews with open-ended questions. As part of the clinical case-note audit reported elsewhere (Mikocka-Walus, Gordon, Stewart, & Andrews, 2012), patient details were collected from the IBD database at the IBD Unit, RAH. Patients were included in the present study if: (1) they had been diagnosed with Crohn's disease by a gastroenterologist; (2) were on the RAH Gastroenterology Clinic IBD database; (3) were in contact with RAH IBD Service within the preceding six months; and (4) were currently prescribed antidepressants.

Procedure

Of 287 individuals who met the first three inclusion criteria, 51 were found to currently take

antidepressants. Of these, a computer-generated random sample of 15 was selected for interviews. The sample was based on previous literature showing that data saturation is typically reached with groups of 10–15 individuals (Creswell, 2003). In this case, data saturation was reached after the 12th patient and the results are presented for these 12. Patients were invited to the study via a letter from their treating doctor. An opt-out slip was also included. If patients did not respond within a month an attempt was made to contact them via a telephone up to three times to ascertain their willingness to participate. All contacted patients agreed to participate. On average interviews lasted 30 minutes, they were digitally recorded and transcribed verbatim. Transcripts were then checked for accuracy.

Measurement

A protocol for the semi-structured interviews was designed. Questions were open-ended and pertained to whether a patient used psychological therapies, types of therapies used, their outcome in terms of mental and physical health and particularly their IBD.

Analysis

A qualitative content analysis (Creswell, 2003) was conducted. Firstly, the transcripts were read twice to increase familiarity with the data. Interviewer and respondent dialogue was then transferred into Microsoft Excel, with each question given a separate worksheet, and each uninterrupted segment of dialogue of the interviewer and respondent given a separate cell within the worksheet for a given question. Each segment of dialogue from a respondent was sequentially and systematically coded according to the explicit and implicit response to the given question.

Responses were coded in the context of the question, any subsequent prompts or probes used by the interviewer, and the preceding and following segments of dialogue from the interviewee in response to that question. New codes were created when the implicit or explicit content of a given segment of dialogue did not correspond with a previously developed code. Any interrelated questions and their respective codes were allocated to groups based on the similar focus of given sets of questions. Following the coding of all questions in a given group, the codes and general trends were assessed across questions. Any new emerging codes or inconsistencies observed were used to revise the content analysis. Codes were then summarised and quantified where appropriate and the analysis was written up using supporting quotes where necessary. Two independent reviewers checked the codes.

Ethical considerations

This study was approved by the Royal Adelaide Hospital and University of South Australia Research Ethics Committees. Patients were given adequate time to consider their participation and each participant gave written informed consent prior to their interview.

Reflexive statement

This paper is a collaborative work of four individuals who share a passion for improving the lives of chronic disease sufferers. A psychologist, who has spent the last eight years studying mental health co-morbidities in patients with IBD and developing interventions to manage them, leads the group. She is also an IBD sufferer and a keen believer in the role of stress and maladaptive coping as modifiers of disease course in IBD. Together with the group comprising a pharmacologist interested in mental health and substance use, another psychologist interested in management of chronic gastrointestinal and hepatologic conditions with psychotherapy, and a senior gastroenterologist interested in the psychological impact of IBD, she recently conducted a retrospective case-note study in order to better understand the impact of antidepressants on the disease course (Mikocka-Walus et al., 2012). The present paper follows from the previous one and involves a sample of IBD sufferers who also take antidepressants. The authors were interested in patients' experiences with any form of psychotherapy since, based on previous studies (Bennebroek Evertsz et al., 2012), it was suspected that this group may not receive adequate care. The interviews were conducted by the third author, who has much smaller personal involvement with the topic of the paper than the first author, and is very skilled in building a rapport with patients. He recorded his immediate impressions in the research journal and then coded the data, which was confirmed by the first author and analysed with the help of other investigators. The authors are of the view that thanks

to using this collaborative team approach to analysis and interpretation of data the presented results are not highly influenced by the subjective views of any of the authors.

Results

Patient characteristics

Overall, 12 CD sufferers participated in interviews. Of these, six were female and six male. The mean age was 45.5 years, with the minimum of 21 years and the maximum of 76 years. The time since diagnosis ranged from three to 30.5 years. Mental health problems included: anxiety (five participants), depression (four participants), a combined anxiety and depression disorder (three participants).

Psychotherapy and its efficacy in managing psychological symptoms and IBD

When asked whether they had received psychological therapy, four patients indicated that they had. Of these, all patients had seen a psychologist; one patient had also seen a psychiatrist. Those patients who had received psychotherapy stated that this involved debriefing and talking about stressors, challenges, or worries in their life. One patient stated they helped him through the use of a particular therapy.

> Yes, I'm currently with a psychologist, working with a psychologist. Doing a bit of cognitive-behaviour therapy. I've been doing that for probably the last six months. And that's helping a fair bit too. (Patient 6)

Another patient said she was offered relaxation techniques by her therapist but was not interested in them and just liked talking about her worries and concerns.

> I go in there for an hour session and basically we just talk through issues, she tries to do relaxation techniques with me . . . But I just enjoy going in there to talk to someone. Just to get it off my chest cause . . . I don't always like talking to my husband about things . . . I'm not that kind of person that does like - sits there and just does deep breathing and stuff like that. It doesn't work for me like I'm not into . . . relaxation and stuff like that. (Patient 3)

In alleviating the psychological burden of IBD, two patients felt that psychotherapy had helped them, one patient had not attended long enough for any improvement to manifest, and the remaining patient felt that the therapy had not been effective. Of the patients who felt it had helped them psychologically, they emphasised the benefits of being able to debrief with someone they didn't know who was non-judgemental. This allowed them to relieve a burden they felt they were carrying with them.

> So having the benefit of talking to someone without them judging you and whatever else like yeah, I think it did help. (Patient 3)

Another patient who described being administered CBT felt that this had helped change his maladaptive thought processes and reduced his depression and anxiety.

> Yeah it's changing my thinking. Changing my thinking towards situations. Where normally I'd get anxious and stressful about. It's changing that, yeah. I mean like coming here today. You know, before I would have been quite anxious and nervous about it. Now I've sort of changed my thinking a little bit, so that's improved a little bit. (Patient 6)

One patient felt that seeing a psychologist and psychiatrist had not helped her psychologically, due to their use of techniques which she did not find helpful and a perception that they did not believe that the challenges she was facing and the worries she raised were real. She felt that they did not understand her lived experience of the disease, and that by merely discussing these issues with a stranger in whom she didn't have rapport or trust, her anxiety had in fact worsened.

> And it just felt like . . . they didn't believe what I was saying. It was just like in my head. I dunno . . . When you go and see a stranger that has no idea what it even is and you try and explain to them, you know, yeah. (Patient 10)

However, the lack of response to this therapy could also have been attributed to different expectations between a patient and a therapist, with the former looking for a person to talk to and the latter focused on skill building.

> Because they wanted me to like to do a diary and stuff but I really didn't wanna do it. I just wanted to talk to somebody. (Patient 10)

Of the four patients who had received psychotherapy, two indicated that they felt it had ameliorated the symptoms of their IBD to some extent, one stated that it had not affected their disease, and one reported that he had received therapy prior to his diagnosis with IBD so was unable to comment on this issue. Those who felt their IBD had benefited from psychotherapy thought that the therapy had reduced their stress or anxiety, which had in turn reduced their IBD symptoms as they felt that stress invariably preceded the manifestation of these symptoms.

> Yeah it probably has. I mean because she like . . . it makes me feel better so . . . And I honestly believe that my Crohn's is directly related to my stress levels and . . . my . . . like mental state of mind. When I'm not feeling- If I'm feeling upset and stressed out like instantly my Crohn's flares up. (Patient 3)

> I mean that was basically the idea of it actually, is to try and get me to change the way I think and things so that I don't get so anxious and stressed. Because obviously the relationship there is the stress and anxiety which is causing the flare-ups. So definitely, yeah. (Patient 6)

Of the eight people who did not report experience with psychotherapy, all stated that the experience of their illness influenced their psychological outcomes, with commonly reported symptoms of anxiety, depression, irritability and fatigue. The predominant reason for these feelings was their experience of IBD symptoms and, in some cases, the subsequent need for hospitalisation.

> And so you just keep thinking 'Oh this is just never going to end'. (Patient 2)

Those who reported an adverse psychological impact felt that the limitation their disease imposed on their ability to perform routine activities and engage in social events was a major factor in this psychological burden.

> I don't feel sorry for myself, I feel sorry for, like, my daughter and my husband. Like what they're putting up with as such, you know, 'cause, you know, if I eat dinner or something like that, I won't wanna go out for a while or – I don't really like going out to eat. We've missed out on things 'cause I'm not feeling well and they'd rather just stay home with me than go out by themselves. (Patient 3)

Of the psychotherapy non-users, one patient felt that there should be more psychological support for patients in inpatient settings and thus indicating a gap in routine care and the need for better access to psychotherapy.

> But psychologically, there definitely should be something there for patients to say, you know, 'How are you feeling at the moment?' You know. 'What's your main worry? What's your main problem?' Because if you sit in the hospital ward by yourself and just . . . a thousand things race through your mind and that starts stressing you out. Whereas if you can talk to someone about it, it makes you feel a lot easier yourself. I mean that might sound a bit strange but that's definitely the way I feel about it, you know. (Patient 2)

Discussion

This research is the only qualitative investigation offering insight into IBD patients' perceptions of psychotherapy. We purposely selected patients in need of psychotherapy – as evidenced by their current use of anti-depressants – and thus their views may not be generally representative of all IBD patients. However, this is the patient group where psychotherapy is likely to be offered, and hence they are the appropriate group to examine as an initial enquiry. In addition, the paper focused on patients with Crohn's disease rather than both CD and UC patients since the evidence suggests that CD patients may present a more immature defensive profile than patients with UC (Hyphantis et al., 2005), which may be important when the focus of the intervention is psychotherapy.

Of these 12 interviewees, despite being prescribed antidepressants, only four had received any form of psychotherapy. Of psychotherapy users, two considered this kind of therapy useful and beneficial. The most helpful aspect of psychotherapy was reportedly the opportunity to talk rather than getting particular skills, with only one patient specifically mentioning the benefit arising from changing thinking patterns

as part of a CBT they participated in. The single patient that reported not finding the therapy to work claimed this was likely due to the therapist having no understanding of their disease. IBD, like other gastrointestinal conditions, may present challenges to therapists not trained in understanding the complexity of these medical problems, including unpredictable course, presence of symptoms (including chronic pain in some patients) despite being in remission, side-effects of medication, highly prevalent fatigue, co-morbidities with other inflammatory conditions such as arthritis, frequent toilet dependence, impact of symptoms on work and ability to travel/commute as well as many others including fertility and sexuality. Because of this, psychologists working at gastroenterology clinics may need additional medical training to better understand these patients' specific needs relevant in this context.

Interestingly, the two patients who used psychotherapy reported that it improved their disease course, possibly due to teaching them skills in reducing stress and thus, delaying relapse of the disease. This concept is currently being tested using CBT to observe if it prolongs remission or ameliorates inflammatory parameters (Mikocka-Walus et al., 2010). In functional gut disorders, various types of psychotherapy (with a particularly strong evidence for CBT) have been found beneficial for both psychological and somatic symptoms (Ford, Talley, Schoenfeld, Quigley, & Moayyedi, 2009). Good quality newer studies also report the efficacy of psychodynamic interpersonal therapy with respect to improving health status in irritable bowel syndrome (Hyphantis, Guthrie, Tomenson, & Creed, 2009). Thus it is likely a similar benefit may be expected in IBD.

Given the proven benefit of psychotherapy in many other situations, and the perceived benefit these IBD patients report from it, the low number of patients being offered psychotherapy requires attention. The participants had mental health problems requiring antidepressant treatment and were thus potentially eligible for psychotherapy. Based on the low rate of psychotherapy use it seems barriers to the delivery of psychotherapy may exist in the gastroenterology setting. Australia offers very good access to psychological services; currently funding up to 14 sessions of psychotherapy a year as part standard care – but only if patients are referred via a General Practitioner (GP). However, many IBD patients receive most of their care via specialist gastroenterologists as GPs generally do not have sufficient experience with IBD care – as would be expected from IBD epidemiology (Tan, Holloway, Lange, & Andrews, 2011), and thus the lack of access to funded psychology services within hospital and specialist care setting needs to be rectified.

Additionally, the primary care psychology resources should be more frequently utilised to prevent patients relying solely on antidepressants. Antidepressant treatment coupled with psychotherapy is reported to have greater long-term benefit than pharmacological treatment alone (Bacaltchuk, Hay, & Trefiglio, 2001; Furukawa, Watanabe, & Churchill, 2007). However, it is worth noting that psychotherapy alone has been found to prevent mental health symptoms relapse more effectively than antidepressants, with a remission rate of 39% achieved through psychotherapy versus 20% for antidepressants (Bacaltchuk et al., 2001). In other countries where resources are limited, online therapies may be a treatment option. Online therapies have been found comparably effective to face-to-face formats (Bee et al., 2008; Kaltenthaler et al., 2006). Websites focused only on IBD have been designed by at least two centres (both in Australia, Adelaide and Melbourne) and are currently available to patients as part of clinical trials. Future studies are likely to focus on testing these websites on larger IBD samples, including international comparisons.

Limitations

This study is limited to patients with CD and thus its results cannot be generalised to all IBD sufferers. Future studies could compare the psychotherapy use and attitudes in both CD and UC sufferers to delineate any differences or the lack thereof. In addition, the study was focused on patients currently taking an antidepressant and thus it is likely these participants may have had more serious mental health problems than an average psychotherapy user. Larger studies, with more diverse IBD populations would address these limitations.

Conclusion

Psychotherapy seems to be underutilised in IBD patients with mental health problems taking antidepressants. Yet, psychotherapy may act as a preventer of disease relapse in some patients and this observation needs to be tested in further quantitative

studies. Online therapies may be the answer to limited psychotherapeutic resources in gastroenterology clinics.

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Biographies

Antonina Mikocka-Walus is a registered psychologist and health scientist with an interest in IBD. She has published papers on mental health co-morbidities, psychotherapy and antidepressants in IBD and maintains an active private practice focused on supportive psychotherapy for patients with chronic gastrointestinal conditions.

Andrea Gordon is a pharmacologist interested in substance use in healthy and chronically ill populations. In her research, she is particularly focused on mental health and substance abuse. Together with AMW, she has conducted and published studies on the role of antidepressants in the management of IBD.

Benjamin Stewart is a doctoral student in Psychology with an interest in psychotherapy to manage chronic gastrointestinal and hepatologic conditions. Together with AMW and AG he has been involved in studies on mental health and antidepressant use in patients with IBD. His doctoral research is focused on psychotherapy in patients with chronic hepatitis C.

Jane Andrews is a senior gastroenterologist and health scientist with an interest in mental health co-morbidities and quality of life in IBD. Together with AMW she has published several papers on anxiety and depression and their management via psychotherapy and antidepressants in IBD.