



How do online patient support communities affect the experience of inflammatory bowel disease? An online survey

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DECLARATIONS

Competing interests

None declared

Funding

This study was supported by a research grant from Crohn's & Colitis UK (SP2009_1).

Ethical Approval

This study was given ethical approval by the University of Nottingham, UK.

Guarantor

NC

Contributorship

Neil Coulson was solely responsible for all aspects of the planning, design, analysis and reporting of this study.

Acknowledgements

None

Summary

Objective To explore how participation in an online support community may impact upon the experience of inflammatory bowel disease (IBD).

Design An online survey.

Setting Study participants recruited through 35 IBD online communities.

Participants A total of 249 males and females aged 16–69 years, living with either Crohn's disease (65.9%) or ulcerative colitis (26.1%) or awaiting formal diagnosis (8%).

Results Patients reported being members for an average of two years, with the majority accessing the community on a daily (46.9%) or weekly (40%) basis. Spending on average four hours per week online, approximately two-thirds of members posted between one and five messages per week. Members joined to find others in a similar situation and to obtain and share information and emotional support. Through participation members accessed a wealth of knowledge about all aspects of living with IBD and this was helpful in terms of accepting their illness and learning to manage it. The community also helped members see their illness more positively as well as contributing to an improvement in subjective well-being. However, some negatives aspects were noted.

Conclusions Online support communities may provide a useful shared space through which IBD patients may seek and provide both informational and emotional support. Many of these benefits may not be available through traditional healthcare. Whilst online support communities may be beneficial for those who choose to participate in them, they are not without limitations. Health professionals should be aware of the potential benefits and limitations of online communities.

Provenance

Submitted, peer
reviewed by
Heather Buchanan

Introduction

The Internet plays an increasingly important role in our everyday lives and has rapidly become an easily accessible user-friendly source of health-related information, advice and support.¹ A growing number of studies have described the benefits derived from browsing the Internet for those patients managing long-term illness. For example, Ziebland *et al.*² described how the Internet was an important information tool for patients at all stages of cancer care. This included using the Internet to seek a second opinion, finding out about tests and treatment, helping understand consultations and formulating questions for discussion.

With increased access to the Internet and advances in technology, there has been an exponential increase in the number of patients living with long-term illness who access and participate in online peer-to-peer support communities (also known as 'online support groups'), particularly since the launch in February 2004 of the social networking service Facebook. Through online support communities, patients are able to interact with other patients through either synchronous (e.g. chat rooms) or asynchronous (e.g. discussion forums) written communication and these communities may be professionally moderated or peer moderated.

The rise in popularity of online support communities may be explained, in part, by a number of unique features of the Internet-mediated nature of the communication. These include: (1) access to support at any time of the day or night, making it easy to obtain support at times that are convenient to the individual;^{3,4} (2) members can take their time to read messages and compose carefully written replies; (3) the removal of difficulties that might be associated with travelling to or accessing traditional face-to-face support provision;^{4,5} (4) socio-demographic factors such as ethnicity, age or gender are not readily obvious in online support communities.^{6,7} Furthermore, they provide an environment where the visible effects of a disease can remain hidden, making it easier for individuals with stigmatizing or disfiguring conditions to obtain support^{8,9}; (5) the anonymous nature of the Internet makes it easier for individuals to discuss sensitive or embarrassing topics, and may increase honesty, intimacy and

self-disclosure^{10,11} and (6) online support communities are not limited by the number of people who can join them, thereby allowing members access to a potentially broader range of experiences and opinions than would be available in the face-to-face setting.¹²

Whilst there has been much work exploring how patients living with long-term illness search, access and use health-related information on the Internet, there is comparatively less which has sought to explore their engagement with online support communities, including social networking sites. This study therefore surveyed 249 patients living with inflammatory bowel disease (IBD) about their online support community experiences including reasons for joining, patterns of use and how participation has impacted on their illness experience.

Methods

Participants

A total of 249 patients, drawn from 35 asynchronous (i.e. discussion forums) IBD-related online support communities, completed an online survey. The majority of the sample were female (78.3%) ($n = 195$) with a mean age of 35.9 years ($SD = 11.3$ years). Participants were from the US (32.5%), the UK (24.9%), Australia (19.3%) and Canada (11.2%) and various European countries (7.2%). The majority of the sample reported that they were diagnosed with either Crohn's disease (65.9%) or ulcerative colitis (26.1%) with the remaining participants (8%) awaiting formal diagnosis.

Data collection

Using a database of IBD online communities developed for the project, the moderator/administrator for each online community was contacted. The purpose and nature of the study were outlined and the views of the moderator/administrator regarding the content of the survey invited. All groups who responded positively to our initial contact were happy with the content of the survey and agreed that we could invite participants from their online community to participate in the study through a 'news item' being posted to the discussion forums. Individuals who wished to

Box 1.

Open-ended questions.

What do you consider to be the main advantages of accessing an IBD-related online support community?
 What do you consider to be the main disadvantages of accessing an IBD-related online support community?
 How have these advantages and disadvantages affected your use of the IBD-related online community?
 Has accessing an IBD-related online community had an impact on how you cope with your condition?
 If so, could you provide some examples of this?

participate in our survey were invited to visit a webpage that outlined, in lay terms, the nature and purpose of the study, their rights as a participant in the research process as well as information on what was involved. Ethical approval for the study was granted from the author's institution. The survey included some background questions about the participant and use of IBD online support communities. In addition, participants were asked to indicate their reasons for accessing the community using a list of predetermined reasons derived from the extant literature and pilot work. Finally, participants were asked a series of open-ended questions about their online experiences (see Box 1), which were qualitatively analysed using thematic analysis.¹³

Results

Patterns of use

On average, members had been accessing IBD online support communities for a period of two years (SD=2.3 years, range 0–15 years). The majority reported using the online community on a daily (46.9%) or weekly (40%) basis spending four hours online on average per week. Only a small minority (14.6%) of patients indicated that they had never posted, with the majority (64.2%) reporting they posted between one and five messages in the average week.

Why do patients use IBD online communities?

As can be seen from Table 1, the most popular reason endorsed by online community members was to find others in a similar situation. Next were a range of reasons reflecting both altruistic motives and a desire to obtain information, advice and emotional support.

Throughout the responses to the open-ended questions, members further described the practical benefits of accessing support through this novel medium. In particular, patients often described the convenient, accessible and anonymous nature of online support communities, especially in light of IBD symptoms.

Accessible from home – being ill means that we're often unable to leave the house. Online support means we don't have to

My computer is near my bed, which is near my bedroom. I am isolated because I cannot go out into the community for extended periods of time

It is not a pretty disease by any means and it helps to maintain anonymity while being able to speak freely about symptoms and experiences

In addition, the online support community also provided a shared space where any aspect of living with IBD could be discussed. Indeed, for some the online community provided a place where they could vent about their illness.

I have a forum to vent my feelings should I need to

How online support communities affect the experience of IBD

Members described a range of ways in which they considered participation in online support communities had impacted upon their experience of living with IBD. These reflected four key areas: knowledge; emotional support; illness reappraisal and wellbeing.

Table 1.
Reasons for accessing an IBD online support community.

<i>Reason</i>	<i>No. of participants</i>	<i>% of total</i>
To find others in a similar situation	201	80.7
To learn new information about my condition	165	66.3
To share experiences	162	65.1
To share information with others	146	58.6
To find emotional support	142	57.0
To seek advice	140	56.2
To offer support to others	135	54.2
To ask a question about my condition	128	51.4
Because it was convenient	107	43.0
Because it was available 24/7	90	36.1
Because I was feeling lonely	77	30.9
To understand medical terminology better	65	26.1
Because of an increase in the severity of symptoms	64	25.7
Because I was experiencing new symptoms	50	20.1

Note: Participants could endorse more than one reason.

Knowledge

As a result of the asynchronous nature of the online support communities, members were able to access a substantial repository of IBD-related experiential knowledge. The information available had been generated by the many thousands of conversations that had taken place and members could search through conversation threads until they found a discussion topic of interest.

One can search online support posts going back years. There is a far greater chance of finding the answer to a question in an archive of posts going back to the mid 1990s. You don't get that accumulated wealth of experience with a 'physical' support group

However, online support communities were also regarded as an up to date source of information, a venue where new research, treatments or cures may be disseminated and discussed.

It is a useful thing to learn new things about the disease. If a cure for Crohn's was found tomorrow, I bet social networking sites are where I would hear about it first, because information like that just flies through the internet, especially when you have groups

dedicated to sending that information to people who need it

Members described the benefits of being able to learn more about IBD through reading messages as well as asking questions. Basic information about IBD and its aetiology, symptoms and likely disease progression appeared to be of value to members, particularly those who were more recently diagnosed or were experiencing new symptoms. Similarly, members often described how reading messages posted by others had educated them about dietary habits, some of which were then tried out.

I have learned various tips or suggestions for supplements to add to my daily regime that I would never have known about otherwise

Finally, discussion of various treatment options, including surgery, was helpful to members. In particular, members who were starting new treatments found comfort and reassurance from reading about the experiences of others.

I am starting a number of treatments and it is great to know other people are doing well on them – makes me calmer

Emotional support

Through participation in the online support communities members appeared to derive considerable benefit from the ability to interact online with others who were also living with IBD. Indeed, solace was taken from the realization that they were not alone and that they had people they could turn to for support who truly understood their feelings and the daily struggles they had to confront. Through this shared understanding of the illness, members felt safe and secure within the community and welcomed the active encouragement by its members and the camaraderie that was experienced (see Box 2).

Illness reappraisal

Members described how they would compare themselves to other members of the online support community. The first type of comparison evident was a 'downward comparison' and in this scenario, members would compare their own illness experience with that of others in terms of either symptom severity and/or coping. For example, some members described how the symptoms experienced by other members appeared to be more severe in comparison to their own and as a result they came to see their own illness experience in a more positive light.

It has introduced me to people who have far worse symptoms than I, and perhaps made me less inclined to complain and to just get on with life

A second type of comparison which was identified was that of an 'upward comparison' and in this scenario members felt inspired by the stories of recovery or successful coping described by other members. Through reading about these 'success' stories, members described how they came to see their illness as something that could 'be beaten' or successfully managed and this gave them hope.

Although I have really suffered with this disease, there are plenty of people who have made a good recovery from flare up and it gives me hope

Wellbeing

Many members described how they felt participation in the online community had contributed to an improvement in their general wellbeing with a range of examples being provided which included: a sense of control, confidence and resilience, a positive attitude and improved mental health (see Box 3).

Box 2.

Emotional support.

Knowing you are not alone

Knowing you are not alone in your suffering and symptoms. There is always someone to talk to and communicate with

You do not feel alone, you realise how many people are going through the same emotional distress etc as you

Understanding

It's nice to talk to people who can understand on a personal level. I often think my specialist has no idea what impact this disease has, they might know the textbook back to front but to sit in a patient's shoes gives a whole new perspective, these people have a similar perspective to their disease

It just helps to know that there are people ready to offer unconditional support which stems from an understanding based on firsthand experience. It is not pity or superficial 'understanding' which even those who are close to you usually offer

Encouragement

Other members are so terrific at encouraging me to battle this horrid disease. They truly believe in me and their support is such a comfort

At times I could easily have given up but they are there to support each other and they always encourage me when I am feeling low

Box 3.

Self-reported improvements in subjective wellbeing.

Sense of control

I feel I am able to take some control over my health

I am more in control than I would be otherwise. I am learning about how to eat and how my body works

Confidence and resilience

Helped me feel more confident. Hearing how other people are coping and what they are able to achieve makes you think about how good it can get when you have been feeling low

It has helped me come to terms with my Crohn's disease and it has made me a stronger person by having people to talk to

It's renewed my spirit with living with Crohn's. I don't feel so defeated

Positive attitude

Because IBD is a chronic illness which waxes and wanes, it is encouraging to discuss this aspect of the disease online. I have felt much more positive about the illness, knowing many others have gone through something similar, and eventually improved

It's helped me to retain a more positive outlook about my health situation which in turn positively affects my life day to day overall

It's helped me become a bit more optimistic, it's empowered me more to be able to manage my IBD

Mental health

It has relieved some of the stress I was feeling about my condition

I'm not as depressed nor am I as anxious now

I have less stress. I am nowhere near feeling as hopeless

Problems with online support communities

Online support communities were not without their limitations and three areas of concern were described by patients: *obtaining information and assessing quality; too much negativity and interacting with others online.*

Obtaining information and assessing quality

By far the most commonly expressed concern focussed on aspects of information provision within the online support community and a range of issues were noted.

Some members described their disappointment when they posted a message seeking information, advice or support but had to wait some time before they received a response. In some cases, no reply was forthcoming.

Sometimes you can build yourself up in the hopes of receiving an answer, and wait for days for anyone to reply

Other members found searching through large amounts of information and identifying what was

relevant a challenge. Moreover, patients often described how they were concerned about the quality of the information that was being shared by others.

Occasionally there can be conflicting or bad advice. One needs to be aware constantly that these are people's experiences and opinions and not hard facts that apply to everyone

Advice needs to be treated with a large 'grain of salt' as not all people posting are truly knowledgeable technically

However, some did express a more cynical view that some messages may even be posted by imposters.

You don't know if a person was a drug rep. or someone who is not legitimate

Too much negativity

It was commonly observed that members tended to post more frequently when their symptoms were particularly bad, such as a flare up. As a consequence, several commented that there

seemed to be a bias towards the negative side of IBD and that reading 'horror stories' had become almost unavoidable. As a result, this created a sense of anxiety and concern about what might happen to them in the future.

Can cause you to panic about what could happen. You can read too much into the symptoms that other Crohn's patients suffer and worry this could happen to you

For others, it was felt that a focus on the negative side of IBD was demoralising and members may miss out from messages which were more positive and could provide hope.

There are a lot of horror stories as mainly really sick people are online (too sick to be elsewhere). People who recover or are in remission stop posting. So we lose access to people who could add immense value by sharing how they recovered

Sometimes when I log on, there may be a lot of sob-stories, rather than supportive, uplifting advice. Instead of asking for better ways of managing with their disease...and what they can do to improve their situations, people post up giant columns of negative 'just letting you know' posts, and for me this is unhelpful and annoying.

Interacting with others online

For some, it was not an easy thing to talk to others about their illness, especially strangers, as they felt embarrassed and ashamed. In particular, it was the intimate nature of the illness which posed the greatest challenge in terms of interacting online. For others, the concern was simply that of being misunderstood.

Sometimes it's very difficult to open up and talk to strangers about something so personal and upsetting

Other members discussed how the absence of physical proximity meant they could not offer physical affection, such as hugs, nor could they develop meaningful face to face relationships.

You can't sit down with a person and you can't hug them through the computer or hold their hand

It is not a good place to develop meaningful relationships

It was also noted by some members that the opportunity to interact with others was time limited in that once they had logged off they felt isolated once again.

The fact that it is online and after you log off you feel alone in it again

Discussion

Key findings

The results of the online survey revealed that participation in an IBD online support community had become a regular feature of daily or weekly activities, with participants spending several hours per week online. The results suggest that one key reason patients choose to participate in such online communities is in order to connect with others who they believe understand what they are going through. However, participants also described several other reasons for participation, not least the opportunity to both receive and provide informational and emotional support. The results also suggest that for those who choose to use them, online support communities provide a much needed opportunity to share illness experiences and learn from how others have coped. Moreover, many commented on how this helped in their everyday lives and described various ways in which they felt they had directly benefited. However, online support communities are not without their drawbacks and patients noted challenges with regards obtaining information and judging its quality, the bias towards a negative representation of the illness and the difficulties of relating to others online.

Strengths and weaknesses of the study

This study focussed on IBD and has benefited from the experiences shared by those who actively engage with online support communities and

who chose to participate in the research. A strength of this study is that unlike similar other studies, this online survey included representation from multiple online support communities ($N=35$). It does not, however, tell us about the experiences of other patients who choose not to participate in online peer-to-peer support. Furthermore, it does not tell us about those who may have joined such an online community but subsequently discontinued their use of it.

Comparison with other studies

Until recently, the focus of research has been on IBD patients' use of websites and the quality of information contained within them. The present study is one of the first such studies to explore the use of online support by patients living with IBD and illustrates nicely the potential value of a shared space online through which patients living with this deeply personal and often debilitating illness can seek peer support. Indeed, the findings of the survey are consistent with studies exploring the use of online communities by patients living with a range of chronic illnesses^{2,4,11,12} and similarly note a range of both positive and negative experiences, though the observation that the online communities may be dominated by too much negativity appears to be especially notable in the current survey findings.

Future research

Future research must seek to explore the broader experiences of members according to their level of participation and must also seek to examine why some patients choose to leave an online community. In addition, there is little longitudinal research on this topic and a notable lack of randomized controlled trials using pure peer-to-peer online support as the intervention content. Finally, future research should seek to explore the impact of participation in online support communities on interaction with health professionals.

Conclusions

Online support communities have grown exponentially and more and more patients are accessing them. There may be some benefits attached to participation in IBD-related online support communities but equally there may be some limitations. Patients should be guided by professionals on how best to engage with online peer-to-peer support.

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