

**Patterns of engagement with Inflammatory Bowel Disease online support groups:  
comparing posters and lurkers**

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## **Abstract**

Little is known about the varying patterns of member engagement with IBD online support groups. The aim of the study is, therefore, to compare posters and lurkers (i.e. those who read messages but choose not to post) in terms of engagement and motives for accessing online groups as well as to explore reasons why lurkers do not make an active contribution through posting messages. The findings revealed that those who posted messages visited groups more often and spent longer periods of time accessing them. However, there was no difference between posters and lurkers in terms of length of time as a group member. Furthermore, posters were more inclined to access online support groups to both seek and provide emotional, informational and experiential support. Finally, four main reasons were described by lurkers for not posting messages and these focussed on personal factors, illness severity, being helpful and new member. For those health professionals or patient volunteers who are involved in supporting IBD online support groups there are a number of practical strategies arising from these results which can be implemented to help integrate and encourage active participation by all members.

## **Background**

As access to the Internet continues to increase (Internet World Stats, 2013), a growing number of patients are searching online for Inflammatory Bowel Disease specific (IBD) information (Cima et al., 2007). In addition to this, there has been a rapid growth in the number of online support groups which have been set up to provide a shared virtual space where patients can seek and provide information, advice and support (Powell et al., 2003). There are a number of unique characteristics associated with the internet-mediated nature of such groups that are likely to underpin their rise in popularity. For example, groups typically employ an asynchronous discussion forum format that allows members the opportunity to read and post messages in their own time (White & Dorman, 2001). In the absence of any temporal or geographical constraints often associated with face to face groups, members can access support at any time of the day or night and seven days a week (Coulson & Knibb, 2007). In addition, the anonymous nature of such forums has been shown to be helpful in terms of patients discussing difficult, embarrassing or sensitive topics related to living with Inflammatory Bowel Disease (Coulson, in press).

In comparison to many other chronic conditions, there has been comparatively less research that has explored the impact of online support group participation on the experience of living with Inflammatory Bowel Disease. One notable exception is that of Coulson (in press) who surveyed 249 members from 35 different IBD online support groups. The results suggested that through participation members accessed a wealth of knowledge about many aspects of living with IBD and this was helpful in terms of accepting their illness and learning to manage it. The groups also helped members view their illness more positively as well as contributing to an improvement in subjective wellbeing. The potential therapeutic contribution that IBD online support groups may offer patients was further illustrated in a study by Malik & Coulson (2011). Through a content analysis of 1505 messages posted to an online IBD group

aimed at supporting the needs of patients aged 16-29 who were living with the condition, a range of self-help mechanisms were identified. In particular, their analysis revealed that through the posting of messages members could connect with other young people and share personal experiences and information related to their condition. Taken together these studies suggest that for those who actively engage with IBD online support groups there may be a range of positive benefits that may impact on their illness experience and management of their condition.

### **Patterns of engagement: ‘lurking’ behaviour**

Recently, a number of studies have begun to examine patterns of member engagement within online support groups and have contrasted two broad types of user. The first type includes those who actively engage with an online support group through posting messages (‘posters’). The other describes those who do not actively engage in this way but read messages only (‘lurkers’). Whilst the majority of work examining the benefits of online support has focussed on those who actively post messages, it has been noted that ‘lurkers’ may represent a sizeable proportion of online support group users. Indeed, Nonnecke & Preece (2000a) have suggested that a typical health-related online support group is likely to have approximately 45% of the membership being ‘lurkers’. However, the extent to which members of IBD online support groups may lurk remains unclear.

Another emerging body of literature has attempted to unravel the reasons that may underpin the decision to lurk within an online support group. For example, Kim (2000) suggests that lurking behaviour may reflect the fact that a member is new to a group and they are simply observing the group and its dynamics before choosing to fully engage through posting messages. However, other authors have suggested that there may be additional reasons that

may account for the lack of active engagement with online groups. In a study of MSN bulletin board communities, Preece et al., (2004) identified a range of reasons that included: not needing to post; needing to find out more about a group before participating; believing that not posting was helpful; not being able to make the software work and disliking the group dynamics. However, the majority of these communities were non-health and therefore it remains unclear why members of health-related online support groups, such as IBD groups, may not post messages.

### **Study purpose**

In the context of IBD, little is known about lurking behaviour therefore the aim of the present study is to compare posters and lurkers in terms of engagement with online support groups and their motives for accessing them. In addition, this study will explore the possible reasons for lurking behaviour within IBD online support groups.

### **Methods**

#### **Participants**

A total of 249 patients, drawn from 35 asynchronous (i.e. discussion forum) IBD-related online support groups, completed an online survey. The majority of the sample was female 78.3% (n=195) with a mean age of 35.9 years (SD=11.3 years). Participants were from the USA (32.5%), 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**

The data reported in the present article comes from a larger study exploring patients' experiences of accessing IBD online support groups. The specific details of the methodology are reported elsewhere (Coulson, in press) together with selected findings.

## **Use of IBD online support groups: lurkers versus posters**

Of the 249 respondents to the survey 15 chose not to disclose whether they posted messages or not. In terms of the remaining participants, 13.2% (N=33) reported that they had never posted a message to the online support group and were therefore classified as lurkers. It was revealed through Mann-Whitney *U* tests and Chi-square that members who posted messages visited the groups more frequently compared with lurkers ( $\chi^2(5) = 70.45, p < .001$ ), with 50.5% of posters visiting the group at least once a day compared with 24.2% of lurkers. In terms of amount of time spent online, posters reported spending more time online each week ( $M=4.64, SD=6.1$ ) compared with lurkers ( $M=1.76, SD=1.64$ ) (Mann-Whitney *U* = 1570.0,  $p < .001$ ). However, there was no significant difference found between posters and lurkers in terms of length of time they had been members of an IBD online support group (see Table 1).

<< insert Table 1 about here >>

## **Reasons for accessing online IBD support groups**

Members indicated which, from a choice of 14 possible options, reflected their reasons for accessing an IBD online support group. Using Chi-square tests it was found that posters were more likely to report accessing an IBD online support group in order to find others and obtain emotional support. Furthermore, they were more likely to access a group in order to ask a question and seek advice. Posters also reported that they were more likely to access groups in

order to share information and experiences and to support others. Finally, they were more likely to report accessing a group because they were feeling lonely. There were no significant differences between posters and lurkers for the remaining six reasons (see Table 2).

<< insert Table 2 about here >>

### **Reasons for ‘lurking’**

The 33 respondents classified into this category offered comments about why they chose not to actively engage with groups through posting messages. These responses were thematically analysed (Braun & Clarke, 2006) and reflected four broad themes: *personal factors*, *illness severity*, *being helpful* and *new member*.

#### *Personal factors*

Several lurkers described a range of personal reasons as to why they either chose not to or felt they could not post a message to the group. For some they felt uncomfortable in making a ‘public’ statement either because they felt inhibited or because it involved speaking to strangers whilst others noted privacy concerns. Some examples of comments include:

*“im a bit shy”*

*“don’t like to talk about myself with people i do not no”*

*“Don’t like my personal business up for everybody to read”*

*“i would not want to discuss my personal situation publicly online”*

Others indicated that they did not feel ready to participate through posting messages at the current time. A range of reasons were offered:

*“I feel that I don’t know enough to contribute at this time”*

*“i am not ready yet to make that emotional investment”*

*“I haven’t felt the need as yet”*

One member also described personal commitments that meant they did not have enough time to actively engage with the group. For example:

*“I haven’t posted as I don’t get enough time with work commitments to get on and have a look”*

### *Illness severity*

For some the decision about whether to post a message or not appeared to be related to their own experience of living with IBD. The examples from two individuals reflect differing experiences but which nevertheless contributed to the same decision not to post:

*“My crohns has always been quite mild so I don’t feel like a true ‘suffer’, thus am embarrassed to mention my thoughts and experiences”*

*“My condition has been very serious many times and reads like a horror story, I have had lots of complications during/following surgery. I don’t post about myself as I don’t want to scare people – most people will never experience what I have – why frighten them, Crohn’s is scary enough without knowing about extremes that will only affect a tiny percentage of people, people in these communities need support not fear”*

### *Being helpful*

Some reasons revolved around the notion of trying to be helpful and particularly if it was felt that nothing new could be added to what has already been posted. For others, it was simply felt that there was no value to the group to simply post a message and ‘moan’.

*“because i would give the same advice as everyone else”*



*“I have not had anything to offer that was not already posted on XXXX page”*

*“I don’t want to seem like I’m moaning sometimes and repeating what other people have already said and been through”*

#### *New member*

One member described being new to the online group and that was the reason for not posting messages but indicated that they intended to post soon.

*“I have only just joined this week, but I am intending on writing a message soon”*

### **Discussion**

The aim of this study was to explore patterns and motives for engagement with Inflammatory Bowel Disease online support groups from the perspective of those who post messages compared with those who do not (i.e lurkers). In addition, to explore possible reasons which may underpin the decision not to post messages to a group.

The findings reveal that lurkers did not access online support groups as frequently or for as long each time as compared with posters. However, there was no difference between the two types in terms of length of time they had been members of an IBD online support group. This latter finding merits comment since it does not support earlier studies that appeared to suggest a relationship between lurking and length of time being a group member (Kim, 2000). As a consequence it would suggest that there could be other factors that explain differences in engagement with IBD online support groups.

If we turn our attention towards reasons for accessing IBD online support groups the findings reveal a number of motives that appear to differentiate posters from those who lurk. Specifically, posters were more likely to access a group in order to find similar others, obtain emotional support and to ask a question or seek advice. However, posters also reported that

they were more likely to access a group in order to share information and experiences as well as supporting others. One possible explanation for these findings may be that posters, through their active contribution, are able to obtain important and potentially more relevant information and advice and through this process develop social contacts and feel invested in the group in such a way that they want to reciprocate and give back to the group through supporting other members.

For those who were classified as being a lurker, four types of explanation were put forward to justify why they chose not to post messages to the group. For those health professionals or patient volunteers engaged in supporting IBD online support groups these findings may have important implications on how best to integrate, involve and support lurkers and a number of possible strategies are described below.

The first category focussed on personal factors and included notions of shyness, a desire to remain anonymous as well as time restrictions. These are consistent with the work of Preece et al., (2004) who found similar concerns among lurkers in non-health online communities. In the context of supporting IBD patients, there may be a number of possible ways to address these concerns. For example, a group may create a separate section within a forum for 'new members' where individuals can introduce themselves and other members can welcome them. Alternatively, moderators may wish to welcome new members through a personalised email encouraging them to contribute and reassuring them that the shared virtual space is safe and welcoming. Such a strategy might also help address concerns about perceived privacy issues and suggestions on how to remain safe online could be offered. Indeed, groups may consider encouraging members to provide login names, such as mickeymouse123, and to develop online personas. Similarly, groups may wish to consider offering a daily email digest or publicise the most discussed items for those who may be limited in time to fully browse through all conversations.

The experience of living with Inflammatory Bowel Disease varies markedly between individuals and this was evident in the reflections of those who chose not to post because of the severity of their own illness. At one end of the spectrum were individuals who appraised their own experience as not being severe enough to merit comment. However, in contrast other individuals regarded their own experience as being too serious and were concerned that the sharing of their illness experience could provoke anxiety and worry for other members. Whilst these experiences may be divergent there is consensus in the fact that these individuals decided not to share their thoughts, stories or opinions. Such reflections suggest that some lurkers may be sensitive to both the dynamics of online support groups and potential reactions of other members. In such instances, moderators again may play a role in encouraging all experiences to be shared but reminding members that one size does not fit all and that within an online group a very diverse set of experiences may be discussed. Alternative strategies may include establishing sub forums which may be labelled according to a specific illness attribute (e.g. coping with fatigue), situation (e.g. newly diagnosed) or other criteria (e.g. employment and IBD). However, the issue of ‘horror stories’ is indeed highly relevant and the work of Coulson (in press) has described how members may feel IBD online support groups can become skewed towards the negative end of illness experience. As such, groups may wish to provide a clearly demarcated space to share positive, uplifting and ‘success stories’.

The third category considered the reasons for not posting a message as being an attempt to be helpful on the part of a group member. For some, there was a fear about repetition and so their own experience, advice or opinions were not shared. Online support groups could usefully address this issue either through moderator involvement (as described previously) or through the integration of additional functionality which may allow individuals to register their views on a topic easily (e.g. ‘liking’ on a facebook). From the perspective of group members, it may

be useful to see the extent to which a specific comment, piece of information or advice is endorsed by a group.

The final category, but smallest, concerned new members and many of the aforementioned strategies could usefully be applied to encourage active contribution to an IBD online support group.

### *Study limitations*

There are a number of limitations to the present study that should be taken into account when considering the results of this study. Firstly, the number of respondents to the survey who were classified as lurkers was relatively small (13.2%) though this is comparable to other recent studies (e.g. Malik & Coulson, 2011). As a result it remains uncertain as to the extent to which the patterns of engagement and views of these lurkers represent other lurkers within IBD online support groups. Secondly, the present study defined lurkers as those members who had not posted a message to the group. Future research may wish to review this definition and consider whether such a dichotomous categorisation (i.e. posters versus lurkers) needs to be refined to reflect the fact that some members may post many messages whilst others may post very few. Finally, the present study employed a cross-sectional design and future studies may wish to develop more longitudinal approaches to understanding the behaviours of members of online support groups in order to explore causal processes.

### *Conclusions*

In order to fully engage all members in IBD online support groups there is a need to be mindful of the different patterns of engagement that might be witnessed. As the present study reveals, lurkers may choose not to post messages but the reasons may not necessarily be because they

are new to a group. As a consequence, a range of practical initiatives can be undertaken to fully integrate members such that an active online group can be developed and sustained.

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**Table 1 Engagement with IBD online support groups**

	<b>Range</b>	<b>Lurkers (N=33)</b>	<b>Posters (N=192)</b>	<b>Difference between groups</b>
Length of membership in years (Mean, SD.)	0-15	1.42 (SD=1.44)	2.13 (SD = 2.43)	Mann–Whitney $U = 2212.5$
Frequency of visits to an online support group				$\chi^2(5) = 70.45^{***}$
More than once a day		1 (3%)	54 (28.4)	
Once a day		7 (21.2%)	42 (22.1%)	
More than once a week		6 (18.2%)	60 (31.6%)	
Once a week		5 (15.2%)	19 (10.0%)	
Monthly		9 (27.3)	13 (6.8%)	
Less than once a month		5 (15.2%)	2 (1.1%)	
Duration of visits to an online support in hours (Mean, S.D.)	0-48	1.76 (SD=1.64)	4.64 (SD=6.1)	Mann–Whitney $U = 1570.0^{***}$

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

**Table 2 Motives for accessing IBD online support groups**

	<b>Lurkers</b>	<b>Posters</b>	<b>Difference between groups</b>
To find others in a similar situation	24 (72.7%)	171 (89.1%)	$\chi^2(1) = 6.5^*$
To ask a question about my condition	7 (21.2%)	118 (61.5%)	$\chi^2(1) = 18.47^{***}$
To seek advice	14 (42.4%)	123 (64.1%)	$\chi^2(1) = 5.54^*$
To learn new information about my condition	26 (78.8%)	133 (69.3%)	$\chi^2(1) = 1.23$
To share information with others	3 (9.1%)	138 (71.9%)	$\chi^2(1) = 47.45^{***}$
To understand medical terminology better	5 (15.2%)	58 (30.4%)	$\chi^2(1) = 3.22$
To find emotional support	10 (31.2%)	128 (67.0%)	$\chi^2(1) = 14.86^{***}$
To offer support to others	4 (12.1%)	126 (65.6%)	$\chi^2(1) = 33.04^{***}$
To share experiences	9 (27.3%)	149 (77.6%)	$\chi^2(1) = 34.12^{***}$
To retain a degree of anonymity	6 (18.2%)	36 (18.8%)	$\chi^2(1) = 0.06$
Because it was available 24/7	9 (28.1%)	80 (41.7%)	$\chi^2(1) = 2.1$
Because of an increase the severity of symptoms	6 (18.2%)	57(29.7%)	$\chi^2(1) = 1.85$
Because I was experiencing new symptoms	5 (15.2%)	45 (23.4%)	$\chi^2(1) = 1.12$
Because I was feeling lonely	6 (18.2%)	71 (37.0%)	$\chi^2(1) = 4.42^*$

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$