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**Exploring patient's engagement with web-based peer support for Inflammatory Bowel Disease: forums or Facebook?**

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## **Abstract**

Whilst the popularity of health-related peer-to-peer web-based support shows no sign of diminishing, comparatively little is known about the factors associated with engagement in alternative web-based types of support (e.g. chat rooms, discussion forums, social networking sites). In this study, 147 patients living with Inflammatory Bowel Disease (IBD) completed an online questionnaire and described their use of either IBD forums or IBD Facebook groups along with a range of socio-demographic, disease-related and psychosocial factors. The findings revealed that over half (59%) of respondents accessed forums with the remaining accessing Facebook groups. Members of Facebook groups were more likely to be younger, single and achieved a higher level of educational attainment compared with forum members but there was no difference in terms of disease-related characteristics. However, differences did exist in how they used web-based support with forum members having been members for longer, accessing them more frequently and spending longer online as well as posting more messages. Taking into account these background variables, there were no differences in terms of perceived stress, perceived social support and health-related quality of life between members of these two types of support communities.

## **Introduction**

A developing body of literature has described web-based support communities for those affected by physical (e.g. HIV/AIDS) and mental health-related (e.g. depression) problems. Indeed, a number of factors may account for their popularity, for example, convenience and accessibility (Coulson & Knibb, 2007), anonymity (White & Dorman, 2001), access to large and diverse patient groups (Braithewaite et al., 1999). Moreover, there has been much qualitative work and several cross-sectional studies which have sought to explore member engagement with various web-based support communities with asynchronous forums being among the most frequently researched (e.g. Coulson, Buchanan & Aubeeluck, 2007). However, since the development of the social networking site Facebook in 2004 there has been a steadily growing number of special interest groups which have been created to bring together those affected by a range of health problems thereby increasing potential access to web-based peer support. However, to date there has been little attention given to exploring any differences (or similarities) between users of these types of support. Therefore, the aim of this exploratory study was to examine socio-demographic, disease-related and psychosocial factors in relation to those patients who access web-based support through either an asynchronous forum or via a Facebook group, using Inflammatory Bowel Disease<sup>1</sup> as a case example.

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<sup>1</sup> Inflammatory Bowel Disease is a group of inflammatory conditions of the colon and small intestine. The two major forms of IBD are known as ulcerative colitis and Crohn's disease. Together, these are estimated to affect approximately 180,000 in the UK with 2.2 million and 1.4 million people affected in Europe and the United States respectively.

## Methods

### *Sample characteristics*

A total of 147 individuals completed the online survey. The socio-demographic and disease-related characteristics of participants are presented in Table 1. The majority were female 78.9% (n=116) with a mean age of 35.5 years (SD=10.9). Participants were from the USA (32.0%), Australia (24.5%), and UK (23.1%) followed by Canada (12.2%) and other European countries (8.2%). Slightly less than half of the participants were educated to degree level (46.5%). The majority of the participants stated that they were currently in a relationship (80.3%).

<<Table 1 about here>>

The majority of the sample reported that they were diagnosed with either Crohn's Disease (74.0%) or Ulcerative Colitis (22.6%). Approximately half of respondents (51.1%) described their symptoms as severe at last flare up, while the rest reported the severity of their symptoms as moderate (39.7%) or mild (9.2%). On average respondents had been diagnosed for 8.7 years (SD=8.6) and less than half of the participants (43.5%) stated that their disease was currently in a period of remission.

### *Measures*

*Use of web-based IBD support:* A series of questions were asked to explore the pattern of engagement with web-based IBD peer support. Firstly, participants were asked to indicate whether they accessed web-based peer support for IBD through either forums or through Facebook groups. Next, participants were asked how long they had been accessing online support, how frequently they visited an online IBD support community, the number of

messages they posted and the number of hours they spent in the IBD support community in a typical week.

*Social support:* Perceptions of social support were measured using the Medical Outcomes Social Support Survey (MOS-SSS), which is a 19-item scale assessing the perceived availability of various dimensions of social support. The scale consists of 4 subscales ( $\alpha$  = ranged from .95 to .96) measuring the following domains of support: emotional/informational support, tangible support, affectionate support and positive social interaction (Sherbourne & Stewart, 1991). A 5-point Likert scale ranging from 1= *None of the time* to 5= *All of the time* is provided for each question item, with higher scores indicating greater perceived social support.

*Perceived stress:* Perceived stress was measured using the 14-item Perceived Stress Scale (PSS) which is designed to measure the degree to which situations in an individual's life are appraised as stressful (Cohen et al., 1983). Participants were asked to rate how often they felt or experienced certain situations on a 5-point Likert scale ranging from 1=*Never* to 5=*Very often*, with higher scores indicating higher levels of perceived stress ( $\alpha$  = .91).

*Health-related quality of life:* Health-related quality of life was measured using the Short Inflammatory Bowel Disease Questionnaire (SIBDQ) (Irvine et al, 1996). A 10-item scale which measures bowel, systemic, emotional and social domains of quality of life in IBD patients, with each item being answered on a Likert scale ranging from 1=*All of the time* to 7=*None of the time*, with higher scores reflecting better quality of life ( $\alpha$  = .86).

*Coping:* Coping was measured using the Brief Cope (Carver, 1997). It is a 28-item scale that measures 14 types of cognitive or behavioural coping processes: positive reframing, religion, substance abuse, venting, humour, instrumental support, acceptance, active coping, behavioural disengagement, self-blame, denial, self-distraction, emotional support, and planning ( $\alpha$  ranged from .6 to .9). Participants were asked how often they used those coping

strategies to deal with the stress associated with Inflammatory Bowel Disease on a 3-point Likert Scale ranging from 1 = *I haven't been doing this at all* to 3 = *I've been doing this a lot*, with higher scores indicating greater use of the coping process.

## **Results**

### *Engagement with IBD web-based support*

Details of engagement with web-based Inflammatory Bowel Disease support are presented in Table 2. Respondents reported accessing web-based support for an average of 25.02 months and spending on average 4.5 hours per week with 59% using IBD forums.

<< **Table 2 about here** >>

### *Comparing Facebook with forum users*

As can be seen from Table 1, the results from independent samples *t*-tests revealed that individuals accessing Facebook groups were younger ( $t(145) = 3.80, p < .001$ ) and according to Chi Square tests were also more likely to be single ( $\chi^2(3) = 17.11, p < .01$ ) as well as achieving a higher level of educational attainment ( $\chi^2(3) = 16.4, p < .01$ ). However, there was no association between gender and type of support accessed, nor any association with employment status. In relation to disease-related characteristics, there were no associations found.

As can be seen in Table 2, individuals accessing online IBD forums had been doing so for a considerably longer period of time as compared with those who accessed Facebook groups and they also reported spending significantly more hours online in the average week

accessing IBD support. In addition, those accessing IBD forums visited them more often than those accessing IBD Facebook groups and posted more messages in the average week.

In order to explore whether there existed any differences between forum and Facebook group members on the four subscales of the MOS-SSS, a MANOVA was undertaken. Whilst the overall multivariate effect was not significant ( $F(4,135) = 1.43, ns.$ ) inspection of the univariate tests did reveal a significant effect for the subscale *positive social interaction* (see Table 3) with higher scores being reported for forum members compared with Facebook group members. The analysis was repeated including age, education, relationship status, length of membership, frequency of visits, hours spend online and number of messages posted included as covariates and the significant difference for this subscale was now non-significant ( $F(4,86) = .64, ns.$ ).

<< Table 3 about here >>

Next, ANOVA was used to explore whether there existed any difference between forum and Facebook members on the perceived stress scale (PSS). The results revealed a significant difference ( $F(1,136) = 5.51, p<.05$ ) with IBD Facebook group members reporting higher levels of stress ( $M = 2.17, SD = .63$ ) compared with members of IBD forums ( $M = 1.9; SD=.68$ ). This analysis was repeated (ANCOVA) with age, education, relationship status, length of membership, frequency of visits, hours spend online and number of messages posted included as covariates. The results revealed no significant difference now ( $F(1,97) = .88, ns.$ ) between the two groups.

Similarly, ANOVA revealed a significant difference ( $F(1,141) = 10.89, p<.01$ ) in terms of the SIDBQ with IBD forum members reporting a better quality of life ( $M = 4.21, SD = 1.16$ ) compared with IBD Facebook group members ( $M = 3.65, SD = 1.10$ ). This analysis was



also repeated (ANCOVA) with age, education, relationship status, length of membership, frequency of visits, hours spend online and number of messages posted included as covariates. The difference between the two groups was no longer significant ( $F(1,99) = 1.85, ns.$ ).

There was no difference between user groups in terms of coping ( $F(1,131) = 1.49, ns.$ ).

## **Discussion**

The aim of this study was to explore factors associated with engagement in two popular types of web-based peer support by individuals living with Inflammatory Bowel Disease, namely forums and Facebook groups. The findings reveal socio-demographic differences in the type of support accessed with Facebook group members more likely to be younger, have a higher level of educational achievement and single. This profile is consistent with socio-demographic data published on the use of Facebook (Duggan & Brenner, 2013) by adults in North America and Europe.

Furthermore, differences between the two types of support were also evident in relation to measures of engagement. In this respect, forum members reported accessing the support community for longer, logged in more frequently, spent longer online and posted more messages than those who accessed support via Facebook groups. A number of factors may explain these differences, including the association with socio-demographic characteristics and social networking mentioned earlier. However, since Facebook is a more recent Internet development it may be that older patients have yet to fully embrace social networking sites as a means of obtaining peer support for chronic conditions, though recent reports (e.g. Madden, 2010) suggest that this may well change as the number of over 50s engaging with social networking, such as Facebook, increases. The findings did not, however, suggest that disease-related or psychosocial factors were associated with the type of support accessed. Future work

may usefully explore whether there exists any other individual factors (e.g. personality, shyness, ehealth literacy) that are relevant to choice of support type.

There are a number of limitations to the present study that should be considered. For example, the present study focussed only on one condition (i.e. IBD) and the sample was relatively small. Moreover, respondents provided details of their access to either forums or Facebook but as access to the Internet and use of Facebook continues to increase (Internet World Stats, 2013) there is a need to consider those individuals who engage in both types of web-based support. Indeed, it is conceivable that an individual may belong to multiple forums as well as multiple Facebook groups simultaneously. Finally, there is a need for more robust research designs in order to explore longitudinally patterns of engagement and related outcomes arising from engagement with different types of web-based support and support modalities (e.g. via a networked PC or mobile phone application).

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**Table 1** Socio-demographic and disease-related characteristics of participants by mode of access

| Variables                      | Total (N=147)         | Forums (N=87)       | Facebook (N=60)       | Difference            | Post hoc |
|--------------------------------|-----------------------|---------------------|-----------------------|-----------------------|----------|
| <i>Gender</i>                  |                       |                     |                       |                       |          |
| Male                           | 31 (21.1%)            | 23                  | 8                     | $\chi^2(1) = 3.66$    |          |
| Female                         | 116 (78.9%)           | 64                  | 52                    |                       |          |
| <i>Age</i>                     |                       |                     |                       |                       |          |
|                                | M = 35.5<br>SD = 10.9 | M=38.2<br>SD = 10.6 | M = 31.6<br>SD = 10.1 | t(145)= 3.80***       | F > FB   |
| <i>Education</i>               |                       |                     |                       |                       |          |
| High school                    | 23                    | 3                   | 20                    | $\chi^2(3) = 10.18^*$ |          |
| College                        | 53                    | 25                  | 28                    |                       |          |
| University                     | 45                    | 23                  | 22                    |                       |          |
| Postgraduate                   | 21                    | 8                   | 13                    |                       |          |
| <i>Relationship status</i>     |                       |                     |                       |                       |          |
| Single/ Divorced/widowed       | 24                    | 7                   | 17                    | $\chi^2(1) = 5.60^*$  | FB > F   |
| In a relationship/married      | 98                    | 55                  | 43                    |                       |          |
| <i>Employment status</i>       |                       |                     |                       |                       |          |
| Employed/studying              | 100                   | 53                  | 47                    | $\chi^2(1) = 8.21$    |          |
| Unemployed/retired             | 46                    | 34                  | 12                    |                       |          |
| <i>Type of IBD</i>             |                       |                     |                       |                       |          |
| Crohn's                        | 108                   | 64                  | 23                    | $\chi^2(1) = .89$     |          |
| Colitis                        | 38                    | 23                  | 15                    |                       |          |
| <i>Time since diagnosis</i>    |                       |                     |                       |                       |          |
|                                | M=8.8<br>SD=8.6       | M=9.9<br>SD=9.3     | M=7.1<br>SD = 7.3     | t(143)= 1.89          |          |
| <i>Disease characteristics</i> |                       |                     |                       |                       |          |
| In remission                   | 64                    | 43                  | 21                    | $\chi^2(1) = 3.00$    |          |
| Not in remission               | 83                    | 44                  | 39                    |                       |          |
| <i>Severity of illness</i>     |                       |                     |                       |                       |          |
| Mild                           | 13                    | 7                   | 6                     | $\chi^2(2) = .85$     |          |
| Moderate                       | 56                    | 32                  | 24                    |                       |          |
| Severe                         | 72                    | 46                  | 26                    |                       |          |

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

**Table 2** Engagement with web-based IBD support by mode of access

| Variables  | Total<br>(N=147)        | Forums (N=87)           | Facebook (N=60)        | Difference                |
|--|-------------------------|-------------------------|------------------------|---------------------------|
| <i>Length of membership<br/>(in months)</i>                  | M = 25.02<br>SD = 28.57 | M = 33.16<br>SD = 33.43 | M = 12.19<br>SD = 8.89 | $t(132) = -4.42^{***}$    |
| <i>Hours spent accessing online<br/>support per week</i>     | M = 4.50<br>SD = 6.44   | M = 5.62<br>SD = 6.25   | M = 2.88<br>SD = 6.42  | $t(138) = -2.53^*$        |
| <i>Number of times accessing online<br/>support per week</i> |                         |                         |                        | $\chi^2(5) = 25.23^{***}$ |
| Less than once a month                                       | 5                       | 1                       | 4                      |                           |
| Monthly  | 15                      | 4                       | 11                     |                           |
| Once a week  | 18                      | 9                       | 9                      |                           |
| More than once a week  | 46                      | 24                      | 22                     |                           |
| Once a day   | 24                      | 15                      | 9                      |                           |
| More than once a day   | 37                      | 33                      | 4                      |                           |
| <i>Number of messages posted per week</i>                    |                         |                         |                        | $\chi^2(3) = 23.70^{***}$ |
| 0  | 19                      | 4                       | 15                     |                           |
| 1-5  | 93                      | 54                      | 39                     |                           |
| 6-10   | 11                      | 8                       | 3                      |                           |
| 11+  | 21                      | 20                      | 1                      |                           |

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

**Table 3** Difference in perceived social support for IBD discussion forum and Facebook group users

| Variables                          | Total<br>(N=140)<br><br>M(SD) | Forums (N=82)<br><br>M(SD) | Facebook<br>(N=58)<br><br>M(SD) | Difference between<br>groups (MANOVA)<br><br>F(1, 135) | Difference between<br>groups controlling<br>for covariates<br>(MANCOVA) <sup>a</sup> |
|------------------------------------|-------------------------------|----------------------------|---------------------------------|--|--|
| <i>Emotional/informational</i>     | 3.32 (1.03)                   | 3.41 (1.02)                | 3.19 (1.04)                     | 1.59   | 1.92   |
| <i>Tangible</i>                    | 3.65 (1.22)                   | 3.74 (1.22)                | 3.52 (1.22)                     | 1.13   | 1.39   |
| <i>Affectionate</i>                | 4.02 (1.20)                   | 4.14 (1.21)                | 3.85 (1.180)                    | 1.96   | 2.31   |
| <i>Positive social interaction</i> | 3.86 (1.05)                   | 4.02 (1.01)                | 3.62 (1.06)                     | 5.18*  | 3.46   |

a Controlling for age, education, relationship status, length of membership, frequency of visits, hours spent online and number of messages posted

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