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User characteristics and usage of an open access moderated internet support group for depression and other mental disorders: A prospective study



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ABSTRACT

Background: Internet support groups (ISGs) for mental ill-health are common but little is known about the characteristics of users, the usage and predictors of ISG usage and if and how these change over time.

Aim: This study evaluated the attributes of a publically accessible ISG for depression and other mental disorders including: (1) the demographic and other characteristics of its users; (2) their patterns of usage; and (3) the factors which predict posts to and retention on the ISG.

Method: User characteristics (gender, age, user type, country and location of residence) were collected at the time of registration on the ISG BlueBoard (blueboard.anu.edu.au). All board log data were downloaded for the period October 2008 to May 2014. Predictors of post frequency and retention on the board were examined using logistic regressions. Other data were analysed using descriptive statistics.

Results: 2932 users contributed 131,004 posts to the ISG. The majority were female, aged 20 to 34 years, and mental health consumers. Although most users were city dwellers, 19% resided in rural or remote regions. Frequency of posts and retention on the board varied across users, with a moderate association between retention and number of posts. Growth in posts substantially exceeded the growth in new users over the monitoring period. Multivariate analysis demonstrated that consumers posted more often and remained longer than carers or others, and that younger users posted less often; however, the model predicted very little of the variance.

Conclusions: A small minority of active users are sufficient to ensure the sustainability and growth of an online mental health ISG. Further research is required to understand why so many support group members limit their contributions to one or a very small number of posts and what factors predict and promote active engagement and long-term retention in virtual mental health communities.

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1. Introduction

Internet support groups (ISGs) are accessible and popular (Dosani et al., 2014; Fox and Duggan, 2013; Parikh and Huniewicz, 2015) and have the potential to provide valued social support to individuals with depression and other common mental disorders (Barak et al., 2008; Griffiths et al., 2015). While there is uncertainty regarding the effectiveness and safety of ISGs (Eysenbach et al., 2004; Griffiths et al., 2009a; Hoybye et al., 2010; Parikh and Huniewicz, 2015; Rice et al., 2014; Takahashi et al., 2009), recent high quality evidence suggests that such support groups may improve mental health outcomes (e.g., (Griffiths et al., 2012, Ali et al., 2015)) and increase users' sense of empowerment (Crisp et al., 2014), self-esteem (Crisp et al., 2014)

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and perceived quality of life (Crisp et al., 2014). However, there is little systematically collected evidence on the characteristics of those who use ISGs for depression or mental ill-health, or what determines the level of participation and retention of users in these groups (Griffiths et al., 2009b).

There is some evidence that the predominant users of depression support groups are consumers (Houston et al., 2002; Powell et al., 2003; Salem et al., 1997; Alexander et al., 2003; Nimrod, 2012) who are primarily in their mid-20s to 40s (Dosani et al., 2014; Houston et al., 2002; Nimrod, 2012; Powell et al., 2003); there is mixed evidence regarding gender of users (Dosani et al., 2014; Fekete, 2002; Houston et al., 2002; Nimrod, 2012; Powell et al., 2003; Salem et al., 1997; Takahashi et al., 2009). However as noted by Griffiths et al. (2009b), a limitation of most previous studies of public depression support groups is that they have been derived from surveys posted on ISGs or by inferring the users' status from posts. Thus, the data collected from these studies is typically either restricted to those ISG members who remain on the board and who chose to participate in the surveys, or conclusions

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are based on inferences of unknown validity. A more valid approach would analyse data collected at the time of registration.

To date, few studies have investigated patterns of usage of open access mental health support groups across forum topics or over time (Griffiths et al., 2009b) based on all registered users and registration details. Although one group has undertaken a study of membership duration and its predictors in a cross-sectional survey (Nimrod, 2012), as noted above there are limitations to the conclusions that can be drawn from such methodologies. We are not aware of any systematic studies of the retention patterns for all users of an online mental health support group. Nor - with the exception of cross-sectional studies - are we aware of studies that have systematically investigated individual differences in mental health support group usage by ISG members or the predictors of any such differences based on details at registration. We have recently reported the distribution of posts across an entire online support group for depression and related disorders (blueboard.anu. edu.au), finding that they conformed to a Zipfian distribution (Carron-Arthur et al., 2014). However, the study did not investigate individual differences in detail.

Accordingly, the current study sought to document: (1) the demographic and other characteristics of users of the publically accessible bulletin board on registration; (2) the patterns of usage on the board; and (3) the factors which predict usage of the board and retention on the board.

2. Method

Data were collected from the database of the peer-to-peer ISG BlueBoard. Ethics clearance was obtained from the ANU Human Research Ethics Committee prior to the establishment of the board to enable the investigators to undertake research investigating the characteristics of the board and its users.

2.1. The Internet support group: BlueBoard (blueboard, anu. edu. au)

This service was provided by the National Institute for Mental Health Research/Centre for Mental Health Research at the Australian National University with funding from Australia's Department of Health. BlueBoard comprised 10 forums including: (1) Eight condition forums each focused on a different mental disorder (depression, bipolar disorder, generalised anxiety, social anxiety, panic disorder, obsessive compulsive disorder, borderline personality disorders and eating disorders). Each of the condition forums comprised two sub-forums: "Living with [condition, e.g., depression]" and "Taking care of our ourselves"; (2) A carer forum ("Caring for someone with a mental health problem") comprising four sub-forums: "General", "Depression and Bipolar disorder"; "Anxiety disorders" and "Other disorders"; and (3) a general forum comprising four sub-forums 'Chit-chat', "Having a laugh", "Creative corner" and "Suggestions box". The Board was moderated by consumers who were trained and supervised by a registered clinical psychologist (JR). The Board was originally established as a mood disorder support group in 2003 but was closed in 2007 and 2008 due to lack of funding. The current study is focused on the second phase of the service. All forums were established on 1 October 2008 except the Obsessive Compulsive, Borderline Personality and Eating Disorder forums which were established on the 1 June 2009, 1 March 2010 and 30 July 2012 respectively. Further details of the Board can be found elsewhere (Griffiths et al., 2015).

2.2. Measures

User characteristics were collected at the time of registration on BlueBoard and included: age range, gender, country of residence, location of residence (rural/capital city/other city) and type of user (consumer/carer/other). *Usage* data were collected by downloading all

posts, their time stamps, and forum and sub-forum details, for the period 1 October 2008 and 23 May 2014.

2.3. Analyses

Analyses were undertaken using SPSS Statistics Version 22.0. User characteristics and usage (number of posts contributed, and user retention on the board in months) were analysed using descriptive statistics. Simple bivariate relationships between user characteristics and usage were assessed using Kruskall-Wallis and Mann-Whitney tests. Multivariate analysis of predictors of usage were examined using logistic regression analyses. Retention data were further analysed using Cox proportional hazards regressions with (i) no censoring; (ii) right censoring of users who posted in the last 2 weeks of the data collection period and (iii) right censoring of users who posted in the last 12 weeks.

3. Results

A total 4823 individuals registered on BlueBoard (excluding those who were banned for spamming or related activity) in the relevant period, of whom 2932 contributed at least one post. The focus of this paper is on those registrants who contributed one or more posts; they will be referred to here as 'users'.

3.1. Characteristics of users

Table 1 summarises the characteristics of the BlueBoard users who provided demographic and other data. Missing data ranged from 8.6% (gender) to 15% (participant type). Two-thirds of users were women and the majority were consumers. Although the Board was used by older people including some aged over 75 years, the majority of users were aged between 20 and 34 years. Users resided in 76 different countries, with most living in Australia. The next most frequent user locations were the United States and the United Kingdom. Approximately half of all users lived in a capital city but a substantial minority (almost 19%) resided in rural or remote areas.

Table 1 Characteristics of users (≥ 1 post, n=2932) at registration. Values are numbers (percentages) unless otherwise stated.

Characteristic	n (%)	
Gender ($n = 2680$)		
Women:	1812 (67.6%)	Chi-square (1) = 1812, $p < 0.001$
Age category ($n = 2662$)		
<20 yrs	174 (6.5%)	
20-34 yrs	1489 (55.9%)	
35-49 yrs	737 (27.7%)	
50-64 yrs	243 (9.1%)	Chi-square $(4) = 2691.07$,
		<i>p</i> < 0.001
65 yrs +	19 (0.7%)	
Location/rurality ($n = 2602$)		
Rural/remote	483 (18.6%)	
Capital city	1367 (52.5%)	Chi-square (2) = 473.50 , $p < 0.001$
Other city	752 (28.9%)	
Country ($n = 2671$)		
Australia	2195 (82.2%)	
United States	202 (7.6%)	
United Kingdom	70 (2.6%)	
Canada	29 (1.1%)	
New Zealand	16 (0.6%)	
India	15 (0.6%)	
Other	144 (5.4%)	
User type ($n = 2493$)		
Consumer	1664 (66.7%)	
Carer	238 (9.6%)	
Other	591 (23.7%)	Chi-square $(2) = 1327.48$,
		<i>p</i> < 0.001

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