# Social Support Online: Benefits and Barriers to Participation in an Internet Support Group for Heart Patients

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The purpose of this study was to investigate if using an Internet support group for cardiac patients was associated with reduced psychosocial risk factors for heart disease and to discover why some group members became active users and others did not. The application of the Health Belief Model to determine the predictive power of participation in an online support group makes a novel contribution to community psychology, particularly because it was developed to predict health behavior. Six measures of social support/negative affect were used to determine risk reduction. One hundred and twenty (63 males, 57 females) active and inactive members of the *HeartNET* online community completed a survey; results indicated that the extent of participation in the group was not associated with measures of depression, anxiety, stress, perceived interpersonal support, or social network size, but was related to ratings of the perceived benefits of using the web-based forum. Specifically, participants in online peer support groups who offer and receive support may experience greater satisfaction than those who simply observe the interactions of others. This has implications for electronic health applications, as well as for researchers and practitioners, which seek to improve the lives of those who suffer from chronic disease.

The ever increasing popularity of the Internet as an integrated aspect of people's lives has meant that its uses are being extended to all manner of applications, including healthcare. As an example of this, the renowned Pew Internet Research Institute (2005) estimated that over 36 million people had become members of online support groups in the last decade or more. In comparison to face-to-face support services, virtual groups offer privacy, convenience, and cost efficiency, which has rendered them as one of the most promising developments in the realm of electronic health (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004).

With the increasing stronghold of cardiovascular disease, cancer, and diabetes on the population, it is not surprising that the Internet has provided an environment for selfhelp (Madara, 1997) and risk reduction (La Corsiere, 2001) in these areas of healthcare.

While cardiovascular disease is listed as the number one cause of death globally (World Health Organization, 2009), contributing substantially to the escalating costs of healthcare (Lopez, Mathers, Ezzati, Jamison, & Murray, 2006), social support has not been adequately verified as an effective strategy for cardiovascular risk reduction. Given depression, anxiety, and social isolation are identified by the National Heart Foundation (2003) and other well respected researchers (Bunker et al., 2003; Ormel et al., 2007) as the most pertinent to cardiac risk, there is a need to establish what role social support groups play, particularly in the online setting, in the reduction of these. One study has provided some evidence of a reduction in psychosocial risk for heart patients in the context of an online community, HeartNET. This research demonstrated that the social support provided by online peers minimised the negative experience of heart

disease (Bonniface, Green, & Swanson, 2005) and provided adaptation strategies for the healthpromoting acceptance of heart conditions (Green, Bonniface, & McMahon, 2007). While the HeartNET study has been the subject of an in-depth qualitative research agenda since its inception in 2004, this current study seeks to verify and quantify to what extent the social support provided by peers in the HeartNET setting reduces psychosocial risk factors for heart disease. This is an important contribution to the field of community psychology, particularly if peer-to-peer social support groups are to be taken seriously in the ever expanding area of electronic health, and so that researchers and practitioners might leverage their success for other health promoting purposes. The Role of Peer Support in Cardiac

## Rehabilitation

Peer support groups are usually described by members as beneficial and while their widespread popularity is testament to this, relatively few studies have substantiated the outcomes of such groups. To explore the effects of one-on-one peer support for cardiac patients, Parent and Fortin (2000) conducted a randomised, controlled trial in which 27 patients awaiting a coronary bypass graft were visited by a former patient 24 hours prior to surgery on the fifth post-operative day and four weeks after discharge. These former patients provided the experimental group with 'living proof' of a successful surgery and rehabilitation, listened and responded to concerns, reinforced the need for healthy behaviours, encouraged physical activity, and provided other emotional or informational support tailored to individual patient needs. The control group received standard medical information and care. Although the experimental group had higher anxiety scores at baseline, their anxiety level dropped after the first visit from a former patient and remained lower than that of the control group at five days and four weeks post surgery. The experimental group also reported higher levels of self-efficacy and physical activity at discharge than the control group, suggesting that peers can support

recovery from heart surgery. Even though the peers in their study underwent training before offering support, it is possible that these benefits might also translate to more natural community settings, including the online setting, particularly if the true value of the support provided is by virtue of the experience shared by former patients.

As a broader strategy for risk reduction in cardiac care, cardiac rehabilitation programs are made widely available to Australian heart patients. However, it is reported that only 24% of heart patients take advantage of these programs despite the fact that the mortality rates for those who do attend reduce significantly (Sundararajan, Bunker, Begg, Marshall, & McBurney, 2004). This may be due to the opportunity for social support that rehabilitation programs provide; although this is missed for the majority.

In Sweden, all cardiac patients are invited to participate in peer support groups for exercise, diet, stress management, and smoking cessation as part of a program offered by the Heart and Lung School. Hildingh and Fridlund (2003) investigated the outcomes of this program over a period of three years and found attendees reported denser social networks and higher levels of social support than controls at both 12 months and three years. Although physical health outcomes were similar between groups, 71% of attendees also reported physical activity several times per week compared with 40% of controls, and only 6% smoked compared with 20% of the control group. As there were no significant differences between groups at baseline, results may be attributed to program participation (Hildingh & Fridlund, 2004). However, the experimental group in this study was self-selected and attended different activities over varying periods of time, meaning that randomisation and control was not achievable. Thus, the variation within groups and interventions limits the generalisability of the research, though it may also more accurately reflect the variable uptake and effect of peer support interventions in the community.

The poor rehabilitation attendance noted in Australia may be partly reflected in patients' general dislike for group formats (Farley, Wade, & Birchmore, 2003); this calls for alternative strategies to achieve risk reduction and the secondary prevention of heart disease (Jelinek, 2004). However, more recent studies (e.g., Fernandez, Salamonson, Juergens, Griffiths, & Davidson, 2007) suggest that traditional cardiac rehabilitation, and their low attendance, remains the norm. Therefore, the provision of online social support as an alternative strategy may provide a more comfortable (anonymous) group format to satisfy patients who are uncomfortable with traditional group formats and may ultimately boost participation. Health-related Peer Support on the Internet

Given the convenience and cost efficiency of social networking online, it is unsurprising that crude Internet searches produce thousands of 'hits' for support groups making them easily accessible; although, digital inclusion is a matter of having access to computers and knowing how to use them (Willson, 2006). As with the traditional face-to-face formats, online support groups are often facilitated by peers and are frequently health related (Coile, 2000). For cancer support online, thematic analyses have indicated that both male and female cancer patients are primarily concerned with the emotional and informational support offered by their peers online (Blank & Adams-Blodnieks, 2007; Gooden & Winefield, 2007). What is more, participants in these groups may also seek to provide this support.

After analysing messages sent by members of an online cancer support group, Winefield (2006) interviewed two correspondents who wrote approximately twice as many posts as the average user, the majority of which were supportive rather than support seeking. Both indicated they had gained emotional satisfaction from their role as 'volunteer emotion workers' and from feeling they had done something valuable for someone else. In the comprehensive HeartNET study mentioned earlier, the researchers reported that "the self-help element of the support site is triggered through helping others, and reciprocal impulses mean that where a member joins the site in order to get help they may then stay involved in order to offer it (Bonniface & Green, 2007a).

A review of 100 face-to-face social support groups similarly suggested that engaging in reciprocal (peer-to-peer) support may be more efficacious than simply receiving support (Hogan, Linden, & Najarian, 2002), as observed in an investigation of support groups for stress, overeating and multiple sclerosis (Maton, 1988). In this earlier study, participants who provided or received support reported less favourable wellbeing and group appraisal than members who did both. Thus, giving support may be as potent a motivator as receiving support for members who continue to participate in groups online or in person, perhaps because of the 'ego boost' this provides, a dynamic which has previously been referred to as a gift economy (Raymond, 2000) and one which occurred on the HeartNET website (Bonniface & Green, 2007a).

To quantify the reported benefits of online support for people with medical conditions, Lieberman and Goldstein (2005) asked 114 women from five breast cancer bulletin boards to complete measures of depression and quality of life upon joining the groups and six months later. A repeated measures analysis of variance showed scores on the Centre for Epidemiological Study Depression Scale (CES-D) were improved at follow-up (F[1, 90] =10.54, p = .002) and that changes interacted with duration of group participation (F[1, 90] =10.28, p = .002). Interestingly, the largest decrease in CES-D scores was observed in those who participated for less than two months, with many stating their needs had been fulfilled before the end of the six month study. Increases in quality of life measures were not significant. Overall, the authors concluded that group participation had positive psychosocial outcomes for members, particularly those who were clinically depressed at baseline. In contrast to the cross-sectional design often used in

online group research, the strength of this study was the collection of baseline data for new members before they were exposed to the group, which is often not possible when studying existing support groups. However, the absence of a control group means that depression symptoms may have resolved over time; whether members experienced faster or greater improvements in their psychosocial wellbeing as a result of participating in the groups remains unclear.

#### Active Participation and Emotional Relief Consistent with the findings of

Lieberman and Goldstein (2005), measurable improvements in emotional wellbeing have been observed in a one year prospective cohort study of Internet support groups for depression. With the dual aims of describing user characteristics and assessing change in depression symptoms and social support over time, Houston, Cooper and Ford (2002) administered the Medical Outcomes Study (MOS) Social Support Survey and CES-D to 103 support group members at baseline and 12 months later. Participants came from North America, Australia and Europe; 78.6% were female and 82.6% were tertiary educated. Contrary to fears that the anonymity of online groups may encourage deception or inappropriate use (Lamberg, 2003), results showed 86.4% of users were currently depressed (CES-D scale score >22) and the remaining members had previously received a diagnosis of depression. Participants also had low levels of tangible, affectionate and emotional support as baseline, making their participation in the group an appropriate choice for both their depression and social isolation. While social support scores remained unchanged at follow-up, depression had resolved (CES-D scale score <22) in 33.8% of individuals with depression at baseline. Over 95% of participants believed chatting on the Internet helped their symptoms and 37.9% preferred this to traditional counseling, although 81% were still receiving face-to-face care, which may indicate that online support in

this capacity is a useful adjunct or is an important element of a more cohesive treatment regime. Emotional support was the most popular reason to use the group, followed by the support which comes through the sharing of information (informational support). Over 50% of participants were frequent users of the support group (five or more hours a fortnight) and 72.6% were still participating after 12 months. Interestingly, depression resolved in 42.9% of frequent users, compared with 20.7% in those who used the group less than five times per fortnight. This relationship remained significant after adjustment for age, gender and baseline CES-D scores. In sum, participants with depression believed they experienced considerable benefit from the Internet support group and higher levels of participation were associated with a greater resolution of depression symptoms over time.

In the previous study of breast cancer bulletin boards, 77% of participants delayed their participation for a period of time before posting (Lieberman & Goldstein, 2005) – usually referred to as 'lurking' – perhaps by taking the time to read the posts made by others before authenticating themselves through visible text. As there is some evidence that passive readers far outnumber active participants in online discussion groups (Zrebiec & Jacobsen, 2001), the authors suggested that there may be a therapeutic benefit in simply reading posts and that the outcomes of passive participation or 'lurking' should be more closely examined.

Though this has not previously been the subject of empirical research, the relationship between activity level and emotional relief has been investigated by Israeli researchers Barak and Dolev-Cohen (2006), who analysed 790 messages posted by 20 randomly selected members of an online support group for suicidal and severely distressed adolescents. Each message was given a 'distress rating' by three specially trained adjudicators and an analysis of variance was carried out using the total distress scores for each participant. Although the

emotional distress of the group did not decrease over the three-month period of participation, members who posted and received more messages during the first month expressed lower levels of distress in the following two months. The authors concluded that online support groups may often have little effect on average, yet significantly benefit certain individuals. More specifically, positive outcomes are most likely to be experienced by those who have the highest level of active participation in the group. As passive participants were excluded from this study, the experience of the lurkers remains unknown and it is possible that the distress of some participants was significantly worse after joining the group rather than better. However, the converse relationship between active involvement and later distress is consistent with previous findings that support group members who give and receive support experience greater satisfaction than those who do either or neither. Lurkers may therefore experience less benefit from online support than those actively involved. **Online Support for Heart Patients** 

Cardiac patients have been the recipients of various electronic health services including specialist consultations via videolink (Sekar & Vilvanathan, 2007), monitoring of electrocardiogram results transmitted from mobile phones to hospital databases (Salvador et al., 2005), web-based education for patients awaiting surgery (Scherrer-Bannerman et al., 2000) and the creation of purpose-built online peer support groups (Bonniface et al., 2006). While HeartNET is perhaps the best Australian example of the growing evidence for online peer-to-peer social support, with psychosocial and behavioural outcomes pending publication, online social support interventions, generally, are notable for the lack of empirical evidence underlying their widespread use and popularity. The HeartNET online community was created to provide heart patients with opportunities to share experiences with others facing similar circumstances, to offer mutual support, and to access this support from rural or remote regions. The group was initially designed as a member's

only (closed) website available only to research recruits from a specific demographic and regional area. This design proved unsuccessful in the early stages, primarily because there were insufficient numbers to create ongoing communication exchanges; for those who did engage, they soon lost interest and participation ceased altogether by the eleventh week of the trial (Green et al., 2007).

Due to the failure of the first HeartNET site, the randomised-controlled design was suspended and HeartNET was opened to the public. The group subsequently became popular amongst people from a range of locations, agegroups and backgrounds, supporting the notion that meaningful social connections cannot easily be orchestrated in research trials. In the main, this may be due to the extremely large samples needed to capture the 'natural' aspects of selection and engagement in online groups, which include negative as well as positive interactions. In fact, disputes between HeartNET members did occur, perhaps because it was more representative of real life rather than a controlled research setting, yet the potential for positive experiences appeared to outweigh the risk of conflict (Bonniface & Green, 2007b). Analysis of discussion board posts and interviews with participants indicated that the group had rallied together in spite of the conflict and continued to provide the emotional support which had been evident beforehand (Green & Costello, 2009). Many posts addressed the fear, anger or distress experienced by members in relation to cardiac disease and it was concluded that the prospect of reducing negative emotions contributed considerably to the success of the group (Bonniface et al., 2005). The site also created opportunities for newly diagnosed heart patients to redefine their sense of self in light of their medical condition (Green et al., 2007) and to assess health-related information found online in a supportive environment, with the assistance of other members (Bonniface & Green, 2007a). Furthermore, HeartNET members initiated their own system for reporting their exercise

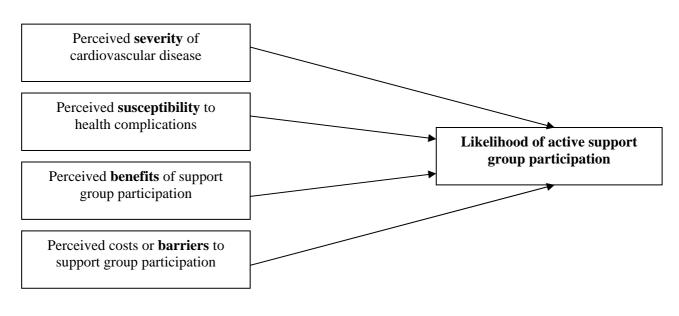


Figure 1. Health Belief Model.

achievements and encouraging the physical activities of their peers (Bonniface, Omari, & Swanson, 2006). Thus, the group facilitated multiple aspects of cardiac rehabilitation by providing emotional and informational support and promoting physical fitness after cardiac events.

#### Predicting Health-Related Behaviour

As greater participation in online peer support has been linked to reduced levels of depression and emotional distress, predicting which group members are likely to become active participants may assist in the referral of appropriate individuals to support groups and increase their efficacy. The Health Belief Model (HBM) has been used to explain variations in health behaviour among coronary heart disease patients in the past (Ali, 2002) and may also serve as a framework for the prediction of participation in online support groups for cardiac patients, if we consider this a health supporting action purposefully undertaken by members to enhance their physical and mental wellbeing.

The HBM posits that the likelihood of performing a health behaviour is determined by perceptions of susceptibility to and severity of the health condition, coupled with an analysis of the benefits and barriers to performing the health promoting action. Figure 1 illustrates the HBM as it was applied in the current research project Considering the literature reviewed here provides some evidence of the positive outcomes of support groups for people with cardiac disease, this study examined: 1) the relationship between participating in an online support group and psychosocial risk factors, and 2) reasons for active group participation.

# Method

#### Participants With permit

With permission from the HeartNET team of researchers, a total of 203 active members and 516 inactive members of the HeartNET online community were invited to participate, with response rates of 28% and 12% respectively. Sixty-three male (63) and 57 HeartNET members, aged between 22 and 79 years (M = 53.73, SD = 11.88), participated in this study. Fifty-seven participants had posted messages on HeartNET discussion boards and were thus classified as active Members. The sixty-three inactive participants included those who either never logged on to the website after their initial visit or had not posted any messages on the discussion boards after logging on (therefore, including those who may have 'lurked' the site). Eighty-eight percent of

participants were heart patients and the remaining 12% were carers, family members or friends of someone with a heart condition. Heart patients were diagnosed up to 52 years prior (M= 8.65, SD = 10.35) and all participants had been members of HeartNET for between 1 and 208 weeks (M = 127.13, SD = 60.64). The majority of participants had a tertiary education (69%), lived in urban areas (68%), and were married or living with a partner (76%). They had between 2 and 35 years (M = 15.91, SD = 7.40) experience using computers and had a home or work computer connected to the Internet for at least 3 years (M = 11.10, SD = 4.46). *Measures* 

An online survey was constructed incorporating six established measures of negative affect and social support, as well as a 38-item questionnaire based on the HBM. The questionnaire addressed the benefits and barriers to HeartNET membership, health-related perceptions, and demographic information. The first two predictors posited by the HBM, perceived severity of the heart condition and susceptibility to health complications, were rated on a scale from 1 to 10, where 1 was 'Not Severe' and 10 was 'Extremely Severe'. The remaining two predictors, perceived benefits and barriers to participating in the HeartNET group, were assessed using 26 statements, which were rated on a 5-point scale. Ratings were summed to produce a total benefit and barrier score for each participant, with higher scores reflecting a greater importance of those factors to the individual.

The other six measures included in the survey, which have all achieved good reliability and validity scores in verifying studies, were: 1) *The Depression, Anxiety and Stress Scales* (DASS; Lovibond & Lovibond, 1995); 2) *The ESSI Instrument - Enhancing Recovery in Coronary Heart Disease Patients (ENRICHD) Social Support Instrument* (Vaglio et al., 2004); 3) *The Interpersonal Support Evaluation List* (ISEL; Cohen, Mermelstein, Kamarck, & Hoberman, 1985); 4) *The Social Connections Index* (SCI; Kaplan, Salonen, Cohen, Brand,

The Australian Community Psychologist © The Australian Psychological Society Ltd Syme, & Psuka, 1988); 5) *The Social Networks Questionnaire* (SNQ; Glass, Mendes de Leon, Seeman, & Berkman, 1997); and 6) *The Perceived Social Support Scale* (PSSS; Dahlem, Zimet, & Walker, 1991). *Procedure* 

Participants in the broader HeartNET study were initially recruited through local cardiology clinics and through databases kept by National Heart Foundation of Australia (WA). Recruitment was promoted via word of mouth, Internet browser listings, poster advertisements in medical centres, and articles in newspapers and in magazines. Members give consent upon registering with the HeartNET group for their website activity to be logged and for this information to be used for research purposes. A reminder to review terms and conditions is also presented each time a member logs on to the website.

With support from the HeartNET researchers and web developers, 719 members of the website were invited via email to complete the online survey for the current investigation. An invitation to participate was also posted on the website discussion board and two reminders were emailed to members who had not yet completed the survey during the two months of data collection. In addition to asynchronous discussion boards which allow members to leave public messages on a range of different topics for the group to 'discuss', the HeartNET website also features a chat room, private messaging system, and informational resources related to heart disease. However, as the discussion boards are the most popular aspect of the site, the number of discussion board posts contributed by each member was gathered from the existing HeartNET database and was used to determine if participants were active or inactive members. Consent and contact details were collected through an independent webpage and participants were matched with survey responses using unique correlation codes in order to ensure anonymity. The median response time taken to complete the survey

Table 1

Mean DASS, ESSI, ISEL, PSSS, SCI and SNQ Scores as a Function of Support Group Participation Level

|      | Active<br>Members<br>(n = 40) | Inactive<br>Members<br>(n = 34) | Total $(n = 74)$ |  |
|------|-------------------------------|---------------------------------|------------------|--|
| DASS | 25 (24.4)                     | 30 (26.3)                       | 28 (25.4)        |  |
| ESSI | 17 (5.8)                      | 15 (6.2)                        | 16 (6.0)         |  |
| ISEL | 124 (23.4)                    | 117 (24.5)                      | 120 (24.0)       |  |
| PSSS | 67 (14.1)                     | 64 (15.2)                       | 66 (14.7)        |  |
| SCI  | 15 (4.1)                      | 15 (3.7)                        | 15 (3.9)         |  |
| SNQ  | 36 (20.9)                     | 30 (15.3)                       | 34 (18.6)        |  |

Note: Standard deviations are presented in parentheses.

was 22 minutes. Responses were not compulsory and participants were therefore free to skip questions at their discretion.

#### Results

The mean and standard deviation of scores on the DASS, ESSI, ISEL, PSSS, SCI and SNQ for active and inactive members of HeartNET are presented in Table 1. A multivariate analysis of variance (MANOVA) was undertaken to explore the relationship between negative affect, social support, and active participation in the group. Composite test scores for the DASS, ISEL and PSSS were used to increase the power of analyses. The variance-covariance matrices were homogeneous, Box's M = 29.366, F(21,18010 = 1.27, p = .181, and hence Wilks' Lambda was used. Results of the MANOVA, contained in Table 2, showed participation in the group was not related to measures of negative affect or social support, F(6,67) = .97, p = .930. As emotional status has been found to improve most during the first few months of participation

in online support groups (Lieberman & Goldstein, 2005), data were examined to assess if duration of membership could be included as a factor in post hoc tests. Only six participants were identified as being new members who had joined the group less than three months earlier and this small sample was therefore not suitable for further analysis.

A logistic regression was conducted to ascertain whether demographic variables and HBM predictors were related to HeartNET participation. As shown in Table 3, active members of the support group tended to rate the benefits of participation as more important and barriers as less important than inactive members, after controlling for age, gender, location, level of education, computer literacy, perceived severity of their illness and perceived susceptibility to health complications. None of the other predictors achieved significance.

## Table 2

|      | df | F    | Р   |
|------|----|------|-----|
| DASS | 1  | .93  | .34 |
| ESSI | 1  | .69  | .41 |
| ISEL | 1  | 1.02 | .31 |
| PSSS | 1  | .46  | .50 |
| SCI  | 1  | .48  | .49 |
| SNQ  | 1  | 1.06 | .32 |
|      |    |      |     |

F Ratios for Univariate Main Effects of Negative Affect and Social Support on Support Group Participation Level

## Table 3

Beta, Standard Error and Wald Values for Age, Gender, Location, Education, Computer Use, and HBM Predictors in Active and Inactive Members

|                | В    | Standard<br>error | Wald  |  |
|----------------|------|-------------------|-------|--|
| Age            | 01   | .02               | .08   |  |
| Gender         | 10   | .50               | .04   |  |
| Location       | 05   | .50               | .01   |  |
| Education      | .15  | .24 .40           |       |  |
| Computer Use   | 06   | .04               | 2.79  |  |
| Severity       | 09   | .13 .46           |       |  |
| Susceptibility | .01  | .13               | .01   |  |
| Benefits       | 09   | .03               | 7.03* |  |
| Barriers       | .11  | .04               | 6.99* |  |
| Constant       | 2.74 | 2.75              | 1.00  |  |

\* p < 0.05

NB:  $\chi^2$  (9, N = 87) = 21.51, p < 0.05

#### Social support online

|   | Not at all important             | Not very<br>important | Sometimes<br>important      | Very<br>important          | Most<br>important    |
|---|----------------------------------|-----------------------|-----------------------------|----------------------------|----------------------|
| Learning from the experience of others.   | portunt                          | portunt               | mportunt                    |                            | 4.1 (.1)             |
| Getting advice about preparing for surgery or medical treatments.   |                                  |                       |                             | 3.7<br>3.5 (.2<br>3.4 (.2) |                      |
| Receiving encouragement for making healthy changes to my diet or lifestyle.                                     |                                  |                       |                             | 3.5 (.2)                   | 3.9 (.1)             |
| The understanding of others with similar experiences.   |                                  |                       |                             |                            | 4.3 (.1)<br>3.8 (.1) |
| Having someone to share my worries with when I'm stressed.  |                                  |                       |                             | 3.4 (.1)                   | 4.0 (.2)             |
| Being able to support others in times of need.  |                                  |                       |                             |                            | 4.1 (.1)             |
| Sharing my knowledge or experience when it may be<br>helpful to others.   |                                  |                       |                             |                            | 4.0 (.1)<br>7 (.1)   |
| Having a laugh and not taking things too seriously.   |                                  |                       |                             |                            | 4.1 (.1)<br>4.0 (.1) |
| Sharing my thoughts when I'm feeling down.  |                                  |                       |                             | 3.6<br>3.4 (.1)            | (.2)                 |
| Socialising and chatting with members online.   | 3.3 (.2)<br>2.9 (.1)             |                       |                             |                            |                      |
| Attending social events in person with other group members.   | 2.9 (.1)<br>3.0 (.2)<br>2.4 (.2) |                       |                             |                            |                      |
| I know I can trust group members with my private thoughts and feelings.   | 3.7 (.2)                         |                       |                             | 3.7 (.2)                   |                      |
| Participating in HeartNET reminds me that I am not alone.   |                                  |                       |                             | 4.1 (.1)                   |                      |
| My Internet connection or technical problems make<br>it hard for me to participate.                             |                                  |                       | 2.0 (.2)<br>2.0 (.2)        |                            |                      |
| I don't have time to be involved in an online community.  |                                  |                       | 2.5 (.2                     | )<br>.7 (.2)               |                      |
| I have been put off by disagreements or arguments among members.  |                                  |                       | 1.9 (.2)<br>1.8 (.1)        |                            |                      |
| Sometimes I find comparing my situation with others online upsetting, because I feel I am worse off.            |                                  |                       | 1.8 (.1)<br>1.9 (.1)        |                            |                      |
| I don't feel other members would understand my perspective.   |                                  | 1.                    | 7 (.1)                      |                            |                      |
| I don't have the computer literacy or skills to be able<br>to use the website properly.                         |                                  | 1.5 (.                |                             |                            |                      |
| I feel uncomfortable about sharing my feelings with strangers online.   |                                  |                       | 1.8 (.1)<br>2.6 (           | 2)                         |                      |
| I am not sure I can trust the information shared online by others.  |                                  |                       | 2.1 (.2)                    |                            |                      |
| Sometimes I am offended if I don't receive quick responses to my posts.   |                                  | 1.6<br>1.5 (.         | (.1)                        | ,                          |                      |
| I find the website difficult to navigate and have   |                                  |                       | 7 (.1)                      |                            |                      |
| trouble finding the information I am looking for.<br>HeartNET is available at any time of the day or<br>night.* |                                  |                       | 2.1 (.2)<br>2.0 (.2)<br>2.7 | (.2)                       |                      |
| HeartNET is accessible from anywhere in the world<br>and requires no traveling.*                                |                                  |                       | 2.0 (.2)                    |                            |                      |
| Membership to online groups is free.*   |                                  | 1.                    | 2.6 (<br>7 (.1)             | .2)                        |                      |

Active Members (n = 43) Inactive Members (n = 44) \* Reverse coded items

Figure 2. Mean ratings of benefits and barriers to support group participation for Active and Inactive Members (Standard deviations are presented in parentheses).

All benefits of HeartNET membership were rated as important by over 75% of participants, except 'attending social events in person with other group members', which was rated as important by only 59% of participants. The highest rated benefit was 'learning from the experience of others', with 98% of participants indicating this was important. Figure 2 presents mean ratings of benefits and barriers to HeartNET participation by active and inactive members.

#### Discussion

The hypothesis that active participation in an online peer support group for cardiac patients would be associated with reduced psychosocial risk factors for heart disease was not supported by this study. Members who posted messages on the discussion boards did not have significantly lower levels of negative affect than those who were classified as inactive members and participation in the group was not related to current symptoms of depression, anxiety, and stress. However, unpublished doctoral research (Costello, 2009) conducted by a member of the HeartNET research team does provide detailed interpretive evidence to the contrary, possibly pointing to the value of qualitative research in revealing the finer details not exposed through this quantitative approach. Although the results of this study are inconsistent with qualitative findings and the observed relationship between activity level in online support groups and measures of depression (Houston et al., 2002) and emotional distress (Barak & Dolev-Cohen, 2006), variations in duration of group membership may partly explain this discrepancy. Participants in the current study had been members of the support group for up to four years before data collection, while participants in these previous studies had provided baseline data or were followed for a period of only three months. Furthermore, Lieberman and Goldstein (2005) found women who contributed to breast cancer bulletin boards for one to two months had greater decreases in their depression scores than those who participated for three to six

months. It is therefore possible that active participants in the current study experienced similar changes in their emotional status after first joining the group and that these effects dissipated over time. Still, Gustafson et al. (1999) asserted previously that for individuals who were isolated, benefits could be delivered, regardless of time – when they needed it most – even if those benefits were not maintained over the longer term. Although these authors recognised that while the maintaining of benefits is ideal, delivering any 'amount' of benefit, particularly for those who cannot access support easily, is a worthwhile outcome.

In addition to equal levels of negative affect, active and inactive members of the online support group had equivalent levels of perceived social support and similarly sized social networks. However, as users were not required to log on to read discussion board posts, we cannot be sure how many inactive members might have been 'lurking' the site and it is possible that these lurkers gained social support by reading the posts of others. Considering both groups had comparable social resources available to them, lower levels of perceived support from family and friends did not appear to promote greater activity or reliance on the support group. Again, the interpretive research already conducted with HeartNET might add some explanation here, in that heart patients, generally, do not necessarily see their family and friends as being capable of providing good support because of their inability to truly understand experiences (Costello, 2009).

Given that established social support measures tend to focus on face-to-face interpersonal contact, rather than online communication and connectedness, there were some indications by participants that the questionnaire did not assess the contribution virtual interactions made to their social lives. For example, one participant who had frequent 'chats' with family members living interstate or overseas commented that 'not having tangible contact doesn't necessarily cause loneliness, as seems to be implied in your survey.' Further to this, 'attending social events in person with other

group members' was the lowest rated benefit of HeartNET membership, suggesting that participants were generally not seeking to expand their face-to-face social interactions. Users of social networking websites might therefore consider their virtual communications to be a completely different but no less a valuable source of support, not wholely captured by the measures employed in this study. If this is the case, future research may benefit from using an instrument specifically designed to assess online peer-to-peer social support, provided a valid and reliable tool becomes available. However, social events were not available to many HeartNET members due to logistical challenges and these members have expressed a desire for face-to-face connectivity with their online peers (Bonniface & Green, 2007b; Green & Costello, 2009). More in-depth interpretive research is therefore needed to fully explore the relationship between online and face-to-face interactions of support group members and bring to light the meanings and outcomes associated with this modality.

## Benefits of HeartNET Participation

The assumption that the HBM could be used to predict extent of participation in the online community was partially confirmed by the finding that active members considered the benefits of the group to be more important, and barriers to be less important, than inactive members. Active participation in the peer support group may therefore have led to greater satisfaction, as was found in previous studies by Winefield (2006) and Maton (1988). Conversely, more positive appraisals of the group may have led to greater participation. In either case, the perceived severity of cardiac disease and susceptibility to health complications of members did not predict level of participation, suggesting that the predictive power of the HBM in this context is limited. Other models of health behaviour, such as the Transtheoretical Model (Prochaska et al., 1994), may offer greater predictive power and could be investigated in future, particularly in relation to the stages heart patients might need to move through before they

are ready to take up membership in online support settings. While the majority of respondents to the survey were tertiary educated and lived in urban areas, this is likely to reflect the attributes of Internet users generally and demographic variables were unrelated to level of support or group participation. Thus, the group seems to appeal to a diverse range of people and it would be inadvisable to base referral of new members on the characteristics examined. Furthermore, the number of male and female participants in this study was approximately equal, suggesting a similar willingness of each gender to seek and contribute to this peer support group.

Although the cost-benefit analyses of active members were more favourable, inactive members of the HeartNET site rated 10 of the 13 benefits of membership as very important aspects of the group. These included learning from the experience of others, getting advice, being understood, receiving encouragement, sharing worries, being able to offer support, helping others, having a laugh, socialising, sharing thoughts when feeling down and feeling less alone. As the benefits of participation received high ratings from both groups, even members who were classified as inactive appeared to appreciate what the group had to offer and viewed the service as valuable. This suggests that there may have been a substantial number of lurkers in the inactive sample and that they do derive some social support from reading posts rather than actively participating. Any therapeutic effect experienced by active members as a result of these benefits might therefore be experienced to a lesser extent by lurkers and this relationship warrants further investigation. In this respect, the role that health workers or moderators of online groups have in converting inactive participants to active participants is highlighted. Therefore, there remains a need for further research to determine the level of engagement needed to encourage broader participation.

Methodological Challenges and Limitations Peer support groups are necessarily not standardised interventions. Participants select themselves and attend intermittently over varying periods of time. The flexibility of these therapeutic communities can allow effective responses to the unique social, emotional and informational needs of individuals and attempts to replicate this in researcher-controlled environments are unlikely to be successful because of the difficulty in replicating the 'natural' setting. The ability of participants to initiate their own membership and pattern of involvement may therefore be vital to the success of such services. For these reasons, the present study utilised an existing online community to explore the relationship between level of group participation, psychosocial risk factors for heart disease and a range of predictor variables. Although this ensured a more naturalistic research setting, many limitations common to investigations of peer support efficacy remained, including the absence of an appropriate control group, a lack of opportunity to collect baseline data, and a restricted sample size. Despite approximately equal numbers of active and inactive members participating in the study, the response rate of active members was, not surprisingly, more than double that of inactive members, which may have biased outcomes. Inconsistent definitions of social support throughout the psychological literature also resulted in a need to use multiple measures of this construct and increased response burden on participants, which may have led to incomplete survey responses.

At the time of data collection the HeartNET group had over 700 members, yet the response rate to the survey was low. However, the reviewed evaluations of breast cancer bulletins boards (Lieberman & Goldstein, 2005) and online emotional support (Barak & Dolev-Cohen, 2006; Houston et al., 2002) had smaller samples than the present study, despite recruiting from many different support groups. In the area of face-to-face peer support for heart patients, the randomised-controlled trial conducted by Parent and Fortin (2000) had a sample of only 27 males and 125 of the 160 participants recruited by Hildingh and Fridlund (2003) did not attend a peer support intervention, even though every heart patient in Sweden had been invited to participate in the program they evaluated. As such, the problem of small sample size is not unique to this study. Given that peer support group evaluations are observational, larger samples are required and could be achieved by pooling data across studies. *Conclusions* 

The results of the present study indicate that active participation in an online support group for heart patients is associated with greater perceived benefits than simply observing the interactions of others. This is consistent with previous findings that support group members who give and receive support experience greater satisfaction than those who do one or the other. Members indicated that 'learning from the experience of others' was the most important benefit of group participation, the value of which has been examined in earlier publications by the HeartNET research team (Bonniface & Green, 2007a). Benefits of membership received high ratings from both active and inactive members, suggesting that any effects of active participation might be conferred, albeit less efficiently, by passively reading discussion board posts. As demographic variables did not differ between the two groups, referral of cardiac patients by healthcare professionals based on these characteristics would not be recommended. The hypothesis that active participation would be associated with reduced negative affectivity and social isolation was not supported by this study, despite the widely held belief among participants that the group provided valuable emotional support. Although it is possible that participants experienced changes in emotional status during the initial months of their membership, causal relationships between support group participation and reduced negative affect are difficult to determine through observational studies. The cyclical nature of depressive symptoms over time must therefore be considered as an explanation for

both the findings of the current study and those of previous researchers; even so, these benefits are commendable and applicable. Given that the dynamic social aspects of online peer support groups cannot be easily replicated in randomised-controlled trials and that the popularity of these groups continues to grow, larger longitudinal studies using baseline data and in-depth interpretive research are required to investigate if these groups have measurable effects on cardiovascular risk. If this can be achieved, the dynamics of online social support groups may be better utilised by various health professionals in order to reduce the burden of disease and enhance the health of those who adopt their membership.

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