The health impact of an online heart disease support group: a comparison of moderated versus unmoderated support

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Abstract

The aim of this study was to assess whether our online closed community heart care support group and information resource could sustain changes in health behaviour after the moderators withdrew their support. Heart patients (n = 108) living in a deprived area of Greater Manchester were recruited from general practitioners’ coronary heart disease registries. The sample for this randomized controlled trial was divided in half at random where half of the participants received password-protected access to our health portal and the other half did not. At 6 months follow-up (based on the moderated phase), there was a significant difference between the experimental group and the controls in terms of self-reported diet (eating bad foods less often). This change in behaviour was not sustained during the 3-month unmoderated phase. During this unmoderated phase of the intervention, the experimental group had significantly more health care visits compared with the controls. There was no significant difference between the two phases for either group in terms of exercise, smoking or social support. This study offers insight into the potential implications for health changes of moderating arrangements for online health communities.

Introduction

Coronary heart disease (CHD) is the most common cause of death in the UK [1]. Although mortality from CHD has been declining, morbidity has been increasing [2]. This means that patients are now living longer with CHD and must learn to self-manage their condition accordingly. Social support and effective self-management of chronic conditions are linked with more efficient use of health professionals’ time, less severe symptoms, more confidence and self-efficacy [3–6]. Becoming competent at self-managing an illness is largely based on patients having quality information, good knowledge-processing skills and appropriate social networks [3, 4]. Thus, offering information and support online may be an effective means of achieving this [3, 4, 7, 8].

Virtual communities are now a commonly used forum for health communication and health promotion [9–12]. Health resources on the Internet are especially relevant for people with chronic conditions who may encounter barriers in obtaining information on self-management and coping strategies [8, 13, 14]. Online communities can eliminate geographical barriers, allow for anonymity and supply 24-hour access to information that can help participants to feel more informed and in control [8, 15, 16].

Online support groups have the advantage of being flexible in their delivery and offer a variety of options compared with face-to-face groups. Several studies have promoted group support while a health
professional has functioned mainly as a facilitator [17–19]. Computer-mediated support groups often act as ‘weak tie’ networks [20] where relationships often take place between individuals who communicate frequently but are not necessarily close [21, 22]. The Internet also supports closed (password-protected) online communities, which offer a place to disclose personal information in a safe environment. Such a sense of safety can be provided through security controls but in practice it is often attributable to the anonymity of online communication [23, 24]. Thus, participants can feel more comfortable talking about their condition, which may help them to develop supportive relationships [24, 25, 26]. Despite the increase in online health communities, formal evaluations of their impact on health are lacking [9, 18].

Online interventions for CHD have found that they help to increase social support [27], decrease anxiety [28], increase knowledge about managing a health condition [3, 4, 29], improve symptoms, mitigate physical dysfunction and depression [17] and enhance health-related quality of life and perceived control [7, 9, 18, 30, 31].

A notable limitation to studies that have examined the impact of online interventions on health is that they tend to focus on people who already have home computers and the skills to use them. E-health promotion can be particularly valuable to deprived populations because it can facilitate healthy behaviour change, increase social support and build community [3, 4, 32]. This study builds on past research in that we have given free home computers and an Internet subscription to heart patients in a deprived community.

**Moderated versus unmoderated online discussion groups**

A moderator refers to a person who facilitates and reviews the postings of the discussants, censors the material [33–35] and often helps participants to feel at ease. Moderating Internet discussions typically involves a strategic function, which establishes the goals and boundaries of the discussion [33]. A second function of moderating involves providing information and any supporting technologies as well as encouraging participants to join the discussion. Finally, a third function of a moderator includes a ‘process function’, which refers to managing the discussion process as a collective purposeful activity through agenda-, schedule- and rule-setting [33].

Moderators in online support groups for patients are often health professionals who stimulate discussions by posing questions or topics of interest to the group [36]. In a review of Internet-based support groups for cancer, most websites used a bulletin board format where participants posted messages to other group members [37]. One study used a chat room format where participants and a moderator met online at a scheduled time to discuss health-related topics. Both types of support groups found that peer support provided encouragement, empowerment, information and a sense of cohesion [38].

Eysenbach *et al.* [9] reviewed 38 studies on the effects of peer-to-peer interactions in health-related virtual communities and found that only six studies evaluated pure peer-to-peer communities. Most studies used non-experimental designs with small sample sizes. Thus, the impact of moderated support groups on health remains unclear. Only two of the 38 studies they reviewed were unmoderated while the remainder had some degree of facilitation by a health professional or trained facilitator who led the group and stimulated discussion. The 32 complex interventions were seen as ‘moderated’ by definition because of the involvement of health professionals, even if they had peer-to-peer forums as ‘adjuncts’ [9]. Although there is evidence to suggest that online health support groups can influence health [3, 4, 8, 12, 16], little is known about the impact of type of moderation on health behaviour [3, 9].

**Online learning and behaviour change**

The Internet offers potential for interaction and is a medium for influencing learning and behaviour change [4, 14, 39, 40]. Health promotion is often guided by the idea that providing quality information should be sufficient to change beliefs and that changing beliefs should be sufficient to change behaviour [41]. Learning and behaviour change, however, are greatly influenced by how well
A health message is heard, understood and trusted and how much support individuals receive in translating new knowledge into changing practices [4, 40, 42].

A virtual learning environment can offer a space and the impetus for reflection and it can also guide participants towards key resources [43, 44]. Evidence suggests that peer-led social support can have positive health benefits [45]. Thus, learning through an informal, peer-facilitated interaction may be effective in encouraging patients to manage their health [3, 46].

Social interactions can play a key role in learning [47]. Thus, collaborative learning is increasingly being used in educational settings [47] and has numerous benefits. For example, computer technology can enable collaborative learning when face-to-face communications are difficult [48]. Evidence suggests that when participants have more active control over their learning process, their learning increases [3, 4, 40, 47, 49]. Others, however, argue that participation in electronic discussions is often minimal without a moderator [48, 50, 51] because they can smooth the process of collaboration [52] and can encourage active and effective learning [53]. It remains unclear how moderated versus unmoderated online communities influence health behaviours and which specific moderating roles encourage behaviour-changing learning.

The purpose of this study is to test the sustainability of our online intervention after the support of the website moderators was withdrawn. This study addresses two important gaps in the literature on online health support groups. First, most studies focus on those who already have computers or significant experience in using them. Here we gave free new computers and broadband access to heart patients from a deprived area. It is important to include people who may not have access to computers because they may have the most to benefit [54], specifically in terms of healthy behaviour change and increased social support. Many studies enrol participants who are already online, which could be somewhat biased. Finally, little is known about how the type of moderation of an online support group influences a change in behaviour.

### Method

#### Design

The overriding aim of this 9-month randomized controlled trial (RCT) was to test whether the type of moderation (community-based, moderated or unmoderated and peer-support-based access) to an Internet health portal could influence health behaviours among men and women with CHD. The sample was divided at random into an experimental \( (n = 54) \) and a control group \( (n = 54) \) of equal sizes. All participants received a new home computer and 1-year broadband subscription. The experimental group received access to the password-protected portal. Measurements were made using paper and pencil questionnaires at the beginning of the project, at 6 and 9 months. These data were complemented with the log data and transcripts of online discussions that took place. The first 6 months of the project were moderated by the first two authors, while the remaining 3 months were unmoderated.

#### Participants

This RCT drew a sample \( (n = 108) \) of men and women aged 50–74 from general practitioners’ (GPs) CHD registries. Our sample was drawn from a deprived area of Greater Manchester, UK, because nearly half of the electoral wards in this area are in the top 10% of the most multiply deprived wards (i.e. including measures of resources and living standards) in UK, including an increased risk for CHD. For a more detailed description of the sample and intervention, see Lindsay et al. [4].

The overriding reason for focusing on heart patients, one age group and deprived areas is to minimize the range of variation within the sample and to increase the power of the trial. We also focus on where improvement is most needed in order to provide a critical test of what value the Internet may add. Ethical approval for this study was obtained by the University Research Ethics Board and the local National Health Service (NHS) research ethics committee.

#### Intervention

Access to the project website was through a purpose-built, password-protected portal where the
experimental group could interact in one of five dedicated closed groups, with facilitation from the researchers for the first 6 months. Controls were also divided into five groups for ease of managing recruitment and introductory project meetings. All participants were given new computers and a 1-year broadband subscription; however, only the experimental group received training and access to the project portal. A technician installed the computers in the participants’ homes and also assisted with any technical difficulties that arose for the duration of the project. Weekly drop-in sessions and phone in support were also available to both groups.

The portal social architecture was initially constrained by the terms of the research design in the sense that mixing between successively recruited groups was prevented until each had the benefit of 6 months’ facilitated access. This was construed as a period of socialization and familiarization with the online environment, which took place within a safe private space for 10 people who had met one another in person at an introductory meeting and training session. In addition to the opportunity to meet, participants’ real names were used online, and there was the option of adding a photograph of oneself and a biography to one’s user profile. Thus, communication between participants was not anonymous.

The website contained a glossary and information resources about CHD, diet, exercise and smoking. Links and references to local community resources where they could seek help and advice were also given. The moderators began discussion topics during the moderated phase. Despite the fact that most participants had used a computer before, their computer skills and experience were generally low, so there were a lot of discussions and facilitation around how to use a computer and the Internet. The remaining 3 months of the project were unmoderated and all the members of the experimental group formed one ‘big group’. At this stage, real names were still used but there was certain anonymity insofar as most participants had not met face-to-face.

The portal’s discussion forums were moderated by two researchers, one male and one female, and both considerably younger than the participants. Log data on portal use were collected, showing ‘hits’ on different pages and use of the various tools available to participants (e.g. logging on and off, posting and browsing messages).

During the moderated phase, participants had access to two forms of communication with moderators within the portal: discussion forums and one-to-one instant messaging. Within the discussion forums, the moderators’ primary task was to stimulate discussions and encourage participants to join in. Moderators also joined in open discussion threads, providing information where appropriate. The moderators also fulfilled a surveillance function, checking all new posts daily. In the unmoderated phase, the moderators still performed the same surveillance role but they no longer started new threads, so control over content passed to participants.

Measures
Two forms of data are brought together in this paper: 6- and 9-month responses to the same questionnaire by all participants, cases and controls and selected exchanges within the website discussion forums by cases over the duration of the project. Repeat questionnaires were collected from May 2006 to June 2007 to assess the influence of our health portal on the management of heart conditions before participants were given the computers and 6 months after they were introduced to the Internet health portal. A baseline survey about history of residence, employment, health status, lifestyles and use of health care was administered to each group at the initial project meetings.

The t-tests for within and between groups were used to examine the influence of our health portal on health behaviours. Changes in behaviour were determined by calculating the difference in scores from Time 1 (6 months) to Time 2 (9 months) and carrying out a paired t-test, while the differences for experimental and control groups were compared by a grouped t-test. Exercise frequency was measured in terms of ‘how many days during a typical week you spend in moderate exercise’ where a higher score indicates more time spent in exercise. Smoking was measured by average number of cigarettes smoked per day. Diet was measured by adding a
series of variables together, which are standardized from the Health Survey for England [55] and include: ‘how often do you eat the following foods: chips, sweets, crisps, fried foods, ready-made meals and cakes/biscuits.’ For each option, the participant could select from a scale ranging from ‘at least once per day’, ‘several times per week’, ‘about once a week’, ‘rarely’ and ‘never’. A higher score indicates eating these foods more often. A total score was summed for all of these six items where the scores could range from 6 to 30. Health visits included all visits to a GP, nurse, specialist and other health care providers in the past month. These measures were chosen because they are the factors which are most likely to influence health behaviour change among heart patients [1]. These are reliable measures that are frequently used in the Health Survey for England [55].

Analyses

The t-tests [between Time 1 (after 6 months of moderated access) and Time 2 (after 3 months of unmoderated access)] were used to examine the influence of our health portal on health behaviours. The difference in scores between 6 months (moderated phase) and 9 months (unmoderated phase) was calculated and used as a means to examine change that occurred over the time period.

Results

The age of the sample ranged from 50 to 74 and the mean was 62.9. Sixty-six percent of the participants were male. Although the majority of participants had used a computer at some point prior to the study (75.9%), less than half of them (43.5%) owned their own home computer. Slightly over half of the sample (56.5%) had used the Internet before the study but only 36.1% of them had home access to the Internet.

Portal use

During and after the moderated phase, the trend was for an increase in the ratio of posting to browsing in the discussion forums and an increase in the ratio of time spent ‘communicating’ to time spent using the informational resources. Message writing to moderators decreased from the moderated to the unmoderated phase by 23% while message writing between participants increased by 50% between moderated and unmoderated phases. This suggests that there was a decrease in reliance on moderators, with participants becoming more inclined to turn to each other for one-to-one communication instead of to the moderators. This transition was a gradual one, however, and for ethical reasons, moderators remained available to participants, if needed. Because the content of instant messages was treated as private, we cannot say whether the exchange of messages between participants was used to give and receive the same or different types of social support as the exchange of messages with moderators. Table I shows the changes in health behaviour between the moderated and unmoderated phase for the experimental group. They spent significantly fewer days per week in moderate exercise in this phase of the project compared with their scores for the moderated phase. There were no significant changes in the number of cigarettes smoked, social support, diet or number of health visits.

Table I. Changes in health behaviour, experimental group (n = 52)

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Time</th>
<th>Mean</th>
<th>SD</th>
<th>t</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Days per week moderate exercise (+)</td>
<td>1</td>
<td>2.63</td>
<td>1.78</td>
<td>3.73</td>
<td>0.000***</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>1.71</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cigarettes smoked per day (−)</td>
<td>1</td>
<td>9.00</td>
<td>8.20</td>
<td>−0.993</td>
<td>0.344</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>11.45</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social support score (+)</td>
<td>1</td>
<td>17.59</td>
<td>4.30</td>
<td>0.322</td>
<td>0.749</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>17.40</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diet (frequency of bad foods) (−)</td>
<td>1</td>
<td>13.76</td>
<td>2.47</td>
<td>0.503</td>
<td>0.617</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>13.59</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No. of health visits (−)</td>
<td>1</td>
<td>4.05</td>
<td>4.69</td>
<td>−1.61</td>
<td>0.113</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>5.09</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(+): Refers to a higher value is better for this outcome. (−): Refers to a lower value is better for this outcome. ***P = 0.000096.
ate significantly less ‘bad’ foods compared with the controls. As we can see from Table I, this change in health behaviour was not sustained during the unmoderated part of the experiment.

The control group also experienced a significant reduction in the number of days per week spent in moderate exercise (refer to Table II). There were no significant differences in the number of cigarettes smoked, social support, diet or number of health visits.

Table III shows the combined differences between the moderated and unmoderated phase among the experimental and the control groups. There was a significant difference in health care visits between the experimental and control groups where the experimental group had significantly more health care visits compared with the controls. Although the experimental group had only a slightly higher average number of health care visits compared with the moderated phase, the control group had a decrease in the average number of visits (refer to Tables I and II). There were no significant differences between the experimental group and controls in terms of exercise, smoking, social support or diet.

**Discussion and conclusions**

The Internet is increasingly being used as an effective health promotion tool. Our study addresses important gaps in the literature on e-health and is one of the few of its kind to distribute home computers and free Internet access among an older group of heart patients. Past research tends to focus on the use of the Internet for health information among those who already have a computer and/or who are already online, while less is known about the impact on health behaviour change among older populations in deprived areas [3]. Secondly, little is known about how the type of moderation of an online support group influences a change in behaviour.

Our online intervention for heart patients was associated with visiting health professionals more often during the unmoderated phase. Past studies have suggested that interventions which raise patient’s self-efficacy can help to reduce health care visits because they are more confident in self-managing their condition [56, 57]. Such interventions, however, are typically moderated throughout and are of short duration. The longer term impacts are often not followed up, nor has there been an examination of what would happen if the groups were unmoderated. These samples are also typically from middle-class backgrounds that tend to be more

### Table II. Changes in health behaviour, control group (n = 54)

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Time</th>
<th>Mean</th>
<th>SD</th>
<th>t</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Days per week moderate exercise (+)</td>
<td>1</td>
<td>2.31</td>
<td>1.59</td>
<td>2.20</td>
<td>0.033*</td>
</tr>
<tr>
<td>Cigarettes smoked per day (−)</td>
<td>2</td>
<td>1.86</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social support score (+)</td>
<td>1</td>
<td>8.15</td>
<td>7.20</td>
<td>0.192</td>
<td>0.851</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>7.76</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diet (frequency of bad foods)</td>
<td>1</td>
<td>16.16</td>
<td>4.14</td>
<td>−1.63</td>
<td>0.109</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>17.21</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No. of health visits (−)</td>
<td>1</td>
<td>14.50</td>
<td>2.55</td>
<td>1.93</td>
<td>0.060</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>13.73</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(+) Refers to a higher value is better for this outcome. (−) Refers to a lower value is better for this outcome.

*P < 0.05.

### Table III. Differences in health behaviour between experimental group and control (moderated versus unmoderated phase) (n = 108)

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Group</th>
<th>Mean</th>
<th>SD</th>
<th>t</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Days per week moderate exercise (+)</td>
<td>Cases (53)</td>
<td>1.73</td>
<td>1.16</td>
<td>0.383</td>
<td>0.703</td>
</tr>
<tr>
<td>Cigarettes smoked per day (−)</td>
<td>Controls (45)</td>
<td>1.82</td>
<td>1.05</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social support score (+)</td>
<td>Cases (54)</td>
<td>2.45</td>
<td>8.20</td>
<td>0.903</td>
<td>0.376</td>
</tr>
<tr>
<td></td>
<td>Controls (54)</td>
<td>0.384</td>
<td>7.20</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diet (frequency of bad foods)</td>
<td>Cases (53)</td>
<td>8.53</td>
<td>6.32</td>
<td>0.650</td>
<td>0.517</td>
</tr>
<tr>
<td></td>
<td>Controls (44)</td>
<td>7.64</td>
<td>7.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No. of health visits (−)</td>
<td>Cases (53)</td>
<td>1.03</td>
<td>4.69</td>
<td>2.04</td>
<td>0.044*</td>
</tr>
<tr>
<td></td>
<td>Controls (45)</td>
<td>0.681</td>
<td>3.32</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Sample sizes vary because of missing data. (+) Refers to a higher value is better for this outcome. (−) Refers to a lower value is better for this outcome.

*P < 0.05.
engaged in healthy behaviours and also have the resources to consume healthy lifestyles. The sample in our study was from a deprived urban area and they may have been less confident in managing their health, especially during the unmoderated phase. It could even be that the unmoderated phase decreased some of the participants’ confidence if they felt uncertain about what to do with the information they were encountering. Alternatively, the increased number of health care visits may be a result of their many discussions about medications and their side effects as they encouraged one another to visit their GP or pharmacist for a medication review.

Our findings from our 6-month moderated phase [4] suggest that higher levels of social support have an influence on eating bad foods less often. This may be a result of the context in which these interactions took place and the interventions of a moderator. Our subsequent findings in the second phase of the study show that the original change in diet was not sustained in the unmoderated phase of the project. Given that dietary behaviour is particularly susceptible to social influences [56], it could be that the participants were not receiving as much support and encouragement during the unmoderated phase and thus did not continue with their healthy eating changes. Upon examining their discussions on the website, there was certainly not a lack of posts discussing healthy foods and diet during the unmoderated phase.

There may be a difference between the type of support they received from each other (continually) and the type they received from the moderators during the first phase. The perceived authority of advice offered by the latter (usually by providing links to reliable web resources) may have provided a more compelling case for behaviour change (and although the moderators made it clear that they had no special medical or dietary knowledge, their status as ‘academics’, and the type of language they used, may have influenced these perceptions).

The moderators in this project were seen as key actors in processes of translation, tailoring and mapping the knowledge of groups formed on our project portal and the wider social networks interlinked through each member [4, 40]. Many of the participants initially relied on the moderator’s comments and feedback as there was often little response from other group members. When participants were left to navigate the website and the World Wide Web by themselves, they may have felt discouraged which could have hindered their motivation and self-confidence.

The main implication of this study for (online) health educators is that having a moderator in an online support group may play an important role in changing and maintaining healthy behaviours and reducing health care visits especially for older persons who may lack skills and confidence in using a computer. If a website is to continue after the initial intervention, then it is also important to have an exit strategy in place to smooth the transfer of moderating responsibilities to participants or a third party. Given the limitations with multiple comparisons, these results should be taken as suggestive rather than significant. Further, although many of the participants did not have a home computer or home access to the Internet prior to the study, many of them did have some prior experience to using the Internet and may have been atypical compared with those who had no computer experience at all. Finally, the extent of some conditions may be under-reported due to self-denial of their heart condition.

One of this study’s strengths was that the sample was drawn from an older population living in a deprived area. Future studies should examine a variety of age groups and diseases in order to explore the conditions under which different forms of moderation work best.

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Conflict of interest statement

None declared.

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