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Communication on a Health-Related Website Offering Therapeutic Support: Phase 1 of the HeartNET Website

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Phase 1 of the HeartNET website

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ABSTRACT: *This paper investigates the usefulness of a modest-budget website set up to support people recovering from heart-related incidents through a combination of all or some of the following: surgery, drugs, and lifestyle change.*

Online communities have been shown to offer support for their members. Ideally, the members of this experimental site would eventually constitute an online community. Effective interaction and personal communication indicate that an online community is developing. The opposite is also true: declining and aborted exchanges might indicate a failure to establish community. This paper reports on the first eight weeks of the experimental website HeartNET. As a result of findings during phase one, researchers are radically rethinking the second phase of the research project. Even so, the early findings include some evidence of effective communication and hint that phase two may see the emergence of online community.

Background

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This paper reports on phase one of the experimental website HeartNET, which was set up to support people recovering from heart-related incidents through a combination of all or some of the following: surgery, drugs, and lifestyle change.

If the website is proven effective, it might offer a way for the National Heart Foundation of Australia to support country and remote

patients recovering from the impact of a significant health event. Since the Heart Foundation's support budget is stretched, and there are limited funds for dedicated, health-professional website moderators, the trial is partly to investigate whether the community of users is self-supporting and can be run therapeutically with minimal intervention from experienced volunteer facilitators.

The challenge of forging communication

The communicating of affect and emotion with regard to the important topics of life, health, and hope has traditionally been associated with face to face (F2F) or 'rich' communication environments. The general rule of thumb has been that the more senses used in a communicative interaction, the greater the potential for effective communication. However, communication is not dependent upon the senses used in the communicative exchange. When the information being communicated carries a significant affective load, even poor communicative environments can have a huge impact. Routine encounters in everyday life rarely register significant emotional impact, despite their being F2F, while an old photograph can evoke an array of emotions of great intensity (Barthes, 1980). Thus the affective load in a communicative interaction is a complex interplay of information to be communicated, communicative channel, physical and psychological context, communicative intent, and reception. If affective connection is determined through a range of complex factors, however, can it be engendered in a given medium as a result of the scientific application of principles? Specifically, in terms of this paper, can online interactions be deliberately generated and sustained in such a way that participants develop a sense of authentic relationship to individuals in the community and to the community as a whole?

The challenge in this scenario is not to take an existing pattern of online communication and ask 'does this constitute a community?' Rather, it is to take a range of people—all of whom are strangers to one another, and many of whom have limited experience with online communication—and see if they can be coaxed into adopting behaviours that lead to the development of a community. If the infrastructure is created, and a group of participants recruited, will community be generated? This paper outlines the first stages of a research project that set out to answer these questions. It investigates the impacts of a therapeutic online community for 'baby boomers' (people born between 1946 and 1964) facing the implications of heart disease. This study explores whether the group of individuals

concerned could be accurately described as communicating effectively and moving towards the formation of an online community.

The online community

In 1993, Howard Rheingold defined virtual communities as 'social aggregations that emerge from the Net when enough people carry on those public discussions long enough, with sufficient human feeling, to form webs of personal relationships in cyberspace' (p. 5). The subjectivity surrounding the phrase 'sufficient human feeling' is self-evident, but the definition remains useful because it alludes to the necessary personal component of the communication and identifies this as critical to the establishment of community. Apart from Rheingold, others have described how 'neighbourhoods of affect and interest— "psychological neighbourhoods"—are engendered by technologies such as the telephone, email, and Internet chat' (Green 2002, p. 76), although these are often based upon prior social knowledge in F2F circumstances.

Wellman and his colleagues are also appreciated for recording their shift in perspective on the nature of community. Their concept of community changed when they realised they 'had only been looking for the obvious physical signs of local community—on front porches and street corners—without noticing the more subtle reality of community ties' (Wellman et al., 1988 p. 130). Informal networks of companionship and support between people are elements sometimes missed when communities are framed solely as tightly-bound solidarities (Wellman et al., 1988). 'Although community was once synonymous with densely knit, bounded neighborhood groups, it is now seen as a less bounded social network of relationships that provide sociability, support, information and a sense of belonging' (Wellman, 2001 p. 2031).

The Internet is an ideal medium for supporting these new networked communities (Wellman, 2001), and the concepts of sociability, support, and a sense of belonging all involve some element of effective and affective communication. Wilbur talks movingly of the emotional dimension to online communication: 'for those who doubt the possibility of online intimacy, I can only speak of [...] hours sitting at my keyboard with tears streaming down my face, or convulsed with laughter' (Wilbur 1997, p. 18). Nonetheless, he later cautions (p. 20): 'It is too easy to log into an online chat system and imagine that it is just like wandering into a local bar. It is too easy to login and imagine

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that it is all make-believe. It is altogether too easy to enter a virtual world and imagine that this allows us to understand the "real" one'.

Given that some people do describe their online experiences in terms of community, the notion of an online community is difficult to deny. However, simply referring to any group of people who gather together online as a community overlooks the role of the emotional attachment that Rheingold and Wilbur have documented—the affective communication. True community must be legitimised as something beyond the gathering together of people online. Although there is a range of literature that suggests that communication technologies can create and sustain a sense of community (Dayan, 1998; Watson, 1997), the literature does not provide a blueprint as to how this might be achieved, nor a comprehensive framework for assessing the community-ness of online experience.

The aim of the research project outlined here is to take people who do not know each other and who are geographically distant, but who face a common health challenge, and attempt to develop patterns of affective communication. Two types of community are particularly relevant to the construction of such online interaction: 'communities of circumstance' and 'communities of interest'. Communities of circumstance form when members are bound by some similar life experience or predicament (Cummings, Heeks, & Huysman, 2003). This is a relevant definition for the community envisaged because the members face a common health challenge. A community of interest, on the other hand, forms when members are bound together because of a shared interest or pastime (Cummings et al., 2003). The two are not mutually exclusive and a group of people facing a health challenge might well see themselves as sharing a common interest in developing therapeutic habits and protective behaviours.

Although there is no single agreed definition of online community, the following attributes derived from the literature are applicable to communities of circumstance and interest. Beginning with Rheingold (1993) and Wellman (2001), the core aspects of community evident in definitions include social support, a sense of belonging, and intimate communication between a network of individuals. A report produced by Maria Papadakis (2003) provides a useful overview of attributes that might be found in online community, including 'social interactions; common ties; reciprocity in relationships; shared beliefs, values, and cultural habits among members; a sense of belonging among members; a sense of solidarity or community identity, among members; standards

of conduct for members; and members' ability to take collective action' (p. 9). To these we might add 'affective communication'. Some of these characteristics are conceptually similar or related in some way, allowing a combination and elision of categories into three major aspects characterising community: 1) social capital, 2) social support, and 3) a common culture. These three dimensions aggregate the characteristics of community that I have listed.

Social capital

Social capital, like community, resists definition. In a landmark paper about America's declining social capital, Robert Putnam (1995) referred to it as the 'features of social organisation—such as networks, norms, and social trust—that facilitate coordination and cooperation for mutual benefit' (p. 67). Putnam (1995) is interested in the breakdown of social connectedness and civic engagement, which he took to represent a decline in social capital (and perhaps community) in America. The concept of connectedness is similar to the 'web of relationships' and 'intimate communication' that Rheingold (1993) and Wellman (2001) use to define online community. However, Putnam (1995) is mainly concerned about the impact that the decline in social capital has on civic engagement. Therefore, the concepts of 'reciprocity' and 'collective action' that are used to describe online community are relevant to civic engagement and social capital.

In a recent study, Kritsotokis and Gamarnikow (2004) compare social capital with social support. They suggest that social capital relates to the *collective* influence of society, while social support relates to the *individual* relationships within society. This perspective recognises that, while a community may be devoid of social capital, it may portray social support (Kritsotakis & Gamarnikow, 2004), possibly via affective communication. As a collective concept, social capital does not consider the quality of relationships between individuals, whereas social support, being an individual concept, allows for such qualitative description (Kritsotakis & Gamarnikow, 2004). The website project addresses individual aspects of social support as well as collective aspects of social capital.

Social support

According to some authorities, online support groups are proliferating because they are satisfying unmet needs and offer an alternative to F2F support programs (Madara, 1997). Social support combines some of the elements of community discussed above, namely *belongingness,*

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intimacy, and *reciprocity.* These community elements can be observed through the three levels or layers of social support: 1) belongingness, or a sense of integration; 2) bonding, which is somewhat more personal and involves linkages between people; and 3) binding, whereby a sense of responsibility for others is experienced and expressed (Lin, 1986).

La Coursiere (2001) developed a theory of online social support that considers social support from a multidisciplinary perspective. The theory includes: 1) initiating and mediating factors that affect the way in which online social support is sought, 2) transactional filters that result in qualitative outcomes, 3) cognitive and perceptual filters that result in quantitative outcomes, and 4) the linking of both qualitative and quantitative outcomes. Although her theory is concerned with online environments only in terms of social support, a sense of community necessarily includes social support.

Other studies have found that websites with bulletin boards are a useful way to provide social support because people share information about their similar conditions (Schultz, Stava, Beck, & Vassilopoulou-Sellin, 2003). For example, individuals with depression reported receiving up to 50% of their social support online, which they felt helped to reduce their depression symptoms (Houston, Cooper, & Ford, 2002). This might imply that affective communication would best be seen as an aspect of the social support element of online community. In another study, which tested four different Internet-based support interventions, participants involved in the online discussion intervention perceived the greatest increase in social support (Barrera, Glasgow, McKay, Boles, & Feil, 2002). The other three interventions used were 1) information only; 2) information and a personal coach; and 3) information, a personal coach and involvement in the discussion forum. These results suggest that interactions between people who share similar experiences are important to the amount of perceived social support, although the Barrera et al study (2002) takes online interactions as a given, rather than as something to be engendered.

Common culture

Ulrich (1998) argues that shared values, rather than proximity, are what really creates community because they allow members to be distinguished from non-members (1998). Communities that are based on values are established when: 1) members forge a unique identity; 2) rules are used to include and exclude members; 3) members share

and transfer information easily; 4) the community as a whole receives benefits from individuals; 5) values are promoted through symbols, myths, and stories; and 6) consistency is used to build familiarity among members (Ulrich, 1998). These elements are also applicable to communities that emerge online, since a dispersed network of individuals can still share common values or culture. The example of the Phish.Net community (an online fan community) provides a useful case study of behavioural norms, and the subsequent emergence of a common culture, because members attempted to preserve the site for 'true' fans only (see Watson, 1997). Similarly, Rheingold's (1993) study of the WELL revealed that members refer to each other as 'WELLites', which in itself demonstrates the strong sense of identity that can be built online.

A concept that underpins the common culture aspect of online communities has been referred to as a 'consciousness of kind'(Gusfield, 1975). This phrase is particularly helpful when thinking about online communities because it emphasises something that is inherently believed or known by members about the community. It does not suggest that members must have physically met each other in order to appreciate the community. Gusfield noted that 'consciousness of kind thus depends on perceiving that there is such a kind and that one is part of it' (1975, p. 34). Perception, or perhaps imagination, as Anderson (1991) suggests, is particularly relevant to building a common culture in online communities.

Designing therapeutic online interventions

There are some notable examples of therapeutic online interventions, not least in Australia where MoodGYM (http://moodgym.anu.edu.au/), Beyondblue (http://www.beyondblue.org/), and BluePages (http://bluepages.anu.edu.au/) have all been developed as strategies to support positive mental health. These approaches are well supported by publicity and staff, and benefit from significant financial resources. BluePages lists over 20 people in team and advisory roles in addition to the Web design company charged with the construction of the site. Such online services provide proof of concept in terms of the efficacy of online health information, but do not necessarily create the environment for affective communication or online community. MoodGYM, for example, is a self-paced online education course to 'help develop good coping skills for the future so that you can enjoy good mental health', and involves negligible online interaction with other people. These sites are 'expert-moderated', and information is

dispensed according to a strict hierarchy of professional competencies, from the experts to the clients. This is very different from most communities where there is an expressed civic equivalence between members (tempered by age, intellectual faculties, and perceived degree of commitment to the community).

Among the significant differences between the community in the research project and the communities described by Rheingold (1993), Watson (1997), and others as 'online communities' is the fact that members were sought and screened as part of the research design. The health charity research-partner (The National Heart Foundation of Australia, WA division) held database records of 753 people (donors and information seekers) and provided these as a starting point for recruiting the 80 participants of the study. 623 of these were known to be charity supporters of the appropriate age and an additional 130 people, whose age was not known, were on a separate patients' database. Since the health challenge common to community members is more prevalent with age, it was assumed that many of the age-appropriate financial donors would have some indications of the health challenge at hand. With the charity providing a letter of introduction, and actively supporting the project, we anticipated that these databases would supply 80 eligible community members (born between 1946 and 1964, with one or more symptoms of the health challenge at issue and with access to the Internet). Eligible participants were then to be assigned to either the 'community' group or the 'control' group, with 40 members for each.

In practice, the charity's databases provided only a small fraction of the participants required by the study and a prolonged period of active recruitment campaign followed, involving public relations, medical specialists' patient lists, and a whole new layer of ethics clearance. By the time the numbers were achieved (in fact, exceeded, with 68 eligible people invited to become community members), the first recruits had been 'kept warm' for almost six months, waiting for a critical mass of participants to allow the online study to begin. As a result of the earlier experience, the online sample group was expanded to take all eligible volunteers except for the 40 people assigned to the control. This turned out to be a wise precaution. Although all the participants had access to the Internet and had identified themselves as facing a health challenge, being in the right age group, and being willing to participate, ultimately 15 of the 68 declined to login to the site even once, despite being encouraged by phone and letter, and provided

with support. This paper will now examine the findings from the first eight weeks of operation.

First steps towards effective communication

Three 'meet-and-greet' chat sessions were run during weeks two and three of the intervention in order to introduce members to each other and help provide a friendly environment. The first session was attended by four members, the second was attended by three members and the third was attended by one member. The researcher, Leesa Bonniface, also attended these sessions to facilitate general discussion. During these sessions the process of communication became difficult to manage. Even with small numbers, participants felt overwhelmed and were reluctant to engage. For one member, the chat session was too confronting at this early stage of community development, and she effectively communicated her affective discomfort. Her concerns are illustrated in the following excerpts from the first chat session (all names have been changed):

> *Researcher: Well, we have two willing participants. I thought this session might be a bit light on—so thanks for coming! Shall we get started?*
>
> *Alice: foot in the door.*
>
> *Researcher: Are you with us Bryce?*
>
> *Bryce: I'm here*
>
> *Researcher: Great! 1st question...*
>
> *Alice: Who puts the questions?*
>
> *Researcher: Do you both know what the Members' Network is?*
>
> *Alice: I feel all shy*
>
> *Bryce: I'm not too sure. How do you want to start this? Perhaps Alice would like to go first...*
>
> *Alice: The water looks cold*
>
> *Bryce: Yes, it looks quite overwhelming according to Alice. As we are pioneers in a sense, how about easing us into the questions? Or perhaps answering a general questions [sic]...?*
>
> *Researcher: Good idea Bryce - How about we start by asking each of you what you would like to do on [the website]? What would be useful for you?*

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Alice: I take exeption [sic] to being asked questions so early, on the site, in the chat room when I have not yet bonded and achieved some sort of confort [sic].

Bryce: Well, I would like to tell my "story" about how my condition came about. Would that be an appropriate start?

As an alternative to the 'meet-and-greet' chat sessions, the 'open-discussion forum' was offered to encourage participation in a non-threatening and asynchronous format. In this forum, members were asked to introduce themselves and comment on their first-impressions of the HeartNET website. Only two members used this forum to introduce themselves and offer some feedback about the site during the eight weeks of Phase 1. Additionally, an experienced peer support facilitator, Johnno—who has many years of F2F experience with the charity although no formal counselling training—acted as welcomer and participant supporter.

Despite efforts to increase traffic to the forums via group e-mailing and site news announcements, only 7 members used the chat sessions and open discussion forum during Phase 1. However, the Members' Network was used somewhat more during this time. Table 1 identifies the number of posts made per member on the Members' Network. While this shows that more than half (31) of the participants who logged on had not contributed at this time, 17 members made between 1 and 4 postings. The remaining 5 members were responsible for the remaining postings made during this Phase. It should be noted that the website did not have a stand alone private e-mail service for members, who were encouraged to use public forums to build community (although there was the possibility of private chat). Members registered using aliases in order to preserve their privacy, so
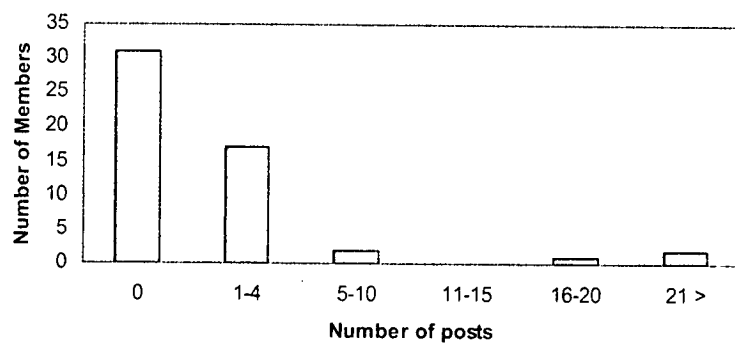

Figure 1. Number of posts made per member on the Members' Network.

there was no movement offsite to individual (privately provided) e-mail exchanges.

There was some early confusion about the use of the Members' Network. Initially, this communication tool was designed to be used like a web log (blog). That is, each member was allocated their own 'page' where they could post comments and other members could post replies or follow-up messages. However, members began to use the Network like an internal messaging system. That is, rather than reply to messages at their point of origin (within the original blog) members would post replies by selecting the appropriate name from the list of blogs on the Members' Network. Following threads of conversations became difficult when members used the network in this way. Some members understood the process of 'blogging' and posted replies to messages correctly. However, this too became difficult to manage because members then needed to visit all 68 blogs regularly to begin forming relationships with the rest of the group. To make the Members' Network more user friendly, a search tool was added, so members could locate and communicate with others with similar conditions and life circumstances.

In hindsight, the forums provided a better way for members to communicate with the entire group, but they seemed to prefer the more personal and private form of communication provided by the Members' Network—from member to member, rather than from member to group. Figure 2 shows that interaction between members gradually increased during the first three weeks of the intervention, finally peaking during week four. Interaction then declined, with occasional bursts of communication between some members between the fourth and eighth week.

Given the lack of interaction on the chat and discussion forums, the online discourse produced on the Members' Network was analysed to conduct an early investigation of the research questions for Phase 1, with a view to potentially informing a radical rethink for Phase 2. The findings from the analysis provide a useful record of the emerging themes over the course of the intervention—from introduction, through eight weeks of interaction to conclusion. The emerging themes are presented in terms of identifying a sense of community via evidence of developing relationships, social support, and expressing gratitude.
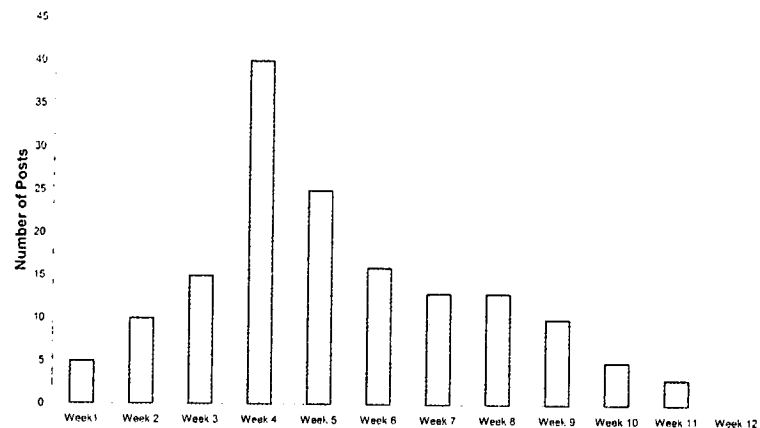
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Figure 2: Number of postings made on the HeartNET website during Phase 1 (from Bonniface, Green, & Swanson, [2005])

Developing relationships

Sociology literature identifies bonding as a key aspect of community. In order for bonding to occur, relationships first need to develop. Relationships began to develop when members: 1) introduced themselves to others and attempted to 'draw others out', 2) began to enquire after or check on other members, 3) tried to find people to communicate with who had similar conditions, and 4) began to connect with real people.

Introductions and 'drawing others out'

Website members were asked to provide an individual health story when they first logged in to the site. They were encouraged to record any information about their health or treatment histories they wanted to share, as a way of introducing themselves to other members. This may have been a difficult task, given that members had not been exposed to the nature of the website at the time. A range of health stories was offered by members: some were brief and discreet, others were more descriptive, allowing the reader to gain some understanding of their experiences. Only a few members provided detailed stories, describing the emotional aspects of their experiences. Regardless of depth, the stories offered by members seemed to promote some initial communication. Some members became instantly active, while others were more reluctant to engage. A number of the people logging in to the site chose not to disclose their health stories. In response to these 'blank' stories, active members tried to encourage participation or draw these other members into conversation:

Hi Sam, What's that secret you're hiding from us? Welcome to this network. One thing unites us like no other. No matter what our differences we all speak the language only we can speak— the language of the [recovering] patient. So share with us. We'd like to know you. (Johnno)

Despite these efforts to encourage interaction, the majority of recipients did not respond. In most cases, the members who did not provide a health story, or provided a very brief one, did not return to the website and therefore would not necessarily have known that other members had attempted to communicate with them.

Enquiring after and checking on other members

Some health stories offered to the online group offered a unique way to 'break the ice'. They led to discussion, with members making further enquiries and engaging with other members. This provided a useful way for individuals to inform other members about the progress they were making. For example, Patrick mentioned that he was awaiting a definitive diagnosis. In response, a few relatively active members asked him to keep them informed:

Comment 1: Hi Patrick. Let's know what the results are. This network has been introduced so that all of us who suffer from [heart disease] can support each other. It must have come as a bit of a shock.

Comment 2: Hope all is well. It's a bit of a shock to find these thing's [sic] out, but at least you can be treated now before anything major happened. Good Luck Wishing you well.

Although this type of interaction provides an encouraging indication of a developing community, in most cases where the more active individuals posted messages to other members, they did not receive replies.

Finding similarities

A few members in Phase 1 attempted to communicate with people who had similar conditions. Maureen wrote that she found it 'hard meeting people' her age with the same problem, and that she had not 'found anyone' with her problem in Perth. One member replied to Maureen's post:

Hi Maureen, Looks like you have the same problem as me. I had my problem since I was about 11... Why don't you contact me and we'll have a chat about this – you are the first person I've

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met in Perth since arriving here from the UK 5 years ago, who has a similar type of heart defect as me. I'll try to log into the chat room tonight if I can. (Bryce)

Although Maureen and Bryce were able to communicate during one of the scheduled chat sessions, they did not communicate again during Phase 1. Another member attempted to communicate with a member who had a similar condition; however, he did not receive a response.

Connecting with real people

During Phase 1, some members were able to connect with people they had met before. This became apparent when one member of a regional F2F support group sent a message to Johnno (the experienced facilitator of self-help groups for the health condition):

> **Mark's comment:** *Greetings from your Esperance 'children', we are powering on.*
>
> **Johnno's comment:** *There never was a single doubt in my mind that my Esperance 'children' would be anything else but great! [...] Greetings 'children'.*

These comments opened up a dialogue about the Esperance support group. This exchange suggests that online support sites can help to bridge the gap between the virtual and the real, but also underlines the difference between affective interaction between those who already know each other in F2F situations and those who are attempting to build social connections 'from cold' on the web.

Social support

Another characteristic of 'community' identified in the literature is social support. Even at this early stage, when relationships were still evolving, there was some evidence of social support on the site. These early indicators of social support included 1) understanding and empathy, 2) coaching and encouragement, and 3) help seeking or offering. However, these themes were observed only for the few active members who were participating at this early stage. Much of the support identified was offered by Johnno, who was involved in the research because of his support expertise, although he was also 'modelling' supportive behaviour to others.

Understanding and empathy

Some members were understanding and empathetic in response to the health stories offered. This might also be a necessary part of forming relationships. That is, unless members can demonstrate understanding and empathy towards each other, relationships may not develop into strong bonds. Therefore, understanding and empathy may be inextricably linked to both forming relationships and social support at this early stage.

Coaching and encouragement

Johnno was also able to identify members who needed to be coached in some way. For example, below, he was able to discuss aspects of Amanda's depression and suggest she consult her GP for more information:

> **Amanda's story:** *[...] I accept I will be taking medication for the rest of my life. I'm fine physically but am having treatment for depression, which was diagnosed 6 months after my [illness].*

> **Johnno's comment:** *Hi Amanda, You mention depression diagnosed 6 months after your [illness]. Can you remember if you felt depressed immediately after [...] or did the symptoms become apparent later resulting in the need for diagnosis and treatment? [...] Have you checked with your GP if your medication could be the cause of your depression?*

One other active member was also identified as performing this coaching role. However, this coaching was slightly different from the coaching offered by Johnno, in that it involved the sharing of information (based on personal experience) that might have assisted the other member involved. This sharing of information was then supported by Johnno. Given that Johnno has been entrusted with a special role on the site, he took it upon himself to moderate or reinforce statements made by other members. The following statement illustrates this:

> *Hi Alice, [...] just because there is a history of [the illness] in your family does not mean you are a potential victim of the disease. The answer is to endeavour to stop assuming something's going to happen. Set out to prove you are the exception. Continue to live and enjoy. (Johnno)*

Again, despite such efforts to coach and encourage other members, most recipients did not respond. Still, perhaps the ability to coach and encourage other members is therapeutic for the active members.

However, it is unlikely that this will continue if other members do not participate.

Help seeking and offering

Although coaching may sound similar to offering help, coaching was observed when members had not specifically asked for help, whereas 'offering help' occurred in response to a member's request for help. Some help-seeking and help-offering behaviours were identified during Phase 1. Sue, for example, mentioned that she was losing motivation to exercise. Two of the more active members were able to offer help:

> **Sue's story:** Hi, my name is Sue [...] I have to admit I am losing my motivation to [exercise]. Perhaps someone could help my [sic] to get out there and walk more often than I am.

> **Rachel's comment:** Hi Sue, [...] I gave up smoking the day [I] went to hospital, and haven't even wavered at the thought. But the down side is I have accrude [sic] a horrid 20 kg, my doctor is constantly on about it but can understand how you feel about motivation. I work Full time school hours and find I'm To[o] tired most night's [sic]. So how about us pushing each other to at least get out there 4 night's [sic] a week. NO CHEATING. I will keep in touch.

> **Sue's comment:** Thank you everyone for the encouragement - it has boosted my resolve immensely. My daughter goes walking with me occasionally and that helps, however, I will be out pounding the pathways very soon even if it is on my own.

In this instance, the member seeking help responded positively. Although, behaviours cannot be directly measured by analysing online dialogue, Sue's response indicates progress towards a healthy outcome in terms of behaviour change.

Expressing admiration

Expressing admiration also seems to be an important aspect of community building. Members appreciate the opportunity to express admiration for people whose support they valued throughout their recovery. A number of members discussed the gratitude they felt towards their partners, while others discussed the special qualities of their medical specialists. The sentiments members expressed about these people seemed to resonate with other members on the site:

> **Russell:** Thank you very much for the message about partners,

mine is so important to me in every way. It doesn't matter what I have to do she is always there right beside me. It really does make it alot easier in the long run.

Johnno's Comment: Hi Russell, I noticed your earlier comment to Antonio about the gentle support of our partners. What would we do without them eh? I remember the first morning after discharge waking up in bed and seeing my wife looking at me. I had such a wonderful sleep. She had bags under her eyes. 'Darling, are you alright?' I asked. 'Alright!', she replied, 'I've laid awake all night in case you stopped breathing!'

Considering that site members have experienced a life-challenging condition, expressing admiration for those who support them may be something they inherently desire to do and understand. Given that 'community' literature suggests that a shared culture is one aspect of a sense of community, their sentiments may represent the beginning of this shared culture on the website.

Conclusion

There is little evidence in support of the notion that if we simply build an opportunity for personal communication online, the community will come. Although the participants had all volunteered in response to (repeated) requests, hundreds had not responded to the researcher's requests, indicating that those who volunteered had a desire to be involved. All participants had access to the website and all had experienced related health problems. Even so, they did not have enough in common to be able to communicate effectively with the web tools made available. This may be due to the age-group of participants (baby boomers), many of whom use the Internet mainly for e-mail.

Following phase 1, The HeartNET website was re-engineered for a research phase 2, and there is clear evidence that the lessons learned here have helped to bring about an affective therapeutic community. Further analysis of phase 2 will seek to determine whether opening the site to a broader community (friends, relatives, and supporters of patients) has helped to engender effective communication and support—and ultimately a strong sense of community online.

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Edith Cowan University. Ms Leesa Bonniface is a PhD candidate and scholarship holder in the School of Communications and Contemporary Arts, ECU. Mr Maurice Swanson is CEO, National Heart Foundation (WA division) and a Partner Investigator. Dr Lelia Green is the research Co-Chief Investigator (with Dr Arshad Omari, both ECU).

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