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SHUFFLING BUDDIES: HOW AN ONLINE COMMUNITY SUPPORTS HEART PATIENTS WITH HEALTHIER LIFESTYLE CHOICES

An early indication of physical activity and exercise outcomes from the HeartNET intervention

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Abstract. While the therapeutic benefits of online health interventions have been recognized, evidence of tangible outcomes is required. At the moment, most formalised web-based interventions are facilitated by health professionals and offer some kind of patient-to-professional interaction. This paper reports some early outcomes of a web-based intervention (HeartNET) built on the basis of a community of heart patients supporting each other. Through the provision of an online forum for patient-to-patient communication, heart patients began a buddy-system to support each other in their physical activity and exercise efforts. We use Eysenbach's (2001) attributes of e-health to demonstrate how patients remained interested in the buddy-system. This paper adds to the premise that patients therapeutically support each other and also suggests that there is evidence they can empower each other to maintain healthy lifestyles. Effectively, online community provided the mechanism for mutual aid – and resulted in heart patients reporting their physical activity and exercise achievements.

1. Introduction

Millions of patients around the world are joining online communities as adjunct therapies for the management of serious illness. This prompted the National Heart Foundation of Australia (WA Division), in partnership with Edith Cowan University, to consider the possibilities of an online community to facilitate heart patient support. The partnership resulted in a successful research grant awarded by the Australian Research Council to establish a website (HeartNET) which would provide an opportunity for heart patients to communicate with each other. The significance of the research is grounded in the Heart Foundation's reasons for being and as such seeks to determine if an online community for heart patients can 1) provide therapeutic support 2) support healthy lifestyle choices, and 3) promote a philanthropic response. At this stage the

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research is ongoing but there is early evidence that peer-to-peer communication does support healthy lifestyle choices.

Website generated dialogue, survey data and one-on-one interviews will be used to interrogate the broader aims of the project. However, this paper uses only the web-generated dialogue about physical activity and exercise to showcase how HeartNET was used by heart patients to start a type of non-competitive honour system where they would voluntarily "check-in" to report on their weekly exercise achievements and encourage each other (the system was aptly named the "shuffling buddies" by one member). It was an important outcome of this research project that the initiative was suggested, developed and sustained by the grass-roots, the heart patients themselves. In this context, the Internet is no longer just the Internet *per se*. Rather, it is where real people, with real problems seek to make a difference in their lives and in the lives of others who daily become more significant.

2. The Construction of Community

The concept of community is multidimensional and as there is no single agreed definition, we appreciate a report produced by Maria Papadakis (2003) which provides a useful overview of the attributes that might be found in online communities 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 conducts for members; and members' ability to take collective action" (p. 9).

Howard Rheingold, defines 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" (1993 p. 5). Wellman also recognised that community is about a "social network of relationships that provide sociability, support, information and a sense of belonging" (Wellman, 2001 p. 2031).

As yet the data has not been adequately mined to address these comprehensive aspects of community on HeartNET. However, one paper (in a series of planned papers) has already been published which tracks the *emergence* of the HeartNET community through the emotive postings of participants. Given that communities can also flourish when members are bound together because of a shared circumstance, interest or pastime (Cummings, Heeks and Huysman, 2003) a sense of community might naturally flow when heart patients discuss their common interests and experiences. This paper uses this view of community to illustrate how heart patients were able to support each other by discussing their physical activity and exercise efforts in an online forum.

It might also hold that heart patients are in fact born into a new community after their heart events and are integrated into it during their hospital stay. Once they leave the ward however, they are left to seek out their new community members in other places which to some might be far more confronting than in the medical wing where they had no option but to be there. Anecdotal evidence, during the course of this study, has shown that many heart patients find little to no support upon leaving hospital. For them, they were left to "figure it out on their own". Some are more successful than others, finding various support groups or enrolling in rehabilitation programs. Given

that heart patients are a widely dispersed group, and not immediately visible to each other in the community, the Internet constitutes an ideal place for disjointed communities to connect.

This is particularly noteworthy when we consider that Western Australians represent a larger proportion of people living in remote areas (ABS, 2003) than other Australian States. Since people in remote areas do not have access to the same health services as people in the city, the Internet helps to bridge the gap when it comes to online support services and information. There is still concern about the so-called digital divide which naturally selects the more affluent participants over those who are less so (Korp, 2006): in terms of health care, the less affluent are often those who require more assistance. However, this imbalance is of particular concern for public health initiatives and while it is important to recognise the limitations of the Internet and overcome access issues, it does not negate the usefulness of Internet-enabled health communities for those who are able to be reached here and now. That is, while online health communities may not yet be able to help minority groups with the biggest health problems, compounded by lack of access to online resources, they are able to help majority groups in big ways.

Online communication tools can be either synchronous (e.g. chat rooms) or asynchronous (e.g. discussion boards), offering a duality of interaction. If someone is seeking immediate support or information, synchronous communication enables a real time discussion. On the other hand, asynchronous tools allow people to make posts at the most pertinent or convenient times. Although responses are not in real time, they become 'alive' when they are received by others and tend to allow more considered and complete responses to issues. That is, the moment participants read a post, they experience the message as if it were sent in real time. Weise (1996) experienced this when she found support online among women she did not know: it was as if they "sat down beside me and offered comfort" (p. xi). Likewise, Wilbur (1997) described instances of his online life where he had tears streaming down his face or was in fits of laughter. Emoticons and computer language, such as the use of 'LOL' (which means 'laughs out loud' – not, 'lots of love' like one of our members thought!) facilitate this transfer of meaning in virtual settings.

If heart patients do feel cut-off after they leave hospital, it is not surprising that they will use the Internet to source relevant information. However, instead of using the Internet as a kind of "giant medical encyclopaedia" patients use it to communicate with fellow patients, friends, and family in a way that provides them with "information in the context of community" (Ferguson, 1997 p. 31). This runs parallel to Rheingold's (1993) discussion of a 'groupmind' in his book about the WELL (Whole Earth 'Lectronic Link). He cites many examples, particularly from the parenting forum, where WELL users offered helpful and supportive information, often in response to some kind of medical dilemma.

For our HeartNET community, patients construct the Internet primarily as a portal for communication where they share experiences and extend support. Although it not intended as an information service, (the National Heart Foundation already has a dedicated information service staffed by trained nurses and health practitioners) the nature of online communication means that information is often shared between individuals. Due to the problems associated with the exchange of medical information amongst

non-experts, heart patients are reminded that information which they might acquire through HeartNET should not be acted on without seeking advice from their GP or Cardiologist. To reinforce this message, two volunteer moderators were able to informally moderate discussions that might be considered suspect and remind recipients that they ought to seek professional advice. In due course, a kind of culture emerged to help reinforce and police this position where members engaged in self-moderation. That is, some members cut and paste the HeartNET disclaimer/warning message into their posts and informed other members that certain topics of discussion were not appropriate for our forums. This is particularly relevant to computer-mediated communication studies because a shared culture might help to establish norms and rules of interaction online.

Although online communities have been accused of eroding humanness and fostering a false sense of reality (Slouka, 1995) most scholars have recognised that online settings are inextricably entwined within everyday life and therefore must not be treated in isolation from other relationships (Wellman, 2001; Bakardjieva, 2003). This perspective recognises that people who are bound together in traditional communities may also be bound together online; which constructs a much broader notion of community. If heart patients are, by the very nature of their disease, part of the heart community, then it would be misleading to separate their online community experience from their offline experience. That is, they are heart patients regardless of whether they are logged in or out. Therefore, telepresence, along with physical presence, may help to sustain relationships in mutually supportive ways (Naughton, 2001).

3. Outcomes of Online Community

Although more evidence is needed to demonstrate how online experiences intersect with every day life, members of HIGHnet - an online community for haemophiliacs - said they felt psychologically and physically better-off (Scheerhorn, 1997). For heart patients, Wise, Yun and Shaw (2000) investigated if a module on the CHES website (Comprehensive, Health Enhancement Support System) called Living with Heart Disease correlated with behavioural change. They tested to see if three learning interventions - information, interactive planning, and online communication - facilitated four lifestyle changes including exercise, diet, stress reduction and smoking cessation. Based on the stages of change model, Prochaska et al., (1994) found that only communication correlated positively with diet change and smoking cessation. Although they acknowledge that this finding must be viewed as preliminary, they point out that in-depth interpretive research should verify whether communication activity can directly impact upon behavioural change. Given that communication is an important precursor to community (Watson, 1997; Green, 2002), examining an online heart community with rich communication patterns may be one way to verify their findings.

Two other noteworthy sites developed in conjunction with the Australian National University are MoodGYM and BluePages. BluePages is mainly concerned with the provision of information about depression while MoodGYM is designed to prevent and manage depression through a series of self-help and attitude awareness modules. Both sites are of particular interest to this paper because they involve communication interventions; BluePages includes a bulletin board, and MoodGYM is fully interactive. In a randomised study, the depression symptoms of individuals were reduced through

both of these interventions (Christenson, Griffiths and Jorm, 2004). Although a sense of community was not the focus of this research, community characteristics may well have contributed to these positive results.

Overall, social networks (rather than electronic networks) have demonstrated positive outcomes for physical activity and diet modification, (Boutin-Foster, 2005; Litt, Kleppinger and Judge, 2002). However, one online health intervention for physical activity (i.e. Leslie, Marshall, Owen and Baumar, 2005) reported rather disappointing results. Due to the lack of interest and high defection rates of online participants, they concluded that website-delivered information about physical activity may be somewhat passive, leaving them wondering how they could enhance the online experience. Although our research is not concerned with online information per se, we experienced a similar scenario with HeartNET, when, early on, Sue mentioned that her motivation to exercise was dwindling. When she asked if "someone could help [her] to get out there and walk more often," she received a few positive responses initially:

Margo: 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 accrued [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.

Jane: Do you have someone to walk with at least a couple of times a week to keep you motivated. I exercise regularly now after a bypass in '99 but I did build up gradually but right from the start I did a bit of walking each day. Winter is a bit tricky too especially if you are working as the daylight hours are fewer. Anyway I am willing to "check" on you as an exercise buddy.

Sue: 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.

Although this seemed to boost Sue's "resolve", the conversation did not continue and as such we had no way of knowing if she maintained her commitment to exercise. The main reason that this thread did not continue was because the site's overall participation began to fall away, eventually grinding to a halt in week 11. A number of faults in the web-design contributed to this lack of interaction (which is to be documented in another paper) and the 'closed' structure of the website restricted new and needy members from entering the site. The recommendation at the end of the first 12 weeks (Phase I) was to radically redesign the research and re-launch the website (as Phase II) in a way that allowed for new members to enter and communicate more effectively. Phase I relied on the recruitment of heart patients through mail and media releases. Willing participants were then given a username and password to access the website. In Phase II, the site was thrown open and anyone linked to heart disease could register for immediate access. This allows patients to self-select - an improvement on the previous design which requested participation and as a result may have recruited those who were less prone to engagement.

Participation began to increase after the site was relaunched in its fourteenth week. This new design allowed more people to enter the site in order to build a critical mass and provided a more dynamic interaction. While the main communication functionality of Phase 1 included a bulletin board and a Blog for members, Phase 2 provided a more personal interface, including: avatars, private messaging, member profile pages, and a more functional bulletin board.

Since then, people have been "making consecutive postings, updating and developing their stories, revealing their need for support and recognising the help when they receive it" (Bonniface, Green and Swanson, 2005). One significant outcome of this development became clear when the idea about having a "buddy system" re-surfaced. This time, however, the thread continued for 3 months (and still counting). Part of its success is attributed to the emergence of a larger and more active community of contributors (which was lacking in Phase I). That is, before patients would engage in mutually supportive ways, they needed to feel affectively connected. Perhaps the success of the new-style "buddy system" also lies in its ability to pique the interest of participants who have an invested interest in improving their heart health through physical activity and exercise.

Unlike people who exercise for preventative or general health, some heart patients know all too well the consequences of not exercising, or at least recognise that exercise can reduce their chances of a secondary heart event or further complications. Given that many of the heart patients in this study agree that "they have been given a second chance at life" it's not surprising that they share a common interest in ways and means to ensure they do it better this time round. Electronic health (e-health) interventions that are delivered in the context of community (like HeartNET) might provide a more meaningful means to this end.

Eysenbach (2001) defined e-health broadly as "a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology" (p. 20). More importantly here, though, is his multi-attribute approach to the 'e' in e-health. He points out that it stands for something more than 'electronic' by listing more than 10 other dimensions. Of these, empowerment, encouragement, excitement and entertainment seem particularly fitting for e-health interventions dealing with virtual communities. Given that the current catch-cry for health communication is to improve outcomes, virtual communities that are encouraging, exciting, empowering and entertaining may be more apt at supporting healthy lifestyle change than other e-health interventions.

This paper presents an example of how these e-attributes apply to the online community setting. They usefully illustrate the success of the buddy-system which members created on the Physical Activity and Exercise forum. They also seem to have strengthened the community spirit which has been developing continuously since Phase II of the website started.

4. Shuffling Buddies deliver Mutual Aid

Only a few weeks after re-launching the HeartNET website one post stood out as a glimmer of hope that community was again beginning to emerge. Jane, one of the

original short-lived buddy posters wondered about jogging (or what she called shuffling) and if anyone was willing to share some training tips. However, history stood ready to repeat itself when some six months had passed before Eric logged in to save the day:

Eric: I know it's been awhile so I thought I might ask as to how the jogging was going? If you've stopped shuffling [jogging] for what ever reason and need an online 'shuffling buddy', I'm more than happy to keep you posted (& guilt you!) on a daily basis as to how my shuffling is going & you might be able to do the same for me? I find one of the hardest things about continuing exercising is that there are way to[o] many reasons not to keep going. This might be a good way of keeping us motivated? Is anyone else up for a bit of an online exercise 'buddy' system. All I'm thinking is simply posting what you do (time/distance/how you felt/what you did. etc). I know I can do with all the help I can get! Any takers???

This sparked the interest of participants who were active on other HeartNET forums. Some 207 posts (and counting) have been made since the Shuffling Buddy system was suggested. Drawing on Eysenbach's (2001) empowering, encouraging, exciting and entertaining dimensions of e-health as a loose framework, these posts were analysed to demonstrate that online communities can effectively support healthy lifestyle choice – in this case members' resolve to increase and maintain exercise regimes.

For the first few weeks three members committed to this new buddy system and the *excitement* started to build:

Helen: How about if we can challenge ourselves to get out X times a week and go for x distances relevant...have to figure out how to make it fair across the variations of our abilities.

Jane: [Eric] I like the idea of motivating ourselves in the form of a challenge, just need to think of a good way to do it

Eric: Ok, here's an idea. Instead of competing against each other for distance & time etc, as we might be at different levels, why don't we make a 'public' commitment (sheesh, men are so bad with this idea!) for our own weekly routine? That way at the end of month we can tally up how many times we actually did what we said we were going to do? The person who 'scores' the highest (the most 'actuals' against the 'planned') wins for that month. No cheating now girls!

New members soon joined in and after just one month 8 members were regularly posting their exercise activity:

Jo: I am doing 20 minutes twice a day at least 4 times per week. So I've now decided that (as I walk 20 mins from work to busstop) instead I walk 20 mins to city train station and then 20 mins home from local station say twice a week as it's easy to incorporate into my day. I could also add a weekend day's walk and attempt to jog parts of that.

Eric: Well that's 4 of us, any other takers out there? You don't need to be marathon runners or sprinters! Just pledge the exercise that you're going to do that suits you, and stick to it!

Carol: I walked to the letterbox and back ...I have a long driveway! Will start doing a bit more everyday. Taking it easy for a few more days as still a lot of healing going on after the op.

Richard: Went for my first run last night. Power walk for 5 mins, then 5 min run then walk then run, you get the idea

As the number of postings grew, so did their *enthusiasm* and *encouragement* of each other.

Eric: [Jane], that's great consistency! You're certainly showing the rest of us how to do it. Damn at this rate you're going to have your name permanently plastered in first place!

Although it appears that a tally had been calculated placing Jane in first place, in fact it was a subjective decision. Tallies or winners have not been mentioned since. Instead, the buddy-system continued as a kind of virtual cheer squad, where members felt comfortable to post their incremental improvements:

Richard: Excellent effort Jo. I started out the same way, just walking before increasing the pace and the length of time of my walks. At one stage I was "power walking" for 2 hours before I converted and started to include some runs in it. Just started out with run 5 mins, walk 5 mins, run, walk. It is amazing how quickly your endurance fitness returns and before you know it you'll be pounding out the K's. Wooahoo!

By the end of a three month period, 18 members were consistently posting updates on their physical activity and setting new goals. This *empowered* members as they began to realise the benefits. For two members in particular, walking to the letterbox was a difficult task when they first began posting: They reveled in sharing their successes:

Peter: Over the last few days I've been getting out of[*sic*] a[t] night after tea and going for a 30-60 mins walk. I'm feeling a little sore after doing it but it's making me feel a lot better seeing some of my weight coming off.

Carol: I just did a 20 min walk...past the letterbox and around the streets!

The following posts also show how members were *empowered* through their postings and subsequent successes:

Richard: This is a fantastic forum to keep us moving to attain our goals. It is a significant management tool which if people use it correctly will certainly motivate our sedentary...backsides into activity. I am happy with my progress to date.

Sue: Exercise, oh, how hard it is to keep motivated! This past week I have really impressed myself, well, actually I've been trying really hard to do some walking and have done about 3.5k's on Sunday, Monday and Tuesday then today, another 3.5k's but

oh, it takes about an hour to recuperate - but hey! I'm trying. How's everyone else going?

Carol: Pleased to say [b]een walking or swim[m]ing every day. Mind you I did miss a couple of days when it was raining hard. But [t]hat isnt bad for me .I havnt [sic] had any chocolate either....Heart feels normal.... great.

Honey: The rehab sessions recommence this week after the holiday break and I am pleased to say I kept up my exercises during that time. My goal is to be again doing the 6km x 3 [days] per week.

Many of the posts made during this period were also written to be *entertaining*. Members became more familiar with each other through humour and added interest to the threads. One joke led to a member changing his avatar (an electronic identifier usually in the form of a picture or cartoon) to Superman. In one of his earlier posts about his pledge to make the Gold Coast Marathon he writes, "so now I'll just go and put on my blue undershirt [the one with the "S" on it, my red underpants and tie a towel around my neck], and head out for another run." This prompted a new light-heartedness in conversations whereby members seemed to be at ease with one another:

Nicole: You go get em [Richard]. Up, Up & Awayyyyyyy

Jane: Hey [Richard] thought I saw you when I was jogging today but then again it could have been a bird or a plane.

Kelly: [Richard], you have done it again, made me laugh out loud... Way to go kiddo.

Richard: Ok folks it's that time of day again, Its EXERCISE UPDATE TIME... Anyway fellow bitumen bandits, let go out there and pound some pavement.

In addition to Eysenbach's e-health attributes used to illustrate the discussions between members (above), we are able to add our own e-health dimensions including – efficacy, extramural activity, and exposure. Members also shared *expertise* regarding their exercise experiences.

Richard: For those who are venturing into the uncharted waters of running, remember, when you run to move your arms rhythmically [sic] and to hold the elbow joint at about 90 degree's [sic] also completely relax your hands and just let them flop about - [you actually don't need hands to run], and don't pound away at the road with your feet, just let your footfall strike the road with the heel first and roll down onto the toes. If your [sic] running up a hill, consciously lift your knee's [sic] and swing your arms a bit harder and faster, this will permit you to run up the incline with a lot more ease.

But most importantly, don't bite off too much, work up to it. Remember we are all different and all have differing levels of fitness to start with. And, it doesn't matter if you run for 5 minutes or 2 hours and 5 minute's [sic], so long as you start somewhere. The kilometre's [sic] will come as you get fitter, and the ease of your run will also improve as you train both the body and mind in the art of non-petroleum based transportation

This often resulted in an enhanced sense of self-*efficacy* (or one's confidence to perform a particular activity):

Jane: I think I should check my method too. I've got the arm thing happening as I read up about this before I started and although my naural [sic] tendency was to swing my arms slightly from side to side I now automatically swing them from front to back. I don't think I've got the feet right though as I tend to want to land on the ball of my foot, you know a kind of prancing along thing - what I must look like is...I don't know what, but anyway I don't care about that but I will pay more attention to how my foot is striking. Thanks for the info. I feel a bit more confident now running next to my son!

Bandura (1997) referred to four main sources that strengthen self-*efficacy*, including; *mastering* the ability to succeed through experiences, learning the successes of others vicariously, listening to verbal persuasion (or in this case, reading it online), and enhancing physical and emotional status. It is conceivable that all four sources have their place here: verbal persuasion and enhanced emotional status seem particularly fitted to the buddy system. However, other members reading posts may also benefit vicariously and begin to explore and master their own abilities.

Extramural activity was observed when three of the members organised their own walking group. They voluntarily exchanged information via Private Messaging and reported that they get together regularly and appreciate the company. This sparked more face-to-face meetings finally culminating in a commitment to participate in the annual 'City to Surf' event in Perth. While up to this point members had only interacted virtually, their commitment to extramural activities made a connection to their real lives, and to sharing face-to-face friendship.

After it became apparent that quite a few members wanted to participate in fun runs and similar activities, a few members contacted us privately to ask if some HeartNET branded t-shirts could be provided. They wanted to be identified as a group and thought it would be great *exposure* for HeartNET.

5. Discussion

In terms of our shuffling buddies, the Internet is 'no longer just the Internet' but resembles a transformational relationship where patients take charge of their health and offer mutual-aid to one another. They say they understand each other without having to explain; accept each other without prior knowledge; and share their thoughts and feelings in a non-threatening way. Rather than having to forge a relationship in a new community, they find a kind of instant community where membership has already been issued as a result of their shared experience of heart disease. Their only task then is to find meaningful connections with each other, like we see here with our 'shuffling buddies.'

Using some of Eysenbach's e-attributes, along with some of our own, has helped us to isolate aspects of the emergence of community on HeartNET. Supporting healthy lifestyle choices online (and ensuring that participants remain interested) may be enhanced when interaction is exciting, enthusiastic, encouraging and entertaining. Participants may soon feel empowered, offer shared expertise and strengthen their sense of self-*efficacy*.

A model known as PRECEDE/PROCEDE is being used in the broader research project because it integrates the majority of health behaviour theories by organising them into three factors - predisposing, enabling and reinforcing (Skinner and Kreuter, 1997). Some of the specific theories covered in this model include the health belief model, social learning theory, attribution theory, theory of reasoned action, and the transtheoretical model because these theories have been used successfully in health interventions. The PRECEDE/PROCEDE model will be used to analyse the behaviours of heart patients at the conclusion of the HeartNET intervention in order to track any health-related outcomes. For these early finding however, patients' motivation may be re reinforced when they can communicate in a mutually-supportive way online. Other factors which predispose and enable behaviours may also be influenced through patient-to-patient communication. This will be investigated further throughout the remainder of the research.

In this study, we have used patients' self-reports of physical activity and exercise as an indication of their real actions. Short of conducting covert observations, it is difficult to determine if what they say is what they actually do. As such, most of our forthcoming data will seek to triangulate and add weight to these initial findings. The broader research project (from which this is extrapolated) will also continue to evaluate the outcomes of online community in terms of healthy behaviours such as diet and smoking cessation.

Regardless, for some HeartNET members, the Internet is 'no longer just the Internet' - it is a second shot at a healthy future.

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