

1-1-2010

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Rodan, D. , Uridge, L. , & Green, L. R. (2010). Using nicknames, pseudonyms and avatars on HeartNET: A snapshot of an online health support community. Proceedings of Australian and New Zealand Communication Association Conference 2010. Canberra, Australia. Australian and New Zealand Communication Association. Available [here](#)  
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# Using nicknames, pseudonyms and avatars on HeartNET: A snapshot of an online health support community

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Lynsey Uridge is a PhD Candidate on an ARC Linkage Grant with the National Heart Foundation WA Division in the School of Communication and Arts at Edith Cowan University. Prior to this, Lynsey worked for over 20 years in nursing, health promotion and information services and is the current moderator and researcher on HeartNET, a WA-based online community for people affected by cardiovascular disease.

Lelia Green is an experienced ethnographer who herself spent eighteen months working as a bus conductor, back in the days when buses had conductors. She is the Chief Investigator on the grant for which this research is being undertaken

## Abstract

*Cardiovascular disease remains one of the leading causes of death and long-term disability for the ageing Australian population. During recovery from a heart event, many people seek an alternative to traditional support groups and look to the Internet and World Wide Web to establish a connection with others who have had a similar experience. HeartNET provides just such an alternative support structure for anyone affected by heart disease. One issue faced by members of any online support community is whether to remain anonymous by using pseudonyms, nicknames or avatars or whether to accept a certain level of risk, usually in contravention of the site's guidelines, and reveal personal information in what is really the public domain. The authors found that when nicknames and avatars are used they can become part of the member's persona and facilitate emotional recognition as names do, thus becoming a way for others to make contact. Using the same nickname over time can facilitate authentic exchanges. Although the use of pseudonyms is recommended as a way of protecting anonymity, the authors' research of HeartNET reveals that ethical issues for both the moderator and participants continually arise, and are not easily resolved.*

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Cardiovascular disease remains the leading cause of death among the Australian population, "accounting for 17% of all male deaths and 16% of all female deaths" (Australian Bureau of Statistics, 2010). The Heart Foundation claim that cardiovascular disease accounts "for one Australian death every ten minutes"—affecting one in every five Australians and two out of three families. Cardiovascular disease also accounts for over one million people having a long-term disability directly related to cardiovascular

disease (National Heart Foundation, 2009). Face-to-face support groups are comparatively stretched in a large country like Australia and many people look to the Internet and World Wide Web to establish a connection with others who have had a similar experience.

Online groups supporting members who face specific health issues have increased in number and importance on the web. Many sites like HeartNET have forums and chat rooms where members can talk about their health concerns etc. Such sites provide members with the opportunity to read and contribute to discussion boards, chat with others in real time and swap private messages and information. HeartNET provides 24-hour access to support and social networking along with links to health related resources and information. Access of this kind is essential as

many people experience moments of dark thoughts and panic in the middle of the night: having the online support available allows people . . . to express their thoughts at any time . . . because sometimes there are other sleepless or international HeartNETters online. (Uridge, Green & Rodan, 2008, p. 148)

Most importantly, HeartNET offers opportunities to connect with others who may similarly be negotiating the day-to-day reality of their own heart event journey (Uridge, Green & Rodan, 2009; 2008). Members of groups such as HeartNET are able to use their interactions on the site to “supplement what their family members provide”—i.e. “emotional familiarity” (Eun-Ok, Lee & Chee, 2010, p. E20).

The relative anonymity of any online forum allows members to write and ask questions, connect with others in a similar situation and discuss issues that might be too confronting or inhibiting in a face-to-face setting. While the HeartNET site recommends that members protect their identity with nicknames, pseudonyms or avatars, some HeartNETters challenge community boundaries by divulging intimate personal details online or replacing their avatars with personal family photos. Many members are confronted with a choice between the anonymity of using a nickname and avatar and the desire to be authentic, revealing aspects of their “real” selves. These divergent wishes of anonymity versus authenticity challenge the HeartNET moderator, whose primary aim is to ensure a protective environment for community members without unnecessarily intervening in the life of that community. At the same time, the moderator and the wider community recognises that reciprocal self revelation is generally an important part of developing trust.

This paper examines the difficulties faced by the HeartNET member who wishes to establish an authentic online relationship that conforms with expectations around trust and authenticity from the offline world, but who sees the benefit of anonymity in what is an open and very public environment. As a starting point, the authors offer four categories of engagement characterising people who participate in online communities. From there, we examine the value of anonymity versus the need for authenticity in an environment set up to facilitate the delivery of mutual support. We conclude that authenticity is a necessary characteristic of engagement if a person wishes to maximise the benefits of participating in a self-revelatory, mutually supportive online environment. However, authenticity need not entail the revelation of identifying information. The authors argue that nicknames themselves become part of the member’s persona and become associated with their reputation. Using the same nickname over time facilitates authentic exchanges.

## Methodology

The findings reported in this paper occurred in the context of online interactions prior to the interview phase. These posts and comments were recorded and analysed with a view to identifying recurring themes, according to principles generally applied using Glaser and Strauss's (1967) Grounded Theory approach. After themes had been identified, posts relating to those themes were considered in light of what they indicated about the meanings and understandings that underpinned the communication. The findings in this paper form part of a 3-year ARC Linkage project investigating the identity of the heart patient in the gift economy. The paper begins with an overview of heart disease in Australia, and goes on to consider the use of online support by people affected by cardiovascular disease, breast cancer, prostate cancer and mesothelioma. It explores Kozinets's (2002; 1999) schema classifying different degrees of participation in online forums—considering site users as tourists, minglers, devotees and insiders. In this case, two further categories are offered: lurkers and the moderator complete the groups of HeartNET members.

Ultimately the research will incorporate the analysis of interactions of all components of the HeartNET site, and will include in-depth interviews of both members and non-members of HeartNET. This paper comprises only bulletin board, chatroom, and private messaging interactions, however. Pseudonyms have been used throughout this paper to protect the identities and confidentiality of all participants. However, as indicated by Daniel Miller's Theory of Consumption (1987), where the self is represented by a "natural view" to provide access to a "real" person (p. 192), an individual may sign on using a nickname, avatar or pseudonym but sign off as themselves. Hence, the pseudonyms used here to mask the online identities may offer a misleading conformity and may hide a transitioning online between self-disguise and self-disclosure.

According to theories of consumption, the online environment offers value in two ways. The technology allows an individual to integrate digital culture within their daily life; and the individual can claim an enhanced social presence through converting digital cultural products into material used for identity development and display and other interpersonal exchange (Miller, 1987, pp. 178-217). The implication of the process of consumption is, as Hearn, Mandeville and Anthony argue, that "social identity can be interpreted as a function of consumption" (1997, p. 106). The media products people consume, and which they produce and to which they contribute, become important ways through which they develop and express their identity.

## Online community members: Who are they?

Edith Cowan University remains at the forefront of collaborating with business partners to develop online communities such as HeartNET. New collaborations include the Men's Ehealth Network, which encourages men to adopt healthier lifestyle choices (Men's Ehealth Network, 2010) and work with The Breast Cancer Foundation of Western Australia's website and forum for people affected by breast cancer (Breast Cancer Foundation of Western Australia, 2010). Additionally, Murdoch University has developed the AsbestosStories website to allow people affected by asbestos-related conditions to tell their stories (Phillips, Smyth, Lindgren, Layman & Desai, 2009).

While online communities are a fairly recent phenomenon and their success is still being debated, it is known that quality support for metastatic breast cancer patients

was found in the 1980s to be of greater benefit than drug regimens available at that time (Spiegel, Bloom, Kraemer & Gottheil, 1989). While this is difficult to measure on HeartNET, members have indicated that “belonging to a community [HeartNET] gives the individual experience of illness some ‘meaning’ because that experience provides the raw material through which one member can help another” (Bonniface & Green, 2007, p. 69).

Online communities are characterised by different frequencies and intensities of engagement. Most people, for instance, post only rarely, whereas a minority of people post with some regularity on a daily or weekly basis. Kozinets identifies four different types of online support group members: tourists, minglers, devotees and insiders (1999, p. 254). In this case, the term “tourist” refers to the least-invested engagement, whereas the term “insider” indicates that a person is as fully involved with the site as possible. Typifications such as these are a useful tool for reflecting upon an individual’s participation, and considering how the situation may change over time. In the case of HeartNET, arguably, tourists and minglers are only drawn to the site if the theme of “heart disease support” has relevance for them. Depending on how relevant that site becomes in their individual situation, the tourist or mingler may become more actively involved. It is likely that active members of any online community tend to be predominantly devotees and insiders.

Under Kozinets’s schema, tourists have the weakest ties with a site and participate in superficial or limited ways (1999, p. 254). They may read and use information gathered in their offline lives, but they participate online in very limited ways. Sometimes the site requires a person to take out membership before they can access all aspects of the community. In these cases, the tourists may be one-visit-only, but they require the membership status to decide whether they wish to participate further. In contrast, minglers have stronger social ties with online community members, but only visit the site or participate in a perfunctory manner. Whereas both sets of participants may gather and use information from the site, they tend to keep interactions relatively impersonal; rarely do they establish strong relationships with others in the online community. The majority of participants on online communities dealing with health-related issues can be classified as tourists and minglers (Kozinets, 1999).

Tourist and minglers on HeartNET often post general questions, but rarely return to read the responses from other members. Alternatively, they may return months after the initial posting, by which time the original question they asked no longer requires an answer. While members have spent time and energy answering the question and providing emotional support, they are then left puzzled as to why there has been no response and/or minimal interaction from the original poster. This behaviour supports Kozinets’ (2002, p. 66) definition of tourists as lacking “strong social ties and deep interest in the [online] activity”, which is why “they often post casual questions”.

The minglers on HeartNET only ever interact online. Often they will initiate and accept invitations to offline events, but rarely do they attend. After an offline social event, minglers will sometimes offer an explanation for their absence and demonstrate regret that they were unable to attend. On HeartNET, this response from minglers is continually repeated. In line with Kozinets’ (2002, p. 66) schema, “minglers have strong social ties but minimal interest in the consumption activity”. This behaviour of holding

back from greater engagement with other community members is frequently evident on the HeartNET site.

People who can be classified as devotees and insiders are of particular interest for an online community such as HeartNET. This subset of members, usually in the minority, performs a pivotal function for the community and participates in the majority of interactions. Indeed, it tends to be the activity of the devotees and insiders that creates the substance of community life that less-involved members experience as tourists and minglers. In Kozinets' (1999) typology, devotees exhibit strong interest in the information and interactions occurring on the site, yet they have few social attachments to others in the community. It is the insiders who have strong social ties with other members and maintain a strong interest in everything that occurs on the site and are clearly engaged. Insiders are the most visibly active members of an online community, but few people are insiders (Kozinets, 1999).

Devotees, according to Kozinets (1999, p. 255; 2002, p. 66) fit a number of criteria: they "use the factual informational mode of interaction"; their "social orientation" is "clearly individualistic"; communication online is used "as means for the accomplishment of other ends"; and they "have strong consumption interests, but few attachments to the online group". On HeartNET, this criteria is not so clearly delineated—some of the devotees use the site to journal their story, which is an individualistic activity, yet at the same time it is therapeutic for others. For instance, while Clara often uses HeartNET for her own ends, when anyone is distressed she offers emotional support. However, Clara also goes missing for months on end and then, when she returns, she spends a lot of time posting lengthy descriptions telling the group about her recent successes. While she is online, Clara is a strong consumer of HeartNET information and interaction, but she seems to develop few attachments to the group. Because some members see her as an insider, the authors consider Clara to be a combination of devotee and insider. From the perspective of a lived community, the devotee/insider categories seem to overlap, and are not so easily separated as Kozinets (2002, p. 66) suggests.

For Kozinets (2002, p.66), insiders "have strong ties to the online group and to the consumption activity, and tend to be long-standing and frequently referenced members". Insiders are also "far more social and relational" (Kozinets, 1999, p. 255). HeartNET members Sarah and Fred are good examples of insiders. On HeartNET, members often defer to Sarah and Fred who are prolific users of the site. For instance, Sarah is generally seen as someone who "calms the troubled waters": members will communicate with her privately to get her response and advice about a particular situation. From this perspective Sarah matches Kozinets insider category as she is "far more social and relational" (Kozinets, 1999, p. 255) than most members. Most insiders on HeartNET suit these sociability and relational criteria.

While tourists and minglers appear occasionally on HeartNET, it is the devotees and insiders who are active, enthusiastic participants. These are the members who give freely of their time to help newer members navigate the site or deal with their recently diagnosed cardiovascular disease. It is worth noting that new members to the site often start as tourists or minglers and, as they gain confidence in navigating and posting to the site, they may become devotees or insiders. In turn, when members gain confidence and become more involved in an online community, they can then answer or provide support to other new members (Kozinets, 1999; 2002).

Another group of online users identified in the literature are the “lurkers” (Preece, Nonnecke & Andrews, 2004). Lurkers are members of a community who do not participate in any of the public dialogue—i.e. they do not post or chat in online forums or email other members. New members often lurk on sites before joining an online community. Lurking allows them time to identify the way the site works, the key players, and how to post or respond to messages. Some lurkers identify so strongly with a community, even though they are not members, that they may see themselves as part of the site (Preece, Nonnecke & Andrews 2004, p. 203; Reed, 2009).

Some lurkers come back and register; other lurkers do not, yet they demonstrate some level of commitment and continue to access the site and read the posts. Some studies have pointed to members of health support sites accepting such lurkers as part of the community (Nonnecke & Preece, 1999). Interestingly, at some times on HeartNET, there may be a four to one ratio between people who have accessed the site (4), and those who have posted to the actual board (1).

As well as visitors to the site, HeartNET members can lurk under a guest access. The moderator has access to IP addresses and login details of all members accessing the site, so can determine who is a “genuine” lurker, and who is a lurking member. HeartNET also has a group of members who first accessed the site as guests before they entered the site as members. The moderator queried members using guest status to access the HeartNET site. The guest-members responded that they were trying to avoid contact with particular people who wanted to chat whenever they came on the site. Guest-members only wanted to read the posts and respond where they saw fit. The moderator suggested that these members ignore the posts of the chatty member and this is what they have done.

The lurkers identified in this paper are people who have already taken out site membership, but who are yet to become community members though become part of the “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” (Rheingold, 2000, p. xx). People who come onto HeartNET as guests do not have identifiable IP addresses but can lurk as reader. The only exception is the members using the guest status as discussed above.

Many people may join an online community but never post. While this may seem as though they decided, upon deeper investigation, that the community was not for them, these non-posting members still receive a positive outcome from their non-participation because they are repeat visitors, accessing information on the site and, according to Walther and Boyd (cited in Preece, Nonnecke & Andrews, 2004, p. 203), enjoy participating vicariously in the life of the community. Through reading about others’ experiences and thoughts, individuals become better informed and may experience increased optimism, self esteem and social well-being (Shock, 2008). Morahan-Martin and Schumacher (2003) suggest that lurkers can “choose not only whom and when to communicate, but also have time to compose messages”, suggesting that lurking “provides an arena for the practice and development of social skills” (p. 662). This is the view taken by the HeartNET moderator, even though some sites perceive lurkers to have a negative influence with active members, judging lurkers to be “free riders” who use the online site as a resource and take, but do not reciprocate in return (van Uden-Kraan, Drossaert, Taal, Seydel & van de Laar, 2008, p. 5).

HeartNET members seem not to perceive lurking as negative:

It is great that guests can come on and poke around a bit, then they can find out if this is something that can help them, then they can join. There is nothing quite like having to give personal details to stop people spamming. (Well hopefully anyway) (Susan, Forum posting)

This view may result from HeartNET's ethos, which is to provide members who are vulnerable, and in many cases ill or marginalised, with a safe and secure environment in which to share their experiences. Even so, it seems to be appropriate to be concerned about the number of people who join the site, but never return. Do these site members who fail to become community members join the site and then absent themselves from it because the online community doesn't meet their emotional needs as a support group? Or do they leave because of technical difficulties, because they find the site difficult to navigate and use? Should the moderator and research team respond to these absences in some way?

People who do not have adequate skill levels when using a range of formats and delivery modes on the Internet are often intimidated by the technology and quickly become "passive engagers" (Schultz & Beach, 2004, p. 8). Because non-members can only access the bulletin board, and through the bulletin board gain a comparatively superficial overview of the site's public activity, it is possible that guest access presents a limited picture of the type of support provided by members of HeartNET. Perhaps visitors and lurkers are unwilling to risk the emotional engagement required to involve themselves more deeply in the life of the community. Further research is needed to address these issues.

In addition to the membership typologies identified by Kozinets (2002), Preece, Nonnecke and Andrews (2004) add that of "the Moderator". Some sites have many moderators, and volunteer moderators drawn from the membership. This is not the case of HeartNET, although that model was briefly adopted (Green & Costello, 2009). On HeartNET, the moderator has a dual role—to moderate all material posted on the site and to participate as a researcher. Most researchers investigating communities experience a dilemma concerning their insider/outsider status. For this reason, Breen (2007, p. 163) claims that the role of the researcher in a community is more complex than the role of a straightforward community member and, as this paper shows, so is the role of the moderator on HeartNET. Retaining autonomy and taking on the role of rule-keeper and negotiator is especially important for the moderator of an online support site because the environment does not allow the communication of face-to-face cues and body language, thus misunderstanding become increasingly likely when exchanges have high intensity (Green & Costello, 2009).

### **Anonymity online versus authenticity and "real" relationships**

Researchers continuously explore the opportunities for disembodiment and anonymity that the Internet provides its users (Wajcman cited in Orgad, 2005, p. 143). Initially some researchers were concerned that the isolating effects of the Internet would or could affect identity formation among users. Others, such as Waskul, Douglass and Edgley (cited in Eun-Ok, Chee, Lim, Liu, Guevara & Kim, 2007), "believed that individuals would be freer on the Internet to choose their identities as a result of non face-to-face interactions" (p. 706). In a similar vein, Wajcman (cited in Orgad, 2005, p. 143) asserts "that the nature of online communication is seen as enabling the



experiencing of a new self, one that is significantly gender free, fluid and decentred". Likewise, the dilemma about whether members choose to be anonymous versus choosing to be authentic has frequently been a topic explored on HeartNET.

A key issue that members of any online support group face is whether use to a nickname, pseudonym or avatar; or whether to use their "real" offline name. Whichever option members choose, anonymity or authenticity, it can create dilemmas for site moderators. One major dilemma that arises is how to accommodate these competing desires—the desire for authenticity, as well as the desire for security. Officially, members are usually advised in the formal terms and conditions of the site, to which they subscribe when joining, that they should not provide identifying information. The temptations of immediate authenticity can prove compelling, however.

Nicknames serve many functions. Often nicknames "say something about who the participants are and act as an invitation for others to talk to them" (Crystal, 2001, p. 160), offering "a discourse value because they provide semantic threads in potentially incoherent situations" (p. 161). The majority of nicknames chosen by users relate to themselves in some way, and are the individual's way of identifying with their nickname (Bechar-Israeli, 1995) because, in the virtual world, users often choose to express themselves by text (written, video and pictorial) (Bonniface, Omari & Swanson, 2006). Nicknames become part of the member's persona, as well as an anchor for others around which their reputation takes shape. Over time, using the same nicknames can facilitate authentic exchanges (Bonniface, Omari & Swanson, 2006, p. 98).

People use avatars (visual representations) and nicknames for a variety of reasons (Van Fossen, 2007; Suler, 2004; 2001). For some, the nickname provides anonymity; while for others, it represents an opportunity to experiment with a new or reinforced identity. Alternatively, a person may choose to use their "real" name (while still managing to protect their offline personality to some degree), rather than offering a pseudonym or nickname. This may be because they wish to appear to others, or to themselves, as more honest and uninhibited in their interactions.

Anonymity, on the other hand, can be disinhibiting, allowing people to behave inappropriately, particularly in an environment which allows pseudonyms. Inappropriate conduct in the case of online community may include: threats to members and moderators; making dismissive remarks; displays of anger; statements of racial hatred; not accepting responsibility for online behaviour; and making the recipients of angst vulnerable, open to increased hurt and distress etc. (Suler, 2004). These incidents are rare on HeartNET; nevertheless, they do occur as evidenced by the following interaction between two members. One member felt another member was being deceptive, so the aggrieved member went to great lengths to investigate and validate the other member's identity. When the former felt they had enough information to prove to their own satisfaction that the latter's identity was not legitimate, the aggrieved member sent a private message:

Just in case U have another peek in hear Dude . . .  
I checked with the hospital . . . Denise didn't exist [sic]. I checked out your street address [sic], you don't live in a 2 storey house. all the other bull dust you posted, I was awake to you the second time we spoke . . . I was amazed that so many others were too. You seriously need help . . . let us help you with your sickness . . . we could all be happy then. (forum posting, member Henry)

The upshot of this challenge was that the member who received the message resigned from the site. The member who wrote the message appears occasionally on HeartNET, but has taken no responsibility for their actions. Indeed, they may feel that the other's resignation was a vindication of their suspicions. However, in both cases, people who had been actively engaged and were presumably deriving benefit from their site membership have now disengaged and, in one case, left entirely.

Regular community members have no long-term trouble in identifying others in their group who may engage in the (potentially anti-social) behaviour of anonymous postings (Green 2002, p. 165). Palandri and Green offer two examples:

Long-term chatter Iron Filings (IF) was asked if he communicated differently in VL communications in RL, given that cyber presented him with an opportunity to try out different personae: "VL communication is indeed another medium to practice another persona . . . but why? . . . I find that no matter what handle [name] I use . . . I am still recognized . . . why? Because I have the same 'personality' for all of them . . . the handles just hang out in different rooms is all" . . . grinning . . . (Palandri & Green, 2000, p. 637)

The second example is the story of Marian Palandri's attempt to be anonymous when "passive-aggressive flaming"—verbally attacking—"those with whom I did not agree" (Palandri & Green, 2000). Palandri ultimately realised

that I was acting anonymously out of fear of risking their disapproval. Of course, one's writing style is one's signature, and soon I was found out. I chose to stay and work through my reasons for this behavior, in the face of some hostility from those I had anonymously antagonized. (cited in Palandri & Green, 2000, p. 638)

Having invested some years of interactivity within her community, Palandri realised she could not easily walk away from her technocultural social connections.

On HeartNET, while the nickname may remain constant, members will often change their avatar. This causes confusion at times because members identify an image with a particular name and therefore with a person. Members take ownership of their nickname, which becomes their electronic identity on the site. HeartNET does not have the capacity for creating personas and avatars such as those found on Second Life or other virtual 3D worlds; still, members can choose a virtual image or photograph for identification purposes. The chosen image appears on all posts made by that particular member and the maximum size of the image or graphic is 80 x 80 pixels, in .jpg or .png format. A disclaimer on the site states that the image members choose will be visible to all and appear on their profile, as well as any posts they make, going into the future.

To date, no member has used an inappropriate image. Suler (2001) identified and coded the types of avatars people use when identifying themselves online. These include: animals, cartoons, celebrities, evil-looking faces and humane faces. Sometimes icons or graphics depicting images of power, seduction or the idiosyncratic are used, as well as shocking abstracts from other visuals, billboard and lifestyle images etc. and, on occasion, animated avatars (Suler, 2001). Members of HeartNET predominantly utilise images of animals, often their pets or favourite animal, cartoon characters, a photo of themselves or a family image, and lifestyle images such as an avatar of a skier.

Researchers believe that people who use avatars that relate to their own self-image are displaying a gesture of honesty or an overture of intimacy and friendship; while lifestyle avatars depict significant aspects of the user's life (Vasilou & Joinson, 2009). HeartNET members often use heart-related images as their avatar. A few of the more active

members use animated images, changing them frequently to depict their emotional feelings, or their situation at the time of writing. Members who manipulate their avatars often tend to be the more computer-literate members on the site.

Occasionally, members may try to access the site using an alternative name or identity—in reality, a member can be anyone they want to be in the HeartNET environment. HeartNET members register once; to gain full access to the site, and following activation of their account they do not need to register again. On one occasion, a member (Joshua) seems to have taken on the persona of more than one person in his family, posting numerous times about the family circumstances from different perspectives. This behaviour continued until other members became suspicious and confronted him. At this point, Joshua asked to be immediately withdrawn from the site. (Even though members ask for their membership to be withdrawn, all their postings remain on the site unless total deletion is requested). While members of HeartNET will never know if this person was deceiving them, it is often the case that those attempting deception give themselves away by using the same language nuances in all their messages (Palandri & Green, 2000). Online users who try to deceive also seem to post escalating stories, make contradictory remarks and may even admit that they are lying when challenged by others on the site (Crumlish, 2007).

Those members who practice deceptive behaviour tend to move quickly on to another source of support if challenged (Feldman, Bibby & Crites, 1998). The challenges occur because members offer support and sympathy and may begin to feel that they are being “taken for a ride” if an exchange become increasingly unlikely or inauthentic. When site members are hurt by the deceptive actions of other members, a range of events may occur. Sometimes, all parties involved move on; on other occasions, people will want to discuss the situation openly, which can prove problematic in an online forum and raises issues of prejudicial and defamatory posting. Occasionally, people will be deeply hurt and, very occasionally, some members may feel they can never get beyond their feelings of despair and distrust (Stone, 1991). HeartNET members have dealt with past deceptions in various ways: some members have left; others have reduced their involvement; while others have taken the opportunity to be openly critical of the site’s handling of the situation when previously they were staunch supporters. This reaction may partly be because the moderator never challenges an apparently fraudulent series of posts, even though some members might request this response and then go on to challenge the posts and the poster themselves (without the moderator’s agreement). In the end, some members remove themselves by choice because they feel the site is no longer providing the support they need in maintaining an environment free of deceit; yet, many such members continue to visit as guests and, often via email, take opportunities to suggest ways in which the moderator can improve “their site”. In this situation, it is as if the now-guest has distanced themselves from the pain of the precipitating activities but cannot bear to leave the community entirely and instead tries to get the site to revert to the positive environment remembered, or imagined.

HeartNET membership is for some an extension of their offline interactions, as is evident in the fact that many members discuss issues (not necessarily heart-related) that are relevant to them. Being open about personal issues is similar in online contexts to interaction in offline communities. Members develop trust through self-revelation and can find an affinity and deep friendships with other participants, both online and away from the virtual arena. As Aarsand (2008, p. 148) states, “life consists of multiple

activities located in different places such as chat rooms, on the Internet as well as the corner pub". Such a perception agrees with Mantovanis' (1996) view that "virtual environments are not alternative 'other worlds', but that they are [positioned] within, not beyond, daily realities" (cited in Tsai, 2002, p. 2). Turkle (1996) and Miller and Slater (2000) also found that self-representations in online chat rooms were closely related to other areas in people's lives. This can also be deduced in HeartNET from the need felt by some members to show family photographs and discuss personal issues online, unrelated to their health issues.

Some members allow photographs of themselves and their children to be viewed by all site members. The moderator is concerned that photographs posted of children may sometimes include the logo of the school they are attending. On the site, the moderator removes personal information such as phone numbers, email addresses and information that would readily identify the person posting the message. The person responsible for the HeartNET photo site also de-identifies or deletes photos that readily identify schools or sport clubs that members' children go to.

Researchers face an additional dilemma when reporting or writing papers on interactions and postings from any website community—altering the name or the distinguishing features of an individual may not be enough. When a researcher analyses and publicly discusses a message, there is the potential to destroy the integrity of the site because participants may feel violated. For instance, participants could believe they have been misrepresented or that their anonymity has been jeopardised, and that they are now potentially identifiable by others which could impact on the level and degree of interaction on the site (King, 1996).

Indeed the researcher of an online community may become friends with community participants and face the dilemma of breaching the trust of members when and if these interactions are included in any future research. Finn (1994) states that "messages posted on BBS (Bulletin Board Systems) are public information and that changing the names on the sample messages they reprinted would insure the privacy of the BBS user" (cited in King, 1996, p. 122). This is unlikely to satisfy ethics requirements today, which require the kind of informed consent involved in participation in HeartNET, which is clearly a research website. While changing names confers privacy to some degree, the authors' research of HeartNET has revealed that ethical issues for both researchers and participants continually arise and are not easily resolved.

Even though participants are de-identified, because they are members of a smallish group of people belonging to HeartNET, there is a chance they could identify themselves or other members. Also, research participants often want to know who has been quoted, but problems arise when participants find out. Participants can get upset because they feel misinterpreted in accounts of the research. Newkirk (1996) comments that "[p]articipants find their actions and beliefs, constructed in ways other than they intended, other than as they perceive them to be" (cited by Brown, 2004, p. 3).

Some participants are also worried about voyeurism online by researchers; they fear that researchers "will take advantage of people in distress" (Sharf cited in Eysenbach, 2001, p. 1104). For many website members, "the idea of using the conversations as data" has "not occurred" to them (Sharf cited in Eysenbach, 2001 p. 1104). One way that the moderator addresses these fears is by reassuring participants that the researchers have a commitment to maintain the university's ethical standards and values. Also, as

the HeartNET site and research is supported by the Australian Research Council, by Edith Cowan University and by the Heart Foundation, members are reassured that the moderator and the researchers are committed to acting in an ethical manner. When the moderator meets and interacts with members, she reminds them of her ethical obligations, which means she cannot respond to requests for personal, private information about members or the site.

Another ethical dilemma faced by researchers of online communities such as HeartNET is that members may give valuable information that could be used in research when meeting in an offline setting. The issue for the researcher lies in using this information without prior approval or consent. The member may feel they have *shared* information in confidence. Often members want the moderator/researcher to be a “friend”, and they may “forget” (see Eysenbach, 2001, p. 1103) over time that the moderator is on the site as a researcher. Eysenbach (2001) says that participants in such research want to be part of “a support group not a fishbowl for a bunch of guineapigs” (pp. 1103-1104). The line between the role of moderator and friend is often blurred. One way the moderator attempts to resolve such issues in social situations (offline) is to get explicit verbal consent from participants to use what is said in the research. If the participant reveals valuable information or insights, the moderator/researcher specifically asks them if their comment can be used. Thus the moderator undertakes not to act in a furtive way.

Another recurring problem is that the moderator is sometimes asked to fix problems, such as the sharing of personal information offline that a site member now wants to retract, maybe because an online friendship has now become problematic. Because people on HeartNET have developed real friendships with each other, they also experience real fallings-out. In each of these situations, the moderator is placed in a dilemma. While some members used to feel annoyed that the moderator would not disclose anything about other members, established participants have now come to accept this. The HeartNET moderator dealt with such impasses early on by openly stating the public things that could be discussed about HeartNET, but also stating what would always be off limits—anything to do with members and their problems.

## **Conclusion**

Whichever option members choose—whether to remain anonymous by using a nickname, pseudonym or avatar or whether to use their “real” offline name—creates dilemmas for researchers and moderators of online support sites. One major dilemma that arises is how to accommodate competing desires—the desire for authenticity as well as the desire for security.

Authenticity is a necessary requirement in order to maximise the benefits of participation in a self-revelatory, mutual-support environment. The study of one online health support site, HeartNET, reveals that nicknames and avatars become part of the member’s persona with continuing use, as well as contributing to their public reputation, and become a means through which others make contact. Over time, using the same nicknames can facilitate authentic exchanges.

Nonetheless, researchers face an additional predicament when reporting or writing papers on interactions and postings from any site—altering the name or distinguishing features of an individual is rarely enough. When a researcher analyses and publicly

discusses a message, there is the potential to compromise the integrity of the site because participants may feel violated by the way in which their messages are written about. While privacy to some degree exists, the authors' research of the HeartNET community has revealed that ethical issues continually arise for both the moderator and participants and these are not easily resolved.

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