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Self-revelation in an online health community: Exploring issues around co-presence for vulnerable members

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Abstract

Problem: *This paper addresses the implications of working with vulnerable groups in the context of an online health community when members move from co-presence online to co-presence offline.*

Theoretical Approach: *The case study presented in this paper challenges the expectation that self-revelations are usually more common in online environments because of the anonymity and comfort experienced there.*

Methodology: *Taking as its example the events in a research project designed to investigate the relative features of online communities and social network sites by using a 'netnographic' approach, this paper examines the introduction of live chat sessions with a view to building social and emotional involvement in community members who had been, to that point, somewhat disengaged.*

Findings: *On the fourth live chat, shortly before Christmas, one community member suggested that they meet for a meal, effectively moving the co-presence from the online community into the offline world. This duly occurred the following week, but the situation did not develop as the research team members had envisioned and instead they found themselves dealing with a member who, in person, was revealed to be feeling suicidal.*

Conclusion: *Addressing the case study in terms of the implications of co-presence and self-revelation in research settings, this paper goes on to describe the changes in policy and process instigated by the support organisation to prepare for other possible events of this nature.*

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Introduction

This paper discusses the challenges faced by the Breast Cancer Click site in the first year of its launch. It argues that the formation of an online health community, where members can seek and acquire support while co-present online, may also lead to members desiring a co-presence offline, in order to reveal new information about themselves which had not been disclosed in the online setting. This is the inverse of what might be expected. It is usually the online setting itself which encourages more open disclosures: a number of studies indicate that co-presence online

enables revelations about one's self that may be too difficult to reveal face-to-face (e.g. Joinson, 2001; Rheingold, 1993; Reid, 1991), at least in the first instance, and early in the relationship. This paper explores the opposite scenario, where an unexpected and disturbing revelation was shared when members of an emerging online community were physically co-present. Prior to this, the interactions which had taken place online gave no indication of what was to be revealed offline. This paper provides an example for other researchers, whose projects might involve co-presence (online or offline), and raises awareness of contingencies that might arise and how to cope with them. It addresses the use of the strategy of having scheduled online sessions to encourage members to participate and to create social capital, and then describes the chaotic outcome of one online meeting, during which participants decided to meet offline.

Research methodology

The authors are members of a research team which includes a project co-ordinator representing the industry partner, two senior academics and a PhD candidate who is the recipient of an APAI award, the second author of this paper, and who is referred to in this paper as the 'netnographer' (see below). The second author is also charged with conducting the broader research project as part of an Australian Research Council (ARC) grant. The two senior academics are experienced in the creation and operation of online communities, but are also aware that this is a fast-evolving space in which to work and that the notion and practice of online community and online engagement is constantly changing (McQueen and Green, 2010).

Although the broader research project applies a netnographic methodology which uses a combination of postings collected online (chat room dialogue, discussion threads, messaging, and other interactive tools), along with interview, focus group and survey data, this paper relies upon one specific data point, excerpts from chat dialogue, and a case study of an event which followed one particular chat session. These two sources of evidence are interrogated to support the assertions made. According to Robert Kozinets, who first introduced the technique in 1998, netnography is 'a specialized form of ethnography adapted to the unique computer-mediated contingencies of today's social worlds' (2010: p. 1). In a similar vein to ethnography, it aims to achieve a scientific description and deep understanding of phenomena but with less emphasis on the application of theory or preconceived frameworks to aid understanding (Ward, 1999). Instead, netnography recognizes that the cultures of online communities are constructed by the members who are invested in their development; hence their description and any construction of theory should be derived from the community members in question. In order to protect the rigour of this approach, a range of cultural studies theories provide the undertone for the broader research and are kept in reserve for checking against the final interpretation.

In this instance, the culture being investigated is that which has been developed by, and expresses, the Breast Cancer Care W A online community, the Click site, and the individuals growing the fledgling community are breast cancer patients and their supporters, i.e. family, friends and carers.

The aim of the broader research is to investigate the impact upon a flat-hierarchy community of the introduction of specialist counselling and advice. The supposition is that this inclusion of 'an expert' changes an otherwise egalitarian dynamic and that guidelines are needed to assist communities such as this one to handle that additional element (Lampel and Bhalla 2007). Such guidelines do not currently exist but will be prepared as one of the outcomes of this research.

The project also offers the opportunity to examine the differences between the operations of an existing social network site (SNS) (boyd and Ellinson 2007), created by the charity partner, Purple Boot Brigade (PBB, 2012), and the operations of the online community, which was set up as part of this research.

The project involved researching what constitutes contemporary best practice in online community construction, within budget, and constructing a community to embody this perspective. There was even the hope that the online community might harness something of the 'viral growth' of social networks (Gross and Acquisti 2005, p. 1; boyd, 2007). The partner organisation already had an award-winning not-for-profit SNS (AMI, 2008) and sought to make the online community and the SNS interoperable, even though the target memberships were very different. Indeed, one of the spurs for the establishment of the online community had been the harnessing of the SNS by members affected by breast cancer who were seeking personal and emotional support. It was clear that there was an unmet need for such services and the online community was set up, in part, to address that need. Even so, notwithstanding existing support seeking behaviours on the SNS, the online community faltered. After some months of trying to establish an authentic, mutually supportive community, none was clearly evident and the research was falling behind schedule.

The aim had been to establish a vibrant community and then add an expert, advice-giving role. It was decided instead to create live discussion forums as part of the preparation for introducing the role of the professional advice-giver. The membership would be circulated to inform them that the netnographer and project co-ordinator would be present for 'live chat' one or two evenings per month (the evening varying between Tues, Wed and Thurs; early evening in W A, late evening on the Australian Eastern coast) and members would be invited to take part. Although only a few members signed in for the first Click site chat, those that did were engaged and contributing, and the chat ran for several hours – longer than had been anticipated. This raised issues about the importance of co-presence for developing a sense of connectedness and belonging, and about the predictability of a human presence at the point of engaging in online communication.

Indeed, the idea of netnographic enquiry implies a need for human presence in communication in that it extends the notion of an ethnographer doing research in order to gain a 'deep involvement in the subject's worlds of experience' (Denzin, 1997: 35), to one which involves the netnographer in the role of being part of the research (Ward, 1999). Given online communication means that a mutual text is created, the netnographer shares the research role with participants as they require and acquire information. Both parties contribute to an ongoing dialogue in the online space. The implications of the 'next step', however, which involved some of the founding members of the Click site and the netnographer and project leader moving from the online space (their virtual co-presence) to a physical co-presence, is the focus of this paper.

Literature review: Online community

Insofar as online communities form around self-disclosure and 'human feeling' sufficient to form 'webs of personal relationships in cyberspace' (Rheingold 1993, p. 5), professional online advice has the potential to introduce hierarchical relationships (Foucault 1980) that change communication dynamics. This may be because the 'altruistic' driver of contribution to an online community is associated with status-seeking behaviour (Lampel and Bhalla 2007) and it is harder

for an amateur to contribute at a level significant enough to win much status where a community also includes expert participation.

Whether or not the introduction of an 'expert' will affect the community dynamic or sense of support created through peer interest and response (e.g. Leiberman and Goldstein, 2005) is the subject of the broader research, which is not reported in this paper. Nonetheless, establishing a basic sense of what constitutes online community provides the contextual foreground when excerpts from the Click site's chat room, and the events that followed, are discussed later.

Although Rheingold's definition of community and research – with well people – is among the most comprehensive and widely cited, Elizabeth Reid's honours thesis is particularly relevant to tracing the origins of online community. Her subsequent works have been included alongside Rheingold's in leading computer-mediated communication (CMC) texts, edited by some of the most influential scholars in the field: Steven Jones (1994), Peter Ludlow (1996), and Marc Smith and Peter Kollock (1999). It was her seminal work (1991), however, on the dynamics of chat specifically, which is most relevant here. She noted that the 'threads holding IRC [Internet Relay Chat] together as a community are made up of shared modes of understanding, and the concepts shared range from the light-hearted and fanciful to the personal and anguished. The success of this is dependent upon the degree to which users can trust that the issues that they communicate will be well received – they depend on the integrity of users' (Ch. 7, online).

Literature review – Therapeutic outcomes of online community

The therapeutic and health outcomes of online community have been varied, perhaps because the benefits have been difficult to attribute to the community component given the lack of controlled settings (Eysenbach et al., 2004). In 2005, however, Rogers and Chen conducted an in-depth and longitudinal study of an internet community group for breast cancer patients and found that there was a positive correlation between the amount of participation and psychosocial well-being. In other studies, online community has demonstrated benefits in diverse settings, including: reducing sense of isolation for those who experience infertility (Malik and Coulson, 2008); increasing emotional support in suicide prevention (Barak, 2007); and, supporting a sense of normalcy and a sense of self for transplant patients (Bers et al., 2010). Blogging, which is often used in online communities, has also been shown to increase social integration and satisfaction with friendship interactions that are important to a sense of wellbeing generally (Baker and Moore, 2008). In terms of behaviour change, Wise, Yun and Shaw found (2000) found that online communication, compared with two other interventions – information and interactive planning – delivered via the CHESS website, correlated positively with diet change and smoking cessation. Although they did not determine if patients established the kind of personal relationships that define online communities, this work does identify that online communication, which is a precursor to online community, delivers measurable benefits.

The take-home message from online community research is that engaging with such communities does tend to improve perceptions of life quality (e.g. Idriss, 2009) for various groups who are in need. Still, online communities should not be viewed in utopian terms; negative outcomes have also been attributed to them. For example, children engaging with others in online community are at risk from sexual predators and underage solicitation (Ybarra and Mitchell, 2008), cyber-bullying (Dooley, Pyzalski and Cross, 2009) and eating disorders (Lynch, 2010). Our previous, health-related research has also demonstrated the negative

dynamics of online community when a dispute between a few members raised issues around privacy, hacking and personal harm (Green and Costello, 2007).

In most cases, however, research has pointed to the positive, health promoting outcomes of online community engagement for people living with a life threatening condition, and studies have documented that the social and emotional links generated online between strangers can transfer into practical support in the offline environment (Bonniface, Omari, and Swanson, 2006). It has also established the existence of a philanthropic response by some (health) patients engaged in the online community that sees them keen to reciprocate by offering support to the community through communication and advice (Bonniface and Green, 2007). However, the kinds of strategies that had worked to establish online communities before SNS were not working on the Click website and other strategies had to be developed and trialled.

Literature Review – Co-presence: Live chat and offline meetings

In relation to online chat, Reid (1991) implicates co-presence by asserting that:

> there is no way to interact with IRC [Internet Relay Chat] without being a part of it – it is interaction that creates the virtual reality of channels and spaces for communication. Immersed in this specific, although not 'local' in any geographic sense, context, players of the IRC game are involved in turning upside down the taken-for-granted norms of the external culture (Chapter 6, online).

What is considered to be normal externally (offline), is negotiated in a new way, to form a new kind of shared culture, when members come together online. A concept underpinning this co-present engagement has been referred to as 'consciousness of kind' (Gusfield, 1975). It communicates something that is inherently believed or known by members about the online environment and does not suggest that members must have physically met each other in order to acquire it and be part of it. Essentially, when members can 'imagine' their own communities (Anderson, 1991) online, they can behave in ways that become more acceptable or accessible than those which might necessarily be afforded in an offline setting.

Turkle (2005) has equated this to a form of compromise offered online, between the 'intimacy' of face-to-face communication and the undemanding nature, but constant availability, of computer-mediated communication:

Terrified of being alone, yet afraid of intimacy, we experience widespread feelings of emptiness, of disconnection, of the unreality of self. And, here the computer, a companion without emotional demands offers a compromise. You can be a loner, but never alone. You can interact, but never feel vulnerable to another person (p. 279).

This is not to say that each environment does not support the other. Indeed, having a 'telepresence', along with a 'physical presence', can be mutually supportive for human relationships (Naughton, 2001). In any respect, Larsen et al., (2006) argue that face-to-face (co-present) meetings are "central to [people's] social lives and to the building and maintenance of their social capital, and of social capital more widely" (Larsen, et. al, 2006, p. 125). Arguably, the centrality of co-presence is also true online where the meeting takes place in a shared temporal space, rather than a shared physical space. That is, co-presence is important online whether it: provides a 'compromise' for face-to-face interactions; strengthens face-to-face interactions, or provides the impetus to seek out face-to-face interactions. Certainly, this capacity for

strengthening emotional engagement was the impetus for establishing the Click site chat service in the fledgling online community, seeking to recruit and inspire new members.

The strategy of live chat certainly had an impact on the type of personal communication experienced on the site and created a core of communicating members who then seemed more willing to invest in online interaction and asynchronous postings. Where a more authentic style of interaction is identified it typically has the result of prompting more communication; on Click Chat this authenticity was experienced when members revealed something of their personal stories, struggles, achievements and a personal appreciation for the site's launch. This sense of communication prompting a desire for co-presence has been argued by Graham (2001, pp. 165–6: original emphasis):

> it has long been recognized that, as well as substituting for travel, telecommunications can actually generate or *induce* many new demands for physical movement … a demand for physical co-presence leading to new forms of physical travel that might not have taken place without the telecommunications linkage.

In the case of the online community in question, the chat session led to suggestions that, since many of those involved were in the same Australian state, people should meet and be physically co-present. Since the research team (Bonniface et al., 2006) had had positive results in equivalent circumstances, along with other CMC scholars whose work informed our strategies (Wilbur, 1997; Xie, 2008; Wellman, 2001), the proposal that people should meet face-to-face was welcomed.

The paper now addresses the transition from community membership to online co-presence, and from co-presence online to co-presence offline, and discusses some of the issues arising from what happened in this research context. This is presented as a case study, which is story-like in nature (Yin, 2009), leaving the more structured netnographic analysis for subsequent papers when all of the data sources have become available.

4. Case Study

There had been four live chats before it was first suggested that participants should meet face to face. The first had been scheduled for a Thursday (7.00pm) and ran for three and a half hours. The members in this the first session concentrated solely on the issues surrounding a diagnosis of breast cancer. The major topic was 'how friends and family had coped (or not coped) with the diagnosis and treatment' of the cancer. There were two members making a major contribution to the first live chat session, Donna and Karina (all names are changed to protect confidentiality).

The second Click Chat was held three weeks after the first, on a Wednesday, and attracted four members, three members with a breast cancer diagnosis and one who was supporting a family member with a diagnosis. Karina was one of the members participating again, which indicated that she had found the first session useful. The research team were glad that the scheduled discussion had successfully attracted additional participants.

The third live chat was on a Tuesday evening, to experiment with different days. It included a specialist practitioner as a guest participant. This health professional was considering taking on the role of breast care nurse for the online community in a contracted capacity as part of the research project. While the chat was going on it could be seen that several people had logged in,

but seemed to be having difficulties in connecting. Eventually one of these, Angel, joined the chat room just as the discussion was concluding at 10.45pm, so she was encouraged to join the fourth live chat and the team resolved to address the access and communication issues that had arisen.

The success of the live chat had been growing steadily over the three sessions. This success was measured, not so much by the number of members online, but by the serious and the amusing conversation, the positive feedback, and the length of time the members spent in discussion. Even though the Click Chat had been advertised as a three-hour session, it had run on occasion for five and a half hours. Its success could also be gauged by participants offering information, advice and support for one another. Five community members attended the fourth session, four with breast cancer plus a support person. The research and support team, including the acting professional advice-giver, were also online. Overall, even in view of its length, this was a lighthearted discussion with a focus on pets and hobbies together with one or two more serious subjects.

Angel was one of the first to join the fourth Click Chat: 'Glad I've actually made it here - last time chat was on, I tried for 2 hrs and couldn't get in….grrrrrrrrrrrr' (Angel). She was the only member in the chat room for more than an hour when Sarah joined, followed at intervals by Lindy, Gaye and Beryl. Possibly because she was first online, the initial chat had focused around Angel's diagnosis and the fact that she wasn't having any treatment for her cancer apart from an operation, which had been carried out 12 months previously. 'I will not compromise the quality of life I have now at 60 yrs of age' said Angel 'for something that may not do me any good and they reckon I haven't got cancer anymore anyway.' The Click team empathised with Angel's decision not to have additional treatments such as chemotherapy and radiotherapy.

After a conversation on other topics, however, some members asked Angel what had influenced her decision not to have additional treatment for her breast cancer. She replied: 'after seeing what my mother went though with chemo I always knew that if ever I had BC I wouldn't want chemo. Mind you, never in my wildest dreams did I think I'd get BC. There was a lot of pressure from the 3 oncologists, the surgeon and my GP to have the chemo. To me it simply didn't make sense to have it.' (Angel). Lindy responded very positively: 'Chemo isn't for everyone. But I've coped really well with it, it does really depend on the individual' (Lindy).

At the conclusion of the evening's chat, Angel suggested that maybe people would like to get together for lunch the following week. This was agreed and two people plus the project coordinator were seated at the lunch table when the netnographer arrived at the scheduled time. As everyone introduced themselves she realised that neither of the diners unknown to her were members of the Click research community. Angel, the organiser of the lunch and Beryl, the other member who had expressed an interest in coming, were nowhere to be seen. Angel arrived just as one of the potential members was leaving, and appeared happy and upbeat, apologising for not being there sooner. At the end of dessert, as people were deciding whether to have coffee or not, Angel took a folded piece of paper from her bag and announced: 'you know I've written a suicide note'.

The lunch companions were extremely shocked. No-one had had any inkling that this was what Angel had been thinking about. The project coordinator persuaded Angel to go with her to see a counsellor associated with the charity. The netnographer volunteered to drive the remaining potential member home since she had been very unsettled by the turn of events. The project coordinator, who does not have a health profession background, found herself tied into an

extremely unsettling counselling session for the rest of the afternoon. Angel was later to write (post edited to remove identifying features):

> [Project coordinator] put me in her fabulous Mazda sports, we had the top back, we put on our Christmas crowns and drove to West Perth… had a… deep [and] meaningful… with a lovely lass there, [the project coordinator] stayed with me the whole time. My son came and got me. Got assessed at the local hospital, they said I could come home… getting back into therapy asap… seeing my GP tomorrow. I will never be able to say this enough times… but… THANK YOU, THANK YOU, THANK YOU… for today, in my deepest despair you supported me… I am beyond words. (Angel)

Angel re-joined the site for a short time after this incident but approximately two weeks later sent a personal message to the netnographer saying that she had just been discharged from a psychiatric ward where she had been admitted the previous week:

> I still have a lot of intense therapy ahead of me, which will be arranged next week. I've decided to pull back from on line BC support as I think it is depressing me, although it's lovely to have the encouragement of the other ladies with BC, I think I have to move my focus to other less stressful things in order to help me recover from my depression.....on day [sic] I hope to come back to...BC Click....but for the moment I think I need to step back. I hope you will understand. (Angel)

Discussion and conclusion

In most cases the anonymity of online interaction means that members can feel freer to disclose their intimate thoughts and feelings, in ways that they may never do in 'real world' settings, face-to-face (e.g. Joinson, 2001). Alternatively, people may self-disclose only after making an initial, minor, disclosure to establish whether the online space is comfortable. The opposite situation is seen in the case presented above. Here, the co-presence shared through the online Click Chat did not provide the reassurance to disclose a vulnerability that was being experienced by one of the members. Instead, the revelation was made offline, only after the members who had previously become acquainted online were all able to meet together face-to-face. This seems to challenge the norms associated with the types of revelations one might expect people to make (or not to make) when members who are relatively unknown to each other meet in the physically co-present; however it does align with some recent research which contests the view that online environments are more ripe for personal disclosure than offline contexts (Ngyuen, Bin, and Campbell, 2012). It is possible, however, that the co-presence shared online generated enough trust to instigate a face-to-face revelation which might otherwise not have been offered. It is also possible that Angel engineered the co-present meeting in order to stage a 'cry for help' in a manner which would ensure that she received people's personal attention.

As a result of this incident, BCCWA developed additional guidelines for handling occurrences such as this. Having been a successful support charity in a complex field, they already had a range of protocols as well as an onsite counsellor, breast care nurse and Indigenous liaison worker, not all of whom were full time. It was acknowledged that similar situations are a possibility, and have happened in the past. The team discussed what had happened and decided to include a statement on Click's home page to notify members that the site is not designed for one-on-one

counselling, and to say that members in an emergency should contact their treating medical practitioner, or Lifeline in their state.

The situation as it developed highlighted the need for research team members to be prepared for all contingencies and to be constantly aware that community members encompass a range of life experiences and health issues, including both physical and mental. Given that two team members were present as the sequence of events developed, duty of care could be provided to those who were affected. It is now a formal policy that at least two team members attend offline meet-ups to support each other should something unexpected occur, and to calm the other group members if one member of their community should unexpectedly have a 'meltdown' or need medical assistance.

The case study indicates that co-presence is an important element of building trust in a community, and in supporting self-revelation. The live-chat sessions seemed to serve as a catalyst in encouraging a fuller and deeper engagement with the online community. It is interesting that it was Angel, the person who might be considered to be in acute need, who suggested moving the online co-presence to an offline co-presence. Arguably, her experience of the online-moderated live discussion helped her to feel that the researchers on the site were trustworthy and could be relied upon. This engagement then deepened with her personal experience of the support team in physical co-presence when Angel arrived (late) at the lunch she had set up. It may be that Angel arrived late because she felt unable to handle social niceties without immediately moving to the crux of her agenda: her desire to seek immediate support in dealing with suicidal feelings.

The netnographic approach employed in this study requires that the researchers implant themselves in the online environment, freeing themselves from pre-conceived ways of knowing. However, it is the cultural studies frameworks which provide the conceptual foundations for investigating online community. The signs of online community are evident here in their early form: that is, the sense of safety and trust in the Click community which underpinned Angel's desire to express her self-concept and her locus of control, juxtaposed with that of her mother. This was hinted at online, but only fully revealed in the offline meeting. We have yet to approach Angel to see if she is willing to take part in the in-depth interview phase of the netnography.

Acknowledgements

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