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"To me, it's my life": Medical communication, trust, and activism in cyberspace

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Abstract

This paper studies the conversations and activities of an online support group for breast cancer sufferers and survivors and their supporters. Using communications medium theory and social capital theory, it examines the mundane and profound exchanges, the poignant self-disclosures, the creative expressions of solidarity, and the minor but not-insignificant political actions of people—initially strangers—who come together as a 'virtuous circle,' not only to assist with medical issues but also to meet emotional and even material needs. Sponsored by the Canadian nonprofit organization Breast Cancer Action Nova Scotia (BCANS), this virtual community has logged over a half million messages since 1996. Not every BCANS participant is an activist—many are just trying to grapple with their disease—but some find ways to shatter the professional "information monopoly," and to press for healthcare improvements. The study illustrates the scope, passion, and complexity of peer-to-peer medical communication in a virtual environment that promotes "thick trust". BCANS participants discuss with candor, warmth and even humor such painful topics as death and dying and the crises in intimate relationships brought about by a terminal illness. The sharing of confidences and fears enables participants to pool their 'collective intelligence' about many things, from how to cope with swelling, to how to think about end-of-life issues, to how to improve social policy.

Keywords: Breast cancer; Virtual community; Trust; Self-help groups; Canada

TO YOU, IT'S A JOB.

TO ME, IT'S MY LIFE.

Introduction

Two hundred women, living in places as distant as Canada, New Zealand, Hong Kong, and Europe, bear this message to their medical appointments. The blunt slogan appears on an oversized pink button to remind medical professionals that patients should be regarded as whole people, not just as medical challenges. "I'm a person, not a tumor," one breast cancer survivor put it.

The pins were inspired by online discussions among breast cancer patients about insensitivity they had endured, from painfully bungled procedures without so much as "I'm sorry," to unnecessarily extended, anxiety-ridden waits to hear about crucial test results. They are just one symbol of solidarity among users of ⟨http://bcans.net⟩, an online community sponsored by a survivor-driven nonprofit organization in Canada, Breast Cancer Action Nova Scotia. Not everyone is an activist—many are just trying to grapple with their

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disease—but some BCANS participants find ways to press for healthcare improvements, whether through the pink buttons, letter-writing, media interviews, or other means. Seldom claiming to be part of a social movement, they nevertheless are using the global communication grid of the Web to connect with like-minded people. For example, on two occasions when someone posted news articles about a woman in the US being fired from her job for taking too much time off during chemotherapy, participants wrote letters and threatened a boycott. On another occasion, some wrote letters to the New Zealand health minister, urging coverage of an expensive new hormonal treatment, Herceptin. This campaign was in response to the plight of BCANS' youngest member, a 21-year-old college student whose family was personally trying to cover payments of $10,000 per treatment, because Herceptin was the only drug seemingly capable of bringing about a remission.

The widely prescribed and widely complained-about Tamoxifen was the subject of a BCANS in-house survey asking about side effects. The woman who created and posted the survey presented the results—a long list of complaints—to scientists. In all three instances, the outcomes—whether much influenced by BCANS activism or not—were favorable: The companies reportedly re-hired the cancer survivors; New Zealand began to provide Herceptin through its national health system; and a high-profile study eventually confirmed the considerable downside of Tamoxifen.

The website's sponsor, Breast Cancer Action Nova Scotia in Halifax, in fact does have a heritage of polite activism and public education, although most of its efforts go to support. It was formed in 1994 with this purpose, according to the website:

> […] to address the obstacles faced by women/families/friends living with breast cancer—things such as delayed diagnosis, not enough information, social/psychological issues, poor communication with the health care team, lack of support, etc. Our members and volunteers are active throughout the Province raising awareness about breast cancer and addressing the unique needs of men and women affected by breast cancer. Members sit on various boards and commissions, and actively promote breast cancer related events, issues and activities.

The site was launched rather casually in December 1996 by its founder Paula Leaman. After a slow first year with just two or three messages monthly, activity began to climb in spring 1998. By spring 2003, the site was logging about 22,000 visits. Today, the various needs of users are accommodated by four forums, a chat room, autobiographies, and numerous archives of reports and information collected by members. In addition to messages—about half a million, all told, since 1996—many participants exchange phone calls, gifts, and practical, emotional and spiritual support. On a more pragmatic front, BCANS participants have collaboratively written two books of support and advice; given media interviews and conference presentations; lobbied for reforms; and produced music and artwork in honor of the group (Harbauer, 1999; Reeve, & Wagner, 1998). This cornucopia of goodwill was described by one participant as "a chain of all things good."

While exceptionally effective in producing support, BCANS is just one of thousands of peer-to-peer systems setup by individuals, nonproft organizations, institutions, and for-profit companies, many of them highly praised by users. These groups have a variety of providers, from grassroots groups and individuals to well capitalized corporations, and they may be labeled "message boards," "discussion forums," and so on. But they have several things in common: a 24-h, interactive site where people post and read messages at their convenience; a single-illness focus; and a tendency for messages to contain both information and expressions of encouragement (see for example Dance, 2000; Sharf, 1997; Curran & Church, 1997). Some are simple question-and-answer sites or guestbooks, but others operate like a real-life community, with a stable core of participants whose candid messages, loving encouragement, and work on behalf of the website make it clear that a productive social network has formed. From a health perspective, networks in general are highly desirable because social cohesion is associated with better health (see for example Putnam, 2000; Freund & McGuire, 1999; Heaney & Israel, 1997; Roter & Hall, 1997; Glanz, Rimer, & Lewis, 1997; Spiegel, Kraemer, Bloom, & Gottheil, 1989).

Use of the Internet for health communication is popular, at least among English-speaking people, who have the widest choice of sites. It is evident that people use it not only for the gathering of professional research: not only for social support but to pool their collective intelligence about many things, from how to cope with swelling to how to think about end-of-life issues (Brant, 2003; Street, Gold, & Manning, 1997). This type of communication casts patients in a much more empowered light. In the course of mutual support, it is only natural that some will identify targets for social action, from poor hospital procedures to environmental poisons. Thus, a community can, in its unstudied way, deal with issues of social policy.

How does a project like BCANS thrive over so many years? What features promote this group's exemplary social cohesion? Can its approach serve other populations as well? Can effective support and even activism emerge from such an informal, voluntary environment? This study hopes to provide answers to these questions and perhaps to suggest some structures that could be useful for other medically oriented online communities (see also Radin 1998, 1999).

Theoretical basis

Medium theory looks at the ways in which emergent communications media interact with society. Methods from economics, history, and sociology are brought to bear on revelatory cases. According to medium theorists (see for example Innis, 1950, 1952; McLuhan, 1964; Melody, 1994; Deibert, 1997), an emergent communication medium begins to create a new communication environment, which is then colonized and modified by users. In response to the opportunities that are created by this new medium, old social structures may weaken and fail, especially if already under pressure. Emergent media can break down "information monopolies," as Innis (1950) calls them, by routing around old roadblocks.

Melody (1994) notes that social institutions are essentially knowledge-based, which suggests that they are dependent on communication flows. Thus, when a new medium emerges, breaking down old ways of communicating, the institution may undergo profound changes, especially if already under pressure to change. Today, few institutions are under such pressure to change as healthcare, which faces growing economic problems and dissatisfaction from professionals and patients alike. In response (in most developed nations, at least), patients are being re-framed as "consumers" (Porter-O'Grady & Wilson, 1995; Roter & Hall, 1997).

This change rewards people who seek information, while it may place at a disadvantage those who continue to rely wholly on their doctor's concern. The Internet is a natural promoter of this change, in three ways: (1) it is a massive expert database, a repository for more than a billion up-to-date articles, (2) it is a global broker, a way for individuals anywhere with special concerns to find each other; (3) it is a global collective memory, allowing people to contribute, store, and annotate comments.

Social capital theory

What makes the BCANS online community so important is how much people—initially strangers—do for each other, not only to assist with medical issues, but also to meet emotional and even material needs. Social capital theory complements medium theory because it explains what conditions are necessary for people to help each other, voluntarily, to such a striking degree. Social capital theory, which considers social cohesion a powerful asset to any society, views communication as a way for people to determine whom to trust, help, and cooperate with in order to engage in productive reciprocal networks (Sirianni & Friedland, 1995). According to Coleman (1990, p. 306):

> Two elements are crucial to this form of social capital: the level of trustworthiness of the social environment, which means that the obligation will be repaid, and the actual extent of obligations held.

A high level of trust allows people to work together effectively without the self-protective intervention of lawyers, contracts, or police—indeed, in a medical setting, people could not get much done in the absence of trust. Unfortunately, a person's normal sense of trust may be shattered in a traumatic situation. According to Matsakis (1998, p. 57): "Trauma survivors not only lose trust in some of the basic premises that keep people functioning (such as the assumptions of personal invulnerability and that the world is just and fair) but they can also lose trust in people, including themselves." Add to that the threat of hacking and spamming, and it is difficult to imagine how trust can be engendered among members of an online community; yet, it seems to thrive.

Types of trust

Lewis (1999, p. 9) postulates a type of trust in business networks that he calls "deep trust"—not just an acknowledgment that two firms need to cooperate, but trusting interpersonal relationships built on liking and mutual appreciation, between people who have to work together toward a mutual goal. As success is achieved, mutual dependency escalates; deep trust, including the assurance that the other side will not give away critical information, becomes ever more important in promoting future success.

While "deep trust" operates interpersonally on behalf of corporate projects, Putnam's similar notion of "thick trust" is an attribute of social networks on behalf of individuals. Putnam (2000, p. 136) says thick trust occurs within dense networks of business associates, relatives, friends and neighbors; it is based on personal experience or up-to-date information from familiar sources about a person's trustworthiness. At the other end of the trust spectrum is "thin trust"—a more generalized decision to give most people the benefit of the doubt—also called "swift trust" (Lewis, 1999) or "scatter trust" (Govier, 1997). Putnam (2000, p. 136) says "a thinner trust in 'the generalized other,' like your new acquaintance from the coffee shop, also rests implicitly on some background of shared social networks and expectations of reciprocity" without the benefit of knowledge about the other party. "Thin trust" is socially beneficial, Putnam argues, because "it extends the radius of trust beyond the roster of people whom we can know personally," thus also extending the benefits of trust beyond one's immediate social network.

While social capital theory offers no explanation of how thin trust sometimes transforms into thick trust, interpersonal scholars have identified a set of factors that contribute to intimate, trusting relationships whether in-person or at a distance. Trenholm and Jensen (2000, pp. 298–302) propose that trusting relationships develop in three stages: first, perceptions of similarity provide an initial attraction; whereupon reciprocal self-disclosure promotes greater intimacy; thus enabling shared episodes to allow people to find out more about each other under various conditions, build shared memories, and become more attached.

Is trust different in cyberspace? Putnam (2000, p. 177) suggests that geographical dispersion of participants and the ease of entry into and exit from an online group may promote superficial "drive-by relationships." On the plus side, the online world has fewer ways for people to differentiate themselves, contributing to the sort of egalitarian atmosphere that promotes trust because people appear to be very much the same. Rheingold (1993) and Schuler (1996) both note that giving information, the main way in which people engage in mutual aid, is easily observable by all in the group, giving the more mistrustful members the idea that there is nothing to fear and much to gain by cooperating. In fact, Bays and Mowbray (2001) and Raymond (1999) demonstrate that many online groups are "gift cultures" in which personal worth is measured by how much participants contribute. Group members even tend to inflate their opinions of their partners because there is little real-life information to contradict the ideal persona that can be presented in cyberspace. According to Blanchard and Horan (1998, p. 299), "Since it is assumed that little information comes through the person's social networks about other group members (especially geographically dispersed communities of interest), highly active members of virtual communities may be more trusting of other group members than is observed in face-to-face communities."

Therefore, it appears that the cultivation of trust in an online community is desirable, and actually occurs, but how? Is there some way that website structure can enhance its development? This case study attempts to answer those questions in an effort to explain how an exemplary online community can thrive.

Breast cancer, communication needs, and trust

To share the profound horror of a breast cancer diagnosis, one need only read this description (Middlebrook, 1996, p. 2): "My surgeon's words *invasive carcinoma* bounced like overripe tomatoes off the hospital walls and splattered us blood-red with fear."

BCANS participants call their disease "the monster" "the beast," while the possibility of death is "the elephant in the living room; you can't ignore it." "Death is in my face," one wrote. Another described herself as "a ball of agony."

Along with dread comes frustration because cancer is cruelly ambiguous. According to Ray and Baum (1985, p. 19):

> For most, a key element of the informational crisis is that [cancer patients] do not know what the outcome will be. They do not know whether their previous assumptions and expectations for health and longevity are valid or invalid.

The American Cancer Society lists 10 different types of breast cancer, five stages of the disease, four levels of cell aggressiveness, and 260 relevant medical terms, from "ablative therapy" to "xeroradiography." Factors that may affect an individual include not only the aggressiveness of the cancer, location of the tumor, and whether the disease seems to be confined to one spot, but the patient's age, treatments, personality, physical condition, economic situation, peer group, family and job situations, capabilities of the health providers, and sheer luck (Cooper, 1988).

With all of these ambiguities, information-gathering becomes a strategy to reduce feelings of uncertainty and produce feelings of control and hope. Consequently, most breast cancer patients urgently seek information. In addition, most people urgently need emotional support. Personal accounts (for example Lorde, 1980; Middlebrook, 1996; Wilson-Hashiguchi, 1995; Gee, 1992; Moch, 1995) report wave upon wave of emotional crises as a suspicion is confirmed, decisions are faced, treatments are endured, family life is dramatically altered, and a long, deep shadow falls across the future. Receiving good emotional support (ranging from pragmatic acts, such as doing a sick person's chores, to sympathetic listening and uncritical love) often has measurable medical benefits (Roter & Hall, 1997, pp 179–205; Spiegel, Kraemer, Bloom, & Gottheil, 1989) as well as "better adjustment, better coping, higher self-esteem, and improved acceptance of the illness" (Kurtz, 1997, p. 11).

Involvement of people who have the same disease is a valuable component of support. Ferguson (1996, p. 41), a physician and cancer survivor, writes: "Online self-help networks are like surrogate families. Members share common problems, help each other toward mutual goals, and support each other through good times and bad. The support they provide is available for free and, in most cases, around the clock, as needed." Johnson (1997a, p. 7) finds that people turn to different information sources for different kinds of questions, and their questions cover a broad range. Besides diagnostics and treatment, they seek details about scientific discovery, alternative approaches, continuing care, rehabilitation, and even the politics of breast cancer. To get this information, Johnson (1997b) found that "women preferred doctors most, friends/family and organizations about the same, and media least for general information," although they reported getting the least information from their doctors (see also Lantz & Booth, 1998; Luker et al., 1995, 1996; Butow et al., 1996).

Studies indicate that breast cancer patients' communication needs occur in waves as they move from a familiar stage of the disease into a new stage. Six basic stages can be identified: firstly, *concern,* a span of years, weeks, or just a few days during which a woman becomes concerned about developing breast cancer for a variety of reasons, followed by *pre-diagnosis, post-diagnosis, post-surgery, recovery and follow-up treatment,* and finally, *end-of-life issues.*

Clearly, most breast cancer survivors can benefit from emotional support at many points during their harrowing journey. However, according to Spiegel (1990, p. 1422): "A feeling of social isolation is the rule, not the exception, with cancer patients." For various reasons, less than 10% join support groups.

Research methods

This research is in the form of a case study. Yin (1994, p. 41) identifies a particular type of case study called "revelatory" where "the investigator has access to a situation previously inaccessible to scientific observation." Such a study, he states, is worth conducting for its descriptive information alone (see also Stake, 1995). An embedded case study design uses several units of analysis within the case. According to Yin (1994, p. 44) "the subunits can often add significant opportunities for extensive analysis, enhancing the insights into the single case." Denzin (1999) advocates the "method of instances" for studying what he terms "cybertalk." This method involves analyzing "uniquely adequate instances" of form and content. Denzin (1999, p. 113): "Postpositivist concerns for representativeness, generalizability, and scientific credibility do not operate in this model. The goal is to achieve a strong reading and an adequate analysis of a particular instance or sequence of experience."

Although there are several other active breast cancer discussion sites, BCANS was chosen as the exemplar because it is the oldest (founded in late 1996), the busiest, and it has the most extensive roster of activities.

The research presented here is based on five data sources: (1) interviews with the BCANS webmistress, by telephone, via e-mail, and in person during three visits to Halifax; (2) historical and online documents; (3) participant observation online and in person; (4) server log analyses; (5) interviews with selected participants.

Participant observation is a preferred way of conducting a case study, because a researcher who identifies with her research subjects and spends substantial time with them is less likely to gather misleading data or to misinterpret good data (Creswell, 1997, pp. 123–125). For example, through participant observation in the present study, I learned that the visibility of individuals online is not the only indicator of their contributions to the group. Server log analyses, used by the webmistress to monitor activity, were made available for this study. While many of these reports are of interest only to web administrators, others are quite usefully interpreted to provide an aggregate picture of user behavior, including: Most Active Countries; Most Requested Pages; Activity Level by Day of Week; Activity Level by Hour of Day; Top Search Keywords; Number of User Sessions; Average User Session Length.

Findings

After a slow first year, activity began to climb dramatically; between April 1998 and April 1999, visits more than tripled from 5611 to 18,917 a month and by spring 2003 they stood at about 22,000 monthly. User sessions average 12–13 min in length. This suggests that some visitors spend a substantial amount of time visiting, since every mistaken hit or hasty visit must have an offsetting visit of nearly half an hour. Some users often pay multiple visits each day. Weekdays are busier than weekends; activity also slows down in summers and during December, illustrating that the site is used mostly by people who are working, celebrating the usual holidays, and spending time with others at weekends. The site is busiest when it is early evening on the east coast of North America, where the largest group of users live. But thanks to "regulars" from all continents of the world, the site never sleeps.

Users

Although the majority of participants are breast cancer survivors themselves, including a handful of men, postings also come from spouses, sisters, sons, daughters, fathers, and friends. Average user age is 46, about 20 years younger than the statistically average breast cancer survivor. The Forum has received messages from teenagers and from people in their 70s.

Visits come from all around the world, predominantly from English-speaking countries; at least two-thirds of participants are American, and another 20% or so are Canadian, but New Zealand and Australia are well represented. Visits in the first 2 weeks of May 2003 came also from Sweden, Belgium, the United Kingdom, the

Netherlands, the Cayman Islands, Japan, the Philippines, Turkey, Finland, Germany, Brazil, Switzerland, Greece, Norway, Malaysia, Saudi Arabia, and France. It may be inferred that most participants are from the high end of the educational and socioeconomic scale, since they have regular computer access and tend to write well, and indeed messages mention business or professional work. However, this group is quite different from the earliest Internet users of the 1980s, who tended to be scientists, computer programmers, and engineers—and nearly all men.

It is difficult to track turnover in this community, because silence on the message forums does not necessarily mean absence, and there is more continuity than is readily observable. Even the most active members sometimes take long breaks wherein their names are not visible in discussions for months, even years; however, they may continue to visit the site or to receive a daily digest of all posts via e-mail. They also may work on special projects and keep in close touch with a selection of BCANS friends. Over all, the site appears to be relatively "sticky," with about one-fourth to one-half of site users still affiliated after a year, and several hundred enduring even after 5 years. Even death does nothing to erase a person from the forum; pictures and autobiographies stored on the site, combined with occasional messages from surviving friends and family members, keep cherished memories alive.

Types of messages

A content analysis for April 2001, showed 303 different thread topics in the main forum. The number of messages addressing thread topics ranged from just one (in 14 cases) to 74, when the conversation turned to death; 56, when a participant reported devastating news of bone metastases; and a total of 116 messages in two waves in response to another bad pathology report. The average number of messages per thread was 12. Messages tended to be written in a characteristic shorthand: "mets" (metastases), "onc" (oncologist), "bmt" (bone marrow transplant), "bc" (breast cancer), "mammo" (mammogarm); "paths" (pathology reports).

The threads fall into five major categories:

Support: The largest group, 114 threads (38%) primarily exchanged supportive comments in moments of stress. Postings requested good wishes and prayers for women facing checkups or procedures; another thread expressed deep sympathy and outrage on behalf of a woman who had just suffered inept medical care.

Heartbreak is met with courage and sensitivity at BCANS. Decisions to enter hospice care or to discontinue treatment are sometimes announced by a member; loving farewells gently exchanged; deaths reported and sometimes described in detail by a survivor; funerals attended where possible; cards, flowers, and donations sent; and memorials of various kinds created to honor the deceased. It is striking that so many "real-life" traditions are merged into this virtual world where so few people have met—but it is important to mention that only a fraction of the community tends to take part in any specific instance.

Queries: Hundred threads (33%) primarily involved medical issues: how to cope with pain, whether to ask for breast reconstruction, what to do about numbness, arm swelling, prostheses, and so on. Some threads questioned the medical establishment and especially long-term medications that brought new risks with statistically marginal improvements in outcomes. "Tamo or not tamo, that is the question," read a typical thread about Tamoxifen. The controversial procedure of removing and dissecting underarm lymph nodes, to see whether the cancer may have spread, was attacked in "Keep Your Nodes and Save that Arm!" One post declared: "Doctors are used to having the last word and they don't expect you to be asking questions but I can tell you asking questions and not agreeing to everything they want you to do will gain you an enormous amount of respect…Don't let them intimidate you!!! YOU ARE THE PATIENT." A woman who had been encouraged to be more assertive with her oncologist reported happily, "It didn't seem like the same doctor." There were announcements from women quitting Tamoxifen because of side effects and Raloxifene because of bone pain. A particularly exasperated Canadian proposed: "What would happen if we all went on strike?! Ha!"

Threads that are clearly activist are infrequent, but when they do appear, they are met with enthusiasm by many. A May 2003 post entitled "A Way You Guys Could Really Help," for example, touched off a letter-writing campaign to the Florida Legislature, urging it to end a doctors' strike by limiting the amount of malpractice awards in court cases. "It doesn't matter if you live in Florida or not," the post said, and indeed there may be some attention-getting value in letters from afar. Broader political issues, such as preventing cancer through greater environmental protection, are sometimes seen as divisive. Rather, the group seems more inclined to support specific instances of discrimination, insurance coverage problems, and more funding of treatment research.

News and information: Participants post links to relevant news and new medical studies so that others can read the original material. Most often, cancer news is simply announced neutrally, or with a hopeful comment from the sender. However, an announcement that bone marrow transplants were judged useless against breast cancer set off an emotional dispute that ended with one of the most active participants temporarily leaving the forum.

Projects being collectively undertaken by BCANS participants marked the theme of 14 discussion threads

(5%). The community is constantly engaged in a variety of projects, including fundraising, surveys, get-togethers, and writing. Eventually, the webmistress instituted special forums for travel, dieting, and general "off-topic" comments (pets, jokes, recipes, etc.) in order to leave the main forum free for more serious discourse.

Site content

The site's main focus is on its users and what they have to say; however, it also is a repository for considerable research. The site comprises 5 main thematic sections, or fields of emphasis: *interactive messages, self-introduction, information, fundraising.* The *interactive messages* field includes a main discussion forum with searchable archive of 250,000 messages, an optional daily e-mail digest of all new messages, an off-topic forum, including a "photo upload" option, a gatherings forum, to arrange and report on get-togethers, a chat room and a "prayer chain" for spiritual messages. *Self-introduction* covers autobiographies and a profiles section. *Information* provides an Introduction to the Breast Cancer Action Nova Scotia organization, links to online breast cancer resources collected by group members, a glossary of 507 breast cancer terms compiled by community members, breast cancer news from the *Yahoo* web server, research studies of interest to the group, and rules and suggestions for using the site. The *Fundraising* section has several links.

"Netiquette" is achieved by means of posted rules and suggestions; peer pressure; and a dedicated webmistress, who removes harmful material, bans disrespectful visitors, and files complaints with the Internet service providers of anyone who dares to send spam.

All of these many site features, practices, and activities can be organized into three distinct trust-building stages that gradually transform casual visits—"thin trust"—into the kind of "thick trust" that generates social capital. Structurally, the system is shown in Table 1.

Table 1
Trust-building stages

	I. De-lurking (thin trust)	II. Self-disclosure (greater trust)	III. Shared episodes (thick trust)
Design	BC symbolism Open forums Usability	Private e-mail option Profiles Autobiographies	Event planning forum Reports on past events
Management	Grassroots site Ban spam	Prevent abusive messages	Assist with projects
Users	Welcome posts Helpful messages	Openness Off-line communication	Initiate projects Support projects

Stage I. Lurking, de-lurking, and "Thin Trust"

BCANS hosts five to six times as many visits as it receives posts. This ratio indicates a substantial amount of "lurking"—reading other people's messages without leaving any of one's own, thus remaining "invisible." However, there are two kinds of lurking—visits by "regulars" who are already committed to the community, just checking up on their friends; and visits by those who have not introduced themselves. In response to a question posted on the forum, 16 people said they visit anywhere from five times a week to three times per day without posting unless they have something unique to say.

According to the online Webopedia.com dictionary, lurking is encouraged by Internet communities because it allows a visitor to observe the group's norms before participating. When a visitor decides she has something to say after a period of lurking, the procedure is called "de-lurking," a term said to be based on the Star Trek "de-cloaking," i.e., removing the invisibility shield from a Klingon warship. Like Klingon warriors, a person in a discussion forum, particularly a person coping with serious illness, will not likely reveal herself unless she feels she is in friendly territory.

Several aspects of the BCANS website signal friendliness toward women with breast cancer and invite their participation: ease of use, visual symbolism such as pink ribbons, and the observable, friendly, varied virtual discussion. These elements are similar to the symbols that attract people to each other in face-to-face situations. Over the years, approximately 1500 have found BCANS reassuring enough that they have de-lurked. The number who have read one or more messages without ever posting is likely in the tens of thousands.

Stage II. Self-disclosure: building trust

Self-disclosure in the "blue nowhere of cyberspace," as a participant put it, can be highly risky. Publicizing one's medical problems can lead to insurance and job discrimination and can be socially stigmatizing. Nevertheless, self-disclosure, which the literature says is a critical step toward deepening trust, does take place in the BCANS community. As a Texas woman put it: "We say things to each other that we tell no one else." Responses to Linda's post on death, for example, included these self-disclosing comments:

> Since I have finished all my treatments I feel as though I am waiting for the other shoe to drop. I sometimes wake up in the middle of the night […] I have never told anyone that before.
>
> When I was first diagnosed I thought of death constantly. Didn't even want to buy new clothes, because I didn't feel I would be around to wear them.
>
> We joined a memorial society […]He didn't want to talk about it, but I insisted.
>
> Mostly I worry that if I get a recurrence and don't die immediately, it will ruin us financially.
>
> [People] do everything but run screaming from the room when I bring [death] up, so I let them go on with their pathetic shallow lives.

Such heartfelt comments serve to raise trust levels by showing that it is safe to be vulnerable. "It feels so safe and comforting here," one woman wrote as she reflected on her first year of participation. An explanation for self-disclosure lies in social capital theory's equation for risk assessment: risk = prospective reward−possible loss. Whether consciously or unconsciously, people calculate the risks based on available information before baring their souls, weighing the probable relief that supportive responses would bring against the hurt of criticism or rejection. In the following post, for example, a young wife and mother held back delicate disclosures about her marital problems until she had fully assessed the risks (Reeve & Wagner, 1998, p. 32):

> Okay guys/girls!!! Now that I feel TOTALLY comfortable on here, I have a really important question to ask. What effect(s), if any, has your BC experience had on your relationship with your spouse or boyfriend? […] My marriage is on the line here.

The BCANS site encourages self-disclosure with a site design that makes it easy for people to read the confidences of others and the responses they receive, without the necessity of registering or logging in. Looking at others' words displayed against a sympathetic pink background, visitors can see for themselves that even the most painful disclosures are usually met with warmth and grace.

Depression, too, is dealt with openly, as in a post called BLACK HOLE, written by an Australian mother of five who had just learned of liver metastases: "I am feeling absolutely horrible. I've really fallen into a black hole." More than 20 women rushed to encourage her and validate her feelings with their own depression stories. This type of conversation illustrates to anyone who is hesitant that self-disclosure, within this community, tends to be a low-risk, high-reward decision.

In addition to sharing confidences about immediate problems, the BCANS website promotes a more open sharing of one's identity in several ways. Instead of using a nickname ("wearing a mask," as one woman put it), BCANS "screen names" normally involve a real first name and last initial or first name and place of residence, such as "Pam (TX)." Some even use their real first and last names. The safe, open atmosphere of BCANS, created by the participants themselves and promoted by website design, is complemented by three specific options that allow members to scale up their self-revelations as they see fit:

1. *A pop-out form* convenient for sending a private e-mail message is linked to every post. This makes it easy for participants to write things to an individual that they would not post to a public message board. The recipient's e-mail address remains hidden, so it cannot be "harvested" by spammers.
2. *Profiles* are thumbnail self-portraits that may be accompanied by a single photo. They are public—an icon linking to the profile is automatically attached to each of that individual's postings. One user explained: "The obvious attraction is that [a visitor] may find someone through the profile who is very close to the age and diagnosis as they are, thus an instant connection and bond."
3. *Autobiographies* are more extensive and more private forms of self-portrait. Besides unlimited space to post a statement, there is room for three photos, which the webmistress will digitize herself if needed. Only those who have filed a biography can receive a password to browse this section.

Stage III. Shared episodes, virtual and real

A petite Maryland woman, a longtime voice of bravery, wisdom, and cheer, had been diagnosed in 1994 at age 44 with an aggressive form of breast cancer. It had spread to most of her lymph nodes, but a mastectomy, heavy chemotherapy and radiation, followed by years of exercise and healthy eating, had left her feeling fit for more than 5 years. But increasingly persistent rib pain brought the diagnosis of widespread bone metastases. This discovery forced a year-long round of various chemotherapies that, while not very successful, left her with lung and heart damage. As 2001 dawned, Lynne was using oxygen, losing weight, feeling exhausted, barely able even to laugh or cry because of rib pain. She wondered whether her appointment on the first Monday in January, to try the drug Herceptin, would just bring more discouragement.

Her ebbing strength touched the many people she had helped over almost 3 years. So, they virtually climbed over snowbanks, abandoned palm-fringed beaches, left their country lanes and city streets, and piled on an imaginary pink bus to join her at her chemotherapy appointment. The bus ride announcement, from a long-time BCANS member, came on Friday:

> To all those who are fairly new here, we occasionally crank up the old BC bus, pick up anyone who wants to come along, and travel our way to a BCANS'ers side for support. I'll be driving the rickety old thing [...] This bus makes the trek to anywhere on the globe BTW [by the way].

The responses were immediate and came from Newfoundland, Ontario, New York, Montana, Texas, and beyond. "Pick me up on snowy Rt. 28 going out of Brockway, Pa.," one message requested. Others announced: "Here I come from a farm in South Dakota." "I'll be standing at the corner of Boise and Hwy 34 in Loveland [Colo.]." "Pick me up on a little island in Puget Sound."

> Please drop by Hong Kong and pick me up.
> You can all thaw out for a minute while we dip in the clear blue Indian Ocean and lie on the warm soft sand.
> Have you room for a small, fat person [from England]?
> We will be two of us from Finland. Hide the winebottles!!!!
> I'll be waiting, impatiently, to be picked up at the bus-stop in Uppsala, Sweden!

There would be gifts, and the spirited riders promised to pack delicacies for the journey: There would also be entertainment aboard. The bus, which the group by now had decided should be a pink double-decker, would be decorated with clouds, angels, flames, banners, ribbons, balloons, and twinkling lights. Those aboard would hang out of the windows blowing bubbles as the bus roared up to its destination in Annapolis. This group tribute was as vivid to its recipient as it obviously was to the givers, because she delightedly thanked them for the visit.

But Lynne continued to be frail, so two more virtual support campaigns were mounted. One was a list of encouraging statements, one for each letter of the alphabet; overnight, 17 people contributed cleverly crafted good wishes to the list and covered every letter, sometimes several different. The other was a "cyber-wave," as the originator called it:

> Each person is holding a balloon full of oxygen and each balloon has an inscription on it. The inscriptions are positive thoughts [...]. All she has to do is mentally break a balloon and she gets not only a positive thought but a burst of oxygen as well.

Two months later, in April 2001, Lynne was almost pain-free, no longer needing oxygen, and tending her garden for the first time in 2 years.

It is not the claim of this paper, of course, that online communication can produce cancer remissions based on this one instance. However, I do propose that virtual experiences give people—even people who are quite sick—vivid shared episodes that combine with other experiences to build a high level of trust, which sets the stage for a "virtuous circle" of caring. In addition to virtual visits, BCANS makes it easy for newfound friends to arrange in-person visits by setting aside part of the site to show off get-together snapshots and plan coming events.

Taken together, all of these devices, from the pink color scheme to the candid comments to the virtual and in-person experiences, tend to funnel site users toward higher levels of trust. Of course, not everyone takes this route, but it does appear that the BCANS formula succeeds in transforming many casual visitors into people who wholeheartedly contribute to the community.

Conclusions

This participatory case study, ongoing since 1998, illustrates the scope, passion, and complexity of peer-to-peer medical communication in a virtual environment that promotes trust. This website represents neither mass nor interpersonal communication as traditionally conceived; it is about relationships, about pooled intelligence, and about the technological structure that promotes a particular set of beneficial outcomes.

The BCANS community is a social movement in the sense that it encourages people with the same disease to intersect and to work cooperatively. The ensuing conversations, in some cases, lead to critiques of the status quo, and since this is a fairly cohesive community, those critiques sometimes evolve into concerted action. Since this process is primarily conducted through messages that are archived, there is a record for others to learn from.

Could the activist function of BCANS be amplified? If so, what would it look like? Might a website be launched strictly for medical activism—much like MoveOn.org, Planned Parenthood, and other organizations that make it easy to send automated messages to designated decision makers? This is technologically possible, although it would probably remain a niche within the BCANS community, not replacing its popular and much-needed support functions. Medicine is highly politicized, and while people with breast cancer, for example, might agree that more research is needed, do they mean more research into prevention? What does that mean—lifestyle choices or pollution reduction? Are they calling for more research into medical treatment? Do they mean, for example, finding out which patients will *not* benefit from a particular treatment, such as Tamoxifen, in order to spare them the risk and spare society the expense? Or, do they mean continuing to subsidize pharmaceutical companies' search for a "cure?" Which government programs are people willing to sacrifice, in their various countries, in order to divert more money into research? It is quite possible for a two-click activist site to be launched, and for the originators to decide the agenda. However, in the case of BCANS, support and harmony are a higher value than political activism, so it is unlikely that the site will evolve in a substantially more political direction.

On the other hand, by their very existence, sites like BCANS are planting the seeds of revolution. They are helping to shatter the professional "information monopoly," allowing lay people to understand their situation in detail, compare notes with others, reconstruct knowledge, and thereby to form opinions and find support. "The internet routes around damage," activists declare. Evidently, many cancer patients view the institutional information they are receiving, and not receiving, day to day as "damage," and they use the Internet to route around this impediment. This is a collective, unsystematic project involving millions of contributions, great and small. It involves emotional intelligence as well as pragmatic information on how to cope. It involves pointers to professional papers, inspiring books, news articles, and personal websites as well as a sharing of personal experiences in answer to posted queries. It involves empowerment in dealing with illness, loved ones, work, and sometimes blundering caregivers. This collective intelligence should be evaluated, not simply dismissed as amateur, unreliable, and possibly even malicious. The medical information monopoly is dead, and how constructively medical professionals accept this will help to determine how widely society will benefit from the new order.

Are there common activist agendas about which participants can agree? Perhaps they can start with this simple declaration: TO ME, IT'S MY LIFE.

Note

This article is being published posthumously, largely in the form that it was originally submitted to the Patient Organization Movement workshop (organized by K. Landzelius and J. Dumit, and held at the University of Gothenburg in June 2003). The editors wish to emphasize that the draft form published here has not had the benefit of the author's own final review and preparation for publication. The editors take responsibility for shortening the original paper, and the correspondent for composing the accompanying abstract.

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