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Illness and Internet empowerment: writing and reading breast cancer in cyberspace

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ABSTRACT The Internet is now a site where women with breast cancer both read and write about the illness, and in doing so negotiate identity and definitions of situation in disembodied space. Cyberspace has been imagined as a liberatory realm where women can transgress gender roles, invent selves and create new forms of knowledge. This study explores the personal web pages of women with breast cancer with an interest in exploring the issue of ‘cyber-agency’ or empowerment in cyberspace. I suggest here that women’s web pages might offer potentially critical opportunities for women’s knowledge-making in relation to what are often highly political aspects of the body, gender and illness. However, the Internet is not an inherently empowering technology, and it can be a medium for affirming norms of femininity, consumerism, individualism and other powerful social messages.

KEYWORDS *breast cancer; cyberspace; gender and illness; Internet*

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The Internet is increasingly becoming a site where women with breast cancer not only receive information about the illness but also compose and circulate their own stories of breast cancer. Women with breast cancer are often deeply interested in self-definition and empowerment, and I describe in this study how they create personal web pages on the Internet as sites for generating new forms of knowledge, awareness and agency in relation to the illness. Debates about the Internet in feminism and cyberstudies have focused on to what extent 'cybersubjects' are free to create new identities, relationships and communities in virtual, disembodied space, or, put more simply, how and to what extent they are empowered by virtual technologies. I suggest here that women's web pages might offer potentially critical opportunities for women's knowledge-making in relation to what are often highly political aspects of the body, gender and illness. However, the Internet is not an inherently empowering technology, and it can be a medium for affirming norms of femininity, consumerism, individualism and other powerful social messages.

Cyberagency: virtual space and the interactive body/self

A debate has been underway since the early 1990s about how identities and definitions of situation emerge out of and operate within disembodied media communities. Theories about the Internet have been variously optimistic and skeptical, suggesting the complexity of what we might call 'cyberagency', particularly in relationship to symbolic forms of oppression and constraint. A number of scholars have celebrated the disembodiedness of interaction on the Internet, which may foster a disruption in the ordinary ways in which our senses of self, or our 'identities', are shaped (Turkle, 1995; Featherstone, 2000; Leary, 2000; Plant, 2000). Corporeal bodies are absent in cyberspace, and thus individuals are left to represent the body through words, images, codes and symbols. This may leave us with greater freedom to perform our identities, since the states of our bodies are no longer 'empirically verifiable'. As Waskul et al. describe,

> In these on-line social worlds, traditional assumptions about self and body do not apply: the activities of participants and experiences of self are neither contained by nor affixed to corporeal bodies . . . both bodies and selves exist only as [emergent] socially constructed representations. (2000: 378)

Waskul et al. describe how instead of fixed identities for bodies and selves, new meanings are continually generated in cyberspace that are the product of intersubjective, temporary expressions of on-line individuals and collectivities. Selves appear in cyberspace not as 'that which the body contains or holds', but rather as constructs that emerge out of communication. Released from traditional bodily constraints, or 'situationally freed from the empirical shell of the body', cybersubjects are left to represent themselves virtually (2000: 378). Thus, *choice* in what our identity is and how others will identify us is part of the promise of the on-line world (Willson, 2000).

Unsurprisingly, then, the Internet has been embraced by a number of theorists for what they see as its radical potential. Some writers have described, for instance, how individuals might create multiple identities and roles within a virtual community, and in so doing de-essentialize fixed, unitary subjectivity (Poster, 1995; Turkle, 1995). Others have explored the particular implications of virtuality for gender and sexuality. In cyberspace, new genders and sexualities can theoretically be imagined and represented outside of physical constraints. Faith Wilding describes the 'net utopianism' within cyberfeminism, which expects that cyberspace will be 'a free space where gender does not matter – [where] you can be anything you want to be regardless of your "real" age, sex, race, or economic position . . .' (1998: 9). Sadie Plant's writings about cyberspace, for instance, might be described this way. Plant declares not only that women have been using cyberspace in radical ways, but also that the very form of cyberspace interaction is already culturally subversive. Because it promotes fluid notions of self and body, she argues that the Net provides women with a space for deconstructing traditional roles and definitions of self and situation. 'There is a virtual reality,' she writes, 'an emergent process for which identity is not the goal but the enemy, precisely what has kept at bay the matrix of potentialities from which women have always downloaded their roles' (2000: 335). Plant's assertion that the Net is a particularly subversive space for women relies on the idea that women can and will embrace fluid identities, forge new kinds of relational networks with other users and employ what she calls 'intuitive leaps and cross-connections' that are not traditionally masculine but rather feminine and empowering.

But the idea of women's cyberliberation has a number of problems. So far, as a number of ethnographies of the Internet suggest, cyberculture has far from achieved freedom from normative gender constraints, or from other oppressions related to embodied identity. Researchers have described how conventional power relations, including those of gender and race, work their way into on-line interactions. As Caroline Bassett suggests in her study of a virtual 'city' in which participants can choose their own on-line genders, *actual* on-line gender performance often involves *both* gender play and 'rigid adherence to gender norms' (1997: 549; see also Kendall, 1998; Waskul et al., 2000). For instance, homophobia has not disappeared from the gender-experimental on-line universe, and Bassett finds 'extreme conformity' in some of the body images employed. To what extent women's writings on the Web resist these problems remains an important research question.

There are other problems to think about in relation to what we might call 'cyberagency', two of which I want to raise here. First, in addition to finding that users might affirm social norms rather than deviate from them, we are increasingly finding that cyberspace itself is not so neutral. While some writers depict it as an ideal site for inventing identities and virtual bodies, cyberspace is hardly free from corporate, media and other consumer influences. Despite the Internet's potential as a forum for diverse viewpoints and interests, it is already highly consumerized and, some argue, homogenized, becoming a 'monoculture' colonized by corporate and media interests rather than a network of local, diverse, fluid and shifting ideas, identities and interactions (Bell and Kennedy, 2000; Cartwright, 2000; Sardar, 2000; Stratton, 2000). Critics are increasingly aware of cyberspace's role as a mass media delivery system (Stratton, 2000). Search engines, which are often owned by major media companies and seen as 'the best bet for advertising revenue', for instance, are the primary way most users locate World Wide Web sites (Croteau and Hoynes, 2000: 73). I am particularly interested in how along with other industries, health is big business in cyberspace. Companies like AOL, Yahoo and CompuServe run popular women's health sites that are saturated with advertising. For example, in my study of Women.com's BreastFest, a web site dedicated to Breast Cancer Awareness Month, I described how it not only promotes awareness of the illness and circulates information about health resources, but also how it directs readers to a broad range of women's 'self-care' and self-improvement issues, defined by a mix of feminist, biomedical and consumerist/beauty aims, including the promotion of Victoria's Secret lingerie and breast-augmentation surgery (Pitts, 2001).[1] Cyberspace is not monolithic though, and is created by and through a number of sources. Women's own personal writings about breast cancer on the Internet, such as can be found on personal web pages, might generate knowledge that is independent from the corporate and advertising interests that are promoted within the for-profit on-line world, but they cannot automatically be assumed to be untouched by these interests.

A second problem with 'cyberliberation' is that the very notion of the flexible, elective identity that is celebrated in theories of cyberliberation may not itself be inherently radical. Anthony Giddens and others have described how the individual's sense of self as something to be continually created is fostered by, and benefits, postmodern consumer culture, which frames identity as a personal accomplishment that is achieved through various consumer practices, body projects and lifestyle choices (Giddens, 1991; see also Turner, 1991; Shilling, 1993). In the current social context, the elective-identity model is often hard to extricate from the consumer model of identity (see Balsamo, 1995). That we each have the ability to 'choose' our identities, in cyberspace and in 'real' space, may actually mean that we each have the social responsibility to consider our selves and bodies as projects that must be continually reworked, improved and upgraded. Norms of female beauty and personal responsibility, for instance, are affirmed even within the women's breast cancer movement, as I describe below. Thus, we need to attend to the ways in which consumerism, beauty norms, individualism and other pressures may be operating in people's experiences of cyberspace, and we need to consider the implications of this for women's agency. While there may be many reasons for feminists to be hopeful about the new technologies, these problems all impact upon cyberspace's promise of empowerment.

Illness, breast cancer and agency

The questions of empowerment and agency are particularly salient issues for women with breast cancer. In addition to the burdens of physical sickness, women with breast cancer face a number of challenges to controlling their own self-definitions and framing their experiences in their own terms. These include the high-tech and masculinist terms in which their bodies are often defined, and how breast cancer has been framed in deeply gendered and ideological ways. For instance, feminists have addressed how women's bodies are subjected to multiple forms of medical surveillance and to powerful social messages in relation to breast cancer detection (see Martin, 1987, 1994; Wilkerson, 1998; Clarke and Olesen, 1999). As feminist scholars have pointed out, the worrisome aspects of surveilling women include the new burdens placed on women to prevent and manage disease. As Jennifer Fosket describes, because the early detection and prevention discourse continually implores them to detect or even prevent the disease, women who do get cancer often feel as if they are blamed by others, or blame themselves (2000; see also Altman, 1996; Fosket et al., 2000; Hallowell, 2000; Potts, 2000; Simpson, 2000; Wilkinson, 2001). Women's experiences of breast cancer have also been shaped by beauty norms and consumerism. Feminist researchers have explored how both the media and medical industries have framed breast cancer in ways that assume heteronormativity, emphasize women's appearance issues and pressure women to look 'normal', erase signs of illness and re-beautify themselves (Lorde, 1980; Fosket, 2000; Saywell, 2000; Wilkinson, 2001). One worrisome example is the 'Look Good, Feel Better' (LGFB) campaign co-sponsored by the American Cancer Society and the cosmetics industry. As Sharon Batt (1994) describes, this campaign aims to 'teach' women recovering from chemotherapy how to disguise signs of their ill health and beautify themselves with makeup and cosmetic techniques.

These pressures shape women's experiences with breast cancer and have influenced the ways in which women narrate their stories about the disease. As Stuart Hall has pointed out, telling stories about ourselves is a way of constructing our identities. In telling stories, we are able to frame our 'certain conditions of existence' (Hall in Thornham, 2000: 3). But *how* we frame our stories is not, Hall argues, wholly a matter of personal choice, but rather influenced by social norms and ideologies and 'constructed within the play of power and exclusion' (Hall, 1996: 5). For example, Laura Potts (2000) describes how autobiographical writings about breast cancer, by which she means print-published memoirs, have generally affirmed, rather than challenged, mainstream conceptions of beauty, gender and illness. Breast cancer memoirs are largely framed as healing experiences for both the writer and the reader, and they may generate solidarities among women. They can facilitate the development of new identities, such as the breast cancer survivor, or the 'warrior' as Audre Lorde (1980) puts it. And they place women and breast cancer center-stage where they can enter into public consciousness. However, Potts and other feminist scholars argue that many women's autobiographies of breast cancer, at least in the print world, have reproduced heteronormative, consumerist and gendered ideologies regarding women's bodies. While Lorde, Kathy Acker, Susan Sontag and other women have written highly critical accounts, many stories repeat what Dorothy Broom, following Arthur Frank (1995), calls the 'restitution narrative', in which women 'put on a brave face', remain 'relentlessly optimistic' and circulate the 'obligatory success stories' (2001: 253, 250; see also Stacey, 1992; Wilkinson, 2001). As Broom describes, women often feel a social duty to hide signs of illness, repress feelings of anger or grief, embrace an optimistic attitude and even focus on beautification techniques. Sociocultural fears and expectations about femininity, women's sexuality and illness encourage a sense of shame and discrediting about breast cancer, and work to 'isolate and silence' women about its horrible realities (Broom, 2001: 250). As Cherise Saywell argues, this kind of silencing has also characterized much of the newspaper coverage of the disease (Saywell, 2000).

Although little research has been conducted on women's web narratives of breast cancer, Broom and another writer, Sue Wilkinson, have questioned whether the World Wide Web might be a site where women might repeat the 'restitution narrative' about breast cancer, or, instead, make visible the injuries that breast cancer brings. Perhaps, if the champions of Internet empowerment are right, the widespread use of this technology may encourage the telling of a wider range of stories and experiences about breast cancer than are tolerated in print and newspaper accounts. For instance, cyberspace may offer women opportunities to challenge the hegemonic authority of medical experts and to research the medical and social aspects of the disease, and may generate opportunities for women to narrate their experiences and generate new definitions of self and identity. The trend since the 1970s toward a democratization of health care, in particular the leveling of hierarchal relationships between doctor and patient, has been linked to its consumerization (see Haug and Lavin, 1983). We might see, as Michael Hardey suggests, that the Internet might play a major part in accelerating this process of transforming the patient's 'sick role' and the doctor's authority. Hardey finds that when they surf the Internet for health information, individuals no longer see themselves as patients (or potential patients), but rather they become 'reflexive consumer[s] . . . evaluating and at times challenging expert knowledge' (1999: 820).

In this study I survey women's writings about breast cancer on the Internet, particularly in personal web pages, and find mixed evidence for the notion of women's Internet empowerment. I find some support for the idea that access to the Internet, in particular its wide array of health information, plays a significant role in individuals' definitions of self as consumers rather than as sick persons. In women's breast cancer pages I also find repeated celebrations of the Internet as an empowering tool for ill women. I also find that women's narratives *do* make 'visible', in Wilkinson's terms, painful and difficult aspects of breast cancer. However, I also find that such narratives are not always subversive in the sense that champions of cyber-empowerment might expect them to be. Rather than always forging new ideas about identity, gender and community, personal breast cancer narratives often circulate conventional messages of individualism, personal responsibility and femininity that are troubling from a critical feminist perspective.

Researching breast cancer web pages

With the advent of the Internet, women with access to computers and servers can participate in autobiographical story-telling about breast cancer that can reach a public audience. On the Internet, autobiographical stories are often told through the construction of personal web pages. Along with e-mail, newsgroups, listservs, chat rooms and other sites, the Internet includes web pages – including corporate, institutional and 'personal' pages – and browsers that can search and find them. *Personal* web pages are usually written by individuals, couples or families and often have little or no fixed institutional or organizational ties (except to the servers that electronically support them). They can disappear overnight (although they usually do not), and often change over time; they are sometimes updated, and the authors often get feedback from readers through electronic guest books. There are hundreds, probably thousands, of breast cancer-related personal web pages. They may include diaries, photographs, personal breast cancer timelines, comments of visitor support and memorials, and are visually varied and illustrated.

Over a period of nine months and with the help of research assistants, I identified 50 personal web sites that claim to be constructed by individual breast cancer survivors in which breast cancer is a primary theme. (Together, these 50 sites comprise hundreds of pages of printed text.) I chose to study 50 because I wanted a large enough group of sites to get some sense of their diversity, but a small enough group to ensure that I had sufficient time and resources to conduct in-depth content analysis of each site. We found the first 10 sites through search engines, but the rest we found through creating a virtual snowball sample from these initial sites. Some writers, for example, advertised their own web pages in the space for 'guest book ' signatures, and advertised other women's pages through providing links. We documented some of the sites' characteristics and, using a grounded theory approach, generated categories for coding. The pages were collected without any criteria of age/race/class/gender or sexuality, but we explicitly looked for web sites that appeared to be ‘personal web pages’ rather than those constructed by health care or women’s organizations.

I can make no claims about the off-line identities of the subjects who wrote the web sites. However, most of the sites we gathered announced themselves as composed by women with breast cancer (others were described as written together with a partner, friend or family members).[2] To the extent that we can estimate off-line identities from the content of the sites, we judged our cyberauthors or ‘cybersubjects’[3] to be racially diverse but not representative: the majority of photographs in the sites appeared to be of white women, and the majority of subjects presented themselves in their sites as heterosexual. Even though I do not assume that on-line identities are necessarily identical to off-line identities, throughout this analysis, I operate under the assumption that the web pages are in some sense ‘truthful’, in that their authors do indeed have breast cancer or know someone with breast cancer, and that the photographs posted that claim to be of the authors actually are. This assumption is not empirically verified and must be considered a limitation of this research.

This problem of verifiability is one of several issues being debated in the literature about how to do Internet research. In addition to the question of the verifiability of subjects or authors, researchers have also disagreed about when researchers may quote freely from Internet text, whether researchers should disguise the on-line names/identities of the subjects and whether Internet researchers are studying people (whose consent is needed) or texts and other ‘artifacts’ (which are copyright protected). While I cannot exhaustively explore these debates in this article, I want to briefly describe my own position.

That no ‘bodies’ can be seen and that the Internet affords a level of anonymity has led to worries over the possibility of ‘misrepresentation of identity’ (Walther, 2001). In this study, I can make no claims about the off-line identities of the authors who wrote the web sites, and I do not assume that cybersubjects’ on-line identities are necessarily identical to their off-line identities. Nonetheless, throughout this analysis, I operate under the assumption that the web pages are indeed, as they claim, authored by someone who has breast cancer or knows someone with breast cancer, and that the issues they raise are real to the writers themselves. That this assumption is not empirically verified must be considered a limitation of this research, but one that I believe is minimal. I take Joseph Walther’s view that the worry about overt ‘misrepresentation’ is probably overemphasized in discussions of on-line research. Researchers need to consider that ‘misrepresentations’ on the Internet, while getting a lot of media coverage, have not been explored well as an empirical phenomenon and are ‘probably highly inflated in public perception’, and that other research methods, such as survey responses, are no less wrought with these problems. While I could undertake research to demonstrate the off-line identities of the participants, I believe that this would go against the spirit of personal web pages, which are intended to be public but also to afford varying levels of anonymity and a choice about making personal disclosures, such as one's real name, location, appearance and so on, to readers.[4]

In this study, I use content analysis to explore the themes that the personal web pages address, and I also quote the web pages in my analysis, following 'fair use' guidelines. Some researchers, following social scientific human subjects standards, argue that Internet users should remain wholly anonymous, and thus quoting, even when using web names that writers themselves invent, is problematic, given that technology can sometimes allow us to trace quotations back to the original source on the Internet (although not necessarily back to the writer herself). This position has been argued in the so-called 'AAAS report', which suggests that Human Subjects guidelines be rather strictly applied to Internet sources (Frankel and Siang, 1999).[5] Others, particularly those writing from a humanities perspective, have argued the opposite view: that Internet material is creative expression and therefore must be acknowledged and properly cited – i.e. that authors should be getting full credit for their work. The Modern Language Association (MLA), for instance, has demanded that those citing Internet sources must use full citations. The MLA considers all Internet material to be 'published', and thus protected by copyright but also subject to 'fair use'. The MLA's guidelines are 'committed to crediting sources and providing reliable pointers back to materials'.[6]

One of the issues at the heart of this debate is whether or not the research is studying people or representations. Michele White, arguing for the humanities perspective, points to the many ways in which computer-mediated communication is not the direct, 'overheard' 'speech' of the participants. The editing and manipulation of Internet material is a creative practice aimed at achieving a desired effect and reaching audiences. 'The advanced skills that users develop in order to create and post content are negated', she writes, 'by describing Internet material as people and failing to note the deeply constructed aspects of interfaces and produced identities' (White, 2001). White and others argue that because Internet texts are efforts of individuals' creative work, 'an ethical conflict occurs when the authorship and products of users are not acknowledged in academic research'.

Like Bruckman (2001) and Walther (2001), I take something of a compromise position. I believe that these decisions cannot be decided about the Internet as a whole, but must take into account the different types of activity and 'data' that make up the Internet. The Internet offers a range of types of data sources – varying between the on-line 'chat' of a number of subjects and personal web pages that are often the sole creation of an individual author. It is not always more 'text' than 'person' and vice versa. Some material may have a higher expectation of privacy and limited use (the conversations of a members-only IRC group, for example), while other material is conceived and presented to the Internet world as a form of planned, creatively executed, public authorship, like personal web pages.[7]

I consider the personal web pages I analyze here to require full citation. The personal web pages are designed to be read by an audience (most, for instance, explicitly 'welcome' visitors to the site) and are clearly purposefully designed, often using poetry, photos, visual graphics and even music to create an aesthetic unique to that site. Pages often even display 'awards' from readers, like 'Angel's Pick for Best Web Page'. These and other aspects of the personal web pages suggest that the authors themselves consider their pages to be publications and creative works. (A few even explicitly 'copyright' their pages.) As creative works intended to be read by anyone who is interested in breast cancer, the pages should be cited properly, and only within 'fair use' guidelines. In order that I may properly cite these pages, I use the authors' self-chosen web names, which may or may not be their off-line names.[8]

In this study I use content analysis – a method used for hermeneutic, qualitative research aims – to explore the themes that cybersubjects address in their sites. I find that breast cancer cybernarratives raise many important issues about virtual representation of the self, body and illness that I described above. I describe a range of issues that the pages raise, pointing to how they illuminate issues of agency and empowerment. I focus in particular on three issues: (1) how web pages describe the use of the Internet to negotiate medical relationships; (2) how the pages contribute to the development of an on-line breast cancer culture; and (3) the ways in which the ill, female body and identity enter these sites through their textual composition, including through narrations of the body's appearance, gender and phenomenological experiences of illness. All three of these issues speak to how women use virtual technologies to negotiate their definitions of self, identity and situation in the context of gendered illness.

Medicine, information technology and empowerment

As I mentioned above, the Internet has created a virtual library of medical information that can be surfed and sorted via search engines; in addition to the general search engines that people use to sort information, there are numerous health and cancer-specific engines that direct users to a whole range of sites, from those of the American Cancer Society to hospitals and cancer centers, which offer information about the disease, treatment, clinical trials, conferences, fundraising events and support groups, among other topics. Many of the narratives in my study describe in detail how finding this information, in particular information about treatment, helps women manage illness. As Regina writes in her account of experiencing breast cancer,

> The Internet became my library. I buried myself in its web site and files, *saving sites that were encouraging, deleting those which were too difficult to handle*. It

> became my lifeline. There was so much knowledge out there, so much to learn. I wanted to know everything there was to know about cancer and its treatment. *I knew I would have to make choices, informed choices*.[9]

Women's own on-line cancer research involves gathering, sorting and learning copious amounts of information. As Hardey (1999) makes clear, sorting through information is not simply a passive act of reading, but involves numerous choices to trace a path through the Web's seemingly endless possibilities. The paths these women trace are not directed only toward instrumental ends. The women's aims are often decidedly practical, but there is sometimes also an emotional reasoning that guides the process of sorting information. Regina describes, for instance, censoring depressing or difficult information and saving 'encouraging' sites. She perceives information that offers encouragement to be as helpful as empirical medical data.

Gaining medical knowledge is also used as a way to level the hierarchal relationships that exist between patient, doctor and the medical industries. Indeed, current debates over the deprofessionalization of medicine address how users of the Internet gain lay knowledge of medicine and access health information for themselves, which may have the effect, as Hardey argues, of demystifying medical expertise (Hardey, 1999; see also Haug and Lavin, 1983). That medicine needs demystifying is an oft-repeated theme in these narratives, which repeatedly describe how the world of medicine can seem alien to laypersons. As one husband named Dean writes in his designated section of 'MaryJo and Dean's' site:

> Where to start ['on your research journey']? When my wife was first diagnosed, I must have felt like a new immigrant. I didn't speak a word of the language (of the doctors) and I had no idea what local customs I was violating.[10]

While Dean puts this in the neutral terms of exploring a new culture, learning medical expertise is often described in these sites as part of an adversarial process. Some women, for instance, describe this process in terms of *arming* themselves with information as they try to negotiate the world of high-tech medicine. Their aim is not only to understand their cancers and choose the best treatments available, but also to demand that doctors share the power over their bodies and health care.

> *Dorit*: I started accumulating information [about Tamoxifen] from the net, the more I read the more I wanted to know . . . *Armed with this information* I went to see my oncologist, *asking him why he had not prescribed Tamoxifen for me* . . . [Later] I found several research papers, on the net, mentioning low-dose Megace (Megestrol Acetate) for treatment of hot flushes after breast cancer. *I consulted with my gynecologist, knowing that my oncologist would not listen. This time my net search was received with open arms*.[11]

> *Stephanie*: Charlee and I continue to photograph and document my story [for my web site]. Now we are focusing on my ability as a patient to navigate the medical system. While the individuals that I encounter tend to be very

> compassionate and sensitive, on many days I feel frustrated that the medical community is not sure about how to treat me. Even when doctors do suggest treatment, it's very invasive and hostile to the body (chemotherapy, surgery, radiation), rather than treatment to boost the body's natural line of defense, the immune system.[12]

These narratives describe new aspects of dealing with medicine. In her site, Dorit describes a number of acts of active negotiation of her medical care: she researches the drugs Tamoxifen and Magace, reads medical research published on the Net, confronts her oncologist and chooses her gynecologist as the doctor more open to suggestions. Stephanie openly criticizes western medicine and consciously uses her web page as a place to document her experiences 'navigating' the medical system.

Reading and surfing Internet health information is a primary use of virtual technologies related to breast cancer, but *writing* is also important. It is in their own web pages that women publicly relate stories about navigating health care. The narratives women create 'out' their efforts to understand and master medical language, which otherwise might have been a 'secret' aspect of having breast cancer (see Sedgwick, 1999). These efforts are partly negotiations over the definitions of self and situation; relative fluency in medical language may help women establish their own credibility in defining the meanings of illness and treatment, as Stephanie and Dorit suggest. The sites actually vary widely in how, and how much, they incorporate medical language. Some of the women learn medical jargon primarily in order to inform their own treatment decisions and to level hierarchal relationships with doctors, but others also use it to frame their breast cancer stories. Some sites are saturated with medical jargon, but as if acknowledging differential understandings of medical terms, also have a pedagogical, explanatory tone, constructing their audience as clearly non-medical. MaryJo's site, like many others, narrates her experience by weaving together ordinary language and medical jargon. In her story about deciding between a lumpectomy and a mastectomy, there are quotation marks around some terms that seem out of place, which in this case are the slang terms she uses, like 'tummy tuck', and not the more medical jargon.[13] But she also pokes fun at the jargon. A caption to a photo of her husband wearing her wig reads:

> Dean with MJ's $3000 human hair wig! (Yes they ARE made of human hair and, yes, they DO cost that much!). But the insurance companies pick up SOME of the tab if a doctor prescribes it and calls it a 'cranial prosthesis'!

Medical language is used in a more serious tone in Lisa's site, where she posts the pathology report from her lumpectomy under the heading 'The official diagnosis is in'. She has added her own commentary as a way of explaining it to readers. Here, Lisa uses the highly 'credible' language of pathology to explain to visitors the relative seriousness of her bodily situation. Her version of the report reads, in part:

> *Infiltrating Ductal Carcinoma* – simply put, this type of cancer begins in the ducts and breaks through into the fatty tissue of the breast./ The size of the tumor was measured to be *2.6 cm./ 0/14 Lymph Nodes* were found to have cancer cells./
>
> *Histologic Tumor Grade 3 of 3* – basically meaning that these cells look as unlike 'normal' cells as possible . . . grade 3 cells tend to spread more rapidly and are more aggressive . . . All of this combined put me at a *Stage IIa* cancer.[14]

Posting this report contributes to Lisa's on-line identity as a well-informed patient by demonstrating an understanding of her medical diagnosis. The report is also a medium for presenting her body and her cancer in this virtual space. Cyberspace presents individuals with opportunities to self-describe, inscribe and 'rewrite' their bodies because they are faced with tasks of identifying themselves (Wakeford, 1997). Women with breast cancer make choices about representation that are complicated not only by ordinary issues of difference, but also by their differentiating experiences of illness. Here, Lisa appropriates medical discourse to embody her virtual space, presenting her body through the revelations of a medical lens. Visitors to the site may not know what she looks like (there are no photographs), but we know the size and grade of her tumor, the stage of her cancer and other cellular-level characteristics of her body.

Sometimes, in researching and learning medical information, individuals are taking on an even greater aim than refining their roles as informed consumers, leveling the hierarchies between doctor and patient and framing their experiences in medical terms. For some women, on-line research is perceived as one of the most important tasks they undertake. The Internet is repeatedly presented as a beacon of hope. Many of these narratives suggest, implicitly or explicitly, that becoming fluent in medical language and treatments is a key to actually surviving breast cancer, rather than a tool for decision making, psychological comfort or intellectual understanding. One friend named Robin, writing on the web page dedicated to her friend Patti, says:

> Please read Patti's breast cancer story and see if you can think of any information which might relate to her. Maybe you have a friend, relative, acquaintance or neighbor who has had this specific type of cancer and maybe they were cured. Maybe YOU know the answers we are desperately searching for.[15]

The notion that information to save lives is out there, and that it is up to individual patients to find, sort, understand and use such information to save their own lives, may be one of the negative effects of the consumerization of health care. Consumer ideology is highly individualistic; through their shopping and information-sorting practices consumers are meant to make themselves informed about available products that are life-enhancing. The Internet heightens this sense that we are capable of this, as well as the fear that we may fail in this task. Robin writes,

> *My biggest fear is that something happens to her and then we would find information later that could have saved her life, that it was right there all along.* That

> fear is what spurred me to make this net wide plea . . . Thank goodness for the internet, with its ability to reach more people in one minute, than we would ever be able to reach in one lifetime. (Emphasis added)

Robin wrote this plea in 1998. Sadly, the web site also announces that Patti died in June 2000. When even life-saving technologies are framed as products that consumers can research and advocate for, they become the responsibility of individual consumers to find and get access to. Like the instances in Jennifer Fosket's study where women blamed themselves for not detecting their tumors early enough through self-exams, such examples may suggest that unrealistic imperatives for individuals to prevent sickness and manage their own treatment, along with feelings of self-blame when they cannot, may be among the outcomes of consumer 'empowerment'.

Creating support networks and giving advice

Despite its high value to these women, medical information is only one form of knowledge circulating in cyberspace about breast cancer. Beyond specialist knowledge, many women view their own experiences as important sources of information that should be shared with each other. The Internet offers breast cancer survivors a plethora of ways to 'seek connections', to put it in Stephanie's terms. These include listservs, e-mail and chat rooms, but also the network of personal web pages, which often provide links to others' web pages, spaces for visitors' comments about the page and invitations to e-mail the site's author or host. The intersections of all of these have created what many see as a virtual community. Personal web sites are often framed as stories that come from women's own standpoint as breast cancer victims and survivors. Many describe how reading other women's stories ameliorated a sense of loneliness and normalized a process that had felt alienating and isolating. Women's experiences with breast cancer may 'fall outside others' common sense', to use Arthur Frank's terms, but their web narratives appear to 'establish new terms of common sense' and familiarity (Frank, 2000: 327). As Sally put it:

> It was a relief to read that all I had gone through was *normal* . . . I have decided to put my story out here for others to read, so that others can know that *they aren't alone* in this fight.[16]

Many women describe an ethical imperative to share what they have learned with other women through documenting their own stories on the Web, like Mari: 'Why divulge all of this personal information? Because I truly believe *that it is my responsibility* to use the experiences, knowledge, and insight I have to help others.'[17]

Frank describes how stories 'can remoralize', or make less alienating, bureaucratic and 'disenchanted' our experiences with illness (2000: 321). In women's web pages, experiences of connection, helping and receiving help are part of the moral of the stories. In 'helping' others, women construct their audiences as female, usually as sister survivors and other times as undiagnosed women. The values that are generated within breast cancer cyberculture include what Pat Hill Collins (1991) has called a female ethics of relationality, which emphasizes connectedness and empathy over individual survival. Dorit writes,

> Then I found the 'Breast Cancer Listserv' mailing list, a great on-line support group where I found people with whom I could share my feelings and fears, express myself openly, and know that someone was listening. Eventually I started feeling better about myself and was able to provide support for women that were going through the same. By then I had learned to ask questions and not to automatically accept everything a doctor tells me.

In sharing stories, women offer each other mutual support, a forum for exploring issues of the body, psyche, relationships and community that are relevant to them, and a sense that their knowledge and experience are resources for others.

The sites are often advice-laden. For instance, women are eager to warn others about the need to be active in negotiating the hierarchies of the doctor–patient relationship:

> *Kelly*: My advice? Get a second, third, and fourth opinion . . . Don't be afraid to ask your doctor(s) questions. And if you do chemotherapy and/or radiation, *demand what you want*, for instance, additional nausea medication if what you have isn't working. Something out there *will* help you – you just need to find it. Don't be afraid to *be your own advocate*.[18]

One woman, Linda, feels so strongly about this, she says, that she continues to chronicle her experiences on her web page despite feeling too sick to do so. This, in order to help others 'be prepared' for some of the 'betrayals' of the medical system: '*The knowledge that many of us go through the same anxieties and betrayals by a system we must rely on during serious illness forced me to write this for you, in the hope that others might be better prepared.*'[19] Linda's narrative suggests how writing a web page might be considered a type of activism. Like Mari and Kelly, Linda expresses a moral imperative to reach out to other women over the Web and share her experience and knowledge with them.

Worryingly, though, advice circulated on these sites may include pressure to take responsibility not just for self-advocacy, but *also for beating the cancer itself*. In these 50 sites, I found repeated calls for women to take action to prevent death from breast cancer. Women are urged to know everything they can, be their own 'best defense' against cancer, and keep getting tested. Fran writes, 'Know your enemy'[20]; Geri argues that 'Breast cancer kills the unaware, the innocent, the untested'.[21] And Sally argues:

> *Every woman is her own first best defense against breast cancer.* Every woman, starting in her teens, needs to become familiar and comfortable with breast self-exams [hyperlinked here to a site for instructions]. Regular mammograms are a must as well . . . Early detection and early treatment can save a life.[22]

The messages that women can defend themselves against breast cancer and can prevent themselves from dying of the disease are not unique; in fact, they echo the empowerment discourse that circulates in much of the breast cancer movement. These messages have also been circulated by advocates of early detection. But the framing of breast cancer in what Christy Simpson identifies as a kind of personal responsibility ideology, in which 'responsibility for diseases are presented in terms of lifestyle choices' (2000: 136), may have worrisome effects from a critical feminist perspective. Asking individual women to be their own primary defense against breast cancer is unrealistic, and displaces responsibility for a large-scale social problem onto the bodies of individual women. (This displacement is linked to a broader trend in contemporary health care that emphasizes risk factor epidemiology. See, for example, Link and Phelan, 1995.) And the idea that breast cancer kills only the unaware is patently wrong – it also kills the aware, the 'tested' – and implies that women who do get sick or die could have prevented this fate. The recent debate on the efficacy of mammograms to improve women's chances of surviving breast cancer makes this problem even more pressing. According to some recent studies, the increased use of mammograms to detect breast cancer has not translated into better chances for women to survive the disease. (In my study, women's web pages are silent on this controversy, which may reflect that many of the pages had been published on the Web before the debate received widespread coverage in the news.)

There are also calls to take on others' suffering as well as to prevent one's own. As a woman who calls herself Putsy puts it, 'We now need to continue to be *crusaders* who tell others there is life after cancer, that there is life after a mastectomy.'[23] This call underscores the other-directedness that characterizes many of these web pages. The advice-and-support focus of women's breast cancer cyberculture suggests that a positive or at least bearable breast cancer experience is a social one that involves making connections with other women. Further, there is an ethics of responsibility: women who are sick try to help other women prevent themselves from getting sick, and those who get well have a responsibility to those who are still sick. The norms of connection, empathy and personal responsibility for others that circulate in these narratives are a stark contrast to women's depictions of medical culture, which is characterized as adversarial, impersonal, bureaucratic and dismissive. From a feminist perspective, women's virtual breast cancer communities might be seen as powerful sources of women-centered knowledge and activism that may help to ameliorate the alienating aspects of medicine.

The imperative to reach out to others in some ways defies the individualism of 'personal responsibility ideology', since women are thinking beyond the care of the individual self toward a care for others. Women are framing the prevention of breast cancer not only as a matter of personal lifestyle but as a community-wide issue where care for the self and others are linked. Women's responsibilities here are defined beyond the role of informed, healthy consumer. Women must look out for each other and share the knowledge they have about their own illness to help other women avoid the same fate. To my mind, though, the messages circulated in these sites are not necessarily unproblematic. Even though women are positioning themselves in ethical communities of caring, the advice they give each other ultimately still asks a great deal of women who are sick and recovering, and does not ask much of the social systems that need to be transformed to address women's illness more adequately, such as the more radical breast cancer environmental movements and the AIDS movements have done (Clarke and Olesen, 1999; Klawiter, 2000; Simpson, 2000). A social ideology of breast cancer, in contrast to a personal responsibility one, would shift the focus from lifestyle and informed health consumerism, 'from individuals to looking at groups of individuals' and the social, environmental and economic conditions which influence their health and illness prospects (Simpson, 2000: 137).

Constructing the body and the self in virtual space

Breast cancer cyberculture is a space not only for the sharing of information, advice and support, but also for the airing of women's embodied experiences of sickness, healing, recovery, mourning and survival. Personal web pages of breast cancer survivors are often very intimate: decorated with photos, sketches, poems and songs; revealing nicknames, personal relationships, favorite things and constructing detailed images of the body and the self. These constructions often combine multiple discourses, including clinical and medical terminology and perspectives, imagery that is conventionally feminine, and narratives that may be seen to offer critical or challenging perspectives on the female body.

Sites are organized as a conceptual 'space', as implied in the term 'home page'. Nearly all the sites welcome visitors to the space, and most declare a kind of statement of purpose at its 'entrance'. Like other personal or 'home' pages, the sites are constructed as individualized reflections of the self and body that mark out personal territory – like a 'home' – on the Web. Rosemarie's site, for instance, welcomes visitors to 'my little corner of the Internet'. These sites are differentiated from other home pages, though, by their clear sense of purpose, which is to carve out a space for 'writing' breast cancer. And Mickie describes her site thus:

> [M]ost of the discussion pages and information pages on breast cancer were very depressing. Well, I am not depressed and I'd rather not be made to feel that way if it's all the same to you. This is going to be *my* page and I am going to use it as *my* diary and so far I haven't had any reason to be down about what is happening to me.[24]

Mickie's use of the term 'diary' is instructive here. The authors of these sites construct them as deeply personal expressions of the self, as in a diary, and at the same time, as inherently and purposefully public. That cyberspace complicates ordinary divisions between public and private (and also self and other, mind and body) is demonstrated in these narratives. The 'public diary' model suggests how women are using their narratives to situate the self and the body and to establish one's identity for others to see (Altheide, 2000). Mickie's insistence that this is going to be '*my* page' suggests that such an assertion of the self's meaning is related to feelings of empowerment.

The sites are nearly all adorned with graphics, and many offer themes of safety, peace and spiritual beauty. The majority of the sites have extensive imagery, and most are visually themed with the color pink. The pink ribbon, of course, is the widely recognized symbol for breast cancer awareness. Pink is also a traditionally feminine color, and many sites include other girlish symbols, such as balloons, hearts, angels, cherubs and rainbows. These seem a stark contrast to the clinical nature of the medical language sometimes used on these sites, and also to the deeply serious nature of many of the topics addressed. The body's presence in many sites, for instance, is often created through frank reports of cancer and treatment. Some of these are narrated directly through the sterile terms of medical diagnoses, like Lisa's posting of her pathology report. More often, a diary-style narrative chronicles cancer's devastating effects on the body. For instance, Sally's lengthy account chronicles several years' worth of struggle with cancer treatment and remission. Sadly, it also reads:

> I received the news that the bone scan showed that the cancer has spread to the bones, in several places – a rib, upper spine, and hip, among other smaller spots. It seemed like a bad, bad dream. Of all the possible ways for breast cancer to metastasize (liver, brain, lungs), bone mets is pretty manageable, for a while. Eventually it will spread to the major organs. Just when, months or maybe years, is the unknown.[25]

Most of the sites analyzed in this study post such chronologies of the bodily experiences of breast cancer, including accounts of mastectomies, lumpectomies, the removal of lymph nodes and its 'broken wing' effect, 'disfigurement', hair loss, nausea and vomiting from chemotherapy, the collapsing of veins from IVs, physical weakness, immobilization, fear, sleep loss, metastasis and, sometimes, impending death.

In spite of these unsettling issues, women appear to have developed a breast cancer-specific culture of humor about breasts, beauty and the body. While subjects such as death are decidedly *not* topics of levity, issues such as breast loss and hair loss, reportedly two of the most difficult cosmetic aspects of breast cancer treatment, often are. Images of women passing around wigs and taking photos, having loved ones shave their heads in solidarity, and giving nicknames to breast prostheses are not unusual in these sites. Such passages construct bodies and selves that suggest new aspects of and attitudes toward ill and altered embodiment. Lillie and MaryJo write:

> *Lillie*: When I went to be fitted for my breast prosthesis, I took my mother along. Mom agreed that the fit 'had to be perfect.' My new bosom buddy was in place. I chose to name my new breast 'Betty Boob.' During the summer of 1994, my mammogram displayed troublesome news once again and Betty got a roommate, 'Bobbie Sue.' (I had a second mastectomy).[26]
>
> *MaryJo*: In keeping with the 'good-bye to my stomach and boob' pizza party prior to my surgery, we had a head shaving event after which my brother decided to shave his head in solidarity. And to keep one of the worst parts of having cancer – the hair loss – a bit more bearable I've kept a photo album of people with my wig on.[27]

Humor is a powerful resource women sometimes employ to compose their post-mastectomy and post-chemotherapy bodies. These ironic writings suggest both that women are acknowledging the powerful norms of femininity and beauty that surround them and actively negotiating the social meanings of the body's changed appearance.

This negotiation is accomplished in other ways as well. Stephanie's site, for example, uses well-lit, black-and-white photographic studies of her nude body along with text. The following words accompany photos of her bare, post-mastectomy chest:

> Feel nothing/ No nipples/ Clean surgical cut
>
> Lost sexuality/ Lost womanhood/ Lost motherhood
>
> Women don't need breasts anyway.

These words address multiple levels of mastectomy discourse and experience. The first set of terms address somatic and surgical aspects of mastectomy, while the second and third address social and symbolic imaginaries of breast loss. The loss of sexuality, motherhood and other gendered aspects of the body is an oft-cited threat to women with breast cancer. Stephanie says she came to her counter-assertion, that 'women don't need breasts anyway', through her photo project. She writes,

> After learning my story, many people glance at my chest almost despite themselves, making me feel embarrassed and ashamed. Then we did the 'Venus' photo. Like a Michelangelo sculpture with the arms knocked off and the head missing, I now see my torso as a work of art. Although I'm missing some pieces, I no longer feel disfigured. This image was a turning point for me.

Stephanie's web site is simultaneously a studio to display her art and a method of altering her body image after mastectomy. Her display of her post-mastectomy body is uncommonly bold, but it illuminates how women might use the Internet to challenge women's sick roles. Creating a representation of her altered body, displaying that representation to unseen others and constructing the virtual gaze of the unseen audience constitute a meaningful process of self-composition that is also highly social. In posting these images, Stephanie challenges the stigmatization and invisibility of female bodies that have lost a breast to surgery.

What is composed with respect to gender can be traced through these multiple representations of the altered body. Images of angels and cherubs, personal chronicles of metastasis, chemotherapy and baldness, pathology reports and critical women's art differently sketch the female body and its post-diagnosis identity. The girlish symbolism used in some women's compositions may suggest that women are asserting a sense of femininity, youthfulness or innocence that is threatened by the social construction of breast cancer. Even though breast cancer is often said to threaten women's sense of femininity, it is also constructed as an archetypical female experience that *reinforces* the genderedness of the body, partly through emphasizing what aspects of femininity are so gravely at stake (Sedgwick, 1999). In fact, as Eve Sedgwick acknowledges, the social and medical treatment of women with breast cancer may promote infantilizing girlishness as a sick role for women with breast cancer. To the extent that they echo or even exaggerate the body-self's femininized identity, these narratives comply with such constructions.

In some ways, though, the narratives confront the gendered discourses of 'loss' rather then simply affirming them. They sometimes do this through creating unexpected images of female embodiment in their stating, and staging, of illness. The chronicling of breast cancer through both graphic descriptions and humor make visible female bodies that are being refigured in the wake of cancer's physical, psychological and social disruptions. The humor that surfaces in some of these accounts suggests an ironic play of norms of the body, beauty and femininity. I find women's accounts of these instances of goofiness, camaraderie and even pleasure remarkable. Giving silly names to prosthetic breasts – and then 'reporting' these names to the on-line world in one's breast cancer web page – is one way of writing new personal and social meanings for them than they might otherwise have. The detailed and harrowing experiences of illness, fear and physical pain that are chronicled diary-style in many sites also create nontraditional representations. To the extent that these narratives use the materiality of sickness to construct women's visibility and difference, they may be deconstructing powerful ideologies of female homogeneity and normalcy. Yet, the representations of difference and defiance may be overwhelmed by the representations of restitution, normalcy and girlishness that circulate in these sites.

Politics and problems of writing the body-self in cyberspace

Technologies of writing and mapping the identity of the body-self, such as those we use on the Internet, help us feel in control. Information technologies offer us opportunities of body and identity composition: through them, information can be gathered and a self can be represented, imagined and textually documented. I describe here the ways in which women are composing their bodies and identities in their narratives on the Web. Yet, they cannot be seen to be wholly autonomous or politically unproblematic. Virtual technologies can be infused with a discourse of empowerment that may not necessarily translate into power for individual women. Cyberspace, which has been hailed by some as a libertarian utopia of free speech, free virtual bodies and free selves, must be seen instead as a site where definitions of situation, body and identity are both contested and are influenced by power relations. It is important to remember that women's narratives are not immune to powerful systems of representation, including medicine and consumerist popular media, and that cyberspace is not a neutral territory in which to construct these narratives. As Rosie Higgins et al. put it, the 'electronic frontier has a history, geography, and demography grounded firmly in the non-virtual realities of gender, class, race and other cultural variables that impact upon our experience of the technological' (1999: 111). Breast cancer is part of the Internet market, responsible for marketing products as well as information. In this sense, breast cancer can be symbolically appropriated by corporate interests and dominant ideologies in cyberspace, such as those invested in gendered notions of beauty and attractiveness. The 'Look Good, Feel Better' campaign has its own web site, for instance, which celebrates women's beautification after chemotherapy and hair loss.

We have to ask, then, how powerful forces influence women's on-line experiences. We can see empowerment in women's taking in and re-distributing medical knowledge, but alternatively, we can also see an expansion of medical power. Some of the narratives here conceive bodies almost entirely through the lens of medical jargon, a process that reveals women's learnedness of this language but also might affirm its nearly hegemonic legitimacy and credibility. In a critique of 'telemedicine', Lisa Cartwright has described how the Internet may not be forcing a democratization of health care, but rather how it may be *extending* the reach and power of medicine by creating a kind of 'indirect management of the population' (2000: 354). This process may be evident in this study. For example, the push for women to take charge of their own health that was described in Jennifer Fosket's research is echoed here in women's advice for each other. Arguments that 'women are their own best defense' against breast cancer are highly pressurizing. Here women appear to be passing on advice they have received from the medical industry and the media, which until very recently have been touting early detection as the primary response to breast cancer.[28] In this study, women appear to be at times challenging medical authority and contesting the 'sick role', while other times framing themselves and their bodies in wholly medical terms and positioning themselves as vehicles for disseminating medical and media advice. One of the conclusions I make from this is that the prospect of health and illness empowerment through the Internet is far from certain, and calls for more thinking and research about how people actually use the Internet for health 'empowerment'.

That the Internet is presented in many of the narratives as a beacon of hope demonstrates how information technology is perceived by women themselves to greatly expand the individual's role in both prevention and treatment. That individuals have much more access to medical information through the Internet has been touted as one of the great promises of information technology.[29] But the notion that the Internet allows individuals to control the fate of their bodies and selves through researching information, shopping for treatments and advocating on their own behalf is borrowed wholesale from consumer society. Of course, access to information does not in any way guarantee treatments' availability and effectiveness. Even so, underlying the excitement about empowerment here is that women now have not just a chance, but a *responsibility*, to save themselves. The message that women really have the choice whether or not to be seriously affected by breast cancer is deeply worrisome. This message not only offers unrealistic – not to mention highly individualistic – ideas of hope, but it also implicates women in their own sickness.

Of course, this problem is not limited to cyberdiscourses of women's illness. A whole literature in the sociology of medicine has developed to critique the individual responsibility ethic that is promoted in many contemporary health care approaches (Link and Phelan, 1995; Hallowell, 2000; Simpson, 2000). But the arrival of the Internet and the celebrations of its empowering possibilities may make these issues even more pressing. Social theories that embrace how it fosters elective identity need to consider ways in which the very projects of re-defining the self, body and identity may not always be liberating, but instead may actually *compound* social pressures that already exist for women to keep inventing and improving themselves. For women with breast cancer, the project of self-invention often involves the roles of 'restitution' and recovery, relentless optimism and even survival.

This study, then, raises some serious issues about women's cyberagency. My sense is that the structural and institutional pressures that are sometimes affirmed in these narratives work against women's empowerment in many ways. Even so, I still find some reasons to admire breast cancer cyberculture. First, the intersubjective, dialogic processes that are a part of women's use of information technology have engendered networks of support. The relational character of these narratives affirms what Laura Potts has written about breast cancer memoirs, that they are written toward connectedness rather than individualism. Perhaps, to some extent even Sadie Plant's excited writings about how women in cyberspace will forge new kinds of connections are also affirmed here. Clearly, the narratives I describe in this study describe a sense of female community women feel as members of the on-line breast cancer world. Second, the networks they create offer a new source of information about breast cancer, much of which goes beyond medical knowledge in its interest in personal and social aspects of the illness, and some of which is directly critical of the power relations of medicine. Although I think there are reasons to be deeply worried about the consumerization of health care via the Internet – particularly that it is embroiled with personal responsibility ideology – I find it hard not to admire the ways women are encouraging each other to demystify medicine and level the hierarchies between doctor and patient.

Finally, women are also creating new forms of knowledge about their ill bodies. On-line women with breast cancer are not necessarily interested in gender-play or too interested in leaving the body behind them. Their public narratives do not 'hide' the body, and they generally do not abandon gender, beauty and conventional femininity. However, they do compose bodies and selves that negotiate medicine, treatment, pain, beauty and bodily experience in unsettling and sometimes unexpected ways. They make visible what used to be highly private experiences of women's embodiment. In detailing some of the more unpleasant bodily aspects of sickness and treatment, they present women's bodies as they are really lived. The bodies that are written into these sites do not 'look good' in the way that the 'Look Good, Feel Better' campaign would have them. They are sometimes beautiful and sometimes not-so-beautiful, but either way, they are sick bodies and getting-better bodies and not-getting-better bodies, and their representation here seems more honest and fair than in most other cultural sites where women's bodies are displayed.

Notes

1. The site was advertised to CompuServe subscribers on its home page and is copyrighted (2000) by CompuServe.
2. In the search of sites, only one site identified itself as being written by a man with breast cancer. Because I only had one male site, which does not allow me to make comparisons with other male sites, I left this site out of the current analysis.
3. I like this term because it allows me to refer to the people writing the web sites without implying that their on-line identities are the same as their off-line identities. Elsewhere, I refer to the people who authored the sites as 'women writing in their web pages' and so on, but I do not mean to suggest that I actually have evidence of their off-line identities.
4. My future research will start from the other direction – from the authors themselves, rather than their writings – and examine how women interpret their own Internet participation and describe it within the context of a research interview.
5. In Walther's (2001) view:

> While the Report raises a number of these questions it does little to answer them. Based on existing guidelines, for better or worse, it seems fairly clear that the analysis of publicly-available Internet-stored conversations does not constitute human subjects research, and may therefore be exempted by

> IRBs [Institutional Review Boards] from human subjects regulation. Researchers must make their own individual ethical decisions with regard to activities such as quoting or reflecting names or pseudonyms in their ultimate publications . . .

However, I did apply for and receive IRB approval for this study.

6. As the MLA directs:

> To cite a synchronous communication posted in a forum such as a MUD (multi-user domain) or MOO (multi-user domain, object oriented), give the name of the speaker (if you are citing just one), a description of the event, the date of the event, the forum for the communication (e.g. LinguaMOO), the date of access, and the network address. (Gibaldi, 1999: 201, cited in White, 2001)

7. The expectation of privacy may be different in these instances, as might be the expectation for receiving ‘credit’ for one’s text or images.
8. In cases where there is no name I create one and indicate this in the text.
9. http://www.geociteis.com/hotsprings/chalet/1674 (emphasis added).
10. http://www.dmccully.com/mjstory.htm
11. http://www.geocities.com/Wellesley/Garden/1562/bc.html (emphasis added).
12. http://eserver.org/cultronix/stephanie/ (emphasis added).
13. http://www.dmccully.com/mjstory.htm
14. http://www.geocities.com/damarna5/lisa.html (emphasis and ellipses in original).
15. http://www.members.aol.com/pattitate/welcome.html
16. http://server30004freeyellow.com/bcancer.html (emphasis added). This person never mentions her name. Sally is my pseudonym for her.
17. http://www.wakeamerica.com/present/mari/ (emphasis added).
18. http://www.azstarnet.com/~pud/ (emphasis in original).
19. http://bcexperience.com/secondpage.htm (emphasis added). Linda is my alias for her, as she is anonymous in this site.
20. http://www.webwitch.com/survivor/
21. http://www.geocities.com/beckholz/Tribute.html. Geri is my alias for her. She is anonymous in this site.
22. http://www.server3004freeyellow.com/bcancer.html (emphasis added).
23. http://members.nbci.com/svihlikm1/BreastCancerSoulMatesForLife.html (emphasis added).
24. http://www.geocities.com/mickie41.geo/breastcancer.html (emphasis added).
25. http://server3004freeyellow.com/bcancer.html
26. http://www.azstarnet.com/~pud/cancer/Lillie.html
27. http://www.dmccully.com/
28. At the time of this writing, the ‘mammogram debate’ is beginning to gain public attention and newspaper coverage.
29. Access to electronic communications is being perceived as an important factor in individuals’ access to optimum health care in the 21st century (Science Panel on Interactive Communication and Health [SciPICH], 1999; Cartwright, 2000).

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