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# **The transformative potential of online communication: The case of breast cancer patients' Internet spaces**

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## **Abstract**

Based on interviews with breast cancer patients, this paper critically examines the transformative potential of patients' online communication of their illness experiences. I explore the possibilities, the challenges, and the constraints it affords to its participants. I argue that, while breast cancer Internet spaces enable women to transform their experience in meaningful ways, and change to some extent the social and cultural environments in which these experiences are embedded, such transformation is nevertheless limited in social and political terms. The proliferation of personal voices speaking online about the experience of breast cancer, does not necessarily translate into a full recognition of the illness as a social issue. I highlight some of the reasons for this limitation, and suggest several directions for both research and website design, about how to enhance the political potential of these online contexts, and more generally, how we think about "the transformative" in the study of online communication.

## **Introduction**

In recent years there has been a proliferation of breast cancer forums, particularly in online spaces (Joshua Fogel, Steven M. Albert, Freya Schnabel, Beth Ann Ditkoff, and Alfred I. Neugut 2002; Victoria Pitts 2004; Barbara Sharf 1997). The abundance of breast cancer online sites is part of the broader phenomenon of use of the Internet for health related purposes (Ronald Rice and James Everett Katz 2001; Pew Internet & American Life 2002), but is also specifically interlinked with the unfortunate reality of the prevalence of the disease. Furthermore, it is embedded in the gradual process of making the disease more visible: from the taboo that surrounded it in the nineteenth century to its emergence into the limelight (Ellen Leopold 1999). In this process, the publication of patients' personal stories has played a significant role in breaking the silence that surrounded the illness and in challenging the impersonal medical discourse that tended to characterise the disease. Perhaps the most influential of these personal stories were those of famous American women such as Shirley Temple Black, Betty Ford, and Happy Rockefeller who, during the 1970s, revealed their diagnoses in the media (Barron H. Lerner 2001, p. 7). The surge in the media was also boosted by books such as Rose Kushner's Why Me? (1977) and Betty Rollin's First, You Cry (1976), as well as pieces in magazines, newspapers, and on radio and television, which in reaching out to mass audiences played a central role in bringing the disease into the open. More recently, the Internet has become a central medium facilitating the further awareness of the illness in the public arena. As Barbara Ehrenreich observes, with the

hundreds of web-sites devoted to it, not to mention newsletters, support groups, a whole genre of first-person breast cancer books ... pink ribbon days and an annual "race for the cure" in the US which attracts a million people... Today breast cancer is the biggest disease on the cultural map ... It is bigger

even than those more prolific killers of women – heart diseases, lung cancer and stroke. (2001, p. 1a)

Yet despite the ongoing emergence of the disease into the public arena, and the voice that is given to women patients who historically were silenced, breast cancer is still predominantly framed and constructed as an essentially private and personal affair. Leopold (1999) argues that public discourse about the disease has focused on the individual, and the inward search for solutions, emphasising the intimate, personal struggle between the disease and its victim (p. 242). Emblematic of this bias is the early detection and prevention discourse, promoted by the medical authorities and the popular media, which continuously implores women who get cancer to blame themselves (Jennifer Fosket 2000). Consequently, women “still see breast cancer as their grandmothers did, as somehow separate from society”, lacking a wider perspective of the disease (Leopold 1999, p. 273). In short, despite the growing public discourse on breast cancer in the last few decades, the ways the illness is communicated confine it to a large extent within narratives of individual struggle, and discourage full recognition of the illness as social.

In this context, this paper seeks to explore the possibilities offered by the Internet and computer mediated communication for breast cancer patients and the communication of the disease. The discussion will focus on how breast cancer patients’ online activities and forums facilitate publicity and recognition of concerns that might otherwise remain peripheral or invisible. At the same time, in light of the critique of the “privatisation of breast cancer” (Leopold 1999), the analysis examines

the challenges and constraints to the kind of recognition that patients' illness experiences are afforded in this communicative space.

I start by briefly contextualising the paper within broader feminist debates on the potential of online communication to transform women's experiences and their cultural and social environments. I then move to the analysis of breast cancer patients' online communicative spaces. In the remainder of this paper I offer some suggestions about how to enhance the transformative potential of these online contexts on a social level, and how to think about the "transformative" in the study of online communication.

The analysis is based on a four-year study I conducted, which involved forty-one interviews (both online and offline) with breast cancer patients who used the Internet in this context. After lurking for several months in breast cancer-related online spaces, I posted messages on message boards, inviting women to share with me their experiences of using the Internet in the context of their illness. I also emailed some women who provided their email addresses in the messages they posted, or on personal homepages. As a result of these notes and personal emails, I received eighty-three replies, from which I chose twenty-nine accounts to use as data for analysis [EN 1]. The next stage involved shifting the relationship with informants offline. Elsewhere I discuss at length the rationale for, and implications of, the move from online to offline relationships with informants (Orgad 2005). I contacted fifteen of the twenty-nine I had selected, with most of whom I had maintained correspondence since their first response, asking if they would agree to meet me for a face-to-face interview to follow up their written stories in greater depth. I conducted eleven face-

to-face and one telephone interview. Ten of the face-to-face interviews took place in the United States, and one in Israel, either in interviewees' homes, or in public places such as diners. Of course, the data suffer from self-selection as well as other biases, for instance cultural and class. Except for one man, who is a cancer website designer, all the participants in the study were white women, mostly American, middle and upper-middle class, aged 32 to 76 (the majority between 40 and 60), most of them married with children. These biases shape the findings of the study in significant ways; however, for the purpose of this paper, and within the space available, I do not discuss them here (see Orgad forthcoming a). I use pseudonyms in the analysis for obvious reasons of informants' confidentiality. In addition to the interviews with patients, the research project also included a textual analysis of related websites and online forums. The analysis presented here, however, relies mainly on the interview data.

## **Feminist debates on the transformative potential of online communication**

The transformative potential of online communication has been an underlying concern in Feminist Internet studies. Broadly speaking, it relates to whether and how online communication (in its various manifestations) transforms women's experiences and their cultural and social environments, and how it shapes, changes, challenges and is shaped by, gender relations. While it is impossible in the space available here to do justice to the scope, richness and complexity of this debate, my aim in the following account is to sketch out the central understandings that have hitherto developed in

relation to this question. This is the basis upon which I examine breast cancer patients' online communication.

A central contribution to the debate on the transformative potential of online communication came from the cyberfeminist approach. Jenny Sundén (2001) identifies two contradictory tendencies in cyberfeminism, each closely related to the question of the transformative capacity of computer-mediated communication. The first formation, highly influenced by Donna Haraway's work, focuses on the cyborg as transcendence of the dichotomous categorisation of male/female towards a genderless utopia. The Internet is seen as a disembodied world where this feminist utopia can be realised (p. 215). The second position stresses women's worldwide networking through their different experiences with technology, as a way to create women's own spaces of resistance in between the patriarchal structures of the Net. This formation calls for an analysis of how women are creating their own spaces of dialogue and action within the Net. In this perspective, "The idea is to explore how the new possibilities presented by the Internet can help change the cultural environment in which women find themselves." (p. 221).

Although clearly not a monolithic field, what these different cyberfeminism approaches share is their stress on the ways in which the networking and connecting of women to each other through online communication can open up new styles of working and consequently social possibilities that are not possible in other spaces and forms. Researchers associated with cyberfeminism regard femininity as the core element of network technology (Liesbet van Zoonen 2001, p. 68).

A related view of the Internet as transforming the relations between the self, the body and machines was endorsed by post-modern approaches, in works such as Sherry Turkle's (1996) and Allucquere Rosanne Stone's (1995). In this view, the Internet's transformative capacity lies in the ways it allows gender categories to become reconfigured through practices such as gender swapping, cross-dressing and making up personas (Mia Consalvo and Susanna Paasonen 2002, p. 2). In particular, it is the disembodied and anonymous nature of online communication that is seen as enabling the experiencing of a new sense of self, one that is significantly gender-free, fluid and decentred (Judy Wajcman 2000).

Other studies, partly in a critical response to the abovementioned views, have shifted from a concern with the Internet as a communicative space in its own right, to focusing on the ways in which users' Internet practices are embedded into structures of everyday life (Consalvo and Paasonen 2002, p. 4). Consequently, in this paradigm, in accounting for the transformative potential of the Internet and computer mediated communication, researchers focus on the ways that this communication is connected to and embedded in existing offline structures and practices. Crucially, unlike cyberfeminist accounts of the cyborg, or post-modern views, this perspective emphasises that a critical evaluation of the transformative potential of online communication must consider the connections between what happens online and what happens offline.

The stress on the inextricable interweaving of online and offline practices has often led to scepticism about, or at least a more cautious approach to, the capacity of online communication to truly transform women's experiences and their cultural and



social environments, and to subvert gender relations. Approaches such as political economy for example, have highlighted the embeddedness of the Internet as a communicative space within wider public discourses, that tend to reproduce traditional representations, for instance of women as consumers (Michelle Rodino 2003; Liesbet van Zoonen 2001, p. 69). Other critics, from linguists to ethnographers, have highlighted the persistence of traditional (offline) gender power relations and domination in online spaces, for instance by exposing women-users' online experiences of flaming, trolling and traditional misogynist sexual harassment (e.g. Elisabeth Jay Friedman 2003; Susan Herring 1999). More optimistic accounts of the transformative aspects of online communication contexts have adopted a somewhat romantic approach to the relationship between participants' online practices and their everyday life. They emphasise the ways in which online spaces, such as online diasporic communities, are actively used (rather than passively consumed) by women to contest and redefine (offline) gender power relations (e.g. Marianne I. Franklin 2001; Ananda Mitra 2001).

While these kinds of accounts have a seductive explanatory power, they have become increasingly subject to criticism, particularly by studies of gender and development (e.g. Radhika Gajjala & Annapurna Mamidipudi 1999; Wendy Harcourt 1999). For them, the significance and impact of online communication can and must be evaluated only in light of its actual consequences for the material conditions and cultural practices within which it is embedded. The fact that women talk to each other online, and that in this process peripheral matters gain public recognition, is not sufficient on its own. The question, they argue, must be whether the material

conditions and cultural practices that gave rise to such circumstances in the first place have changed or remained disregarded (Sujata Moorti and Karen Ross 2003, p. 350).

In the following account, I use this contextual discussion to critically examine the transformative potential of breast cancer patients' online communication. I am interested in whether and how women's online communication of breast cancer transforms their experiences, and their cultural and social environments. I start with a brief introduction of the online landscape of breast cancer patients' online communication, before moving to the actual analysis.

### **The online landscape of breast cancer patients' communication**

The online landscape of breast cancer patients is not monolithic. Rather, it encompasses numerous and varied sites and discursive forums where different aspects of the illness are discussed. Some websites are more informative in character, consisting of features such as downloadable articles, details of medical research, statistics, and glossaries of terms on aspects of a particular problem. There are also some visual features, for example, using Webcamera technology, some websites broadcast surgical operations to help patients prepare themselves for surgery. Most websites also have interactive forums such as peer group e-mails, message boards, discussion lists, newsletters, online personal diaries, and text chat rooms. Notably, in interactive sites focused on chronic illness and cancer in particular, breast cancer forums are often the most active ones. [EN 2].

Breast cancer patients engage in forums that facilitate communication between patients, and between patients and health professionals. This analysis focuses on the former, particularly through activities such as patients' posting messages on message boards, sending e-mails to fellow sufferers, publishing their "journey with breast cancer" (as they often call their personal online diaries), discussing aspects of the illness in text chats, sending prayers on "praying message boards" to women undergoing risky stages in their treatment, and reading and responding to breast cancer mailing lists. The decision to focus on activities that centre on women's supportive and affective exchange of their personal experiences derives from interviewees' accounts. In their interviews, women mainly talked about their participation in activities that were focused on personal and often affective interactions with fellow-sufferers. They occasionally talked about other kinds of online activities, such as fundraising and breast cancer-related political activism, or entering into critical discussions about treatments. Katy reflects on the bias towards the personal and supportive rather than critical discourse in the online forums she encountered:

I came across sites where there were sort of regular groups of women who seemed like they were support groups and they checked in regularly, and they updated each other on their progress and so on. I never ... I didn't get ... I never got to the point of going back to any of these. I came across and passed them. I felt quite alienated by them ... the whole way it was set up. There were certain things that went on; people made supportive comments to each other and you're allowed to raise questions and you can recommend this and recommend that ... it just seemed like these women were involved in a form

that was about mutual support, it wasn't about having arguments at that kind of a level. (Interview 11)

So while I do not deny that there are breast cancer-related political and critical activities and discourses happening online, and that they are significant, my study shows that occurrences of these kinds of sites and activities are relatively minor. I will develop this claim further in my analysis.

The most notable participants in breast cancer related online forums are patients who are going through the illness or those who have gone through it in the past. Naturally, given that the disease is overwhelmingly a women's illness, the majority of consistently active participants in those websites are women diagnosed with, or worried about, breast cancer. Other participants include friends and family, caregivers (other than family), members of medical organisations, medical workers, and other related experts, although they are generally far less present in these forums.

## **Analysis of breast cancer patients' online communication**

### **The pink side of the online ribbon: the transformative potential of patients' online communication**

#### Translating silence into visibility

Perhaps the most obvious and general sense in which women's online spaces can be seen as transformative, is that they provide forums that make the experience of breast cancer publicly visible, rather than just a private source of pain. Launching a

personal homepage to trace the experience of illness and healing, sharing experiences, or posting a question concerning their experience on message boards, are ways that make breast cancer patients visible to each other. Participants often consider their engagement in online sites as a way of breaking the silence and overcoming feelings such as fear, uncertainty, confusion, and shame by putting their personal agenda forward in a public forum.

Beyond the personal benefit a woman may receive from putting her private experience on the public online space, the transformation of individuals' private experiences into a public forum also has wider social and political significance. To understand the social significance of this transformation, we need to see it in relation to the historical trajectory of breast cancer, in particular, the "coming out" of the disease "from the closet to the commonplace", as Leopold describes it (1999). The Feminist movement has fought against silencing techniques by creating forums where survivors can speak. Consequently, patients' forums have burgeoned in the last decades, allowing private experiences of breast cancer into the public arena. The Internet, by facilitating a discursive space where breast cancer survivors can communicate their experience and become visible to each other, has contributed to this. It provides forums that enable what Audre Lorde in her influential account The Cancer Journals (1980), was calling for women with mastectomies to do: to "translate the silence surrounding breast cancer into language and action against this scourge" (cited in Laura K. Potts 2000, pp. 122--123). Echoing this, one breast cancer survivor uses the slogan "Only in silence can breast cancer continue to kill" to introduce her personal homepage.

## Critical debate and the lay-expert voice

The social and political significance of women's online communication of breast cancer is also related to the potential ways in which, by voicing their experiences and views, they can challenge the traditional patient–doctor authority relations. Much of the writing on patients' online communication has celebrated the ways in which patient–doctor power relations are being redefined, as a consequence of patients' "empowerment" by the information they access online. My study corroborates the general observation that online patients often get information that they could not have otherwise obtained, and which sometimes contradicts or challenges the information given by their doctors. The following extract articulates this point:

Tons of information you get from other women who have dealt with BC is different from what the doctor tells you. He tells you what the treatment should do, lists the possible side effects, recommends medications to combat the side effects, etc. The ladies have BEEN THERE, DONE THAT - they give you an honest accounting of how it happens, what it feels like, what side effects are and how to handle them. (E-mail interview 2)

Patients' postings on message boards are sometimes quite critical of available treatments, and the medical establishment. Furthermore, through publishing their texts online, patients' lay, experiential, subjective and anecdotal experience is transferred into knowledge, which becomes valued and recognised. To follow Ananda Mitra's (2001) argument in her account of diasporic websites, the transformative potential of such articulations lies in the possibility for the marginal (women patients) to enter into

a dialogue where the dominant (doctors, and the medical authorities more generally, which are predominantly male) can no longer systematically silence these voices (Leopold 1999). Women's online voices on message boards, in personal journals, e-mail exchanges, chats, and other forums have the potential of producing a call that the dominant---governments, medical systems, pharmaceuticals---has a moral obligation to acknowledge (based on Mitra 2001).

### Control of representation

Yet this kind of lay-expert critical representations increasingly appears in various media contexts, such as autobiographies, newspaper columns, and television talk shows. One aspect that seems particularly salient to, and quite distinctive of the Internet is that it allows patients far more meaningful control over how their experience of breast cancer is represented, than do other mass media contexts. Patients are able to control, or at least have a meaningful impact, on the way the illness is represented, both in terms of process and content.

As far as the process of production and representation is concerned, the mass media is characterised by a relatively high level of editorial control. Although patients are occasionally given a voice in the mass media, elements such as the format in which their account will appear, the timing, and the placement are almost completely controlled by the producers. By contrast, in most online forums patients can publish their accounts in a direct, straightforward and simple way, often without having to register as members, and with minimal (if any) editorial intervention. Online, they also control the temporal aspect of the communication, a capacity they lack when it

comes to other media. In their interviews, women often emphasised the importance of their capacity to go online and engage in personal reflection at their own convenience, at their own pace:

When your [sic.] in this situation you're on such a roller coaster it's nice to calmly sit down and search with out some one over your shoulder. And you don't have to talk to any one at that time. Grieve is a big part of the process and sometimes you just don't know how it will play in it. So there is no pressure ... And you can deal with it on your own time and own way. (E-mail interview 25)

Online, it is the patients who decide, whether, how and when their experience will be depicted publicly.

Perhaps more pivotal, however, is the sense of control online participants gain over the content of the representation of their experience. With mass media like television or even the press, patients have limited control over the way their experience is represented. For instance, Jenny Kitzinger (2001, p. 98) describes how in the 1990s, media representations of child sexual abuse, even if they were positive, often caused considerable discomfort and distress to incest survivors. Survivors felt that their experience had become public property.

Similarly, in my study women were often critical of the way survivors' autobiographical accounts are presented in the mass media, especially television. Interviewees often regarded such representations as populist, not serious, as appealing to the lowest common denominator, misleading and consequently even dangerous (as they might influence women suffering from the disease to take ill-advised decisions



regarding their treatment) [EN 3]. Clearly, patients feel they lack control over these public representations. In contrast to the celebrity-oriented depiction of the illness that often takes place on television shows, where famous figures who are breast cancer survivors tell their stories, online disclosures are seen by women as close to home, that is, experiential and private, or in “the people genre”, as one interviewee calls it:

After absorbing all of the information garnered from the net and from anecdotal information provided by the “people” genre, I’ve arrived at several personal conclusions ... The most important conclusion for me is that each person’s breast cancer is uniquely their own. No two people reach the same medical treatment, nor do any two people with the same diagnosis and survival stats have identical chances of survival. (E-mail interview 24)

In this sense, patients’ online spaces open up communicative possibilities which do not exist in the mass media. Rather than passively consuming public representations, women online produce their own constructions, deciding where, when, and how they would appear. Even as consumers of other women’s stories online, they have greater ability to actively negotiate over the representations they encounter, by responding to these stories in the public forum. For example, frequently newly diagnosed patients post messages on a discussion board expressing their anxiety, shock, and despair. Were such an account to be broadcast on television, or published in the newspaper, fellow sufferers would have very limited ability to comment on it or offer sympathy. Online, however, this kind of posting usually provokes a chain of responses from fellow-sufferers, who help the original poster to reformulate her reactions.

## Personalisation and specificity

Another way in which patients' online communication challenges traditional representations and discourse of the illness---and can thereby transform women's experiences and the broader cultural environment of breast cancer---is that it allows the representation of a range of diverse experiences. Unlike the mass media, where multiple experiences are commonly bundled into one representative figure (what Leopold calls the "exemplary power of celebrity" 1999, p. 253), the online space can accommodate multiple stories and voices. The availability of hundreds of patients' personal stories in numerous forums reflects the variable and unpredictable nature of the illness. As the woman who referred to "the people genre" implies, encountering the abundance of different personal experiences online conveys a clear message: that each patient's experience is unique and specific. This recognition, replicated in many different patients' forums, leaves open to attack the "one-size-fits-all" formulation, that for years characterised the official medical approach to breast cancer treatment (Susan Love 2000, p. xviii).

The emphasis on the personal and specific character of the illness is particularly enhanced by the personalised dimension of the online experience, and even more by the capacity to perform a search for very specific information that relates to the user's personal interests. The "Shared Experience" website ([www.sharedexperience.org](http://www.sharedexperience.org)) is a useful example in this context. It is defined as a "Cancer Support Knowledgebase", designed to enable cancer patients and their caregivers to share their experience of illness online. To search the website's database of patients' stories of their illness, one has first to choose a particular cancer type from

a dropdown list. Thereafter one can enter very specific details in several open text fields for categories such as “diagnosis”, “chemo drugs”, “treatment”, and “quality of life”. The search is designed to look for the private, the specific, and the personal. The search results are displayed in a table where each row represents a patient’s account of her illness and treatment. By clicking on a row, a detailed account of this illness experience is displayed:

[INSERT HERE FIGURE 1 ‘Shared Experience’ cancer stories table]

### Commonality, bonding and sisterhood

However, while Internet forums such as “Shared Experience” enable personalised communication, and frame each patient’s experience as unique and specific, they also convey a sense of similarity and commonality. Take, for instance, the above table of “Shared Experience” cancer stories. On the one hand, as I have shown, it consists of hundreds of patient stories, each recounting a specific experience. At the same time, the search results display a general table which bundles twenty-five stories per page, by predefined categories: “Cancer Type”, “Diagnosis”, “Treatment” and so forth. This table emphasises the commonality between breast cancer patients’ experiences, rather than the uniqueness and particularity of each story. One of my interviewees eloquently articulated this when describing her personal experience as “the everywoman’s story”: “Why would they be curious to read my story? It’s not that it’s so terribly unique, but it’s also part of why I wanted to tell it ... I really felt this could be the everyman, or ‘the everywoman’s story’.”

(Georgia, interview 7)

The commonality aspect of patients' experiences is coupled with another central aspect of breast cancer patients' online communication, namely bonding and sisterhood. One of the implications of breast cancer being relegated to a woman's private sphere was that women had no idea of how large a sorority they belonged to (Leopold 1999, p. 153). Even with the emergence of the illness into mass media, the communication of breast cancer experience remained a one-way street. The opportunity to talk to a fellow sufferer about her experience was not always available, and if it was, constraints such as physical distance, reluctance, or incapacity to meet face-to-face, often rendered it impossible. Some of my interviewees told me how they were geographically remote from other sufferers, and thereby felt isolated. There is not always support available in the local area. Even if support systems, such as face-to-face support groups are available and accessible locally, patients are often too weak physically and emotionally, to be able to participate in embodied supportive interaction. Against this background, the networked organisation of the World Wide Web appears invaluable:

It [the Internet] is a great way [to] avoid becoming isolated---which is so common for cancer patients as either you don't feel well due to surgery or chemo or radiation. Or you don't always look good (I am bald now for the duration of the chemo tx) or just you don't feel like being social for whatever reason. (E-mail interview 11)

For women who are connected to the Internet and are computer literate, the online space offers numerous sites for quick, easy and relatively cheap communication with fellow-sufferers. A strong sense of coalition, collaboration, and

networking often emerges from patients' online experience. As the following excerpt testifies: "The camaraderie is amazing, the love and acceptance of each other's differences is almost overwhelming" (Wendy, e-mail interview 24)

In this sense, breast cancer patients' networks constitute a good example of the transformative potential of online communication for women, as perceived by cyberfeminism. Some interviewees described their experience of networking with other fellow sufferers through the Internet in very similar terms to cyberfeminism, that is, as women's special space, that opens up social possibilities which are not possible in other spaces and forms. For example:

[I]nterpersonal relationships are a vital factor for healing in the body/mind/spirit connection during the entire process. Doctors who treat a patient like an intelligent fellow human, nurses who are careful and considerate of a weakened body and spirit, medical techs who are empathetic to a patient's fear and frayed nerves, and a support system of close friends and loving family make up the mix that's guaranteed to facilitate healing and peace of mind, provided the patient is herself/himself open to healing. **The internet was the only place, in the beginning of my bc [breast cancer] journey, where those vital elements were present.** (E-mail 24; emphasis mine)

That being said, where my analysis of breast cancer patients' networks differs from a cyberfeminist interpretation, is that I do not think that there is necessarily anything inherent in the technology of the Internet that facilitates feminist politics and communicative styles of bonding and supportive networking. The networking and companionship that emerge between breast cancer patients online cannot be reduced

to mere communicative practices and styles of women. Online spaces of breast cancer patients are constructed out of different technical, social, cultural, and personal factors that engender this kind of online experience, for example age and cultural background (I discuss these aspects and others in depth elsewhere, see Orgad, forthcoming a; forthcoming b). Thus, while the supportive relationships enabled by the network technology entail real potential for women participants to transform their experiences and their cultural and social environments, there is nothing specific, primary, or exclusive about the feminine component of these relationships that makes them meaningful.

### Anonymity and disembodiment

One of the key elements that seems to enable the emergence of these productive relationships, and the extension of feelings such as pain, shame, guilt, or anger from the private sphere into the public realm, is the anonymous and disembodied character of online communication. Although interviewees often found it difficult to admit that anonymity played a role in encouraging them to disclose their private experience in breast cancer online forums, they would usually acknowledge the role it played for others with whom they communicated: “Most people who are online are very open about whatever they’re saying. I don’t know if they were that open if they were in person” (Barbara, interview 2). Previous studies corroborate this observation, showing that anonymity provided by online communication encourages self-disclosure (Steve Jones 1998; Howard Rheingold 1994; Sharf 1997).

What do anonymity and disembodiment mean for breast cancer patients who communicate their experience online? What possibilities does the anonymous and disembodied character of the online space open up for those women? For some patients, being able to communicate their experience anonymously online implies a capacity to control the degree of their visibility. It means they can control “leakage” of the experience of their illness into spaces and times where they are not interested in communicating it, something they are unable to do in other aspects of their lives.

Audrey’s account illustrates this point:

The other point that bothered me with breast cancer and living in a small community ... people would tell other people all the time! ... that’s a community. If a young person gets a disease, it’s very choppy and then it goes around ... It gets me very angry when I hear people know my circumstances whom I didn’t tell ... This is not information to share, no one should know that. It’s a very personal thing ... I don’t want to be known as the one with breast cancer. (Interview 1)

Ironically, perhaps, by participating in online breast cancer forums, women like Audrey are precisely taking on the role of being “the one with breast cancer”, but in doing it anonymously, and in a disembodied fashion, they enjoy the control that they would lack in other contexts.

The anonymity and disembodiment of online communication enables patients another aspect of control that they do not usually have in other contexts: they can break-off communication at any time. Georgia reflects on this point:

It gives you this kind of freedom to bottom line something when you just want to do that, and bypass a lot of these social conventions that you couldn’t in a

support group setting, where you have to be polite, everybody has to have their chance to talk, and tell their story, and you can't get up and just walk out of the room! (Interview 7)

For some patients anonymity and disembodiment are also about being able to choose whether to be visible or remain invisible. To a large extent, the experience of breast cancer expropriates patients' bodies from the private sphere into the public realm. The breast, a bodily site invested with meanings of the private (restricted to the sight of very few, concealed and extremely personal), is being transformed through the medical procedure of treatment into a public object. By contrast, online, patients can interact in a public forum while at the same time remaining invisible, and in this sense can maintain their privacy. The ability to lurk plays a significant role in this. Lurking enables the online participant to be there and yet at the same time not to be there: to observe the social interaction and its dynamics, while remaining invisible, with no need to interact.

This disembodied position allows patients also to dissociate themselves from their own bodies. The situation of being behind the screen when one is not physically visible and present, and where one can remain anonymous, constitutes a supportive context for one to step back from one's personal experience. In the story Dear Stranger, Dearest Friend (Katz Becker 2000) Lara, a breast cancer patient, writes in her e-mail to her fellow-sufferer Susan: "I still have that out-of-body experience from time to time. You know, like I'm watching this happen to me instead of it really happening to me" (p. 111). Remaining anonymous and disembodied facilitates this out-of-body experience, of detachment from the cancer: "Sometimes I'll say Anne or



Marie (pseudonyms) ... I find that a lot of young people do want to leave the breast cancer behind” (Audrey, interview 1, my brackets).

At the same time, it is precisely participants’ capacity to interact online while remaining disembodied and anonymous which enables them to rework and express their “real” selves. To engage in supportive interactions in public forums, where they can come to terms with their experience, and yet at the same time enjoy a degree of control, sense of protection and privacy.

Fundamentally, breast cancer patients’ capacity for anonymous and disembodied communication has a very different meaning from the post-modern idea of experiencing a gender-free deconstructed self. The latter view, as discussed earlier, endorsed the radical potential of the online space, regarding the Internet as a transformative space where gender categories become reconfigured (Consalvo and Paasonen 2002, p. 2). By contrast, it seems that for breast cancer patients the transformative potential of the disembodied and anonymous nature of the online communication does not lie in the capacity to experiment with multiple identities and transform gender categories. Rather, as I have explained, the disembodied and anonymous communication enhances their capacity to work and rework their “real” selves.

While the apparent transformation which participants undergo is far less radical than the one suggested by post-modern approaches or by the notion of the cyborg (they basically maintain their “real” identities, even if they do not reveal significant parts of it), the consequences of their participation entail significant transformations: remaining anonymous and disembodied allows women to voice

experiences that would otherwise probably have remained unheard and obscured; it encourages them to develop supportive relationships that in many cases would have otherwise never occurred; it helps them regain the control over the visibility of their bodies, and thus of their selves. In all these ways, anonymity and disembodiment have a meaningful transformative potential. Beyond the transformation women may experience on a personal level, on a broader social and political level, the anonymity enabled by online communication makes possible new forms of participation that these women do not have in other contexts of their social world, and contributes to the continuous public recognition of the disease.

### **The darker side of the online ribbon: the limitations of the transformative potential of patients' online communication [EN 4]**

Thus far, the account of breast cancer patients' online communication has highlighted the ways in which this communicative context can be seen as meaningfully transforming women's experiences and the cultural and social environments in which their experiences are embedded. However, a critical consideration of the question of the transformative potential of this communicative context demands further interrogation. What are the constraints and challenges to the kind of recognition that patients' illness experiences are afforded in online space?

#### Anonymity and invisibility

For all the celebration of the transformative potential that is entailed in patients' capacity to communicate anonymously, that the illness is communicated

anonymously means breast cancer remains, to a certain extent, hidden from public sight. As problematic as the celebrity representations of breast cancer may be, in that they play down the range and depth of controversies around breast cancer (Leopold 1999), they are visible and identifiable mediated representations. By contrast, the online textual representations of breast cancer patients are disembodied and anonymous, and thus they are inevitably less visible and less accessible. As Barbara suggests: “I’m very loud within the [online] breast cancer community, but not in the general public” (interview 1). The voices of Barbara and her fellow sufferers are “loud” mainly (or only) within the online boundaries; they do not permeate through to the “general public”. In this sense, the anonymous online communication of breast cancer reinforces the separation of women’s private experiences from the public political agenda. Thus, the anonymous and disembodied character of online communication, it seems to me, is a double-edged sword. While anonymity has an appealing power, as highlighted earlier, at the same it can be counterproductive insofar as it has a limited capacity to translate private experiences and understanding into meaningfully visible, and thus publicly recognised, terms. At least a third of my interviewees who were quite active in sharing their experience of illness online, put a lot of effort into hiding it and keeping it confidential in their offline lives. Thus, unless their online accounts make their way to public offline forums, such as the mass media, their recognition and therefore their broader social impact remains limited. We certainly need research on the extent to which, and the ways in which, online discourse impacts (or not) on public discourse and representations.

### The privatisation of experience

Another barrier to the transformation of breast cancer patients' online disclosures into wider forms of public recognition and political action is the tendency for patients' discussions to focus predominantly on the individual and the personal. The majority of the online colloquy on breast cancer seems to be characterised by what Leopold (1999) calls the "privatisation of the disease": a construction of breast cancer as a predominantly intimate, individual, and domestic drama. The constraints that Leopold identifies in relation to this bias seem to be extended to the online debate on breast cancer. Women's online accounts of their diagnosis with breast cancer often depict experience of the disease as an essentially private affair, confined within narratives of individual struggle, lacking any wider perspective. The notion in these accounts is that women should change themselves, their attitudes and behaviour, without any recognition that their identities and actions are determined by, and respond to, social conditions that will not change simply because they decide, on an individual basis, to interpret and handle them differently. This observation resembles a critique made by Peck (1996, p. 152) in relation to the way personal problems are recounted in talk shows. Unlike talk shows, however, as I emphasised earlier, online, these women have the control over the representation of their experiences. Yet they seem to predominantly replicate, rather than challenge or subvert, the dominant way that breast cancer is represented in the public discourse: as a private affair. In this sense, breast cancer patients' networks do not fit the realm of cyberfeminism: they do not necessarily open up new social and political possibilities that are not available and possible in other spaces and forms. Rather, patients' networks seem to mainly reproduce similar forms of association, vocabularies, practices, and relations to those that are dominant in the wider culture of breast cancer.

## The bias of self-responsibility

The bias towards the privatisation and personalisation of the illness is manifested in yet another aspect. The key message that emerges from representations produced by breast cancer websites, and patients' personal accounts published there, concerns women's self-responsibility. Women are commonly called upon, whether by their fellow-sufferers or by the websites' producers, to take responsibility for the management of the illness and its treatment. Consider, for instance, the following message, posted by a patient on a breast cancer patients' online forum, in reply to a survivor who is considering whether she should stop taking Tamoxifen, having been cancer-free for four years since diagnosis (emphases mine):

### **RE: STILL TRYING TO DECIDE (Tamoxifen)**

... I guess I would look at it this way. **Ask yourself why you took Tamoxifen in the first place** (I'm sure the percentages were about the same back then).

Then **ask yourself about the side effects and your tolerance to them.**

(Source: Breast Cancer Online: In Our Own Words)

This message depicts breast cancer as a private experience on an intimate scale. The author encourages her fellow-survivor to "ask herself", that is, to look inward rather than outward for the solution of her treatment. "In this construction," which is typical of breast cancer representations in general, says Leopold (1999, p. 172), "the focus is on women and how they respond, not on treatment, which is taken as a given."

Patients often consider the actual participation in online forums as itself a manifestation of a desirable self-determined approach to illness:

There are women on the message board in all stages of breast cancer. The ones who stick around are the fighters ... those that come on and are passive and feel it's just too hard to fight it, give up and give in to their disease and don't stick around. (E-mail Interview 15)

The "fighter" is often seen as the one who "sticks around" online. Not responding to online messages, or not communicating online, is often considered as "losing the battle" against cancer. Similarly, in her interview, Barbara criticised patients who choose to remain silent and not talk about the experience of illness. In so doing, she implicitly justified her own active participation in writing in different online forums, such as message boards, or her personal bi-weekly column on breast cancer.

Websites tend to use a similar rhetoric, portraying women as active self-responsible agents, and emphasising online participation as integral to this sense of agency. "Young Survivors Coalition", which is a website focusing on breast cancer at an early age, is a good case in point. Its homepage displays a list of words, in different font sizes, namely: "challenge, inform, act, support, question, empower, inspire". These are verbs rather than nouns, calling on patients to fulfil their potential as agents by expressing themselves online. Moreover, this kind of design and use of rhetoric implicitly directs patients to express themselves in similar terms to the ones the website employs, i.e. to depict themselves in active terms as "empowered", "active", and "informed".

The message of personal responsibility and enhanced involvement of the patient implies, among other things, a shift in the control of the discursive space of the

disease, primarily from the medical profession to the laypersons. This shift has often been seen as empowering women, but more recently there has been recognition of its disempowering dimension: it is the individual control of the disease, rather than the social control, that has been foregrounded. Consequently, liabilities that properly belong to society at large---government and corporation responsibilities for disease prevention---are being transferred from society at large to individuals (Leopold 1999). As empowering as we can claim this kind of communication to be (I myself depicted it in these terms elsewhere, see Orgad 2004), we should also acknowledge its limitations. While for many breast cancer patients certain online spaces constitute safe therapeutic forums where they support each other, these spaces convey a very limited sense of collective responsibility (see also Pitts, 2004). At the end of the day, the battle against the disease is a matter of personal struggle and redemption behind the screen. Transformation on a personal level may take place, but is limited at the social and political levels.

## **Conclusions: making the personal political online and offline**

“Publicity in women is detestable. Anonymity runs in their blood,” wrote Virginia Woolf in her famous feminist polemic *A Room of One’s Own* in the 1920s ([1929] 1993, p. 46). Back then, breast cancer, like many other women’s matters, was sealed off from the public arena. There was hardly any infrastructure for women to discuss their condition with fellow sufferers, to exchange, for instance, information about treatment, or share feelings of uncertainty, shame, pain, or anxiety.

Anonymity no longer runs in women's blood and in relation to breast cancer has come a long way. As in other contexts, for instance sexual abuse (Kitzinger 2001), in which "women's issues" have been "desequestered" to use John Thompson's (1995) terms, so too in the case of breast cancer the media have played a key role. The Internet constitutes a significant space in the widening infrastructure for the communication of the illness in contemporary society, particularly by the patients themselves. It offers new (and in some aspects distinctive), as well as similar ways of giving recognition to issues that were previously private and invisible. The online space elaborates new social relations in which the identity of breast cancer patients can be lived; developing its particular forms of association, vocabularies, disembodied practices and relations of camaraderie and bonding [EN 5].

However, for all the celebration of the transformative potential of patients' online communication and the various ways in which it facilitates the recognition of breast cancer, as Moorti and Ross (2003) noted in another context, the consequences of such recognition and visibility should be critically appraised. While computer mediated communication contributes to the widening of the communicative infrastructure of the illness, and to its "coming out" into the public arena, at the same time it seems to reinforce the opposite. As a combination of a disembodied, anonymous, patients-only and highly personalised space and discourse, breast cancer online sites seem to separate rather than integrate, the illness experiences from the public political realm.

I do not mean to deny the existence of breast cancer activism online. Nor do I mean to underplay its importance in advocating the political meanings and



consequences of the illness, both offline and online. Yet it seems that the discourse around breast cancer in online spaces occurs mainly outside the progressive feminist tradition. Issues like responsibility for the illness on a societal level are hardly discussed.

Can online communication have the political impact that Rose Kushner's crusade in the press and later in her book in the 1970s had? Probably not, partly because what made an impact on public consciousness was that, among other things, Kushner was an identifiable person who revealed her experience to a wide audience, who were not themselves necessarily breast cancer patients; that she integrated her personal experience with wide-ranging medical and sociological data (Leopold 1999, p. 233); and that her disclosure was personal, but at the same time explicitly driven by a political agenda. In sustaining anonymous participation in online forums, breast cancer patients reinforce what is emblematic of many publics of women's culture: they fail to recognise themselves as publics, because they think of their authenticity and their femininity as rooted necessarily in private feelings and domestic (and thus invisible and peripheral) relations (Warner 2002, p. 39).

Arguably, Kushner's book would not have had the same impact in the absence of the other changes that occurred at the time of its publication, which created a fertile ground for the emergence of the illness into the limelight (for instance, the announcement by famous American women of their diagnosis of breast cancer). For women's online communication to have a meaningful, progressively political significance, for instance of acknowledging breast cancer as a social issue and challenging the emphasis on self-responsibility, it must be embedded in larger

changes of the material conditions and cultural practices. So long as the material reality of breast cancer does not change, and its dominant representation in public discourses (e.g. mass media) remains unchanged, the so-called “empowerment” of patients by online communication remains highly limited.

If we are to try to study the media’s role in influencing public and private understanding of key social and political concerns as Kitzinger urges (2001, p. 100), and if we are to consider the notion of “transformative potential” critically, we need to move beyond the mere observation that the media, and in this case the Internet, transform private and public discourses. While a great deal of feminist enquiry, and recently particularly Internet feminist studies, has been concerned with ensuring that “private” issues are placed in the public arena, we need to question what it really means for these issues to “go public”. For example, aspects such as anonymity and disembodiment, that are often explained in terms of how they appeal to users, and which encourage users to communicate extremely private issues, should be considered also in light of their social and political meanings. How can online spaces such as breast cancer patients’ forums transcend their invisible domestic boundaries? Can they constitute more than anonymous therapeutic spaces, providing resources for confession, inwardness, and self-elaboration? More feminist enquiry into these kinds of questions is desirable.

### **Future directions for research and Web design**

However empowered participants may feel by engaging in online communication, and despite the seductive concept of them as “producers” controlling

the representation, rather than passive “consumers” of public representations, the traditional producers and designers of websites still significantly shape online communicative spaces. For instance, they frame participants’ constructions of their experience by providing them with certain forms that they should complete, and certain categories to which they are asked to relate; they specify for whom the forums are intended, often distinguishing between patients’ and caregivers’ forums (e.g. see <http://www.bcans.org/Support/communityforums.html>); and with the increasing commodification of online space, many websites direct readers to concentrate on women’s self-improvement issues, including the promotion of reconstructive surgery (Pitts 2001). In view of the critique proposed in this essay, website producers should consider how they could make these discursive spaces more politically meaningful. How can they enhance the recognition of breast cancer as a social issue, beyond the private realm of the patient?

Websites can designate specific forums for discussions that are by definition more politicised, and oriented toward a critical reflection on issues related to breast cancer. Many websites have patients and/or survivors who write for them on a regular basis, online columns, or journals. They could ask these writers to point to the social and political aspects of the experience of breast cancer, provided, of course, that they felt comfortable to do so.

Another way to encourage an understanding of breast cancer as a social issue would be enabling a dialogue between breast cancer patients and what Barbara calls “the general public”. This can be done by opening patients’ online forums also to non-patients. This is undoubtedly a difficult task, if the safe, bounded and private

atmosphere that women currently appreciate so much is to be maintained. Breast cancer patients and survivors may not find interaction with non-patient members productive, and this should be certainly taken into account and examined. Yet the need to open up the secluded experience of patients to other groups, seems to be irrefutable if we are to be truly concerned “private” “women’s issues” being placed on and acknowledged by the public agenda.

Opening up “private” online spaces such as breast cancer forums to a dialogue with “public” participants also implies opening up their “feminine” boundaries. There is an obvious tendency to treat spaces such as breast cancer forums as specifically “feminine”. However, while such spaces have a clear feminine dimension, they are certainly constructed of more than just participants’ gender (van Zoonen 2001, p. 71). In my study, only a minority of patients whom I interviewed, surprisingly or not, articulated their perception of breast cancer online spaces as “feminine”, while factors such as age or cultural background emerged as far more significant [EN 6]. Thus, website producers, as much as academics, should be wary of reducing women’s online communicative practices and processes only to “femininity”. The first step in transforming “private” issues such as breast cancer experience, into a political agenda is to stop treating them as exclusively women’s personal issues.

In design terms, this would mean thinking of ways of creating forums that are more inclusive, that truly allow people “from all walks of life and from all over the globe”, as one breast cancer website describes it (<http://bcans.ca/forum/help.htm>), to engage in a productive dialogue. Spaces like breast cancer patients’ forums provide a rare opportunity to glimpse at how patients understand their lives. This opportunity

should not be taken up only by patients who go through similar experiences, although they are naturally the primary participants, but also by other individuals, professionals, academics, and government and corporate agencies such as pharmaceutical companies. As Franklin (2001, p. 389) observed in relation to another women's online context, the political meanings of such public-private-personal online articulations depend not only on who is talking, but also to whom and for whom. The online articulations of the personal and the private will become meaningfully public and political, I suggest, only when patients talk outside their private, safe communicative space, and only when these outside agents, which constitute society at large, start listening.

Lastly, this paper invites reflection on how we think about "the transformative" in the study of online communication. While different interpretations have emerged in Feminist Internet studies, this paper suggests that a more integrative approach may prove helpful. Such an approach, as I have tried to show, examines this question from the users' point of view, and in a historical perspective, in relation to what has been hitherto available; it stresses that the various manifestations of online communication are embedded in wider social and public contexts, thus exploring the connections and disconnections between online practices and other available (offline) forms of social participation and representation. For instance, it accounts for the specificity of online communication in relation to mass media contexts. Finally, it explores how a specific context of online communication may transform women's experiences on a personal level, and also whether and how it can change the wider social and cultural environment in which these experiences are embedded, and the constraints to achieving this transformation.

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## **Endnotes**

[1] For a more detailed account of the methodological design of my study and the process of data selection and analysis see Orgad (forthcoming a).

[2] For example, in the “Shared Experience” website about a quarter (552) of the whole collection of cancer patients’ stories (2,382) are breast cancer stories ([www.sharedexperience.org](http://www.sharedexperience.org), data accessed on 4 August, 2004). In “The Cancer Survivors Network” of the American Cancer society’s discussion board, more than 60% of the messages (16,943) regarding cancer experience, are breast cancer-related ([www.acscsn.org/Forum/Discussion/summary.html](http://www.acscsn.org/Forum/Discussion/summary.html), data accessed on 7 October 2003).

[3] Media representations of breast cancer are occasionally discussed in patients’ forums, especially in relation to the use of celebrities on television. While I did not conduct a systematic study of these discussions, having followed them for a couple of years, it seems to me that there is neither a clear negative nor positive perception among patients of these representations. See also Pitts (2001; 2004) for some discussion of the relationship between mass media representations of breast cancer and the online discourse of the disease.

[4] I borrow this from Leopold (1999), whose book is entitled *A Darker Ribbon*.

[5] In making this observation, I draw loosely on Warner’s account of “counterpublics”.

[6] For a discussion of these aspects see Orgad (forthcoming a; forthcoming b).

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