LSE Research Online

Working paper/ Discussion paper/ Report

Shani Orgad

Patient users and medical websites : the user experience of internet environments

Patients' Experience of Internet Environments: Storytelling, Empowerment and Its Limitations

Shani Orgad

Abstract

What kinds of processes of communication do Internet users who have concerns about health issues engage in? This project builds on research which focused on the online participation of breast cancer patients in Internet spaces. It extends that work to discuss the experiences of a broader range of patients and their experience of medical websites. The paper seeks to expand the focus of existing research on information seeking and social support, to consider an activity that patients engage in, yet which has largely remained overlooked, that of storytelling. Analysis of how patients configure their experiences into stories provides an innovative way of understanding online communication as a socially significant activity and explores some of the limitations of this activity. This exploration concludes with a critique of the concept of empowerment, a concept that governs many accounts of patients' use of the Internet. It also raises several considerations for scholars who study the Internet, those involved in the design of patients' Internet spaces and policymakers that regulate them. This working paper will serve as background to a workshop discussion.

1. Introduction

The growing availability of the Internet has produced an expansion in the number of medical and health websites, paralleled by increased use of the Internet for health related information. This trend is supported by various health policy initiatives. For example, NHS Direct Online in the UK is described as providing a "gateway to high quality Internet information sources"; the Canadian Health Network (CHN) was launched as a national, bilingual Internet-based health information service seeking to become Canadians' premier source of "health information you can trust." (http://www.canadian-health-network.ca); the U.S. Department of Health and Human Services developed 'Healthfinder', a free guide to consumer health and human services information (http://www.healthfinder.gov).

Seeking health related information is one the major reasons patients go online. Both quantitative surveys (e.g. Boyer, Provost & Baujard, 2002; Madden & Fox, 2006) and qualitative research (e.g. Hardey, 2001, 2002; Kivits, 2004), provide evidence of the centrality of users' search for health information online and its impact on patients' conduct of their lives, health, treatment, and relationships with doctors (e.g. Reents, 1999; Williams, Nicholas & Huntington, 2003). In fact, the study of patients' use of the Internet has been almost exclusively concerned with information seeking, its verifiability, credibility, trustworthiness and accuracy (Orgad 2005a; Seale, 2005).

This preoccupation with the use of the Internet for health information is indicative also of contemporary policy. The assumption in both contemporary policy and current academic debate is that greater availability of health information via the Internet (and other resources) will create better-informed patients, who will therefore be better able to assess their condition and treatment (Henwood and Balka, 2004). This assumption is often framed in terms of 'empowerment'. Accessing online health information is seen as central to patients' empowerment and their involvement in decision making about their treatment: patients 'shop around' to ensure they get the best medical service; they can challenge their physicians with information obtained online; and so on.

The Internet is seen as empowering not just by being a source of health information, but through providing a platform for emotional support and exchange of personal experiences. Studies have shown that the proliferating online communities

and support groups for sufferers from Alzheimer's (King and Moreggi, 1998), knee injuries (Preece and Ghozati, 2001), HIV (Reeves, 2000) and cancer (Orgad, 2005a; Seale, 2005; Sharf, 1997; Shaw, McTavish, Hawkins, Gustafson and Pingree 2000), offer patients and carers a platform for information sharing, social support and personal empowerment. This paper seeks to expand the research focus on information seeking and social support, to include a significant activity that has been largely overlooked: storytelling, i.e. patients' configurations of their experiences into stories.

There is an abundance of patients' stories being published online in Internet spaces - message boards, mailing lists, personal journals, and blogs. The stories are not just a means to seek or provide information, nor can they be explained as simply being a means of gaining social support. It can be argued, that fundamentally, patients' storytelling online is an attempt to regain some 'normality' in their lives; lives that have been disrupted by illness. It enables patients to hold on to a sense of themselves as agents who have control, however little, over their lives. Thus, storytelling involves more complex and varied aspects than are encompassed by 'information seeking' and 'social support'.

This is nothing new. The therapeutic nature of storytelling for patients' (particularly those with chronic illnesses) has long been recognised in the social research of health and illness. This paper draws on this research to explore the emergent phenomenon of patients' storytelling on Internet spaces. The aim is to better understand the actual communication processes in which patients engage online, and their significance for coping with illness. The focus on storytelling on the Internet as a significant social activity among patients challenges the preoccupation of policy, academic and popular debate with information seeking, urging an expansion of the agenda to include the more varied ways in which the Internet is and can be used by patients. It also highlights the need to rethink the seductive, yet highly problematic, concept of empowerment.

The discussion in this paper builds on research into the online participation of breast cancer patients in Internet spaces (Orgad, 2005a). It extends that work to discuss the experiences of a broader range of patients and their experience of medical websites. It starts by briefly discussing the connection between storytelling and illness. The intention is not to provide an exhaustive account of the rich body of work on this subject, but rather to indicate the significance of storytelling for patients' coping process. Next, it describes the research methodology. It then explores

storytelling in the context of patients' Internet use, starting with a brief discussion of what is meant by 'storytelling online' and continuing by discussing the two fundamental elements of this activity: ordering experience temporally, and constructing closure. The key distinctive features of storytelling in Internet spaces - its anonymous and disembodied character – are discussed, in particular their implications for patients' willingness to disclose intimate experiences, and the sense of flexibility and control this allows them. In the next section, some of the constraints of this activity are explored. This discussion is developed into a critique of the concept of empowerment, highlighting the need for more complex frameworks to explain patients' use of the Internet. The concluding section offers some suggestions for scholars who study the Internet, those involved in the design of patients' Internet spaces and the policymakers that regulate them.

2. Storytelling and Illness

Medical anthropology and the sociology of health and illness have highlighted the significance of storytelling for patients' coping. Storytelling – the narrating of experience in the form of a story - is seen as helping a patient who has suffered a severe crisis in life to come through it (Hydén, 1997). It is an attempt to produce a discursive framework that organises disconnected elements into a coherent form, directing them towards closure. In narrative studies this process is often referred to as *emplotment*: the procedure that configures the different events into a whole by gathering them together and directing them toward a conclusion or ending, thereby giving significance to independent instances (Polkinghorne, 1991; Somers, 1994, based on Ricoeur, 1984).

This activity gains special meaning and value in the context of patients' coping with the experience of illness. Illness, and chronic illness in particular, constitutes a disruption to the continuity of people's everyday lives (Bury, 1982), often characterised by crisis, confusion, uncertainty and lack of coherence. Patients engage in what Frank (1995, p. 54) describes as "repair work on the wreck": a continuous effort to manage this disturbance by regaining their ontological security and the continuity of their self-identity. As part of this effort, patients employ various strategies that will help them create a sense of coherence, stability, control and order in the aftermath of the 'disruptive' event of illness (Lawton, 2003, p. 27). Storytelling

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is one way in which patients seek to regain order and re-establish continuity. It enables a coming to terms with a problematic experience and making sense of what is happening.

Several academic and popular accounts (e.g. Frank, 1995; Kleinman, 1988; Lorde, 1980) highlight illness as "a call for stories" (Frank, 1995, p. 53): a situation of crisis that invigorates creative engagement in the interpretative activity of constructing a story. Through stories, patients convey how the experience of pain affects the way they thought about themselves, their lives and their futures (Mattingly and Garro, 2000, p. 28). The discussion that follows draws on this theoretical background to explore the emergent phenomenon of patients' storytelling on Internet spaces.

3. Methodology

This paper draws primarily on a study of breast cancer patients' use of the Internet (Orgad, 2005a). It extends that work by examining a broader range of health-related Internet sites using textual analysis. The study of breast cancer patients' online communication spanned four years and involved 41 interviews (both online and face-to-face) with patients who used the Internet in relation to their illness. After observing breast cancer-related online spaces for several months, messages were posted on bulletin boards, inviting patients to share their experiences of using the Internet in the context of their illness. Some patients who provided their e-mail addresses in the messages they posted or on personal homepages were contacted. This produced 83 replies, from which 29 accounts were chosen to use as data for analysis. At a later stage 12 face-to-face interviews were conducted with some of the patients the researcher had 'met' online, and maintained correspondence with.[1]

Since patients' online participation and use of the Internet are deeply embedded in their everyday experience of chronic illness, it was crucial to gain knowledge related to their offline contexts, where they cope with their illness on a daily basis. The purpose of the face-to-face interviews was to explore participants' written stories in greater depth and gain insights into their offline contexts. Ten of the

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[1] Elsewhere I discuss at length the rationale for, and implications of, the move from online to offline relationships with informants (Orgad 2005b).

interviews took place in the United States, one in the United Kingdom, and one in Israel.[2] Except for a cancer website designer, who was male, all the participants in the study were white women, mostly middle and upper-middle class Americans, aged between 32 and 76 (the majority between 40 and 60), and most married with children. Of course, the data suffer from self-selection as well as other biases, for instance most of the interviewees were North American and middle to upper class. These biases shaped the findings of the study in significant ways. However, for the purpose of this paper, and within the space available, these are not discussed here.[3] The analysis is based primarily on these interviews. In the extracts from patients' accounts presented below, names are not revealed to ensure confidentiality.

4. Storytelling Online

Though storytelling seems to be a central activity for patients using the Internet, it has been relatively understudied (the few scholars who studied it include Eley, 2003; Hardey, 2002; Høybye, Johansen & Tjørnhøj-Thomsen, 2004; McLellan, 1997; Orgad, 2005a). The medical profession has only recently started exploring the potential role of the Internet in this context.[4] DIPEx (www.dipex.org) and the NHS-based Expert Patient Programme (http://www.expertpatients.nhs.uk) are two recent UK initiatives that invite patients to share their illness stories online. However, these kinds of initiatives being still in their infancy, there is little evidence to ascertain the degree to which medical professionals accept and/or encourage storytelling on the Internet. The available data relate mainly to health professionals' attitudes towards patients' use of the Internet for information seeking. As mentioned above, this paradigm has largely governed research on patients' use of the Internet.[5]

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[2] There was one exception where, due to the patient's incapacity to meet me face-to-face, a telephone interview was conducted.

[3] For a discussion see Orgad, 2006.

[4] In fact, medical practice has only recently begun to acknowledge the role of storytelling in helping patients to cope with their illness (e.g. Calman, 2001; Carlick and Biley, 2004). Using creative and expressive arts—writing and storytelling being one of them— in cancer care is increasingly seen as helping patients to find meaning in their illness and be able to move on with their lives (Carlick and Biley, 2004; Ferris and Stein, 2002).

[5] Even within the research exploring health professionals' attitudes towards patients' use of the Internet for information seeking there seem to be contradictory findings. Some argue that health professionals welcome and encourage Internet usage by their patients for information (e.g. Williams, Nicholas & Huntington, 2003) while others indicate that health professionals are not comfortable with their patients' growing involvement in information seeking online (e.g. Cox, 2002; Dolan, 2003).

The study of breast cancer patients' use of the Internet revealed that patients' use of the Internet and participation in online spaces does not involve only, or even primarily, seeking health-related information. It is the case that patients' initial motivation is to find information, clarification and answers to questions. However, many patients, after their initial visits to cancer-related Internet spaces, start engaging in other activities and go online for other reasons. And though information seeking may constitute a significant aspect of their use of the Internet at different stages of their illness experience, there are other central communicative processes that need to be better understood. Storytelling is one of them.

Various Internet environments, including blogs, message boards, mailing lists, and personal journals, provide spaces where patients can, and are sometimes invited to, engage in storytelling. Consider the following posting on a cancer-related online board. While the patient could have posted a question, a comment, or a poem, or just 'lurked' and not posted anything, she chose to tell a story:

> ...When I was diagnosed last November, it was already too late. I found a lump in my left breast last summer. I had benign lumps in my breast for years. Normally they went away after some days. So I thought this time, and forgot them. In September I noticed the lump again. It even was a bit bigger. I went to my doctor who told me not to care. In october the lump was nearly twice as big as the lump I first found in July. My doctor still said I do not have to care, the lump is benign and will disappear from alone. In November I moved to a different town, so I had no time to think about the lump. Late in December, I found the lump was much bigger now. But as Christmas was coming, there was no time, too, and I wanted no illness. Things got worse in January. I awake one morning with my breast red and swollen. I was shocked when I saw little ulceration down the breast. My new doctor was shocked when he saw me. He told me after some test that I have terminal inflammatory breast cancer and only a few months left. It was a shock for me, too, finding out that there is a large cancer killing me. It had already spread to my lung, liver, intestines and bladder…I get palliative care. Morphium for pain…Is getting worse. The tumor is growing very fast. My doctor never saw such a fast growing. The skin ulceration of my breast is getting larger. Half of the skin is ulcerated, and the tumor inside my breast nearly fills it. I am getting skin metastasis in my axilliary and around my belly button…I am angry that I did not see a doctor last Summer and forced him to look closer.

This posting is constructed as a narrative: the author chooses to describe her experience along all the moments she had ignored, relating each to a specific month in the year and incorporating them into a coherent story. This story thus becomes a framework that configures different events, actions and experiences into a plot,

through which she tries to make sense of her illness. There are numerous similar examples on Internet sites. Perhaps the most explicit manifestations of patients' storytelling online can be seen on personal home pages and blogs, where they talk about their illness experience in a narrative form, sometimes incorporating visual elements such as photos, or interactive features such as inviting readers to write to them, donate money or click on related links.

When asked why they used the Internet in the context of their illness, several women reflected on their need to share their stories. They said they found the Internet was an available and accessible means to tell their story. While for many users, and patients in particular, this may be a precondition for using the Internet and sharing their stories, accessibility did not appear to be a sufficient reason for patients to go online to share their personal stories. So, why do patients choose to share their stories in Internet environments? What is the significance of this activity for those involved? How is it different from storytelling in more traditional forms? And how does the focus on storytelling inform our understanding of patients' use of the Internet more generally? The discussion that follows, based on analysis of users' experience of cancer Internet environments, seeks to address these questions.

5. An Analysis of Patients' Storytelling in Internet Sites

We start by recalling the definition of storytelling provided earlier. Storytelling involves two main discursive actions: 1) temporal ordering of disconnected events and 2) construction of closure. How do these processes occur online and in what ways are they significant for the patients involved?

5.1 Ordering experience temporally: control and reassurance

The organisation of experience in a coherent sequential order constitutes a significant element in a patient's ability to come to terms with what is happening and re-establish some sense of control following the disruption caused by the illness. Online environments such as message boards provide patients with tools and spaces to organise their experience in a temporal framework, for example, by predefining the categories that users use to construct their posting or search other postings. These

categories often represent temporal 'milestones' in the course of an illness. For example, the Shared Experience Cancer Support website (www.sharedexperience.org) invites users to share their experience asking them to relate key moments and aspects of their experience into predefined categories such as 'diagnosis', 'treatment', and 'quality of life'. The DIPEX website invites breast cancer patients to contribute their own stories or search others', using three key categories: 'Discovery', 'Treatment' and 'Living with it' (see www.dipex.org/breastcancer). Other cancer types and different diseases are similarly categorised on the DIPEX website. For example, for 'Heart Failure', patients' postings are divided into 'Discovery', 'Tests and treatments' and 'Follow-up and support' (see http://www.dipex.org/heartfailure). These categories may seem trivial, an arbitrary way to create a structure for users visiting the websites. However, it could also be argued that this structure requires patients to organise their experience; to weave together moments and events that they perhaps experienced as disconnected, into a narrated form along certain temporal 'milestones'.

The categories presented to patients who wish to share their experience or search for others' construct a temporal order. They include the past (often referred to as 'diagnosis' or 'discovery'), the present (for example 'treatment' or 'quality of life') and the future, as in the DIPEX example of the 'Living with It' or 'Follow up and support' categories. These 'future categories' are particularly significant insofar as they invite patient-users to reflect on the closure of discovery and diagnosis, which are characterised by uncertainty, anxiety and confusion. They 'force' them, albeit in subtle and latent ways, to discuss how they are moving on towards an optimistic future, of positive coping and 'living with it'.

The ability to organise one's experience (which is often confused and even chaotic) by relating it on easily accessible electronic forms, which are subdivided into predefined temporal categories with an emphasis on the future, helps patients to gain control, however little, over events and experiences that generally cannot be contained. Furthermore, using categories that have been used by others to share their experiences is reassuring for first-time posters and proof that they are not alone in their experience. It also can help them realise that others' experience may actually have been worse. Reading others' stories can be reassuring and even produce feelings of having been quite fortunate:

> … looking at these sites, I remember just starting to see these other accounts
> and I'm going through this myself…One of the things that it really brought

home to me, was that I am extremely well-resourced in comparison to lots of women. …
Once you start encountering other women's stories, you realise that there are a lot of situations of people actually loosing their incomes, marriages are breaking up, or they are completely on their own, or they're facing a future of never being able to have children or whatever. … I don't know what's going to happen to me… … But I know that I'm well off in comparison with a lot of other women that have had it. (K, interview 11)

5.2 Constructing closure: moving on but remembering

Closely connected to the temporal organisation of experience is the second fundamental element of storytelling: the direction of the story towards closure. A narrative (unlike some forms of discourse, for example, a poem or informational report), is always geared towards a conclusion or ending. It is in the idea of closure that the therapeutic power of storytelling lies, especially in the context of illness. The construction of closure to the experience of illness enables patients to locate their suffering in the past. It offers them, as Stacey (1997) observes, a path out of the pain.

At the same time, storytelling, especially in written format, guarantees that the experience of illness will not be forgotten (Stacey, 1997). So there is an inherent paradox in storytelling about illnesses such as cancer: on the one hand, the goal is to bring closure to the illness experience, to move on and forget. On the other hand, it is an act of remembering and documenting the painful events, so that they can never be completely forgotten.

Patients' communication on Internet sites plays an interesting role in facilitating this dialectical experience of forgetting, imposing closure, and moving on, while at the same time remembering and acknowledging that complete closure is in fact impossible, especially since, in the case of cancer and many other illnesses, there is a risk of recurrence.

Patients use the Internet to post messages to announce the completion of a particular treatment, for example the last session of chemotherapy, and in so doing create closure for a specific stage of their illness, implying progress towards cure:

If my CAT scan next week comes back normal, like expected, my Cancer Treatment Experience is supposed to be finished on April 1st…Seriously, that's the date of my last radiation treatment! After that, I will be somewhat sunburned and sore cancer survivor!!!!!

The author of the message announces her arrival at the finish line of her 'Cancer Treatment Experience'. She declares the closure to a chapter of cancer in her life. At the same time, her story and her sunburned and sore body are living testimony to her pain. Furthermore, while the message is clearly cheerful and optimistic, it conveys uncertainty through use of the conditional 'if' (Orgad, 2005a). To some extent, there is always some duality; the closure is never complete, and this duality is reflected in patients' online stories.

One of the elements of online communication that facilitates the maintenance of this duality is the ongoing nature of online communication. While some patients post their stories online and then never visit their postings again, others 'rework' them, modifying and updating over time. Some patients maintain a personal weblog, where they share their illness experience, announce their cure –closure of the illness chapter - but continue to update readers (and themselves) with their 'post-closure' experiences. In the research discussed here women who had shared their experience in breast cancer forums, tended to revisit these forums to tell of their life after being cured of cancer. They would do so often five years after their diagnosis (the five-year milestone is considered to be the threshold of reduced likelihood of recurrence), after years of inactivity in online spaces, in order to announce and celebrate the 'all clear': the formal closure of cancer. One interviewee sent an e-mail message to a list of her acquaintances and fellow-sufferers:

> Subject: Ready for a smile???
> Today is 5 years that I have been cancer free! Woooooo Hoooooooo!!!
> I can feel you smiling from here!

Another participant described the urge to keep revisiting online forums and sharing experience after being cured as a 'knock-on-wood' effect:

> I think that a lot of the people that have survived it…I think…they're proud of it, part of it is like a 'knock-on-wood'. If I say I had it 20 years ago, and I keep coming [to the online support group] maybe I won't ever get that. (Interview 2)

Perhaps, as this woman observed, patients unconsciously regard the capacity to revisit Internet sites, re-construct their self-narratives, and update them on an immediate basis at any time, as an 'insurance' policy, with which they can manage the difficult task of bringing an end to an experience that in fact cannot be ever fully closed (Orgad, 2005a). There are, of course, patients who return to online sites to share

unfortunate news about recurrence of illness. They have to re-open their story, re-engage in the storytelling process, and struggle to achieve closure a second time.

So far, the two key elements of storytelling, namely the temporal ordering of experience and the construction of closure have been discussed along with the significance and form they assume in patients' participation in online environments. These elements of storytelling are not of course unique to storytelling on the Internet. Long before the Internet, patients used storytelling as part of their coping either by writing (in a diary for example), or relating them face-to-face, for instance in support groups. In this sense, the Internet has provided an additional space for a familiar communicative practice of patients' storytelling.

At the same time, the Internet is more than just another space for patients' storytelling; storytelling online has some distinctive features. As has been shown, online patients have opportunities that are not necessarily available to them in other contexts: they can share their experiences and configure them into narratives according to predefined categories; they can re-tell their stories and construct and reconstruct their closure on an ongoing basis. However, the features that most significantly distinguish patients' storytelling in Internet spaces from other contexts of storytelling are disembodiment and anonymity.

5.3 Disembodiment and anonymity

Perhaps the most distinctive characteristic of computer-mediated communication is the lack of audio-visual cues and physical presence of the participants in the interaction.[6] For patients, online environments are the only settings where they can interact anonymously and without physical presence during the course of their illness and treatment. Even if they reveal their real identities, which some do, a degree of anonymity is sustained so long as the interaction is disembodied. However, unlike other online contexts, where the disembodied and anonymous character of online environments allows participants to invent personas and disguise their real identity, for example their gender, for patients, the ability to remain anonymous and disembodied while interacting and sharing experiences, has quite different meanings.

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[6] This aspect has been widely discussed in the literature; numerous studies explored how it affects participants' communication in many, often contradicting, directions. For a useful review, see Baym (2002).

Ease of disclosing experience

One of the clearest implications of anonymity is that it motivates patients to disclose their experience.[7] The following patient corroborates this idea:

> … It's easier to pull your heart out when you know you will never gonna have to run into them at the AMP. And I think that that kind of anonymity is a wonderful thing because it allows you to just say what's on your mind. (G, interview 7).

Another interviewee commented on the role of anonymity in patients' participation in online forums. Although she reveals her real name and identity on her online column, she acknowledges that the anonymous and disembodied elements of the Internet have probably helped other patients to contribute to her column:

> At least half of the questions at 'Ask me' [her online column], the writer is listed as anonymous. … 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. (B, interview 2)

For some users it is the distance and degree of detachment facilitated by anonymity and disembodiment that enables them to get involved in a lengthy intimate self-disclosure. The fact that the patient can sit at her/his home, behind the screen, with no pressure for commitment or engagement, which often characterises physical interactions in support groups or meetings with medics, encourages involvement. Thus, the anonymous and disembodied nature of online communication seems to engender two contradictory feelings that are embraced simultaneously by patients: detachment and empathy, dissociation and camaraderie. One interviewee reflected on this duality:

> There's a whole other side to it too, that strangers can give to one another that good friend and family members can't. That's that sort of **emotional detachment**, at least in the beginning. … Once you have your neighbor, your sister, or even somebody who lives in your town, as soon as they start to express their own fears, they're falling apart. You spend so much time trying to comfort them, and that's not what you need! You need somebody who's going to support you, who's going to be strong, and that you're not going to want to look across to see the fear on their face. The Internet gives women the chance to do that. Because even if it's killing [emphasises 'killing'] you that somebody else is going through a bad time, you can tell them, type them a

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[7] As other studies have shown, anonymity provided by online communication encourages individuals' self-disclosure (Baker, 2005; Jones, 1998; Rheingold, 1994; Sharf, 1997).

letter and say: "I'm sitting here, crying for you, that's so bad. I wish there was something I could do to help". (Interview 7, my emphasis)

It is important to emphasise that the anonymous and disembodied character of online communication does more than simply encourage patients to post online; it encourages them to engage in storytelling. Communicating with anonymous strangers, who are going through very similar experiences, creates a particular context that supports patients' self-disclosure and pushes them to configure their experience into a story, rather than simply asking a question or posting a comment.[8] This observation is supported by Sennett (2002) who argues that

> a speaker is more likely to go into things when talking to a foreigner or stranger than to a familiar. The reason is that the speaker uses the occasion to convert tacit understandings and assumptions into explicit, conscious statements, thereby objectifying and exploring the patterns of behavior for him or herself. (p. 17).

This process is evident on many of the Internet sites, for example, message boards, where patients exchange experience. Posters often go to great lengths to describe their experience, translating tacit understandings and assumptions into explicit language, exploring their behaviour and making sense of their thoughts. The presence of disembodied anonymous readers 'out there' often 'forces' the poster to produce a narrative: an account that configures his/her experience into a plausible story, ordered within a sequential framework.

This point is reinforced in the fictional (yet very believable) book *Dear Stranger, Dearest Friend*[9] (Katz Becker, 2000). Immediately after having a mammogram which made the doctor suspect she had breast cancer, Lara, a fictional character, e-mails her online pal who is herself a breast cancer sufferer, recounting her experience of the mammogram:

> I'm tempted to simply skip the details, but I know you'll write with questions about why and how and when, so I'm going to force myself to slow down, *breathe* and tell you what happened, in the order that it happened. (Katz Becker, 2000, p. 87)

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[8] Of course patients engage also in other activities, for example posting questions and comments. However, the emphasis here is that the anonymity and disembodiment of computer–mediated communication specifically encourage patients to express themselves through storytelling.

[9] The book is based on factual research of women with breast cancer and their Internet experiences. The book tells the story of an e-mail friendship that emerges between two breast cancer patients: Susan, a survivor, and Lara, a newly diagnosed patient. They meet on a breast cancer-related message board and enter into an intimate exchange of emotions and experiences.

Writing to an anonymous other, forces Lara to "slow down, breathe and tell what happened, in the order that it happened". It forces her to construct a messy, fragmented experience into a coherent account that configures the details of her mammogram experience into a plausible narrative.

Anytime, anywhere: flexibility and control

Another central implication of anonymity and disembodiment of online environments is that they allow patients to exchange their experience with others (fellow-sufferers, medical experts and caregivers) at their convenience:

> I could surf on my own time ... when I was in the right frame of mind ... and when the house was quiet so I could concentrate. (E-mail 7)

> Never had to leave the house & go to the library had it all at my fingertips!!!!! (E-mail 8)

> …the benefit of finding that information and support in the comfort of one's own home. (E-mail 24)

> It was comforting to know that I could look up whatever I wanted and do it in my PJs [pajamas] at 3 AM if I felt like it. (E-mail 2)

This may seem trivial, but it should be remembered that during the experience of illness and treatment patients often have little control over their time and bodies. The diagnosis of illness, particularly chronic illness, disrupts people's routines and their control over their time. Courses of treatment 'conquer' patients' daily routines, dictating where they should be and when. Patients' ability to do things on their own terms and at their convenience often becomes very limited. Thus, communicating online to exchange experience with fellow-sufferers can play a significant role in allowing patients to regain some degree of flexibility in their interactions with others:

> The idea that the women can reach out to each other whatever the day or time… You can go online when it's convenient, you're not tied to a support group that meets every Monday at 7 o'clock. You're not feeling well, not feeling up to getting dressed, putting clothes on getting into your car, you can still benefit from online support which is always there and you can do it when you can do it. (G, interview 7, my emphasis).

As this woman indicates, sharing stories online provides a more flexible form of support than is often available in everyday life. It is based on a 'you can do it when you can do it' principle: a patient can create and publish her story and there will potentially be someone to read it at any time.

This contrasts with exchanges during doctor's appointments or in support groups, which take place at pre-arranged, non-immediate times and places. Interviewees often referred to their awareness of the limited time available for interaction with their doctors; they used to plan their conversations, making notes in order to arrange their thoughts and frame their questions as coherently as possible. They perceived the online environments as a place where there is always somebody 'out there' to interact with, and share stories with, with no time pressures.[10]

The flexibility that the anonymous and disembodied character of Internet environments endows has particular significance for patients who as a result of treatment are weak and/or physically confined to their homes. The capacity to engage in meaningful exchanges that do not require their physical presence was discussed by many patients in the study as a significant advantage. Take, for example, the following comment:

> If there was no Internet, I might have chosen to tell the story of cancer and coping through lectures and talks with other patients, however that would have required physical and emotional powers that are not always at my disposal. (Letter 3).

Control over self-representation

The anonymous and disembodied character of online communication plays a particularly important role for patients going through illnesses such as breast cancer, which have a strong embodied dimension. The illness and its treatment (chemotherapy, for example) cause many physical changes such as hair loss, weight gain and skin complaints. As one interviewee put it:

> There's so much cosmetics that occurred…I look at the mirror and I wouldn't even recognise myself! [and] it's very difficult, because cosmetically [emphasises "cosmetically"] that's what people notice.(A, interview 1)

The ability to remain anonymous and disembodied while interacting allows patients control over their self-identity and people's reactions to them. Rather than being overwhelmed and judged by their physicality, as implied in the above quote, the texts that patients post online are the only representations of who they are. Unlike

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[10] Furthermore, online communication has an immediate nature. Being only 'a click away' from other fellow-suffers with whom a patient can share her experience plays a very central role in patients' coping, especially given that in other contexts of communication in their lives, particularly their encounters with the medical institutions, patients are often made to wait without knowing what is to happen and when (Frankenberg, 1992).

embodied situations, where patients "cannot control what other people say", as the above woman remarked later in the interview, in disembodied online exchanges, to a large extent, patients can control the interaction. They can choose whether to reveal their identities and share their stories, something that many patients describe as very difficult in their local communities, where news of serious illness tends to spread quickly.

6. The Limitations of Patients' Storytelling Online

As has been shown, patients are situated in particular psychological, social, emotional and physical situations that prompt them to engage (among other activities) in storytelling in Internet environments. This activity can be empowering for patients in various ways, some of which have been discussed. However, it is an activity that also has some constraining aspects to it that can contribute to the exclusion and disempowerment of some patients.

6.1 Unwritten rules: hope and optimism

One of the unwritten rules for patients' storytelling online is an emphasis on optimism and cheerfulness, which represents a limitation to how they can express themselves.[11] As discussed earlier, users are invited to produce a story that is geared towards an ending; the closure of a painful chapter (a bad stage in the illness) and looking forward with optimism to the future. The latent pressure to relate experience in temporal order and construct a story supports the tendency to produce cheerful, and often highly emotional stories. It channels users (albeit subtly) to produce a success story of how they coped with their situation. Patients' online discussions, as Sharf (1997) observed a decade ago and my analysis of storytelling reinforces, are about *living* with the illness, rather than *dying* from it. This is implicit in the names of websites - 'Conquer Cancer' (www.conquercancer.com) - and sections such as 'Stories of Hope' on the American Cancer Society website (see

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[11] This emerges from my analysis of breast cancer patients (see Orgad 2005a, 2006), as well as other studies of cancer patients' online communication (e.g. Pitts 2004; Sharf, 1997

http://www.cancer.org/docroot/FPS/fps_0.asp?SiteArea=SHR), and 'Living with it' on the DIPEx website (see www.dipex.org/breastcancer).[12]

While this positive and cheerful outlook can be helpful in encouraging some patients and helping them cope, for patients who have other feelings, and want to engage in a different kind of communication, for example critical discussion rather than emotional storytelling, it may make them feel excluded. Consider the account of one of the interviewees:

> I came across [Internet] 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)

Later in the interview, this woman said that she felt the Internet sites she visited were governed by "hidden rules" (to use her words) that implicitly defined what and how participants could express themselves in breast cancer forums. In particular, she felt that the focus was on emotion and sentimentality and that critical and more argumentative discussion was not acceptable.

Thus while patients' storytelling online is enabling and empowering, it at the same time limits and may discourage alternative frameworks and other ways of discussing illness, or result in some not discussing it at all. In particular, storytelling sites are a therapeutic resource that enables confession and self-elaboration about an illness, but do not encourage critical or political debate about the illness and its treatment.

6.2 Anonymity, invisibility and the privatisation of illness experience

A second constraint of patients' storytelling online relates to the anonymous and disembodied nature of online communication. While as discussed earlier anonymity and disembodiment can be enabling and empowering for patients in significant ways,

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[12] *Storytelling Online: Talking Breast Cancer on the Internet* (2005a) discusses how newly diagnosed patients who post messages expressing shock, despair and fear, are 'welcomed' by survivors who 'direct' them to adopt a positive attitude. Gradually, those voices of despair and fear are transformed into ones of hope and cheerfulness.

they also have a clear limitation. That patients' stories online are anonymous and disembodied implies that to some extent their voices remain hidden from public sight. As one of my interviewees told me:

> "I'm very loud within the [online] breast cancer community, but not in the general public" (interview 1).

The voices of this woman and her fellow-sufferers are 'loud' mainly (and sometimes only) within the online boundaries; they do not permeate through to public debate, outside the community of cancer patients. At least a third of the interviewees who were quite active in sharing their experience of illness online, invested great effort into hiding it and keeping it confidential in their offline lives. Thus, as I have argued (2005c: 153), the anonymous and disembodied character of online communication is a double-edged sword. While it has an appeal, it can be counterproductive because of its limited capacity to translate private experiences and understandings into meaningfully visible, and thus publicly recognised terms. In sustaining anonymous participation in online forums, patients reinforce what Leopold (1999) called 'the privatisation of the disease':[13] a construction of illness as a predominantly intimate, individual, and domestic drama. Patients' discussion of their experience anonymously, grounds their experience more deeply in the realm of private feelings and domestic (and thus invisible and peripheral) relations.

7. Conclusions: Beyond Empowerment

The broader point that emerges from this examination of two of the limitations of patients' online communication is a critique of the concept of empowerment. Patients' computer–mediated communication has been often discussed in terms of how it empowers them: how the Internet provides patients with information that helps them make informed decision about their health as never before; how the information that patients find online challenges the traditional power-relations between doctors and patients, 'arming' patient-consumers with information that often their doctors do not posses; how Internet sites constitute spaces where patients can disclose extremely private issues thereby helping them to cope better with the illness. However, while the

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[13] Leopold refers specifically to breast cancer, but her point can be extended to apply to other diseases which have been concealed from the public agenda.

concept of empowerment emphasises how the use of the Internet helps patients to cope better with their illness, it does not account for the tensions, constraints, contradictions and dualities, that 'coping better' may involve.[14]

While the cheerful tone of many cancer websites, or the anonymity and disembodiment they offer can be empowering, they may also reduce the potential for patients' experiences to make their way into public offline forums and have a broader social and political impact, for instance, on health policies. Furthermore, the concept of empowerment does not account for the kind of dialectics discussed in this paper, for example, patients-users' attempts to construct closure, while at the same time struggling to maintain ongoing storytelling; reaching out to others and expressing camaraderie, while maintaining distance and anonymity; disclosing intimate experiences while avoiding the 'price' often extracted in embodied interactions. It is argued here that we need more complex and sensitive frameworks than empowerment, information seeking, and social support to explain the actual processes of the communication in which patients engage online, and their consequences.

The paper focused on one of the communicative processes patients engage in online, and which has been largely overlooked, namely storytelling. The multiple consequences this activity were explored, highlighting its therapeutic qualities and its limitations. Patients' storytelling online is a socially significant activity for a number of reasons. First, it can play an important role in a patient's attempt to reconstruct his/her experience of illness and come to terms with it. The Internet – in its different sites and applications, from e-mail through message boards to blogs - provides spaces where patients can make sense of the experience they are going through by configuring their experience into a written story.

Second, storytelling in online sites gives patients an opportunity to exchange experiences. This may seem trivial, but not all patients have spaces where they are able and feel comfortable to talk about their illness. In this context, the anonymous and disembodied aspect of online environments is particularly appealing to patients who wish to exchange experiences with fellow sufferers, but either cannot or do not

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[14] The reason why the notion of empowerment outweighs accounts of patients' use of the Internet in both academic and policy debates, is in part that often both analysts and policymakers subscribe too uncritically to what patients tell them, either on websites or in studies. Patients often reflect on the positive effect of the cheerful stories they read online and the encouraging messages they received in response to their online postings. This is not to dismiss the validity of their accounts or undervalue the real empowering effect that these websites have, but only to suggest that patients' accounts should be considered and understood within wider social, political, and economic contexts.

want to do it physically (for example, in a face-to-face support group). More broadly, the disembodied and anonymous character of online communication provides patients with a 'shield' that they do not have in other spaces of communication in their lives, but often feel they need. This shielded space invites them to share their story at their convenience while maintaining some degree of distance, privacy and sense of safety.

Third, the ability to exchange experience and relate one's personal experience to similar cases, helps patients to reassure themselves that they are not alone, and that there will be an end to their pain.

However, as discussed above, while storytelling online and its unwritten rules may enable some patients to share their experience with others and consequently be empowered, in promoting and encouraging certain forms and contents, it may discourage other voices and 'scripts', resulting in disempowerment and exclusion of others.[15] Thus, there are constraints to the possibility that the Internet is a truly inclusive communicative space, allowing for a variety of patients' voices, including non-mainstream and counter-voices to be published on the web. Indeed, there is growing evidence that there is increasing convergence between the dominant voices and the messages circulated in the mass media and public discourse, and those published on the Internet. In the case of breast cancer online communication, the emphasis on the future, and on optimism, which dominates public discourses on breast cancer, is replicated in the way many breast cancer websites are organised, and particularly the way they invite patients to structure their stories. Similarly, evidence from another recent study of patients' Internet sites shows how a popular prostate cancer UK website conforms to traditional gender patterns, in which emotionality, complementary and alternative therapies, are associated with femininity (Seale, 2005). The real political potential in the idea that patients' self-representations are projected onto a public space and can become part of a dialogue with public representations of health and illness is far from being met.

This reinforces the recognition that the Internet is a communicative space which is embedded within broader public discourse. Therefore, patients' practices and use of the Internet for health purposes must be understood in relation to mainstream

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[15] It is not argued that that patients who want to express themselves in different ways and not necessarily construct their story using these kinds of temporal categories cannot and do not do it online. Some patients only share fragments of their experience and do not post a coherent story which is sequentially organised. Others, such as the woman cited earlier, post a story which, although it is sequentially organised, does not convey optimism about how the patient is coping with her illness.

mass-mediated representations of health and illness. This focus will help us gain a better understanding of the significance of patients' use of the Internet, on both personal and political levels.

Our responsibility as scholars who study the Internet and those involved in the design of patients' Internet spaces and in making the policy that regulates them, is to work towards ensuring that online spaces enable the expression of a genuine variety of voices and experiences, in a wide range of forms and modes. Although the Internet is often seen as an open, inclusive space in terms of the range of meanings and voices it presents and allows, this is not necessarily the reality. Focusing on specific activities patients engage in, such as storytelling, reveals that there are exclusionary mechanisms at work that promote certain voices, and marginalise others. This has significant consequences for certain users' ability and motivation to participate in patients' Internet spaces.

This is particularly important in relation to the websites of official authorities such as national cancer organisations, or governmental health websites. Since patients will tend first to consult the websites of organisations they are familiar with or have heard of, it is crucial that these websites offer a range of services, forums, and voices. For example, that they include discussions which are not only emotionally-driven or governed by a cheerful tone, but also acknowledge issues like death, and provide participants spaces to discuss them; that they develop spaces for storytelling and exchange of experiences but also offer forums for activism and political discussions in relation to health problems.

The first step towards working in the directions discussed above is for contemporary policy, academic and popular debate to extend their agenda to attend to the variety of uses patients make of the Internet, storytelling being one.

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