# Approaching the role of the Internet: experiences from an online self-help group for women with breast cancer

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Abstract

This article enters into the sociological debate on the potential role of the Internet. Initially,

the debate was characterised of 'enthusiastic' responses which emphasised the radical

influence of this new medium. More recent research however, has offered 'contingent and

embedded' responses in which the radical influence of the Internet is downplayed. These

different responses are grounded in different notions of the Internet user. The 'enthusiastic'

responses take the change towards more plural, or post-modern, approaches to health among

health care users as a point of departure for the influence ascribed to the Internet. 'Contingent

and embedded' responses are more careful with the emphasis placed on this change. Through

this latter focus, several conditions that lead to a more complex image of the Internet user are

identified, and the radical role of the Internet has become downplayed. In this article, I

analyse the support provided by an online self-help group for Norwegian women with breast

cancer, revealing that a commitment to a modern patient role needs attention in further efforts

to conceptualise the role of the Internet in a cancer context. I argue that the material

demonstrates further the necessity of a 'contingent' view on the Internet.

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#### Introduction

The Internet is gaining ground as a frequently used source of health information and as communication channel for European health care users (Andreassen et al., 2007). At the same time, its potential role in the health care context is under debate (Broom, 2005; Henwood et al., 2003; Nettleton et al., 2005). Within the sociological debate on this issue, an 'enthusiastic' response has gradually been succeeded by a 'contingent and embedded' approach (Nettleton et al., 2005). These different responses are grounded in different notions of the Internet user. In 'enthusiastic' responses, the shift towards a more pluralistic approach to health among health care users and a post-modern illness experience is taken as a point of departure (Hardey, 1999; Hardey, 2001; Hardey, 2002b). Within this perspective, the facilitating role of the multiplied access to information and the disembodied communication that is offered by the Internet are emphasised.

The "contingent" approach directs more critical attention to the context in which Internet use takes place, in the sense that the shift towards more pluralistic approaches to health is approached more openly (Nettleton et al., 2005). Within these contributions, both a reliance on the biomedical approach to illness (Broom, 2005; Fox et al., 2005; Nettleton et al., 2005) and reluctance to take on the responsibility implied by the "informed patient" discourse (Henwood et al., 2003) is identified. They raise questions towards the notion of changed health care user who is so crucial for the enthusiastic response.

In this article, I enter the sociological debate on the role of the Internet. I analyse the support provided by an online self-help group for Norwegian breast cancer patients. Through the analysis, the image of the shift towards more pluralistic approach to health care among

women with breast cancer is critically approached. I argue that the material illustrates further the need for a 'contingent' perspective on the potential role of the Internet.

#### **Background**

Sociological assumptions of a radical role of the Internet are particularly connected to the British sociologist Michael Hardey (Hardey, 1999; Hardey, 2001; Hardey, 2002a; Hardey, 2002b). Based on his study of households that use the Internet, he suggested that the Internet will facilitate the emergence of pluralistic approaches to health (Hardey, 1999). One of his points was that we are witnessing a further decline in awe and trust in doctors through peoples' turn to the Internet. Through this process, the relationship between health professions and their clients is argued to be transformed (op cit). This point has particularly been emphasised in his further work (Hardey, 2001; Hardey, 2002b). In his article, from 1999, Hardey also suggests that the Internet will contribute to a reconstruction of illness experiences in a broader sense. Directing attention to the anonymous context on the Internet, he argues that global self-help groups provide a space for intimate feelings and that the anonymity of such places provides a fertile ground for giving meaning to life crisis.

In these contributions, Haug's (1973) assumption of a deprofessionalisation of health care and Giddens' (1991) description of the processes of reapproproation in late, or 'high', modernity represent crucial frames for the radical role ascribed to the Internet.

'Contingent and embedded' responses to the Internet (Nettleton et al., 2005) have characterised more recent sociological studies. This response is characterised of more critical attention paid to the context of use, or to the shift towards plural approaches to health that is assumed by Hardey. One contribution from this literature is the identification of a biomedical orientation both among cancer patients using the Internet (Broom, 2005; Ziebland, 2004;

Ziebland et al., 2004) and among other users of the Internet (Fox et al., 2005; Nettleton et al., 2005). In their study, Nettleton et al (2005) describe the way in which people talk about their use of the Internet for health information. According to the authors, the material leads them to conclude that 'the place of medical practices and discourses remains more secure in the culture of the information age than some would have us believe' (Nettleton et al., 2005, 989). Such observations downplay the transforming role of the Internet and offer a more mixed image of the Internet user. The irrelevance of biomedical conceptualisations in peoples' construction of illness that is paid considerable attention within the 'enthusiastic' accounts is described in more complex terms.

In accordance with Hardey (1999), Broom (2005) further demonstrates how the information available on the Internet enables men with prostate cancer patients to enter into a comprehensive negotiation with health professionals. The wish to break down traditional power imbalances is further underscored. However, paying further attention to the context of use, Broom still argues that different forms of risk management related to being 'open' in the anonymous context on the Internet are of influence for its potential role.

From a more 'worried' point of view, a biomedical orientation among women with breast cancer patients who are using the Internet is further described as an illustration of the pervasive power of biomedicine (Pitts, 2004), indicating that a subordination to the 'clinical gaze' can be constitutive for the role of the Internet.

In this article, I analyse the support provided by an online self-help group for Norwegian breast cancer patients. The material illustrates how the helpful role of this group is framed

somewhat differently than assumed by those who underscore the shift towards more pluralistic approaches to health.

# **Design and methods**

The article draws upon an action-oriented study. Action Research describes a whole family of methods which are participative, grounded in experience, action-oriented and that are integrating different knowledge and practices in the pursuit of practical solution to issues of pressing concern to people (Reason & Bradbury, 2001). In this study, the aim was to explore the potential of online self-help groups in breast cancer rehabilitation.

My involvement in the group interaction was conducted through the role as moderator of the group. I administered the group and had the daily editorial responsibility. I did not comment on topics related to treatment and coping, but participated in topics concerning administrative issues and customs of the group. The latter activity was part of an effort to contribute to a supporting community.

In action research, the borders between the role as researcher and implementer of a program are sometimes blurred (Khanlou & Peter, 2005). It requires a particular awareness on how the study participants are approached, both in relation to the knowledge that is produced and towards the ethical requirements that frame the study. The knowledge production in this context is discussed by Trondsen and Sandaunet (submitted paper) in a reflection on the advantages and challenges by using action research with the intention to improve health care. An important aspect to have in mind in this discussion is that both in the information letter and through my role as moderator of the group, the participants were requested to not comply

with treatment advices from other group members without consulting their doctors. I return to this issue in the analysis.

Information about the study was distributed through the Norwegian Cancer Association and the Norwegian Breast Cancer Association. All women who had been diagnosed with breast cancer were welcome to participate. A newsgroup was established and was accessible through the websites of the Norwegian Cancer Association. It was open between October 2003 and March 2005. We started to recruit participants in October 2003 and new members were welcomed during the whole study period. Those who decided to participate signed a written consent form before entering the study.

Forty women returned written consent indicating their interest to participate in this study and received a password. During the study period of 15 months a total of 1114 messages were posted. This makes an average of 2,5 messages each day the group was accessible. Data were obtained through a questionnaire, by means of participant observation of the activity in the group and through qualitative interviews. Within a Norwegian context, these women can roughly be categorised as a group of middle-class women. Except one, all participants could access a computer at home. The majority further reported that they had a strong social network and experienced themselves as comfortable with the Internet. Their experience was related to searching for different kind of information (ordering travels, reading newspapers), while a minority had experience from other newsgroups. The majority of the participants were under treatment or had newly finished treatment. Those under treatment were both women who were treated for primary breast cancer and women who were treated for recurrence. A minority had been reported fit for some years when the group was established.

The group gradually emerged as a "meeting point" for women who had experienced spread of the cancer, and a majority of the participants chose to not participate or to withdraw from the group. Informants for interviews were selected through purposeful sampling. I intended to reach women with different illness courses and different involvement in the group. Twenty-five participants, eight users and seventeen non-users were interviewed. Fourteen interviews were conducted face-to-face (40 to 110 minutes) and 11 through telephone (20 minutes to one hour). The choice to use the telephone was mainly a result of practical considerations, such as the geographical distance.

The analysis has been issue-focused. An issue-focused analysis is concerned with what can be learnt about specific issues, events or processes (Weiss, 1994). Some respondents further contribute more to the analysis, and others less. Beside the postings in the group, this analysis is mainly based on the accounts of the eight active users who were interviewed. However, accounts from participants who withdrew from the group are also included. Some of these women had used the group for a shorter or longer period and contributed to identify its function. In addition, I also had some informal contact with two participants through e-mail and got a permission to include this communication in the material.

For the purpose of this article, it is further important to note that these participants' use of the Internet was not limited to the online self-help group, and some of their reflections did also refer to their more general use of the Internet. Some are included in the analysis below, but also commented as reflections that refer to their general use.

## The support provided by the online self-help group

Three recurring issues were identified in these women's reflections on the support provided by the online group. It provided an increased sense of control during the treatment process, it provided hope and it provided a space for "illness talk". I outline and discuss them in further detail below, aiming to identify how the role of the group is framed.

## Provision of control

The sense of obtaining more control during the treatment process was emphasised by these women as a crucial function of the group. It was however almost consequently related to the exchanges of medical information. An orientation towards a wider range of treatment approaches was not particularly present. Few expressed clearly a negative attitude to a broader orientation, but they did not consider it as being relevant for them. Some commented in the interview that they did not believe in any "wonder drug". One of the participants further made several efforts to introduce a broader orientation in the group. She expressed considerable interest in self-care and how she herself could contribute to her healing. She made some efforts to establish a conversation around such issues, while the engagement among the others was variable. Supplementing or alternative "roads" to healing did never become a salient aspect of the group conversation. It does not mean that a focus on self-realisation and the mental aspects of the disease were absent, rather that their connection to the illness course was toned down and that the reliance on professional medicine was salient on this issue.

It is however important to comment the group studied here in some further detail. As described in the method section, the participating women were asked to not comply with treatment advices from other group members without consulting their doctors. It is reasonable

to assume that this request could have some influence on the topics that were addressed in the group. On the other hand, it is also worth to be aware that the majority of these active users had experienced spread of the cancer and found themselves in a situation in which the cancer could not be cured. They could be expected to be in search for all kind of tools that were available to delay the further progress of the disease. As such, an orientation away from the 'biomedical view' is questioned by this material. It is illustrative for the notion that the medical view might be more pervasive that 'some would have us believe' (Nettleton et al., 2005: 989). Crossley (1998) argued that some illnesses make people remain tied in the most fundamental fashion to the progress of medical knowledge and technique; their life is literally dependent of such knowledge. This is an argument of relevance in studies of cancer patients. It might be reasonable to direct attention to Bury's (1982) description of illness as a "biographical disruption". In this article, Bury argued that medical conceptualisations can provide a fixed point of a terrain of uncertainty, which contributes to illustrate a rootedness of a biomedical orientation among women with breast cancer.

A biomedical orientation among Internet users does still not preclude that Internet use can provide more active involvement during the treatment of a disease. One participant in this study wrote to the others in a posting about how her use of the Internet made her ask more questions and gave her a feeling of participating in the decision-process. It is also interesting to note that this woman wrote to the others that the doctors were impressed by her knowledge and her effort to be 'updated' and that they encouraged her to go on with her 'studies'. Receptiveness for Internet information among the doctors was also commented by other participants, which is interesting compared to Broom's descriptions of negative responses from the doctor's and how this might framed the potential role of the Internet (Broom, 2005).

The experience of being more involved was further underscored by another participant, saying that group participation helped her to feel more "equal" with the doctors. She also described cancer patients use of such networks as a possibility to 'keep the doctors on their toes a bit', giving some further illustrations to the emergence of a consumer-identity in relation to the doctors. However, the sense of obtaining more control among these women was recurrently deepened as becoming 'better prepared' for the treatment, or being able to 'double-check' the information from the doctors, indicating that the need to challenge the power imbalance was not their main intention.

Ziebland (2004) also noted a search to be medically updated and to ensure treatment in the cancer narratives she studied. Ziebland still argue that this activity can be a "felt obligation". She argues that 'one of the consequences of the changing relationship between patients and doctors, a decline in trust and easier access to health information may be the emergence of a felt imperative to be (or to present oneself as) an expert and critical patient, able to question one's doctors and nurses and locate effective treatments for oneself' (Ziebland, 2004, 1792). Such arguments are brought into focus by this material, for example by the examples presented above. This material still raises the question whether a 'natural' distribution of responsibility between themselves as patients and the doctors can be present when ill people turn to the Internet. One woman, who told me in the interview that she used to bring information she had obtained in the group and on the Internet more generally to her doctor, described it like this:

<sup>&</sup>quot;I ask, say: 'what do you think about such and such and such', when I have read about something new. And then he replies, he is very helpful that oncologist, but obviously, he doesn't ask me what we should start with. He suggests what we should start with. It works very well. (I23)

This approach to the Internet might encountered the adoption of an overwhelming responsibility for their treatment and regulated the influence of their Internet use. On one hand, such natural subordination can be related to a confidence of the medical profession within this particular group of women. On the other, it might also be prompted by their experience of the illness and a need to avoid a burdening responsibility for their own fate. For example, reluctance towards entering a too responsible position was demonstrated in a discussion about the necessity of taking Tamoxifen. This is a medication given to prevent recurrence of the disease. However, side-effects as weight-gain, nausea and attacks of heat are observed (AstraZenica, 2006) and were also described by these women. During this discussion, one wrote to the others that she had stopped taking the medication, but emphasised that she decided to stop after consultation with her doctor – a doctor who knew about breast cancer and knew her breast cancer diagnosis. She said it was important for her to discuss this with a doctor and not to make the decision on her own -even though her constraints were considerable and that she also expressed some ambivalence between the weighty medical reasons to continue taking the medication, and the experience that it had burdening side-effects that had considerable impact on her quality of life.

Another example is given by a young woman who had experienced spread. She commented the process when the worsening of the disease was discovered and said that:

And they did not think there was such a big chance that the cancer had spread, but as long as they did not know what it was, and it might be another type of malignancy and it might be benign, there were many different things it might be, they did not know what it was. So then I had to choose whether to have surgery or not - or whether to wait and see whether it grew. So I asked her, the doctor who gave me the choice, 'what would you have done, if it had been you, or your daughter?' She said she would had it taken out herself. So I said, 'OK, then we take it out.' It is a bit, well, difficult, when you get choices like that, 'do you want to do this or that?', a bit like that, that I had to decide, and I did not feel I had the competence to assess that. (I31)

The question that is raised from these examples, and which previously has been raised by Henwood et al (2003), is how much responsibility people want to take for their health care. As argued by Henwood et al, the wish to be more responsible represents a taken for granted assumption in the suggestions of a transforming role of Internet use. It is however argued that in the context of serious illness, people are willing to contradict the value of autonomous independence and to accept passive roles and dependency on the medical profession (Bishop & Yardley, 2004; Lupton, 1997). Further, being able to hold the disease "at a distance" assists the claim that one is a victim of external forces. "To do anything less is to fully accept the burden of responsibility" (Bury, 1982, 173).

## Provision of hope

These women emphasised the hope that was also provided by the group. My argument in this section is that the construction of hope was facilitated by the online self-help group, indicating some support to the notions of reappropriation (Giddens, 1991) that underpins enthusiastic accounts on behalf of the Internet. Below I describe how the participants in this study described the hope that was provided by this group.

Two sources of hope were identified in these women's reflections; the information circulating in the group, and the access to other women's stories. Particularly emphasising the information that was provided by the group, one participant emphasised that knowledge gave her hope. She had experienced spread of the cancer and said that:

Then, it's a matter of having control, feeling that I know as much as possible, that I know that if, if, if... it has meant an enormous amount. (I1)

On one hand, such expressions give associations to expressed worries about the potential role of the Internet as a 'beacon' of hope (Broom, 2001; Pitts, 2004), and give associations to suggestions of a subordination to the 'clinical gaze' among Internet users. However, other authors emphasise that hope can have different functions for cancer patients (Eliott & Olver, 2007; Little & Sayers, 2004; Yaskowich & Stam, 2003). According to Yaskowhich and Stam (2003), there are two main components associated with the concept of hope to which cancer patients refer. First, the hope of survival, and second, the assurance that they will be able to manage the treatments and all of the effects of the disease.

My argument is that the expression above was framed by the second version. This woman expressed that she was not afraid to die, she knew that she was going to die, and she also told me that they were open in the family about this. But she was afraid of an 'unworthy' death, for example that her husband might had to take care of her and help her with her most intimate doings, and also a death in pain. She once wrote to me in an e-mail:

What I know is that bone metastases will become very painful after a while, so I want to try to find out as much as possible about how I can make sure that I get the best possible pain relief when that becomes an issue (II)

The knowledge she gained from the group helped her to be prepared for these future prospects and to potentially reduce their impact on her present experience. At one occasion, she discussed the availability of hospices with another participant who had experienced spread of the cancer, which also contributes to illustrate their realism towards the brutal facts. In other words, it is necessary to be careful with relating an emphasis placed on being informed as a source of hope to an 'unrealistic' focus on hope. As such, the material can be argued to not affirm a relentless focus on survival as underpinning the focus on Internet as a source of hope.

It might rather be argued that these women used the Internet to reframe their situation into a situation of meaning, which the gives some support to Hardey (1999) and his point of departure in a post-modern illness experience. This is further underscored below.

Not only the information that was circulating, but also encounters with role models were underscored as providing a comforting experience among these women. This function of self-help group participation is well-known from the literature (Coreil et al., 2004; Gray et al., 1997; Yaskowich & Stam, 2003). Many cancer patients look for role models of hope; people who have been able to deal with the treatments and they who have survived the odds. This evidence of hope cannot be found anywhere except through the experiences of other cancer patients. It gives associations to a point made by Walther (2004), that the net is not only about what you get, but also who you get. Similar to the hope provided by the information that circulated in the group, the hope provided by the access to role-models appeared to be expressed in terms of a hope of meaning. One participant, who was newly diagnosed with breast cancer, and experienced a considerable fear, said that the other women in the group represented a source of hope, even though they had experienced spread of the cancer. She said:

and after all there are many people whose cancer has spread and who tackle it in such a fantastic way. So that is in a way my consolation if it should happen to me. (132)

It is further important to direct attention to the multiplied access to other people in a similar situation that is provided by the Internet, and particularly to its ability to connect people that have few other possibilities to be connected. Those with spread in this group did not enter meetings in the patient organisation, or were at least careful with telling the others about their diagnosis. One said that she saw some people become 'terrified' when they heard about it and that her story frightened them out of their wits. One woman who was diagnosed with spread

early in the study period said that the group had been extremely important to her during this period, because she accessed women who had lived with spread for several years and that she:

'gained a great deal from reading X's contributions. She lived with cancer that was spreading, and still she tackled it so well. Things have got better for her afterwards'. (I24)

These examples further illustrate how the online self-help group provided hope for a meaningful life also in the situation of spread. The 'restitution' (Frank, 1995) story that is told through the commitment to the 'modern' Parsonian sick-role does not offer any meaning in a situation with spread, and these examples illustrate how the Internet can provide people in this situation with some tools to reframe their situation in other terms, for example the importance of 'extending life in breadth, and not only in length' that was recurrently mentioned among these women.

## Provision of a space for 'illness talk'

A third theme that was crucial in these women's reflections is that they experienced the group as an arena on which they could address issues that were left unspoken in other contexts. It provided a space for illness-talk. Such expressions give associations to the description of self-help groups as new social worlds (Høybye et al., 2005) or as 'separate spaces' (Ussher et al., 2006; Yaskowich & Stam, 2003). Deepening their description, the women in this group emphasised that the forum provided a space for 'illness talk', in which not only the possibility to talk about openly about how the cancer had disrupted their lives, but just as much the medical details of their diagnosis and the treatment, were underscored. This relief connected to the possibility to address medical details might be understood in relation to the fact that most of the active users of this group had experienced spread of the cancer and that details

about negative illness courses inevitably bring the issue of death into a conversation and therefore are kept outside several contexts.

It is worth to note that the asynchronous communication on the Internet appeared to have a crucial function for the experience of this group as a separate space in which elsewhere unspoken issues could be addressed. Beside the increased possibility to reach other women in a similar position, the flexibility of online communication was commented. One of the participants expressed that this aspect of the group suited her well, and that the group had been there for her when she wanted to talk. Another said that the written communication had a positive function. She commented that 'the time is yours in a way'. Additionally, the high probability of getting an answer was mentioned and directs further attention to the benefits of the online group.

In this group, the relief connected to the possibility to address illness was still described in somewhat different terms than assumed by those who emphasise a burdening suppression of the illness experience as a main frame of such experiences (see, for example Høybye et al., 2005). As I will illustrate below, this aspect was part of the experienced belief of being able to address elsewhere unspoken issues in group. At the same time, it appeared to be combined with a need to protect their close environments was also salient among these women. The first is described below.

As noted by Høybye et al (2005), the isolated experience of breast cancer did also underpin these women's experience of the online group as a separate space. However, as commented in the last section, the felt obligation to avoid such issues was related to situations in which they were communicating with other women with breast cancer, particularly newly diagnosed

women. The women with spread felt that their stories often did not 'fit in' in the company of newly diagnosed women, and that they contributed to anxiety with their story. One told me that she did not inform the others about her situation when she was participating at a weekend seminar arranged by the breast cancer association. She just felt that the other participants were on a 'housemother-trip', and said that she experienced herself as 'killjoy' in these contexts. Another commented the establishment of a local group for breast cancer patients and her experience of being excluded in this manner:

– but it should be a cheerful and happy and fun and friendly forum – that is kind of the impression I have. There shouldn't be any sad stuff about how you can get sick again, you should repress all that in a way. And I think that is sad, and then you lose some of the whole picture of what being sick involves. It's things like that that you can express more on a list like this or in a forum. (II)

These women's experience of being responsible for the wellness of other women with breast cancer resonates with Pitts' (2004) and Broom's (2001) focus on the subordination of the 'bleaker' picture of breast cancer. As such, they could use the group to make these aspects more visible and establishing alternative ways of communicating about their illness. This possibly represents a departure from what they experienced as dominating norms in the communication with other women diagnosed with breast cancer and illustrates a need to break with the expectations about restitution and normalisation.

However, as indicated above, this need appeared to be combined with a need to protect their close environments. Within this group of women, the commitment to a normal appearance did not appear as isolating in the same sense as suggested in previous contributions that describes the potential role of Internet use in terms of the irrelevance of the 'modern' patient role. These women gave the impression that their normal appearance in these situations also could represent a 'willed' choice. They did also feel isolated in the company of their close relationships, but their interest of breaking this isolation was not salient. This aspect became

particularly underscored during the interview with the young woman who had experienced spread of the cancer. Reflecting over the positive experience of having the group available when she wanted to talk about the illness, she also commented that she herself needed to leave the issue unspoken in several contexts:

When people ask, I don't always feel like talking so much about it either. I might not be in the mood for that, I might want to talk about things that are more fun. It's very often that. (I31)

This expression might be illuminated by a point made by Album (1996), a Norwegian sociologist who has emphasised that life-threatening illness represents a threat to our takenfor-given assumptions of life and constitutes fragile selves. Commenting the controlled and not at least 'mundane' interaction among hospitalised patients, he suggested that these practices were of crucial importance, representing a link to these peoples' normal lives when they found themselves living on the margins of everyday life. According to Album, participation in 'mundane and ordinary conversations' contribute to ontological security. From this perspective, the above woman's wish to talk about 'things that are more fun' can then be argued to be in accordance with, rather than suppressing, her subjective experience.

A further example is that both this woman and another participant with spread expressed worries about how their family was managing the situation. The latter said that she tried to not 'make it worse for them', while the woman cited above was concerned about how for how long her children had to live with anxiety:

And then with the children, too, I have to watch what I say when they are there. They know that I'm ill, but I don't want there to be such a strong focus on that in their everyday lives, as long as I'm as fit as I am. So if .....since 2002, they would have gone round and worried for two years now, every day, about whether I would die, or what. So I feel in a way, when it gets more acute, and I get worse, that it's better that we talk a bit about it then, instead of them spending a whole lot of their childhood waiting. (I31)

While such expressions give associations to a kind of repression of these women's 'real' emotions, it is also reasonable to consider their protection of their close relationships as also reflecting their own needs. From the expression above, it appeared that this woman needed to protect her children and function as a normal mother, as well as she had a need to enter the role as a sick person. Rather than repression of 'real' emotions, this might illuminated by the ambivalence that is argued to be pervasive in late-modern societies (Bauman, 1991; Halkier, 2001). According to Halkier, there is a need for social scientists to acknowledge the sometimes conflicting roles that people hold. As such, it is reasonable to direct further attention to 'the' social isolation that is argued to be experienced by women with breast cancer and ask if there are any variations in this experience that need to be considered in the debate on the role of the Internet. It might be of importance for revealing a clearer picture of the role of the Internet. These examples illustrate how it can also be a tool to maintain a 'normal' appearance elsewhere, which is in accordance with the women's needs.

#### **Final comments**

In this article, I have analysed the support provided by an online self-help group for Norwegian breast cancer patients, aiming to contribute to the sociological debate on how the role of the Internet can be conceptualised. On one hand, the material does illustrate how the Internet can be approached by the notion of a shift towards more plural approaches to health in late modernity (Hardey, 1999; Hardey, 2002b). For the women who used this group, online group participation, and particularly the access to women with spread, helped them to reframe a situation with spread into a situation of meaning.

On the whole however, the helpful role of this group was framed somewhat differently than accounted for within the notions of a 'new' illness experience. It became particularly visible

in the reflections on how group participation provided an increased sense of control and a space for illness talk. The analysis revealed that a biomedical orientation, subordination to the doctor's view and a protection of close environments also were constitutive for the role of this online self-help group. Particularly the first point contributes to downplay the radical role of the Internet. On the whole, my argument is that a commitment to a 'modern' patient role needs more attention in the further debate on the potential role of the Internet in a cancer context. In a broader context, it demonstrates further the need for a contingent response to the Internet.

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#### Literature

- Album D (1996). Nære fremmede. Pasientkulturen i sykehus (Close strangers. Patient culture in hospital). Tano: Oslo
- Andreassen H, Bujinowska-Fedak M, Chronaki C, Dumitru R, Pudule I, Santana S, Voss H, and Wynn R (2007). European Citizens use of E-health services: a study of seven countries. *BMC Public Health*, Apr 10; 7:53.
- AstraZenica (2006). Nolvadex. www.astrazeneca.no/preparater/Nolvadex.
- Bauman Z (1991). Modernity and Ambivalence. Polity Press: Cambridge.
- Bishop F, Yardley L (2004). Constructing agency in treatment decisions: negotiating responsibility in cancer. *Health* (8) 4: 465-482.
- Broom A (2005). Virtually He@lthy: The Impact of Internet Use on Disease Experience and the Doctor-Patient Relationship. *Qualitative Health Research* (15) 3: 325-345.
- Broom D (2001). Reading breast cancer; reflections on a dangerous intersection. *Health* (5) 2: 249-268.
- Bury M (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness* (4): 167-82.
- Coreil J, Wilke J, Pintado I, (2004). Cultural Models of Illness and Recovery in Breast Cancer Support Groups. *Qualitative Health Research*. (14) 7: 905-23.
- Crossley M (1998). 'Sick role' or 'empowerment'? The ambiguities of life with an HIV-diagnosis. *Sociology of Health and Illness* (20) 4: 507-531.
- Eliott J, Olver I (2007). Hope and hoping in the talk of dying cancer patients. *Social Science and Medicine* (64): 138-149.
- Fox NJ, Ward KJ, O'Rourke AJ (2005). The 'expert patient': empowerment or medical dominance? The case of weight loss, pharmaceutical drugs and the Internet', *Social Science and Medicine* (60): 1299-1309.
- Frank A (1995). *The wounded storyteller; Body, Illness and Ethics.* The University of Chicago Press: Chicago.
- Giddens A (1991). Modernity and self-identity. Cambridge: Polity Press.
- Gray R, Fitch M, Davis C, Phillips C (1997). A qualitative study of breast cancer self-help groups. *Psychooncology* (6): 279-289.
- Halkier B (2001). Consuming ambivalences. Consumer handling of environmentally related risk in food. *Journal of Consumer Culture* (1) 2: 205-224.
- Hardey M (1999). Doctor in the house: The Internet as a source of lay health knowledge and challenge to expertise. *Sociology of Health and Illness* (21) 6: 820-36.
- Hardey M (2001). 'E-health': The Internet and the transformation of patients into consumers and producers of health knowledge. *Information, Communication & society* (4) 3: 388-405.
- Hardey, M. (2002a), 'Life beyond the screen: embodyment and identity through the Internet', *Sociological Review*, 50, 4, 570-585.
- Hardey M (2002b). 'The story of my illness'; Personal Accounts of Illness on the Internet. *Health* (6)1: 31-46.
- Haug M (ed.) (1973). *Deproffesionalisation; an alternative hypothesis for the future*. University of Keele, Keele.
- Henwood F, Wyatt S, Hart A, Smith J (2003). 'Ignorance is bliss sometimes': contraints on the emergence of the 'informed patient' in the changing landscapes of health information. *Sociology of Health and Illness* (25) 6: 589-607.
- Høybye MT, Johansen C, Tjørnhøj-Thomsen T (2005). Online Interaction. Effects of storytelling in an internet breast cancer support group. *Psycho-Oncology* (14) 3: 211-20.

- Khanlou N, Peter E (2005). Participatory action research: considerations for ethical review. *Social Science and Medicine* (60): 2333-2340.
- Little M, Sayers E (2004). 'While there is life'....hope and the experience of cancer. *Social Science and Medicine*, 59, 1329-1337.
- Lupton D (1997). Consumerism, reflexivity and the medical encounter. *Social Science and Medicine* (45) 3: 373-381.
- Nettleton S, Burrows R, O'Malley L (2005). The mundane realities of everyday use of the Internet for health, and their consequences for media convergence. *Sociology of Health and Illness* (27) 7: 972-992.
- Pitts V (2004). Illness and Internet empowerment: writing and reading breast cancer in cyberspace. *Health* (8) 1: 33-59.
- Reason P, Bradbury H (2001). *Handbook in action research*. SAGE: Newsbury Park, California, SAGE.
- Trondsen M, Sandaunet AG (submitted paper). The double-minded action researcher.
- Ussher J, Kirsten L, Butow P, Sandoval M (2006). What do cancer groups provide which other supportive relationships do not? The experience of peer support groups for people with cancer. *Social Science and Medicine* (62): 2565-2576.
- Walther JB (2004). Language and communication technology. Introduction to the special issue. *Journal of Language and Social Psychology* (23) 4: 384-396.
- Weiss RS (1994). *Learning from Strangers. The art and method of qualitative interview studies.* The Free Press: New York.
- Yaskowich K, Stam H (2003). Cancer Narratives and the Cancer Support Group. *Journal of Health Psychology* (8) 6: 720-737.
- Ziebland S (2004). The importance of being an expert: the quest for cancer information on the Internet. *Social Science and Medicine* (59): 1783-1793.
- Ziebland S, Chapple A, Dumelow C, Evans J, Prinjha S, Rozmovits L (2004). How the Internet affects patient's experience of cancer: a qualitative study. *British Medical Journal* 328: 564-570.