The challenge of fitting in: non-participation and withdrawal from an online self-help group for breast cancer patients

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Abstract   Online self-help groups multiply peoples' possibilities to exchange information and social support. Such possibilities are expected to be of crucial value for the 'new' healthcare user. However, similar to experiences from face-to-face based groups, studies of online self-help groups report high drop-out rates. Knowledge about why this happens is scarce. By means of qualitative interviews and participant observation, this article examines non-participation and withdrawal from an online self-help group for Norwegian breast cancer patients. Five conditions are identified as barriers to use; a need to avoid painful details about cancer, not being 'ill enough' to participate, the challenge of establishing a legitimate position in the group, the organisation of everyday life and illness phases that did not motivate for self-help group participation. I suggest that an adoption of the biomedical explanation model represents an important background for this pattern, an argument which contrasts prominent assumptions about the new healthcare user who does not accept the biomedical 'restitution story' in her efforts to make sense of an illness. A further suggestion is that experiences of self-help groups as arenas for successful coping need to be further considered as a barrier to use.

Introduction

Online self-help groups are considered as one of the most promising aspects of e-health (Eysenbach *et al.* 2004). Recent studies among users of such services emphasise their potential to help people cope more effectively with their health problems (Eysenbach *et al.* 2004, Høybye *et al.* 2005, Klemm *et al.* 2003). Within a broader perspective, self-help groups represent a 'bottom up' form of welfare (Burrows *et al.* 2000); they potentially respond to the needs of the consumer-oriented healthcare user and enable effective healthcare to be provided without professional involvement. These are key issues for social policies in Norway and other Western welfare states. Western welfare states are experiencing an unprecedented level of demand, which encourages the development of services that support self-help and informed choice (Coulter and Magee 2003). In Norway, the government has worked out a national plan for self-help, and Internet-based self-help groups are among

the areas which are prioritised in the further corroboration of this area (Report to the Storting nr 16 2002–2003).

Most studies of online self-help groups, however, show high drop-out rates, and the studies have delivered scarce knowledge about why people do not use these services (Eysenbach *et al.* 2004). Non-participation and drop-out is further emphasised in studies of face-to-face based self-help groups (Coreil *et al.* 2004, Luke *et al.* 1993, Ussher *et al.* 2006). This article examines non-participation and withdrawal from an online self-help group for Norwegian breast cancer patients.

Background: the expected potential of self-help group participation

The assumed potential of self-help group participation is rooted in an extensive critique that has been raised against the biomedical expert model on health and illness. Below, I outline this critique in further detail. For a broader overview, see Pierret (2003).

Illness experiences can be understood as critical situations in which the taken-for-granted assumptions of everyday life are disrupted (Bury 1982). Ill people have to renegotiate who they are, who they wish to become and who they still can be (Mathieson and Stam 1995, Yaskowich and Stam 2003). A crucial argument within the critique which is raised against the biomedical expert model is that medical conceptualisations of health and illness are of limited value for describing the experience of being ill, or to help people 'make sense' of their illness (Frank 1995, 1997). According to Arthur Frank, the expert model constructs a 'restitution story' about the illness. This story has the basic storyline: 'Yesterday I was healthy, today I'm sick, but tomorrow I will be healthy again' (Frank 1995: 76). Frank argues that stories about restitution do not describe the *experience* of being ill (emphasis in the original). Even though the ill person wants his or her health to be restored, he proposes that the restitution story only exceptionally represents a self-story. Frank considers it as part of the 'modernist imagination' and that it reflects medicine's obsession with cure. Ill persons who adopt this narrative as their own self-story are deemed thereby to accept a place in a moral order that subordinates them as individuals. They live out illness as a matter of doing their job as patients, preparing for the future after illness, and getting through their own days. The patient's agency is limited to compliance. Frank (1997) introduces the term of being 'successfully ill', which implies that every ill person must work out their own success, or live out a story that finally can be told. According to Frank, this begins with resisting biomedical rhetoric and accepting that the problems are not going away.

During the last decade, this argument has gained more attention in Western welfare states. Within healthcare, ill people have changed from 'patients' to 'consumers' and are increasingly expected to treat medical approaches as one out of multiple sources of knowledge (Coulter 1999, Coulter and Magee 2003, Lupton 1997). Accordingly, they want to provide others with help, information and support, as well as receive it (Burrows *et al.* 2000). These changed expectations of ill people are rooted in influential assumptions about a reflexive late-modern individual who does not accept expert models at face value (Giddens 1991).

Against this background, self-help groups emerge as a potential tool to respond to the needs of the active and involved healthcare user. The Internet multiplies cancer patients' possibilities to exchange experiences with other people who are in a similar situation. By the use of written and disembodied communication the Internet might further facilitate communication about difficult issues (Walther and Boyd 2002).

Breast cancer patients represent one potential target group for the establishment of self-help groups. Difficult changes in the body, disrupted lives and changing relationships

are identified as typical for people who experience an episode of cancer (Mathieson and Stam 1995, Yaskowich and Stam 2003). Cancer survivors describe a sense of uneasiness, an uncertainty about the future and their roles in life which is not reflected in symptoms of depression or post-traumatic stress disorder, but rather in a sense of 'liminality' that is isolating and alienating (Little *et al.* 1998, 2000). In line with the assumed limitation of medical conceptions of health and illness, it is argued that cancer patients may find that the nature of their illness can only be adequately understood by those who have undergone something similar (Little *et al.* 1998). Breast cancer patients can experience particular challenges related to their sense of femininity and sexual functioning (Broom 2001). One of the promising findings in studies of cancer support groups is that the relationships in such groups constitute a 'separate space' for those who are living with the illness (Ussher *et al.* 2006, Yaskowich and Stam 2003). According to Yaskowich and Stam, support groups can provide a reprieve from the isolation that cancer patients experience in the rest of their social world.

Furthermore, breast cancer patients are among the illness groups with the highest tendency to participate in both face-to-face and electronically based self-help groups (Davison *et al.* 2000). In a study of Norwegian women who had been treated for cancer close to 60 per cent of those who said that they did not have access to a support group wished that this had been possible (Kåresen and Langmark 2000). The term 'support group' was widely defined in this study, and the wish to participate in self-help groups was not particularly investigated. It still indicates a need for social support among cancer-diagnosed Norwegian women.

Previous studies, however, have called for more knowledge about the nature of self-help group participation (Luke *et al.* 1993, Ussher *et al.* 2006). Drop-out rates are high, both from face-to-face based groups (Coreil *et al.* 2004, Luke *et al.* 1993) and those on the Internet (Eysenbach *et al.* 2004). Non-participation and withdrawal also emerged as a prominent feature of the online group studied here. In this article, I aim to provide more insight into why potential users choose not to participate or to withdraw from online self-help groups.

Design and methods

The article draws upon an action-oriented study. Action research (AR) 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 and Bradbury 2001). In this study, I aimed to discuss how online self-help groups could supply professional care for cancer patients. The participants were recruited through self-selection. 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. All would-be participants included signed a written consent form before entering the study.

We started to recruit participants in October 2003 and new members were welcomed during the whole study period. A newsgroup was established and was accessible through the websites of the Norwegian Cancer Association. It was open between October 2003 and March 2005. My involvement in the group interaction included 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. A total of 51 women diagnosed with breast cancer conveyed their interest in the self-help group and received information about participation. Forty women returned written consent indicating their interest and received a password. During the study period of 15 months a total of 1,114 messages were posted. Among these were 80 'moderator messages' written by myself, while 1,034 were written by the participants. 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 be categorised as a group of middle class women. Except for one, all participants could access a computer at home. The majority reported that they had a strong social network and that they felt comfortable with the Internet. Their experience was related to searching for different kinds 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 being treated for primary breast cancer and women who were being treated for recurrence. A minority had been reported fit for some years when the group was established.

I defined 29 women as non-users. Either they did not participate at all (11) or they disappeared from the group after they had posted some messages (18). The disappearance of the latter was confirmed when they were contacted some months after their last message. Informants for interviews were selected through purposeful sampling. The initial aim of the study was to explore the potential of online self-help group participation, and I intended to reach women with different illness courses and different involvement in the group. I did gradually become aware of a high tendency towards non-participation in, or withdrawal from, the group. In order to explore this phenomenon, I deliberately recruited a large number of non-users for interviewing. Twenty-five participants, eight users and seventeen non-users were interviewed. Fourteen interviews were conducted face-to-face (40 to 110 minutes) and eleven through the 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 contributed more to the analysis, and others less. This analysis relies mainly on accounts from women who withdrew or chose not to use the group, but also from active users of the group. Some of the accounts from the latter group gave valuable information about the subject discussed in this article.

Constraints on online self-help group participation

As described, 29 of the 40 participants in this study were defined as non-users. Technology-related aspects of the service were close to absent in these participants' reflections on non-participation and withdrawal. To my knowledge, lack of Internet experience represented a barrier for using the service for only one of them. Beyond that, unfamiliarity with newsgroups and the user interface of the application seldom emerged as an issue. If commented on, it was mentioned by the active users as a desire to utilise the application better.

One participant said she left the group because of the lack of professional involvement. She had misunderstood the information about the group and wanted information from professionals. However, on the whole, the participants were motivated by their wish to exchange experiences with other women who were diagnosed with breast cancer.

Below I outline and discuss five conditions which I consider as crucial for understanding non-participation and withdrawal from this online self-help group.

The need to avoid painful details about breast cancer
Several of the women who started to write messages in this group had experienced spread of the cancer. As a consequence, many of the issues addressed were related to spread and recurrence of the cancer and did simultaneously reveal many painful details about potential illness trajectories. Spread means that the disease has recurred and has reappeared in some other parts of the body, for example the lungs, liver or bone. This condition is not curable. One recurring theme related to non-use and withdrawal from the group was the need to protect oneself from the painful details. A 38-year-old woman, who had been diagnosed with breast cancer about six months before she entered this study, said during the interview that she struggled with her own reactions, and expressed a deeply felt need to share experiences with other women diagnosed with breast cancer. This woman left several messages during a short period before she decided to leave the group. Her explanation was that she had discovered 'a lot of nasty things' in the group. She was very clear that she needed rather to meet women who had survived the cancer and thereby provided 'proof' that it was possible to get through.

Another woman, who was newly diagnosed, but to whom the cancer also had spread to the bone, said that the reason that she had dropped out was that she could not bear all the terrible stories:

> I was recently diagnosed with this myself. To hear about all the problems and all recurrences got too much. I had to quit and find information other places (I 26, 56 years).

Such expressions direct attention to previous research which has proposed that the discussion of death might be a factor associated with non-attendance at self-help groups (Ussher *et al.* 2006). Women who have experienced spread certainly bring the issue of death into a self-help group. Even though there are stories about women with spread who have lived up to 15 years, they live on average one to three years. By joining a group of women who had experienced spread of the cancer, this woman said that she felt even more sentenced to death than she already was.

Women who expressed this need to protect themselves were well informed about the illness and their diagnosis. They wanted knowledge, but through their difficulties with encountering the recurrence stories, they also expressed the view that the need for information had some limits. According to themselves, they 'had to' remain in the belief that their prospects were good. Such expressions can be argued to reflect a fundamental need of preserving the hope of recovery which has been emphasised in nursing research (Rustøen 1995). Both Pitts (2004) and Høybye *et al.* (2005) also noted a tendency to search for encouraging information among breast cancer patients who communicated about breast cancer on the Internet. It is further reported that the intervention newly diagnosed women want is to be able to speak with someone who has the same cancer, but has lived through the crisis of treatment and is leading a 'normal' life (Giese-Davis *et al.* 2006). The women referred to above needed proofs that it was possible to get through the cancer, not the opposite. They noticed that other newly diagnosed women managed to participate in the group, but their own fear was too pervasive. Their need to avoid painful details and their withdrawal from the group indicate that the norm of restitution, and medicine's obsession with cure, can be in accordance with the subjective illness experience. It is, however,

important to be aware that the relevance of the restitution story in such situations is also acknowledged by those who generally emphasise its limitations. Frank (1995) argues that the need to believe that one gets well provides the narrative force in the restitution story.

Not being 'ill enough'

Another theme that recurred in the participants' reflections on their choice not to participate was the experience of not 'fitting in'. Such expressions appeared to emerge from a feeling of not being 'ill enough' to participate and/or that it was challenging to establish a legitimate position in the group. The first category is commented on in this section.

In contrast to those who left the group because of their need to avoid painful details about potential illness trajectories, others expressed less fear and simply said that many of the issues discussed had little or no relevance to their own situation. They experienced that they were not able to contribute to the conversations of the group. They compared themselves to the active users and defined themselves as belonging to a quite different category, saying that they were 'not ill enough'. The need to exchange experiences was rather expressed in terms of more practical issues, such as the option of reconstructive surgery and courses for breast cancer survivors. One woman said that it would have been easier for her to participate if more women could talk about prosthesis. Similar distinctions between themselves and active participants in a face-to-face self-help group were made by participants in the study conducted by Damen *et al.* (2000). These authors reported that women who did not return to group sessions experienced the groups as forums for women who were 'worse off' than themselves.

It is important to note that the devastating impact of cancer was not necessarily denied among the participants who felt that they were not ill enough for this group. By some it was expressed as a feeling which they had to accept and live with, or as a 'bag' they had to carry with them for the rest of their life. The need to 'work on' such feelings, in the sense of discussing them with other breast cancer diagnosed women was not clearly expressed. A recurring comment was that the active users 'went so deeply into things'. One woman, who was diagnosed with breast cancer in April 2003 and was registered as a participant in the study in November 2003, disappeared from the group at the end of the year. She agreed to participate in the study during a phase of her illness which many breast cancer patients experience as difficult; the period of active treatment is finished and they are loosing their ties to the health-care system and are left on their own. She said that:

> What caused me to leave, it is that I feel I have worked through things, and then I came to a point, that when I went in then, then I felt that many of those who were there, well, they did get further, but they perhaps dwelt more on some things, needed to talk a great deal about their feelings, the anxiety around the disease, and that aspect. I felt that it got too much. At the same time, I felt a bit unkind in a way, because I went in there and thought 'oh, why do they carry on like that? No, I can't take this'. Because I felt that I had to get on with things (I 19, 42 years).

Such expressions are also associated with an adherence to the norm of restitution. Previous researchers have emphasised that examples of justification must be expected whenever people's views or accounts are sought (Radley and Billig 1996, Werner *et al.* 2004, Ziebland 2004). According to this literature, patients are addressing potential audiences through their accounts, such as the interviewer, health personnel and the general public. In her study, Ziebland directs attention to one patient's need to present himself as *more than* a patient (emphasis in the original). In their study of Norwegian women with chronic pain,

Werner *et al.* (2004), argued that the interviewed women negotiated a picture of themselves which created a distance from the image of the 'whining and complaining' woman, and which fitted with normative biomedical expectations of what illness is and how it should be lived out in 'storied form'. Even though breast cancer is considered as a more legitimate illness than chronic pain, it might be that such motives are also reflected here. Feminist scholars such as Broom (2001), Werner *et al.* (2004) and Pitts (2004), are afraid that important aspects of the illness experience are made invisible through these practices. However, Album (1996) argues that they can be deeply rooted in the patient culture. Directing attention to seriously ill people's position on the 'margins' of everyday life, he argues that adherence to conventional norms, such as distancing illness talk, can strengthen the sense of normality in an abnormal situation. This perspective might throw some further light on the reluctance against being engaged in communication about the extensive impact of cancer.

A further impression is that expressions about not being ill enough for the group signalled a need not to give the cancer too much space in daily life. One of the women, who originally left the group because of her fear, also commented that some active users of the group were too concerned about diet. This woman said that she herself went through a period in which she focused too much on what she was eating, and that this made her distressed. She felt very relieved by her doctor, who had told her to eat normally and not use too much energy on her diet. In line with Bury (1982), it might be reasonable to argue that medical approaches in such situations are not regarded as illegitimate 'reifications' from a lay point of view, but that they provide a fixed point of a terrain of uncertainty.

In some cases, the need for support might also limit itself to practical information. Williams (2000) argues that serious illnesses can also represent a 'normal crisis'. According to Williams, health can be considered as a matter of luck, while illness is 'expected'. Increasing age is suggested as one factor which might make illness more expected than before. Quantitative studies also show that elderly women with breast cancer are reported to experience lower levels of distress than younger women (Rustøen and Begnum 2000). For some of the older women who did not participate or left this group, the breast cancer experience succeeded a variety of other life experiences. Earlier distressing life experiences appeared to reduce the distress caused by breast cancer. For example, when asked specifically about the isolating experience following breast cancer, one responded that she was already familiar with such feelings. This woman had also suffered from a serious rheumatic condition for many years. Others did emphasise that they had experienced difficulties earlier in life, for example marital problems, and that the breast cancer became one out of a number of episodes of distress that they had had to cope with during their life. Having grown-up children who were 'managing for themselves' was further mentioned as a facilitating condition for their experience of the cancer. It is interesting that Ziebland (2004) notes that an Internet support group had been found particularly helpful by a breast cancer diagnosed woman when she was unsure of how to talk to her 11-year-old son about her illness.

The examples discussed above have illuminated the experience of not being ill enough for the group and finding the discussions to be too exhaustive. Other statements about not fitting in appeared to emerge from an experience of wanting to join such discussions, while at the same time experiencing that it was difficult to establish a legitimate position in this group. I turn to this in the next section.

The challenge of finding a legitimate position in the group
A fear of being a complainer was also explicitly expressed and appeared to reflect an anxiety of hurting other women. One of the newly diagnosed women, who did not leave any messages with the group and who described her illness story as predominantly 'happy', said:

if I had been one of these girls, I would've thought that 'oh yes, so she finds something or other to complain about' (I 36, 51 years).

Another, who was seriously distressed by the cancer and experienced a deeply felt need to exchange experiences with other women with breast cancer, said she found it difficult to write about her own difficulties because of the clinically worse situation of many of the other women. She was one of the women who felt that they had to leave the group because of the painful details. However, before she decided to leave the group she had written several messages that she later deleted because of her fear of complaining.

Another woman articulated a fear of presenting 'sunshine stories'. She described pregnancy as her reason for non-use. Interestingly, this woman started to write messages to the group when she had a recurrence and her situation changed.

A fear of complaining and of standing out is revealed in previous research on patient interaction in Norway (Album 1996). However, one important point of departure for this study of online communication was the proposal in previous research that the anonymous context on the Internet might weaken the impact of such conventional norms (Walther and Boyd 2002). The statements presented above do not affirm these expectations. They rather give resonance to perspectives which argue that online interaction must be considered in relation to, and not as disconnected from, conventional norms of interaction (Wynn and Katz 1997). Directing attention to the fact that patients are often strangers to each other, Album (1996) argues that politeness and controlled behaviour also represent a link to normality for ill people. Studying patient interaction in three Norwegian hospital wards, he argues that conventional norms might be considered as a corset rather than a straitjacket.

Another woman expressed a sense of being excluded from the group. She had experienced a recurrence and used the group regularly during most of the study period. She disappeared during the last months and said in the interview that the group meant nothing to her any more. It had been very useful during her treatment, but she expressed very clearly that she was depressed and felt that it was hard to cope with the situation. She told me that she felt that she did not receive any response when indicating depression and helplessness in the group:

> if you try to mention that you are struggling mentally, you do not get any response. They say that 'of course, everybody feels like that once in a while'. Of course they do!! But in a way, you feel they say that 'Ok . . . but we do not want this' (I 27, 51 years).

This woman said that she felt that norms about being successful dominated the interaction in this self-help group. This did not correspond to how she coped with her own illness. Her experience gives some resonance to previous research. Based on their study of the cultural models of illness and recovery that are espoused by face-to-face-based self-help groups for breast cancer diagnosed women, Coreil *et al.* (2004) ask if self-help groups tend to promote an illness recovery experience that underscores the importance of courage, optimism and quality of life. Ussher *et al.* (2006) describe the position of the empowered cancer survivor as dominating in the cancer support groups they studied. Existing literature has only scarcely discussed to what degree this tendency is reflected in online communication between breast cancer patients. Pitts (2004) argues that her study raises some serious issues about women's cyberagency and that the Internet may contribute to compound social pressures that involve the roles of restitution and recovery and relentless optimism. In contrast, another empirical study of online communication between breast cancer patients

illustrates how messages about depression are met by considerable support and other women's depression stories (Radin 2006). The experience of being too unsuccessfully ill for this group gives some further associations to self-help groups as arenas for successful coping. It is however important to be aware that little knowledge is available about whether a predominant motif of successful struggle against cancer is experienced by potential readers as oppressive or liberating (Seale 2002). In other words, to what degree a circulation of courage and positive attitudes should be accounted for as a barrier to online self-help group participation is still unclear.

The organisation of everyday life
Women who are diagnosed with breast cancer are mothers, daughters, spouses and employees, positions which frame their life with obligations. When diagnosed with breast cancer, they are, for a shorter or longer time, exempt from some of their obligations, and in particular those related to participation in working life. Their own recovery is in focus. But most of them are sooner or later caught up again by their normal life and its duties.

Some women who had not participated in the group simply explained their absence as being due to lack of time. As one of them said when I telephoned to ask why she had not used the group:

> The main reason that I dropped out quite quickly was that my mother died, and then there was so much to deal with because of her death, in many ways, that it was not so important just there and then. That was the main reason that I did not continue with it (I 36, 51 years).

This woman had been operated on for breast cancer in November 2003 and had sent an email to ask about joining the group at the beginning of February 2004. Her initial motivation was her positive experiences with the healthcare system and that she felt that she should inform others and help them to make optimal choices.

The influence posed by the obligations of everyday life is particularly underlined by the story of one of the active users of the group. This was a 38-year-old woman with three children, who had been diagnosed with breast cancer in the autumn of 2003. She was an active and enthusiastic user of the group over most of the study period, but slowly disappeared during the autumn of 2004. When interviewed she explained that she had difficulty finding time for the group. She had started in a new job and found that she used all her energy and time on this and her family. However, she emphasised her belonging to the breast cancer group and said that she should have continued her participation to support the others. She, and other active participants in the group, also expressed the view that the participation was time-consuming. The challenge of allocating time for the group is perhaps not so prominent as long as the participants are on sick-leave and exempt from some of their normal duties, but can be decisive for their tendency to engage in self-help groups after this initial period. A Danish study has further shown that unwillingness to use an Internet-based programme for lifestyle changes over time was explained by the inability of integrating use of the service into everyday life (Anhøj and Jensen 2004). Such findings have links with research proposing that the organisation of everyday life might be of crucial influence on how people conduct healthcare activities (Frohlich *et al.* 2001).

One aspect that is stressed in literature on illness experiences is however that a resumption of normal social obligations is often caused by the ill person's social environments and not by the ill person's will to do so (Frank 1995, McKenzie and Crouch 2004). The relevance

of this perspective is reflected also in my empirical material. The woman above, who explained her withdrawal from the group as caused by an engagement in normal social obligations, also commented that her husband disliked her engagement in the group. According to her, he said that she looked depressed when she had visited her 'cancer room'. She did not directly describe his reaction as a barrier to use of the group. She did, however, mention his disapproval on her own initiative and it is reasonable to assume that it influenced her use in combination with her experience of not finding time for the group. A main impression in this material is still that the re-engagement in normal social obligations was not experienced as a burden, but rather as the natural course of these women's lives.

Illness phases which do not motivate for self-help group participation
The last condition emphasised is that some women explained their non-participation or withdrawal from the group in terms of their illness condition. One of the participants in this study was a 32-year-old woman with two children. She had been diagnosed with breast cancer during the summer of 2003. She was an active user of the group from its start until the summer of 2004. She even mentioned that she herself intended to establish an online self-help group if this group did not continue after the study period. However, she disappeared from the group during the autumn of 2004. When interviewed in December of the same year she said that it was as if the need for the group had disappeared. At my request, she later informed the group about this. Her statements give some associations with the experience of not being ill enough for the group, which was outlined in a previous section. However, her experience of not needing the group did gradually appear and was related to the positive development of her illness, not to an experience of not fitting in, which was emphasised in the previous section.

This story does first and foremost tell us about a natural and very healthy development, and it concerns how long self-help groups 'fit into the lives' of breast cancer diagnosed women. This participant also received supporting and understanding comments from other women in the group when she wrote about her new situation. However, this development might also represent a threat to the functions that are important for the quality of self-help groups. Within such voluntary relationships, experienced participants often maintain leadership functions, provide management for the interaction, and communicate norms and ideology of the group to new members (Lieberman and Russo 2001). In turn, important functions may suffer, such as the expressed need for something positive among newly diagnosed women. One question is if an increased representation of women who had finished treatment and were living a 'normal life' again could have made the communication to the group less frightening for those who withdrew because of the dominating recurrence stories. The need for such 'veteran' roles, however, is perhaps not conveyed by the self-help title.

Another example of an illness phase which does not give rise to participation is with one of the women who wrote several messages in the group during the first months. Then she disappeared for a while. When she later returned to the group, she commented on her absence and said that 'sometimes, you just don't manage to write, that is just the way it is'. She later disappeared again and did not return. When I contacted her, she told me that she was depressed and that her life was a mess. The online group was not referred to as a place to seek support. She did not relate these expressions to this particular group. I rather understood it as a general statement about the nature of self-help groups, and not as a criticism. Such expressions, however, still give associations to the assumptions of self-help groups as arenas for successful coping (Coreil *et al.* 2004).

Concluding discussion

By identifying these five conditions as barriers to online self-help group participation, this examination of non-participation and withdrawal from an online self-help group becomes part of a body of research that de-emphasises the role of technology (Nettleton *et al.* 2005, Seale 2006). In line with these previous studies, it illustrates how people's Internet use is often contingent upon their health needs and pertains to particular conditions. It is reasonable to argue that the findings might therefore also provide some insight into the nature of self-help group participation. This investigation revealed several situations in which the cancer and its consequences were treated as something to get through and leave behind, and in which participation in the self-help group did not fit. I suggest that the relevance of the biomedical explanation model of health and illness needs to be reconsidered in further efforts to understand the nature of self-help group participation.

Before this suggestion is further outlined, it is important to underscore the fact that my focus is on a variety of *situations* in which the norm of restitution has been adopted. As argued by Nettleton and colleagues (2004), it is reasonable to expect that individuals occupy various health e-types through their health and illness pathway and that their approach to using e-health resources may alter in response to specific challenges. The history of the woman who did not participate because of pregnancy is illustrative of this point. After her recurrence, she experienced this possibility to communicate about the illness with other breast cancer diagnosed women to be of tremendous significance.

My first reason to call for a reconsideration of the relevance of the biomedical explanation model on health and illness is to be aware how cancer can represent a threat to the 'natural attitude' which permeates individual awareness, and which maintains our taken-for-granted assumptions of a normal lifecourse (Giddens 1991, McKenzie and Crouch 2004). According to Dorothy Broom (2001), we are constantly told about the progress in cancer treatment and how the Big Breakthrough is just around the corner, while the fact is that the field is riddled with uncertainty. The proofs of the insufficiency of medicine can be difficult to bear and might be reflected in the need to avoid painful details about potential illness trajectories. It serves to maintain our connection to and belief in a normal lifecourse. It is important to note that the relevance of adopting the restitution story in situations of overwhelming fear appears to be supported also by Frank (1995), who generally underscores its inability to help people make sense of an illness. A main argument in this study, however, is also that other barriers to group participation that appear to be rooted in a norm of restitution should be considered as links to normality, such as the reluctance towards giving the cancer too much space in daily life. A further example is the wish not to engage too deeply in illness talk and, rather, focus on practical issues. As suggested, it is important to consider elements of self-presentation and justifications in such expressions. In line with Bury (2001), however, I argue that these elements do not exhaust the levels, or 'functions', of the expressions. To maintain taken-for-granted assumptions of a normal lifecourse might represent another function. As such, a 'rootedness' of the restitution story and the biomedical explanation model on health and illness is proposed.

A further reason to reconsider the relevance of the biomedical explanation model is to account for the ambivalence which is argued to characterise modernity (Bauman 1991, Halkier 2001). Based on her study of consumers handling of environmentally related food risks, Halkier suggests that ambivalence in consumption practices needs to be addressed through an acknowledgement of the sometimes conflicting roles that people hold. People's lifeworlds have become fragmented and pluralised and people identify with different roles

(Halkier 2001). The re-engagement in normal social obligations, thereby treating the cancer as something to get through and leave behind, was here identified as a barrier to online self-help group participation. My impression, however, is that this response to the cancer did not represent subordination to a social order. It rather implied that several other practices which were important to the women could be continued, such as being a good mother, a spouse or a working colleague. To treat the cancer as an episode then became a tool with which to handle the conflicting roles.

Finally, I also want to direct attention to another issue that might be considered in further efforts to understand the nature of self-help group participation. An experience of this self-help group as an arena for successful coping also appeared to limit participation in the group. Knowledge about this issue is still scarce, but other authors have commented that empowerment and agency might emerge as the only available positions in self-help groups (Coreil *et al.* 2004, Ussher *et al.* 2006). If this impression is affirmed in further studies, it might imply that the role of self-help groups as separate social spaces for cancer patients should be more closely considered. I will address this issue in a forthcoming work. In turn, such knowledge might throw further light on how and when such groups are used.

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