

A space for suffering?

Communicating breast cancer in an online self-help context

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Abstract

In this article, I explore the communication in an online self-help group for Norwegian women with breast cancer, aiming to add further knowledge to the question of whether the online context functions as a “liberating realm” for alternative discourses about illness. My analysis is conducted within an action oriented frame and is based on participant observation of the online communication and qualitative interviews of women who participated in the group. Based on the analysis, I argue that proposals of a replication of dominating offline discourses in online communication are affirmed. More precisely, the argument is that a “socially desirable” story about the cancer “hero” was further circulated in this online context, and that experiences of resignation and meaninglessness were not woven into the communication. Offering some reflections on this process, I suggest that it has active and voluntary aspects that need attention in further research.

Key words: action research; breast cancer; Internet; Norway; sociology; suffering

Corporeal bodies are absent in online communication, and individuals are left to represent the body through words, images, codes and symbols (Pitts, 2004). It is, however, demonstrated that intimacy can be lived out across the disembodied world of cyberspace (Bar-Lev, 2008; Høybye, Johansen, & Tjørnhøj-Thomsen, 2005; Radin, 2006), and notions about a narrowed sociality within this disembodied context (Kraut, Lundmark, Patterson, Kiesler, Mukopadhyay, & Sherlis, 1998) are toned down (Bar-Lev, 2008; Walther & Boyd, 2002). More knowledge about the bodily, emotional and social consequences of online communication is still needed (Bar-Lev, 2008).

One of the questions that are investigated is whether the online context functions as a “liberating realm” for alternative discourses about illness (Bar-Lev, 2008; Pitts, 2004; Rier, 2007). It has been suggested that the disembodiedness of the Internet might leave us with a greater freedom to perform our identities (Hardey, 2002; Walther & Boyd, 2002). Such prospects might be of crucial significance for persons who are diagnosed with cancer. Cancer patients are argued as facing a number of challenges in controlling their own self-definitions and framing their experiences in their own terms (Broom, 2001; McKenzie & Crouch, 2004; Pitts, 2004). According to Broom (2001), herself a breast cancer survivor and social scientist, sociocultural fears about death, disease, sexuality and femininity isolate and silence women who are diagnosed with breast cancer, frame their choices and experiences, and shape their stories. She argues that their life with the illness thereby takes “socially desirable” forms, and that feelings of anger and grief are repressed.

The question that is then raised, and which is particularly addressed in this article, is whether the online context emerges as an arena in which socially desirable exchanges about breast cancer are replaced by those who make suffering more visible (Broom, 2001; Pitts, 2004). I explore the communication in an online self-help group for Norwegian women with breast cancer. Identifying the constitution of a socially desirable version of breast cancer in

this online self-help contest, my analysis questions the proposals of “cyberliberation” and enters into a body of research that demonstrates a replication of dominating offline discourses in the online context (Bar-Lev, 2008; Fox, Ward, & O'Rourke, 2005; Pitts, 2004; Rier, 2007). However, offering some reflections on the constitution of a desirable version of breast cancer in the communication between these women, I also raise the question whether it also needs attention as an active and voluntary process.

I begin the article by describing how cancer is lived out in late-modern societies, paying particular attention to illustrate the content of socially desirable stories, and, on the other hand, those aspects that are given less space. It will serve as a backdrop for considering the communication in the online context.

Living out cancer in late modernity

In her article “Reading breast cancer; reflections on a dangerous intersection”, Dorothy Broom (2001) refers to the “restitution story” and the “quest-story” described by Arthur Frank (1995) to illustrate socially desirable versions of how women with breast cancer live out their illness. The repressed aspects Broom describes have associations with the third story that Frank describes as “culturally available” within post-modern societies, namely the “chaos” story.

Frank’s suggestion of three culturally available stories about illness in the late modern western context will serve as an important framework for this analysis and will be outlined in some further detail. Key elements in the restitution story are a restricted impact of the illness and a return to normal (Frank, 1995). If Dorothy Broom had entered the restitution storyline, she writes that she would have been “distressed, but proceeded to educate myself. Then, as a well-informed and critical consumer, I braved the unpleasant treatments with courage and humour, and am now back to live a normal life again.” (Broom, 2001, p. 250). Frank describes the restitution story as the culturally preferable story about illness. Mortality is the

ultimate limitation of this story; the confrontation with mortality cannot be part of the story. He further argues that stories about restitution are underpinned by a biomedical explanation model on health and illness. Similar to Broom (2001) he gives them limited relevance as self-stories, or reflections of the subjective illness experience. This argument echoes influential thoughts in contemporary research on the experience of illness, in which the biomedical explanation model is exposed to considerable criticism (Pierret, 2003). Frank argues that the fact that people do get well still provides a narrative force to this story; ill people want to get well.

Quest stories differ from restitution stories by acknowledging a disruptive impact of illness (Frank, 1995). The quest is defined by the ill person's belief that something is to be gained through the experience. Quest stories meet suffering head on; they accept illness and seek to use it. Further, they tell us that learning the integrity of suffering is central to the boom and leave those who listen to it with an image of the individual hero. A crucial point made by Broom (2001) and other feminist authors (Pitts, 2004; Sontag, 1979) is that a wide circulation of the story about the hero can place considerable responsibility on seriously ill people about entering the role as the hero in their own life. Being less critical and giving the quest status as a self-story, Frank also refers to the risk of these stories of presenting the burning process as "too clean" (Frank, 1995, p.135).

Frank describes the third available story about illness in the late modern western context as the story about "chaos". He considers this story to be as anxiety provoking as the restitution story is preferred. A story about chaos is not, using Broom's (2001) terms, socially desirable. In the chaos narrative, troubles go all the way down to bottomless depths, and they are hard to hear because they tell us that the illness and its consequences can not be controlled. Such lack of control is not only revealed by the death of an ill person; anger, grief

and depression are all indications of chaos, because they evoke associations to an individual who can not control herself.

It is important to note that Frank (1995) underscores the role of these suggested stories as ideal types. According to Frank, people tell their own unique stories. His point is that they compose these stories by adapting and combining narrative types, or ideal types, that culture makes available. Ideal types provide a reflexive medium, a language, for talking about what is particular in real bodies. Frank's reason to limit himself to three narratives is the aim of sorting out narrative threads and that more than three seems less than helpful.

He further emphasises that actual tellings combine the different types; "illness stories mix and weave different threads" (op cit, p. 76). Few stories about serious illness are without chaotic elements. His point is that there is a limited space created for the chaotic aspects of the illness experience, or the suffering (see also Frank, 1997). This argument finds resonance in empirical research. The image of the "cancer hero" appears to dominate media portrayals of people with cancer (Seale, 2002). It is further demonstrated that women with breast cancer adjust to social expectations about affirming a desirable story even in their closest relationships (McKenzie & Crouch, 2004). Literature on support groups for cancer patients directs attention to an extended space created for the illness and its injuries (Yaskowich & Stam, 2003, Ussher, Kirsten, Butow and Sandoval 2006). A focus on empowerment and agency is still commented (Coreil, Wilke and Pitado, 2004; Ussher, Kirsten, Butow and Sandoval 2006) and give associations to a constitution of the "individual hero" also in these contexts. Both Pitts (2004) and Broom (2001) further direct attention to the online context as an arena for a strengthened focus on the cancer hero, questioning the proposals of the Internet as a liberating realm for alternative discourses about cancer. In this article, I take the debate further by exploring the communication in an online self-help group for Norwegian women

with breast cancer. Following Frank (1995), I consider his typology as a “listening device” that can be of help to sort out the versions of cancer that are constituted in the online context.

Methods

Research design

The study upon which this article draws was action oriented. Action research has two central concerns – improvements in practice and increased knowledge. It is distinctive in the sense that the researcher has a double role as both implementer and as evaluator of a program (Finne, Levin, & Nilssen, 1995; Olsen & Lindøe, 2004). In this study, an online self-help group for women with breast cancer was established as part of the efforts to improve cancer care.

The online group established was accessible through the website of the Norwegian Cancer Association from November 2003 to February 2005. It was designed as a newsgroup, and the users needed passwords to access the group. 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. New members were further welcomed during the whole study period.

My active involvement in the implementation of the service included a role as moderator of the group. I controlled the communication and worked to ensure an optimal function of the service. This latter activity included efforts to facilitate the emergence of a “safe space”. Both in the information letter and through postings in the group, I encouraged the participants to initiate all kinds of concerns that were related to their diagnosis. However, I also directed attention to a common obligation of warning others if the posting had a difficult content, or to write about issues of death and spread under particular topics. My attention paid to such “rules” of sharing emerged from our dialogue with The Regional Committee for

Medical Research Ethics in Northern Norway, which had to approve the research design. This committee expressed some concerns about how the participants would manage to deal with other women's difficult thoughts and painful details about cancer and emphasised that we had to be very attentive to this aspect. However, certain guidelines and rules for sharing are common in therapeutic groups that rely on mutual sharing, for example Alcoholics Anonymous (AA) (Waldron, Lavitt, & Kelley, 2000). The rules of sharing that were worked out in the group studied here did therefore not add a new dimension to the self-help context.

In order to ensure confidentiality, the email address of the participants and the IP-address of their computer were not logged when they left postings in the group. Furthermore, the participating women were requested to not give too much background information about themselves, such as where they lived and the hospital where they were treated.

Participant observation of the activity in the group and qualitative interviews provide the basis for the analysis.

Participants and activity

Forty women from different parts of Norway returned written consent indicating their interest and received a password. The majority was undergoing treatment or had recently completed treatment. Those under treatment included both women who were being treated for primary breast cancer and women who were being treated for recurrence. Within the Norwegian context, these women can be categorised as a group of middle-class women. Except for one woman, all participants could access a computer at home. The majority reported that they had a strong social network and considered themselves to be comfortable with the Internet. One had experience from a face-to-face-based self-help group, five others had experience from other online self-help groups for breast cancer patients, and one had participated in an online group that addressed another health problem.

During the study period of 15 months, a total of 1114 messages were left in the group. Eighty were “moderator postings” written by me. The messages were distributed on 127 conversational topics, or “threads”, which is the term used to describe the activity in newsgroups on the Internet (see for example Denzin, 1999), and which emerge from a comment-response style that makes Internet life cyclical (op cit). The topics that were introduced and the response to these topics offer an intake to reveal the views on what breast cancer is and how to live with it that were given priority in group communication.

The interviews contribute to deepen the understanding of the interaction in the group. Informants for interviews were selected through purposeful sampling. In this process, their appearance in particular episodes in the group represented one issue of consideration. The selection of informants was however influenced by several considerations, as the liberating potential of online communication represents one out of a number of issues that was investigated in the study that the article draws upon. Twenty-five women were contacted for interview. The interviews were conducted face to face (40 to 110 minutes) and by telephone (20 minutes to one hour). The choice to use telephone interviews was mainly a result of practical considerations, such as the geographical distance.

Analysis

The analysis is issue-focused (Weiss, 1994). Issue-focussed analyses are concerned with what can be learned about specific issues, events or processes. Some respondents can contribute more to the analysis, and others less. In this analysis, the aim was to identify and discuss the version of breast cancer that was constituted through the comment-response style in this online self-help group.

I have divided the analysis into two main parts. First, I focus on the impact that was ascribed to the cancer through the communication in this group. The second part addresses the participants’ communication about how they handled this impact. This divide has analytical

purposes. Stories about “chaos” and the more desirable “quest” have some overlapping elements; they both acknowledge that an illness causes a fundamental change in people’s life. It is in people’s response to their situation we can trace their difference; in chaos stories such changes are overwhelming and without meaning, in quest stories, active responses to these fundamental changes are the recurring theme. A crucial aim of this paper is to investigate whether elements of chaos were given space in group communication. Based on this intention, the participants’ communication about their handling of the cancer is discussed separately. In lived experience, the impact of cancer and how this is handled are overlapping and experienced simultaneously. For example, the experience of a life that is fundamentally changed by the cancer is, at the same time, a way of handling the cancer.

The impact ascribed to breast cancer

In this section, I argue that the group constituted a view on cancer that allowed for communication about the devastating impact that a cancer diagnosis can have on people’s lives. During the communication, the participants placed emphasis on facing an insecure future, of experiencing themselves in an isolated position and on experiences of loss. On the whole, the access to other women in a similar situation appeared as the important reason for the space created for these issues. Less emphasis was placed on the anonymous and written communication.

The insecure future

In a number of messages, the necessity of living day by day was underscored by the women in this group. A recurring statement was that “as a person diagnosed with cancer, you learn not to take anything for granted”. Illustrating the personal relevance of this general statement, some participants said that they tried not to dwell so much on the future. It should be noted that the majority of the active users in the group studied here had experienced spread of the cancer and had been forced to face tough realities about their future prospects. It is

reason to believe that this common experience was important for the shared view of facing an insecure future. Some further commented that it was difficult to reveal this view in their established relationships.

The agreement about facing an insecure future was still not succeeded by more concrete discussions about the experience of possibly facing a premature death. About six months after the group started, one woman expressed to the others that she wished to discuss the issue of death, but that she felt unsure about the other women's opinions about this. She received considerable positive response to her initiative suggesting discussion of this issue. Her initiative further prompted a sequence in which some of the participants exchanged worries about the closing down of a hospice for dying patients and about their worries about how they were going to be cared for during their last days. However, such concrete discussions about the future were not resumed again.

During the interview, one of the younger women who had experienced spreading of the cancer and to whom a further negative development of the illness appeared to be difficult to prevent, said that the group could be a place where she could address her reactions on the negative development. However, she underscored that she still felt fine and that she was not "there". She also gave the impression that she experienced an obligation to be considerate and said to me that she did not want to "put her foot in" it by writing messages that were too heavy for other members. On the other hand, this woman also described it as difficult to assess what issues she could address in the online context, because she could not directly see other women's reactions. She further said to me that she perceived herself as a "killjoy" in the group. It is also notable that she expressed considerable relief to the others when she finally could tell them some positive news about the development of her illness.

The isolated position

The participants in the group further signalled a common experience of finding themselves in an isolated position. It became particularly obvious in some sequences in which the experience of facing a distance to their husbands or partners was addressed. One example is a participant who wrote a message that included a deep sigh about a loving husband who found it very difficult to talk about the illness. She said that she had to cope with much of the strain on her own. Other women responded to her and shared their own experience of a distance from the person to whom they should be closest. A corresponding pattern occurred in another sequence, one of the women with small children told the others that her husband did not ease her load of house work even though she tried to tell him that she was tired and needed more help. Another woman with small children responded and told a corresponding story that included a “tremendous quarrel” with her husband, but which had ended in a constructive manner. She closed her message by saying that she “really hope that you can acquire something similar”. In previous studies (Denzin, 1999; Radin, 2006), such responses are argued to create a space of trust in the online context. My argument is that they here serve to create a space for communication about the isolating experience of breast cancer.

Experiences of loss

A third point that illustrates that a space was created for the deep impact of cancer in this group was an agreement upon experiences of loss as a consequence of the disease. One thread in this group was headed “One breast, two breasts or no breasts”, in which the participants discussed their experiences of removing or keeping their breasts. One woman described the removal as an amputation, her sense of losing a part of herself, and how she had struggled to accept herself afterwards. This prompted recognising comments from other participants, who experienced that her description of an amputation reflected their own experience. It is important to note that some other participants, who did not have their breasts removed or did not experience the removal as traumatic, clearly expressed their empathy to

these women. As in the case of experiencing social isolation, the group signalled receptiveness for this experience of loss.

This example does particularly illustrate that the online context can emerge as an alternative context and that it can liberate the women from the pressure of adhering to norms about not emphasising this aspect. Some women in this group expressed to the others that they experienced themselves as being ungrateful if they were using too much energy on their lost breast, because they should be glad that their cancer was treated. Feelings of loss after mastectomy might cause an experience of not focusing on the things that really matter.

Handling cancer

The possibilities of the individual to do something in response to the cancer were emphasised by these women in their communication about how to handle the deep impact of the cancer. In this section, I outline how self-realisation, being informed and management of fear, were constituted as crucial strategies.

Self-realisation

When communicating about how to handle the deep impact of the cancer, these women paid much attention to how their quality of life could be maintained and also increased. However, what people actually want to do to increase their quality of life may vary between individuals, which were also reflected in this group. Describing her efforts to increase her quality of life, one of the newly diagnosed women wrote to the others that for her it included both a detailed focus on a healthy lifestyle and on her mental health. Emphasising the importance of self-realisation, she told about her use of alternative medicine, of diets, and the importance of being introspective. She closed her message by saying that;

To turn the illness into something positive creates meaning and the awareness that I can influence my own life - during serious illness as well.

Together with one of the other newly diagnosed women, this active woman later had a follow-up conversation in the group about what to do with their situations. Their communication centred on the importance of seeing the possibilities they had in order to find the right direction in life. A third member commented on this conversation after a while, supporting their efforts to find themselves:

Hi. I really enjoyed reading the latest messages on this topic. It's so wonderful that you both use the illness of cancer to reassess life and steer in the right direction. (..) Cancer can be a turning point in life, many have a better life after a diagnosis of cancer than before. Of course I would not wish that diagnosis on anyone, but once things are bad, make the best of it. I am impressed at the way you are tackling this. All the best!

Another participant responded to the initial message and approved of the energy that was revealed through this sequence. However, she also made an effort to moderate the view on what was necessary;

I have never come close to your energy, I don't think, neither in health nor in illness, but for me, this aspect of finding out and knowing as much as possible about the medical treatment and possibilities has been the most important.

Through her approval, she created a space for the wide-ranging strategy, at the same time as she introduced her own, more narrow approach. When interviewed, her distance was more clearly expressed: "these diet things are not for me". Other participants who were interviewed further expressed that they experienced the strategy expressed by the initiator of this section as too broad. However, within the group, the example above was the only effort to modify or challenge the view proposed by the initiator.

The difficulties of being aware of the possibility to act and to value life here and now appeared to be a complicated topic to enter. One woman, who had experienced spread of the cancer, experienced troublesome side-effects of the treatment and knew that things were not going to be better. This woman said to me in the interview that she was not afraid of the future and that she sometimes - however not often - went down to the “basement” and wondered why she could not die. She said that she was not afraid to die, not at all. She never mentioned these thoughts to the other women in the group, and she said to me in the interview that she tried to be careful;

And I am a bit, sort of, cautious, or at least I try to be. This is very intense in many ways, and you should be a bit careful before you say anything.

This woman signalled reluctance to address the meaninglessness she sometimes experienced in the company of the other women in the group. As commented previously, an experienced obligation of being considerate towards other women in the group was revealed.

There were sequences that directed attention to how difficult it could be to value life here and now. One participant said that she found it difficult to maintain a positive attitude and signalled an experience of meaninglessness to the others:

The last thing I will bother you with is the mind. For my part, in periods I function very well, in other periods I have 'nerves' and feel depressed. I have sleep problems all the time. I need to take medicines for this. I also take some alcohol, purely and simply to take a 'break' from myself. This is rather taboo, but I want to say it anyway.

This woman's openness was appreciated, also on a later occasion when she wrote about her struggles, and she was met with considerable warmth and supporting comments. Her use of alcohol to comfort herself was, however, not a topic of comment. Furthermore, we were not introduced to other stories about feeling that life was without meaning. On this and

some other occasions in which this participant touched on this issue, other members responded by saying that “we all struggle from time to time, but the heavy thoughts must never win”. The woman who wrote the “depressed” messages said in the interview that she experienced that a situation of mutual sharing was not established. She experienced the group as “too successful” and was rather negative to the value of group participation on these aspects. She told me that she would rather use her time with other people that were also struggling with their life.

The “conventional” response to her experience of meaninglessness gives an interesting contrast to the more “personal” responses that were given about the experiences of isolation and loss that were commented in the last section. It serves to create an impression of a preference for the stories about the cancer patient who managed to live a life with meaning.

At the same time, it can also appear as challenging to respond directly to the difficult thoughts of other women. Another woman illustrated that the experienced obligation of being considerate also could make it difficult to formulate a good answer to such messages. When touching this issue during the interview, she referred to another online group in which she had participated, and to messages from a woman who knew that she was going to die soon. She commented that “It makes enormous demands on you to reply to something like that.” Her thoughts contribute to give some insight into why difficult postings might not be responded to, or are responded to by use of general and “safe” comments.

Being informed

Another strategy that appeared to be of importance for these women, and which was also commented as important in the study of Høybye et al (2005) was to get as much information as possible and to be “prepared”. It included being receptive to negative information, for example the knowledge about spreading of the cancer. The value of being receptive to all kinds of information does perhaps represent the view that was most openly

contested in this group. Two women informed the group about their discomfort with the heavy details about cancer that were circulating. They received emphatic comments that were obviously intended to create a space for different opinions, and I observed clear efforts to establish a space for the need to avoid painful information. However, at the same time, the responding women emphasised their personal experience of benefiting from their receptive attitude. As one woman wrote:

My thinking is that if this should affect me again, I will be ready. As ready as I can be. Just you try, I know who you are!! (...) Finally, don't forget that even if one reads about tough things and dramatic developments: NO ONE has exactly the same diagnosis. There is always something that makes you different from the person you are reading about. Don't automatically copy bad experiences over to yourself, ask questions and filter out.

This response provides an association with a use of anecdotes, which is described by Steffen (1997) in her study of the social and processual nature of narratives as they are presented in Alcoholics Anonymous (AA) groups. Anecdotes are often told as small pedagogical tales with an implicit moral and may function as discreet efforts to adjust or possibly even to correct other life stories in a more appropriate direction. They have the quality of preserving their authenticity as individual experience while at the same time claiming validity beyond their specific context. An image of the cancer patient who enters the battlefield and fights is further underscored by this posting.

Management of fear

Integrated into the acknowledgement of an insecure future that was described in an earlier section, a sense of fear was agreed upon as inevitable. In several sequences, the fear was commented as a “companion” who would accompany them for the rest of their life. A

view of this fear as manageable was emphasised in the group interaction. As one of those with a spreading cancer expressed to the others:

Sometimes it is necessary to take up the painful thoughts – take the spectre out of the closet. Then you put back the spectre and forget it. It becomes less scary the more often you have seen the spectre, and then you can forget it for long periods.

Together with another participant, who had not experienced spread of the cancer, she repeated the importance of an active “treatment” of the fear at several occasions. Through their own stories, these two women further illustrated that this was possible.

Without placing themselves in this particularly “strong” position, other women with spreading also emphasised that they generally had “good days” or that they “had become skilled in living in the present.” Reluctance to reveal the experience of an overwhelming fear was further expressed. One of the two women who participated actively in the conversation about recognising the possibilities of finding a new direction in life said to me in the interview that they could have been more vulnerable:

I think about this, quite simply, that you dare to go in during a tough period and say that now I am going through a really dreadful time, and I am afraid of all sorts of things. But what keeps me back is that I think of what it does to all those whose cancer has spread... of course they also have some terrible days, and that I would have believed that they don't.

In accordance with what I have pointed out earlier in the article, an obligation to be considerate appeared to underpin this woman’s reluctance to address difficult issues. However, her expression also indicated that she was aware of how she appeared in the group; she was afraid of not giving the right impression of herself. She still linked her reluctance to reveal her fear to her own way of coping and said:

But I am like that after all, I'm not good at ... no, when I'm feeling awful, I keep to myself a bit... and then I can talk about it afterwards.

She also commented that she felt that the women in this group were sharing this coping strategy. At one occasion she still mentioned that her fear was overwhelming, and she closed this message by saying that “You can’t cross the bridges before you come to them, but that is sometimes easier said than done”. She then expressed a deep insecurity about leaving this “negative” message in the group. She was reassured about the legitimacy of such contributions by me and also by other members of the group. The importance of taking the time to face such thoughts and not letting the fear win was underscored during the response. However, similar to the example of meaninglessness described in the last section, this woman’s struggle to leave the overwhelming fear did not prompt a stream of recognising comments. Some of the responding comments can also be categorised as anecdotal, as they illustrated the good experience of taking the spectre out of its closet and putting it back. It is however important to note that in contrast to the disappointment over the lack of recognising comments described in the last section, this woman told me in the interview how much she appreciated the response from the others.

Discussion

Based on the above analysis, I find it reasonable to argue that this group constituted a story about breast cancer that is best described as a story about “quest”, and which gives associations to a further circulation of socially desirable stories about cancer. I will discuss this in further detail below. It is however important to be aware that the group did create a space for the brutal impact that breast cancer can have on peoples’ life, exemplified by the agreement of facing an insecure future, communication about marital problems and the experience of being amputated after mastectomy. The emphasis placed on these aspects

demonstrates a distance from the “rah-rah” rhetoric observed in the groups studied by Coreil et al (2004), as well as a distance to the restitution story.

Through its receptiveness for these details, it is reasonable to argue that this group emerged as an alternative space in which the women could address issues that they were not addressing in their established relationships. As such, it gives associations to Hardey’s proposal of the Internet as a new, unique and global space in which people can rewrite or reconstruct their narrative (Hardey, 2002), and to Ziebland’s (2004) suggestion that Internet use can help cancer patients to make sense of their illness. In this material, the multiplied possibilities to access other women in a similar situation appeared as the most important “facilitator” of the creation of this alternative space, while the anonymity and written communication were less salient.

My point however, is that the communication about these aspects was still not enough to create an impression of an arena in which socially desirable exchanges about cancer were replaced by those who make the suffering, or “chaotic” aspects particularly visible. Self-realisation, the importance of being informed and management of fear still became salient issues in the women’s communication about how to handle the cancer. The difficulties of handling the cancer, such as the experience of meaninglessness and uncontrollable fear, were not woven into the communication. As such, it is reasonable to argue that an image of the breast cancer patient as an “individual hero” was constructed through the group interaction.

This argument resonates with research that directs attention to the replication of mainstream discourses in the online context (Bar-Lev, 2008; Fox, Ward, & O'Rourke, 2005; Pitts, 2004; Rier, 2007; Seale, 2005). For example, in her study of “emotion talk” among members of an HIV/AIDS support group, Bar-Lev (2008) commented on an unwillingness to accept feelings of resignation in the online context which is in accordance with the responses demonstrated in this material. Pitts comments that the advice women with breast cancer gave

each other in the online contexts she studied “asks a great deal of women who are sick and recovering” (Pitts 2004, p. 49), implicitly encouraging them to enter the role as the hero in their own life.

It is, of course, necessary to be critically aware of my reliance on Arthur Frank’s (1995) typology to sort out the communication in the online context. The risk is that my awareness towards three storylines leaves important nuances in the material unnoticed. For example, the story about the hero that emerged through the exchanges in this group was not about the “warrior who beats the enemy by her own will”. An impression of stoicism in a critical situation, rather than being in a war, was salient, and particularly signalled through the common acknowledgement of facing an insecure future. This is an important response to those who express worries that women are further encouraged to “save themselves” from breast cancer in the online context (Pitts, 2004), and which needs to be accounted for in the further debate on the consequences of Internet use. However, similar to the story about the cancer patient who wins a victory over the cancer, the focus on being in control of the situation was salient also among these women. This is the main reason to argue that the women were not liberated from the message of being a hero in this online context. It is particularly underscored through the attention paid to self-realisation and to “extending life in breadth, not only in length”.

Within the group studied here, an experienced obligation to be considerate emerges as an important background for the restricted given space for resignation and meaninglessness. For some, it appeared important to not “force” harsh realities or depressive thoughts on other women. When introduced, such information could further appear as difficult to respond to, which gives some insight into why such messages were responded to in general “safe” terms about the heavy thought that should never win or not responded to at all. Another background is that “bad days” were treated in isolation from others, and that the group was entered when

these difficult feelings were gone and one was again able to see the possibilities to act. A third point is that the involvement and control that was introduced and supported in the group was not openly challenged, even though some of the women revealed that they experienced this focus as being too dominating during the follow-up interview. I turn to a closer discussion of these processes below.

The constitution of a socially desirable story about breast cancer – some reflections.

One question that might be asked is whether the communication in the group was influenced by the requests of being open in a careful manner. The women's awareness of being considerate can imply that this is a reasonable question. Particularly the fear of "doing something wrong" when introducing the experience of having a fear that was difficult to control give associations to an awareness of the directions of how to behave. How rules of sharing and a "controlling" moderator influence the communication in online self-help groups is therefore an issue for further consideration. It underscores the need to pay attention to leadership and how communication in support groups can be facilitated (Till, 2003). A main argument in this article is still that the constitution of a socially desirable story in this online context is more fully illuminated by other dimensions. It implies that the attention is turned to research that view online communication as grounded in the social, bodily and cultural experiences of the users (Pitts, 2004; Rier, 2007; Wynn & Katz, 1997). As such, the influence of more or less formalised rules of how to share experiences in the online context is toned down, and more attention is paid to the expectations and norms of behaviour that is characteristic for the women's off-line life

Research on patient interaction in Norwegian hospital wards (Album, 1993, , 1996) and communication in AA (Alcoholics Anonymous) self-help groups (Steffen, 1997) has paid attention to the interactional frames of such encounters. Album noted a striking conventional and controlled behaviour among the patients he was observing (Album, 1993, , 1996).

Following Goffman and his situational focus (Goffman, 1967), Album turns the attention away from individual motives of the participants in the encounter and argues that this behaviour is connected both to the patients' position as strangers to each other and to their common position on the margins of everyday life.

Similar to Album, I will argue that these women's common position on the margins of everyday life played an important role for the constitution of a socially desirable story about breast cancer in this online context. It is also reasonable to ask if this process also was influenced by their position as strangers to each other. This dimension is particularly brought into focus by the few or almost absent efforts to challenge views that were already present in the online group. However, other studies of online communication between people with common health problems (Denzin, 1999; Rier, 2007), demonstrate that moral issues are debated and deviating views are made visible in this context of strangers, indicating scarce support to the influence of this dimension in the research literature.

Based on his material, Album argues that the stoic and conventional behaviour he observed emerged from the patients' common experience of being in a situation with great uncertainty. To counterbalance the threats of being ill then becomes the crucial function of patient interaction (Album, 1993). I find that this argument also throws an important light on the emphasis placed on being considerate among the participants in this online self-help group, such as the efforts to not "put the foot in" and the reluctance to force harsh realities and meaninglessness on others. It is further interesting that Steffen (1997), in her study of Danish Alcoholic Anonymous (AA) groups, suggests that the interaction in these therapeutic groups had a collective aspect; she argues that personal stories are told as a way of sharing experience in order to solve common problems. The participant in this online group who described herself as "killjoy" during the interview, and who expressed considerable relief when she finally could tell the others some positive news about her condition, gives particular

emphasis to this suggestion. Following Album and his argument that the patients were not entering normatively defined roles and hiding their “true selves” in such encounters (Album, 1993), I further find it reasonable to argue that a voluntary aspect is traced in the emphasis on self-realisation and manageable fear in this context. This focus was needed to frame their common position with meaning.

The voluntary aspect is further underscored in the last dimension to which I will pay some attention. There are perspectives that propose more consistency in the identities that individuals enter than what is suggested through Goffman’s dramaturgical perspective (Turner & Stets, 2005). From an interactionist perspective for example, it is argued that individuals carry a more general self-conception *as well as* multiple identities tied to specific roles and contexts. As such, identities must be consistent with the more global self-conception (Turner & Stets, 2005). It raises the question how *different* people present themselves in online communication with other women in a similar situation, compared to how they appear elsewhere. In this material, the consistency is brought into focus by the woman who was worried about how she appeared in the group if she revealed her overwhelming fear. It is reasonable to argue that these worries illustrate that her behaviour in the group had to be in accordance with her general self-conception.

Notions of emotional management as a biographical trend – or as a more or less pervasive feature of life in late modernity (Williams, 2000) might give some support to this argument. Adhering to these frames, it becomes important for a woman with breast cancer to maintain an image of herself as a person who is in control of her emotions. In the beginning of this article, I referred to literature which expresses concerns about this practice (Broom, 2001; Frank, 1997). However, from an interactionist perspective, the self is not merely a reaction to pressures from others, cultural scripts, and social structural constraints. Rather, the presentation of self in a situation is always an active process (Turner & Stets, 2005). As such,

it brings further attention to the constitution of a socially desirable story about cancer as also having a voluntary aspect. My argument is that this perspective is particularly brought into focus by the women who said that they usually isolated themselves from others when the situation became overwhelming, and the one who said that “she was like that”. I perceived the “active choice” in this practice to be salient.

An important comment related to this latter point is however that it is important to be aware of the middle-class status of the participants in this study. The biographical trend of emotional management is argued to be particularly reflected in these segments of the population (Williams, 2000). Another observation was made by Matthews (2000) in her study of a self-help group in US that was established by rural, religious women. This group rejected the dominant model of fighting spirit and negotiated a cultural consensus that accepted feelings of doubt and pessimism. Through the experience of the group studied here as being “too successful”, the material also calls for more critical attention to the rootedness of emotional management among Norwegian women who are diagnosed with breast cancer.

On the whole however, these final reflections illustrate how the constitution of socially desirable versions of breast cancer in the online self-help context also can have active and voluntary aspects. Within a broader perspective, they imply that the need to replace socially desirable versions of breast cancer with those who make the suffering more visible should be further explored. More knowledge on this issue can provide an important basis for further considerations of the potential role of the disembodied context on the Internet.

References

- Album, D. (1993). The emotional quality of conventional interaction. A first visit to the sociology of emotions *Journal of Sociology (Sosiologisk tidsskrift)*, 2, 91-104.
- Album, D. (1996). *Close strangers. Patient culture in hospital (Nære fremmede. Pasientkulturen i sykehus)*. Oslo: Tano
- Bar-Lev, S. (2008). "We are here to give you emotional support": Performing emotions in an online HIV/AIDS Support Group. *Qualitative Health Research*, 18(509-521).
- Broom, D. (2001). Reading breast cancer; reflections on a dangerous intersection. *Health*, 5(2), 249-268.
- Coreil, J., Wilke, J., & Pintado, I. (2004). Cultural Models of Illness and Recovery in Breast Cancer Support Groups. *Qualitative Health Research*, 14(7), 905-923.
- Denzin, N. (1999). Cybertalk and the Method of Instances. In S. Jones (Ed.), *Doing Internet Research. Critical Issues and Methods for Examining the Net*. Thousand Oaks: SAGE.
- Finne, H., Levin, M., & Nilssen, T. (1995). Trailing research. A Model for Useful Program Evaluation. *Evaluation*, 1(1), 11-31.
- Fox, N. J., Ward, K. J., & O'Rourke, A. J. (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*. Chicago: The University of Chicago Press.
- Frank, A. (1997). Illness as a moral occasion; restoring agency to people. *Health*, 1(2), 131-148.
- Goffman, E. (1967). *Interaction Ritual*. New York: Anchor Books.

- Hardey, M. (2002). "The story of my illness"; Personal Accounts of Illness on the Internet. *Health: An interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 6(1), 31-46.
- Høybye, M. T., Johansen, C., & Tjørnhøj-Thomsen, T. (2005). Online Interaction. Effects of storytelling in an internet breast cancer support group. *Psycho-Oncology*, 14(3), 211-220.
- Kraut, R., Lundmark, V., Patterson, M., Kiesler, S., Mukopadhyay, T., & Sherlis, W. (1998) Internet Paradox: A social technology that reduces social involvement and psychological well-being? *American Psychologist*, 53 (9), 1017-1031.
- Matthews, H. F. (2000). Negotiating Cultural Consensus in a Breast Cancer Self-help Group. *Medical Anthropology Quarterly*, 14(3), 394-413.
- McKenzie, H., & Crouch, M. (2004). Discordant feelings in the lifeworld of cancer survivors. *Health*, 8(2), 139-157.
- Olsen, O., & Lindøe, P. (2004). Trailing Research Based Evaluation: Phases and Roles. *Evaluation and Program Planning*, 27(4), 371-380.
- Pierret, J. (2003). The illness experience: state of knowledge and perspectives for research. *Sociology of Health and Illness*, 25(Silver Anniversary Issue), 4-22.
- Pitts, V. (2004). Illness and Internet empowerment: writing and reading breast cancer in cyberspace. *Health*, 8(1), 33-59.
- Radin, P. (2006). "To me, it's my life"; medical communication, trust and activism in cyberspace. *Social Science and Medicine*, 62, 591-601.
- Rier, D. (2007). Internet support groups as moral agents: the ethical dynamics of HIV+ status disclosure. *Sociology of Health and Illness*, 29(7), 1043-1058.
- Seale, C. (2002). Cancer Heroics: A study of News Reports with particular Reference to Gender. *Sociology*, 36(1), 107-126.

- Seale, C. (2005). New directions for critical internet health studies: representing cancer experience on the web. *Sociology of Health and Illness*, 27(4), 515-540.
- Sontag, S. (1979). *Illness as Metaphor*. London: Allen Lane.
- Steffen, V. (1997). Life stories and shared experience. *Social Science and Medicine*, 45(1), 99-111.
- Till, J.E. (2003). Evaluation of support groups for women with breast cancer: importance of the navigator role. *Health and Quality of Life Outcomes*, 1, 1, 16.
- Turner, J., & Stets, J. (2005). *The sociology of emotions*. New York: Cambridge University Press.
- 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.
- Waldron, V., Lavitt, M., & Kelley, D. (2000). The Nature and Prevention of Harm in Technology-Mediated Self-Help Settings: Three exemplars. *Journal of Technology in Human Services*, 17(2/3), 267-293.
- Walther, J. B., & Boyd, S. (2002). Attraction to computer-mediated social support. In C. A. Lin & D. Atkin (Eds.), *Communication technology and society: Audiences adoption and uses of the new media*. New York: Hampton Press.
- Weiss, R. S. (1994). *Learning from Strangers. The art and method of qualitative interview studies*. New York: The Free Press.
- Williams, S. J. (2000). Chronic illness as a biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health and Illness*, 22, 40-67.

Wynn, E., & Katz, J. (1997). Hyperbole over cyberspace; self-presentation and social boundaries in Internet Home Pages and Discourse. *The Information Society*, 13, 297-327.

Yaskowich, K. & Stam, H. (2003). Cancer Narratives and the Cancer Support Group. *Journal of Health Psychology*, 8, 6, 720-737.

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.

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