Keeping up with the new health care user:

the case of online-help groups for women with breast cancer

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Foreword

”De e itjnå som kjæm tå sæ sjøl” synger Hans Rotmo i en velkjent trøndersk vise. Etter fem års arbeid med denne avhandlingen kan jeg skrive under på det. Jeg er glad for at jeg gikk inn i det med en naiv tro på at alt er gjennomførbart, bare man vil det nok. Den trua har vært god å ha underveis.

Avhandlingen er basert på en gruppe brystkreftopererte kvinners bruk av og erfaringer med en internettbasert selvhjelpsgruppe. En del av disse kvinnene fulgte jeg i store deler av studieperioden, og noen gjennom tunge beskjeder og forverring av sykdommen. Jeg fikk innblikk i noen av de tankene og opplevelsene som oppstår når man må forholde seg til alvorlig sykdom og hva det kan bety å ha tilgang til en internettbasert selvhjelpsgruppe i en slik situasjon. Min sosiologiske tolkning av dette presenteres i avhandlingen. Så er det mye annet som er med meg på andre måter. Takk!

Ellers er det mange som har bidratt på veien og til at arbeidet mitt nå er samlet mellom to permer. Ideen om å se nærmere på potentsialet i internettbaserte selvhjelpsgrupper for brystkreftopererte ble unnfanget ved Nasjonalt Senter ved Telemedisin våren 2001. Daværende leder for Pasientprogrammet ved NST, Deede Gammon, og krefttlege Jan Norum var sentrale i denne innledende fasen. Deede var også den som oppmuntret meg mest til å skrive en artikkelbasert avhandling. Vi har vel tenkt noen tanker om det underveis begge to, men når det nå endelig nærmer seg slutten jeg er først og fremst veldig takknemlig for at du inspirerte meg til å gjøre det.

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Anne-Grete Sandaunet

Content

List of articles

1. Sandaunet, AG. Approaching the role of the Internet: experiences from an online self-help group for Norwegian women with breast cancer. Submitted to *Social Theory and Health*, Jan 2008, under review.

2. Sandaunet, AG. A space for suffering? Communicating breast cancer in an online self-help context. Submitted to *Qualitative Health Research* Sept 2007, accepted for publication May 2008.

3. Sandaunet, AG. The challenge of fitting in: non-participation and withdrawal from an online self-help group for breast cancer patients. Published in *Sociology of Health and Illness*, 2008, vol 30 (1), p 131-144.

4. Trondsen, M., Sandaunet, AG. The double-minded action researcher. Submitted to *Journal of Evaluation and Program Planning,* Dec 2007, under revision (May 2008).

Introduction

1.1 Aim of study

This action-oriented study aims to obtain more knowledge about the potential role of online self-help groups in breast cancer rehabilitation. The study is based on assumptions of a health care user in change and is part of the efforts to respond to the needs of this "new" health care user within health care.

1.2 The potential of online self-help groups

Peoples' use of online self-help groups is argued to represent one of the most promising aspects of e-health (Eysenbach et al., 2004). Such "virtual communities" are social networks formed or facilitated through electronic media, and they appear as mailing lists, newsgroups or UseNet discussion forums, web-based discussion forums and live chat-rooms (Burrows et al., 2000). People use them to offer and receive information, advice and support across a massive range of health and social issues (op cit). Studies of online self-help group participation have demonstrated the helpful function of this activity, both among people with mental illnesses (Kummervold et al., 2002), and among cancer patients (Broom, 2005; Høybye et al., 2005; Klemm et al., 2003; Lieberman et al., 2003; Winzelberg et al., 2003).

In studies of online self-help group participation among cancer patients, break with social isolation, reduced depression and increased control are among the benefits referred to (see, for example Høybye et al., 2005). At the onset of this study, the promising reports on online self-help groups were still few. They were further argued to have several limitations, such as issues related to the design of the studies (Eysenbach et al., 2004). Similar to experiences from face-to-face based groups (Coreil et al., 2004; Luke et al., 1993; Ussher et al., 2006), drop-out in studies of online groups was common, but this was scarcely researched

(Eysenbach et al., 2004; Luke et al., 1993). This latter point did still not "disturb" the image of a phenomenon with interesting and promising aspects.

Through the establishment of an online self-help group for women with breast cancer, we aimed to explore further the potential role of online self-help groups. The findings are presented in the following thesis.

1.2.1 Research questions

The Internet offers multiplied possibilities to exchange information and further, an opportunity of disembodied communication. These two dimensions represent the main point of departure for this investigation. *The multiplied access to information* in this context refers to the access to other people's experiences and knowledge about a health problem. *The disembodiness* on the Internet implies that people interact through written communication. Corporeal bodies are absent and individuals are left to represent the body through words, images, codes and symbols (Pitts, 2004).

We aimed to explore further the potential role of these dimensions. More precisely, the core question asked in this thesis is

"What role can be ascribed to the multiplied possibilities to exchange information and the disembodied context that is offered by an online self-help group in breast cancer rehabilitation?"

This core question is divided into three sub-questions that are addressed in the three first articles in the thesis. These are the support provided, the significance of the disembodied context and the relevance of online self-help groups. In addition, a fourth question directs attention to the action-oriented method that has been used.

The four sub-questions asked are:

1. *What support is provided in online self-help groups for women with breast cancer?*
2. *What significance can be ascribed to the disembodied context in online self-help groups for women with breast cancer?*
3. *What relevance do online self-help groups have in breast cancer rehabilitation?*
4. *How can an action-oriented method be helpful in the efforts to obtain more knowledge about the potential role of online self-help groups for women with breast cancer?*

1.2.2 Research perspectives on technology

As indicated above, the aim of this study is to explore the possibilities provided by new technology. The study was developed and started within an enthusiastic climate which was salient both in media and among health authorities. Obstfelder (2003), who analysed an electronic service that was available for pathologists in Norwegian hospitals, commented an "technological optimism" among the health authorities in the introduction to her doctoral thesis.

Within a sociological context, three main approaches are usually identified in existing studies of technology in health care. Timmermanns and Berg (2003) describe these as technological determinism, social essentialism, and technology-in-practice. Technology determinism comprises two elements; technology develops autonomously, and technology determines societal development to an important degree. It presumes that technology is the dominant moving force in society and that the political agency of culture, interest groups and individuals is to a large extent curtailed by technological momentum (Bijker, 2001; Timmermanns & Berg, 2003).

From a social essentialistic perspective, medical technologies are blank slates to be interpreted and rendered meaningful by culture. They are viewed as influential instruments to be mobilised by social actors and imbued with meanings (Timmermanns & Berg, 2003). The agenda for medical sociologists rooted in social essentialism has been to show that the working of technology is socially constructed, with the emphasis on "social" (Bijker, 2001). The aim of the third perspective on medical technologies described by Timmermanns and Berg (2003), or "technology-in-action", has been to re-conceptualise the role of technology in studies of society and technology. In other words, technology-in-action directs attention to the mutual shaping of society and technology, rather than one being shaped by the other (Bijker, 2001).

Within the sociological context, and on the Internet area, Michael Hardey (Hardey, 1999; Hardey, 2001; Hardey, 2002a; Hardey, 2002b) and Burrows et al (Burrows et al., 2000) represented early and crucial contributors to the enthusiasm that was salient when this study was initiated. I will argue that these authors are still not proponents of a "pure" technological optimism – or the version of technology optimism that is critically commented by Wynn and Katz (Wynn & Katz, 1997). I rather consider them as proponents of a mutual shaping of technology and society (technology-in-action) in which considerable attention still is paid to the causal role of technology (Henwood et al., 2003).

Hardey directs attention to a liberating role of the Internet. He places emphasis on both the multiplied possibilities to exchange information and the disembodied communication on the Internet. He argues that the multiplicity of therapeutic regimes, self-improvement guides and self-help groups on the Internet provides resources for users to construct and reconstruct narratives to maintain or alter their sense of self-identity in a manner which goes way beyond that implied by Parsons' sick-role (Hardey, 1999). The latter is often equated with a "modern" patient role on which I will comment on later. Corresponding arguments were offered by

Burrows et al, who proposed that the privileging of personal experience and lay knowledge over "expert" knowledge would be influenced by peoples' turn to the Internet (Burrows et al., 2000). The possibility to communicate anonymously with strangers on the Internet is further particularly emphasised (Hardey, 1999; Walther & Boyd, 2002). While the "weak ties" of the Internet were initially considered as a problem or challenge (Kraut et al., 1998), the potential benefits of this anonymity, or "disclosure effects", had become an issue of considerable interest when this study was initiated (see, for example Kummervold et al., 2002). According to Walther and Boyd (2002), some online venues are used precisely due to the anonymity and the asynchronous affordances they offer.

What is worth to note was that even though sociology generally has been argued to voice a "pessimistic" technological determinism (Timmermanns & Berg, 2003), this perspective was not salient in the research on Internet use for health at this time. On the whole, there were sceptical contributions to the increased use of Internet for health, but these were particularly provided by health professionals who expressed concerns about the additional demands it might generate and the poor quality of much online information (Nettleton et al., 2005). Worries about equal access and lack of information literacy among underprivileged parts of the population were also offered (Burrows et al., 2000). These worries were however early acknowledged by the Norwegian health authorities. Since then, efforts have been made to ensure the quality of health information and equal access to this medium. Considerable attention is also paid to develop user-friendly services and to educate the users of the services (see, for example The Ministry of Health and Social Affairs, 2004b: 19).

In addition to the enthusiastic response among sociologist that researched the Internet at this point of time, there was an emerging debate on the role of the Internet that went beyond issues of equal access and information literacy. This view became more visible through an article in Sociology of Health and Illness in 2003 (Henwood et al, 2003). These authors directed critical attention to what they described as the “normative assumptions” about peoples’ information needs and movements towards self-care that characterised the enthusiastic contributions. As such, positions that direct more critical attention to the everyday context of Internet use were introduced to the debate on Internet in health care. Such responses have later been described as ”contingent and embedded” responses to the Internet (Nettleton et al., 2005). It implies that considerable attention is paid to describe the social and cultural “landscape” into which online self-help groups are introduced. In the current study, this landscape will emerge as a main focus of the analysis.

I turn next to a more detailed description of how online self-help groups emerged as an area of interest within health care.

1.3 The interest of self-help and the Internet within health care

Both the self-help movement and peoples’ use of the Internet for health are inherently grassroots activities. Self-help has its roots in the US, in which the poverty of the Depression gave rise to many self help service projects (Withorn, 2005). Various definitions of self-help groups make it difficult to provide a good overview over the extent of the phenomenon (Davison et al., 2000; Thuen & Carlsen, 1998), both on the Internet and more generally. Their common frame is mutual help between people who share a common need, overcoming a common handicap or life-disrupting problem (Katz & Bender, 1976). There is a varying degree of professional involvement, and this is one of the aspects that make it difficult to decide what kind of groups that can be described as self-help groups, and therefore their extent.

In this study, the online self-help group established can be described as an "interconnected" self-help group (Thuen & Carlsen, 1998), in which a parent organisation is considerably involved, but which also has a grade of intern autonomy. The group is further described in chapter 3. There are few doubts that the number of self-help groups has grown during the last decades (Nettleton, 1995; Thuen & Carlsen, 1998), independent of the debate on how they can be defined. The number is expected to accelerate further through increased access to the Internet (Burrows et al., 2000).

The growth of the self-help phenomenon during the last decades has first and foremost been salient in US, but also in some European countries (Thuen & Carlsen, 1998). In US 3-4 per cent of the population attend to self-help groups (Davison et al., 2000; Thuen & Carlsen, 1998). Davison et al (2000), based on their study of both online and face-to-face based self-help group participation in US, reported that sufferers of multiple sclerosis, chronic fatigue syndrome, breast cancer and anorexia were the most frequent users of self-help groups. According to the authors, online and face-to-face support patterns were significantly correlated, suggesting that broad tendencies to seek support do vary by diagnostic category.

The growth of the self-help phenomenon in Norway has been more slowly. In 1994, between 0.4 and 0.7 per cent of grown-ups in Norway had attended to a self-help group (Thuen & Carlsen, 1998). However, in 2005, as much as 12 per cent of the population had "participated in forums or self-help groups that addressed health issues" on the Internet (Andreassen et al., 2006). Such observations give indications of a phenomenon in growth.

In 2001, when this study was initiated, one face-to-face based self-help group for breast cancer patients was run by the Norwegian Breast Cancer Society. The online self-help group established in this study was the first online group for women with breast cancer in which the participants could use the Norwegian language. There was however a growing number of online self-help groups for breast cancer patients in which the members communicated in English. Also a mailing list for Scandinavian-speaking breast cancer patients (SCAN-BC list) was available (Høybye, 2002). This mailing list was mainly used by Danish women, but there were also participants from other Nordic countries, among them Norway (op cit).

The social welfare and medical establishments have reacted to the increase of self-help activities with different types of responses. Self-help activities have however gradually been exposed to more interest as an aspect of the social services system both in US (Withorn, 2005) and in Europe (Damen et al., 2000). In Norway, the health authorities have worked out a national plan for self-help (The Directorate for Health and Social Affairs, 2004) and established a nodal point for self-help. In the "Public Health Report" (White Paper nr 16 (2002-2003)), internet-based self-help groups are among the areas that are prioritised in the further corroboration of the self-help area. Additionally, a strategy plane for electronic interaction in the health and social sector named "say @" was introduced by the health authorities in 2001 (The Ministry of Health and Social Affairs, 2001), in which peoples' use of the Internet for health was addressed as a phenomenon in growth.

The attention paid to self-help and the Internet within contemporary health care in Norway is first and foremost linked to what has been described as "the empowerment-strategy". In this strategy, the individuals themselves are considered active actors making choices in accordance with their own preferences (Sørensen & Graff-Iversen, 2001). This strategy was described as a "fundament" in public health care in Norway in a white paper to the parliament in 1999 (White Paper nr 26 (1999-2000)). The focus on empowerment represented a change from a focus on professional influence to a greater sensitiveness to how people themselves define their own situation (Sørensen & Graff-Iversen, 2001). Until now, the efforts to improve the psychosocial status in relation to illness had been managed by professional actors as psychologists and medical doctors (Sørensen & Graff-Iversen, 2001).

This increased focus towards the lay perspective was also traceable in governmental documents. In the National Plan for Cancer Care in Norway from 1997, it was commented that the patients' subjective experience of illness often deviates from the professional approach, and that there is a need to take account for this difference (The Ministry of Health and Social Affairs, 1997: 43). In a more recent report on cancer treatment it is argued that it is wrong to consider the patient as a passive recipient of medical treatment, and the patients' right to participation is emphasised (The Ministry of Health and Social Affairs, 2004a). More generally, users of health care services have further changed from ”patients” to ”consumers” of health care in governmental documents (The Ministry of Health and Social Affairs, 2001; The Ministry of Health and Social Affairs, 2004b), emphasising further the new position of the carer of the health problem. This latter point is now part of governmental health care strategies in most western welfare states (Henwood et al., 2003; Lupton, 1997).

These processes underpin the increased attention that has been paid to self-help groups within health care. According to Damen et al (2000), a changed image of self-help groups has emerged in western societies. From being considered as arenas for strange deviants, they did now have a position as a potential supplement to professional health care. This makes the possibilities provided by the Internet interesting.

It is still of interest to take a closer look at the emphasis placed on empowerment in health care. It reflected a renewed interest in lay perspectives on health and illness that disappeared with the entry of modern medicine (Bury, 2001). Various factors have framed this renewed interest - see for example descriptions by Ziebland (2004), Bury (2001) and Crossley (1998). I do not aim to describe them in full detail here. I will still address three processes that can serve to illuminate the development; the changed illness pattern, the changed patient role and the financial crisis in western welfare states.

1.3.1 The transition from acute to chronic illnesses

An important starting point for a renewed interest for the lay perspective is the relative decline in the importance of the infections on which the bio-medical model was founded, and the growing impact of degenerative and chronic illnesses. The attention is turned from treatment and cure to management and care, and their heterogeneous character became the focus of both lay and professional concerns (Bury, 2001). The temporal horizon of illness is important here. Bury argues that assessment of quality of life, the impact of illness on carers and a renegotiation of the professional role all appear on the professional agenda, and that a consequent loosening of the bio-medical grip provides the space for lay narratives to florish.

Cancer is not among the diagnosis's that is immediately considered as a chronic illness. However, the treatment of cancer is improved and people who have been diagnosed with cancer now live longer with their disease (Cancer Registry of Norway, 2007). Further, some people who have been diagnosed with cancer are declared free of cancer-related symptoms, but have to live with side-effects caused by the cancer treatment, such as lymphoedema. It is therefore more common to emphasise the similarities between life with cancer and life with other chronic conditions. This development illustrates how the health care system has to approach a changed illness pattern and that it calls for a wider range of interventions. It is not central during the further discussion in this thesis, but it is important to be aware that it functions as one of the driving forces behind the renewed interest of lay perspectives within organised health care.

1.3.2 The democratic impulse and the changed patient role

Another aspect that can be argued to underpin the increased focus on lay perspectives within health care is a "democratic" impulse that has emerged more recently (Bury, 2001). This development has been prompted by debates about the effectiveness of the medical response to diseases (Bury, 2001). It has its roots in the "cotton-industry" of critique (Frank, 1997) that has been raised against the biomedical approach and the positivistic research frame within sociology and related disciplines. Professional "health promoters" have been accused for exercising too much "external" control and to not have the necessary respect for peoples' personal preferences, time-frame and definition of health (Sørensen & Graff-Iversen, 2001).

In the wake of this impulse, it is argued that we are witnessing the raise of a "new" health care user, who does not accept expert knowledge on face value (Lupton, 1997). According to some authors, traditional authority – such as the medical expert – is replaced by multiple sources of authority (Burrows et al., 2000; Giddens, 1991). Even though the radical version of the new health care user, the one who treats health care as "just another commodity" is argued to be somewhat overdone (Coulter, 1999), the ”active” or ”consumer oriented” health care user is now a well established figure within health care (Coulter & Magee, 2003; Lupton, 1997). In their effort to figure out the "new" European health consumer, Coulter and Magee conclude that: *"People increasingly want information and support to make their own informed choices of providers and treatments. Services must adapt to accommodate a more consumerist approach to health care utilisation"* (Coulter & Magee, 2003: 229). Their survey in seven European countries demonstrated high levels of demand for more choice and greater patient autonomy among European patients. The authors argue that attitudes to health care are becoming more consumerist and "one size fits all" is no longer acceptable. More detailed knowledge is still needed and considerable attention is now paid to get more insight into peoples' need for information, participation in decision making and so on.

The enormous expansion and access to information about illness, such as the introduction of the Internet, is further emphasised as a contributor to this change (Bury, 2001;

Ferguson, 2000). In Norway, the proportion of the population who had used Internet for health purposes grew from 31 per cent in 2001 to 58 per cent in 2005. Bury (2001) argues that this accessibility to information provides lay people with a much greater opportunity to fashion personal narratives that connect the private sphere with public forms of knowledge. According to Bury, this development too, *“fuels the reduction of medical authority as the fountain of all official knowledge about illness, and expands the range of culturally available narratives that can be articulated”* (Bury, 2001: 268).

However, there is a considerable debate on how and to which degree the Internet has a transforming role in this development, and whether this role facilitates democratisation-processes or not.

1.3.3 The financial crisis in western welfare states

A last point that needs to be mentioned is the “financial crisis”, or the underfunding of public health care in western welfare states (Anderson, 1996; Coulter & Magee, 2003; Matzat, 1987; Ziebland, 2004). In his reflection on final breakthrough of the self-help idea in health care in the previous West-Germany, Matzat (1987) considers this breakthrough as a result of developments in the political sphere. He argues that it was less influenced by the patients’ own organisations and by academic investigations. Matzat suggests that particular challenges within health care, such as professionalisation, bureaucratisation and the placing of patients in positions of childlike dependence were influential for this development. At the same time, he also directs attention to the financial crisis of the welfare state as an important backdrop for this breakthrough. There was an increasing gap between the demands for health care and available resources.

Since his analysis was published in 1987, this gap has grown in most developed countries - among them Norway - and the need to search for ways of using existing budgets more efficiently is urgent (Coulter & Magee, 2003; Ziebland, 2004). The efforts to do this are particularly materialised in the turn to New Public Management (NPM) as a model for organising public sector and thereby health care services in western welfare states. This model underscores the need to focus on cost effectiveness, the market and the users (Christensen & Lægreid, 2001). Self-help groups becomes interesting because they are contributing to a "bottom up" form of welfare (Burrows et al., 2000). Through such services, effective health care can be provided without professional involvement.

1.4 The need to "keep up" with the changed health care user

Some authors place emphasis on the influence of the financial crisis and calls for more attention to the link of the empowerment strategy to this situation (Anderson, 1996; Lupton, 1997; Withorn, 2005). They offer a rather critical view on the empowerment-strategy. Joan Anderson (1996) directs attention to alleged unstated ideologies that underpin the self-care movement. Her question is whether an unreflexive use of the idea of "consumer empowerment" within the health care industry might deflect our attention from the structures that perpetuate social inequities. According to Anderson: "*Empowerment is an outcome of changes in fundamental structures and relations of power, rather than through individual actions alone"* (Anderson, 1996: 698).

Factors belonging to the internal state of the health care system and the financial situation are however not the most salient underpinnings of the governmental empowerment-strategy. Instead the need to "keep up" with the changed health care user is particularly underscored as a backdrop for the efforts to adjust for self-care and the liberation of peoples' own resources (The Ministry of Health and Social Affairs, 2001; The Ministry of Health and Social Affairs, 2004a). The health care authorities are expecting a health care user that is in search for medical information, but who is also assessing this to the subjective illness experience and seeks support in other approaches to health, such as complementary medicine or other experience based approaches. The task for the health authorities then, is to adapt health care deliveries to this new health care user. They do particularly underscore the efforts to develop and establish Internet-based health services (The Ministry of Health and Social Affairs, 2001), which was crucial for the upstart of this study.

1.5 Women with breast cancer

The target group of this exploration of the potential role of online self-help groups is women with breast cancer. In Norway, 1 in 12 women are diagnosed with breast cancer (Kåresen et al., 2004).

Cancer is an illness that elicits considerable distress (Shapiro et al., 2001). Quantitative studies of breast cancer patients report that anxiety and depression are the most frequent problems observed (Shapiro et al., 2001), and that younger patients demonstrate greater level of distress than older patients (Rustøen & Begnum, 2000). On a general level, this pattern appears to be illustrative also for Norwegian breast cancer patients (Fismen & Stanghelle, 2007; Kåresen & Langmark, 2000a). Breast cancer patients can further experience particular challenges related to their sense of femininity and sexual functioning (Broom, 2001).

It is argued that breast cancer have a fundamental impact on peoples' life. Qualitative data have demonstrated that difficult changes in the body, disrupted lives and changing relationships are identified as typical for people who have experienced an episode of cancer (Mathieson & Stam, 1995; Yaskowich & Stam, 2003). Generally, the majority of (breast) cancer survivors have adjusted well after their first 2 years after diagnosis (Kornblith &

Ligibel, 2003). However, a large proportion of survivors report cancer related problems long after treatment completion (op cit). It is argued that 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; Little et al., 2000).

Little et al (1998) noted three recurring elements among cancer patients who reflected on their cancer experience. First, is an awareness of the adhesiveness of the cancer label, "*Once a cancer patient, always a cancer patient"*. Second, is an awareness of the fallibility of the body and its mortality. The body is no longer "transparent" and accepted without thought. Third, is an awareness that the survivor has lived through an extreme experience, and is alone with that experience. According to these authors, the nature of the fears, pains, sense of loss and awareness of death are beyond the scope of language to communicate to others who have not had a similar experience.

Women with breast cancer are among the frequent users of self-help groups. A study of European women with cancer still showed that not more than 15 per cent of the women cited support groups, either professionally or peer-to-peer led, as a wanted form for support (Veronesi et al., 2000). Similar findings were reported by Kåresen and Langmark in their study of the psychosocial situation of Norwegian women with cancer (Kåresen & Langmark, 2000b). In this study, approximately one fifth of the women, and most frequently breast cancer patients, said that they had used some kind of support group. It is important to be aware that the term support group was used very broadly in this study and also referred to meetings with visitors on the hospital who were representing the Norwegian Cancer Society or other voluntary organisations.

What is further important to note from this study is that the Norwegian study reported that two thirds of the participating women said that no support group was available and that more than half of these women wished that this had been an opportunity. Both Veronesi et al (2000) and Kåresen & Langmark (2000b) direct attention to the fact that knowledge about support groups appears to be limited and might explain a modest interest in this form for support. Of importance is also the fact that the above mentioned studies were undertaken before the turn of millennium and before health care activities on the Internet had become very common. These activities have increased rapidly during the last years. For example is breast cancer one of the most common diagnosis sought online (Helft, 2004), and women with breast cancer are described as frequent users of health care services on the Internet (Davison et al., 2000; Lieberman & Goldstein, 2005).

1.6 The position of the thesis

Our establishment of an online self-help group for breast cancer patients in this action-oriented study represented an effort to facilitate a "doing" breast cancer that is in accordance with the lay experience of breast cancer. It rested on the assumption of a patient-role in change and that the Internet can facilitate the emergence of what is considered as a more "authentic" way of being ill. Linking this to a sociological frame, I argue that these expectations reflect crucial thoughts in post-modern readings of illness. In post-modern readings of illness, the local and situational construction of illness is in the centre, and the modern, also described as the "Parsonian" sick-role, is argued to be of less relevance.

Even though it appears as a crucial backdrop of governmental strategies, post-modern conceptualisations of illness is under debate within the sociological context. From a post-structural point of view, their scarce focus on the subordination to the modern patient-role is questioned. Within this perspective, the dominance of the biomedical model is rather brought into focus. According to this position, the empowerment strategy – and thereby the establishment of self-help groups on the Internet - will lead to a strengthened and constraining focus on the individual responsibility of handling illness and turn the attention away from the societal context in which illness is constructed.

However, in spite of their contrasting view on how the empowerment strategy contributes to a broader space for lay perspectives, both post-modern and post-structural readings of illness still have in common that they take the "outsider position" of the medical approach to health and illness as a main point of departure. My argument is that their disagreement is traced in how the raise of "insider" perspectives can be facilitated, and not so much what these insider perspectives contend. Within the sociological debate a third position still questions the conceptualisation of outsider and insider perspectives that underpins both post-modern and post-structural readings of illness. This position draws on ideas inherent in the interactionist paradigm in medical sociology. During the analysis of the material, I demonstrate the relevance of this position in the debate on the potential role of online self-help groups for women with breast cancer.

Being ill in late modernity – sociological perspectives

As described in the introduction, this establishment of an online self-help group for breast cancer patients is part of the priority given to self-help work in contemporary health care. As also commented in the introduction however, this emphasis placed on self-help is questioned. Critical voices express worries about the individual responsibility that is adjusted for by the establishment of such services and the empowerment-strategy more generally. In this chapter, I locate the different views in a sociological frame. The aim is to introduce a framework to understand how new possibilities for exchanging information and experiences with breast cancer can be in accordance with the needs of women with breast cancer.

2.1 Introduction to an area of research

Sociology directs attention to how health and illness interact with sociocultural conditions. Talcott Parsons' sick-role concept represents a starting point for this tradition (Parsons, 1951). Parsons was the first to highlight the fact that sickness and the experience of illness is not just a physical/biological phenomenon but is also part of social and cultural processes (Crossley, 1998; Frank, 1995; Gerhardt, 1989). In his outline of the Parsonian sick-role, Frank (1995) comments that Parsons directs attention to the behaviour the sick person expects from others and what they expect from him and that a formal institutionalisation of these expectations is seen in such matters as sick leave and medical care.

According to Parsons (1951), there seem to be four aspects of what he describes as the "institutionalised" expectation system relative to the sick-role. First is the exemption from normal social role responsibilities. In this process, Parsons writes, the physician often serves as a court of appeal as well as a direct legitimating agent. A second closely related aspect is the institutionalised definition that the sick person can not be experienced to "pulling himself together" as an act of decision or will. According to Parsons *"his 'condition' must be changed, not merely his 'attitude'"* (op cit: 437). The third element is the definition of the state of being ill as itself undesirable with its obligation to "get well". The fourth closely related element Parsons describes is the obligation to seek *technically competent* help, in the most usual case, that of a physician and to *cooperate* with him in the process of trying to get well (emphasis in original). Being ill prompts both rights and obligations. Parsons further regards the expectations around sickness as normal and natural. See for example, his description of the sick-role (Parsons, 1951: 433-449).

The sick-role concept has been exposed of what Frank (1997) describes as a "cotton-industry" of critique, in which its relevance as a description of the illness experience has been questioned. The American physician and anthropologist Arthur Kleinman's study of *"patients and healers in the context of culture"* represents an important contribution to the body of literature that offered an alternative view (Kleinman, 1980). Kleinman made a distinction between disease and illness, in which disease refers to a malfunctioning of biological and/or psychological processes, while illness refers to the psychosocial experience and meaning of perceived disease (op cit). Biomedical models are disease-oriented and have little to offer in relation to healing of illness.

Parsons' sick-role concept is considered as a sociological legitimation of the biomedical approach to health and illness (Crossley, 1998; Frank, 1995; Gerhardt, 1989). Ill peoples' entrance into this role has later been described as an affirmation of the "restitution-story" about illness (Frank, 1995). It has been criticised for not being able to account for the experience of chronic illness (Bury, 2001; Crossley, 1998; Gerhardt, 1989), which is the illness condition under consideration in this study. In chapter one, I described cancer as a chronic-like condition.

In spite of the massive rejection of the modern sick-role and the restitution story as a reflection of the subjective illness experience in the medical sociological literature, the entrance into this role is still defined as “socially desirable” in late-modern western societies (Broom, 2001; Frank, 1995). Frank further argues that it is learned from the institutionalisation of biomedicine and its relentless focus on cure, from media, and from television. He describes medicine as an important power in the background (Frank, 1995). According to those who emphasise that there is a distance between socially desirable appearances and the subjective illness experience, a commitment to these expectations among those being ill contributes to hide and suppress important aspects of the illness experience (Broom, 2001; Frank, 1995). It is within these frames that the potential in online self-help groups emerges.

Parsons is one of the main proponents of a structural-functionalistic approach to social phenomena. Within this perspective, social behaviour is conditioned or shaped by forces which reside at the level of society as a whole, and in which societies are seen as persistent, cohesive, stable, generally integrated wholes, differentiated by their cultural and social-structural arrangements (Cuff et al., 1992). Peoples’ entrance into the sick-role is functional for the society as a whole. The critique of the sick-role concept has its point of departure in micro-sociological orientations, in which the local and situated accomplishment of illness comes into focus.

At a later point of time, the structural-functional approach to illness is further challenged by other structure oriented approaches in which the harmony of structural-functionalism is replaced by a conflict oriented view (Gerhardt, 1989). This chapter offers a more precise description of this development and the alternative views on the illness experience that are offered. The turning point is how the biomedical approach is related to the lay construction of health and illness. As will be shown, different conceptualisations of this relationship represent crucial underpinnings for the different approaches to online self-help groups that will emerge through the presentation.

Before I enter a further presentation of these perspectives, there is need to direct some attention to the inclusion of emotions in sociology. This is a development that has extended the scope of medical sociology. Through this extension, the limitations of the biomedical model and the Parsonian sick-role concept are investigated not only through a focus on the logic that people rely on in their "doing" of illness, but also on the feelings that are involved.

2.1.1 The inclusion of emotions

The pioneering work in sociological studies of emotions was first and foremost provided by Arlie Hochschild (1979; 1983) and Theodor Kemper (1978; 1981). Before these contributions, sociological theories had adhered to individualistic concepts in their analyses of emotions, if they had not neglected emotions totally (Turner & Stets, 2005), or viewed it negatively as failures of instrumental reasoning (Williams, 2000b). The Norwegian sociologist Dag Album (1993) comments that even in symbolic interaction, which has been so influential in micro-sociological analysis, the mental life of individuals had been conceptualised as rational and intellectual.

Following the "linguistic turn" in the social sciences, the given and natural (biological) nature of illnesses was exposed of critical attention and increasingly considered as socially constructed. In turn, the social construction of emotions gradually came into focus.
An illustrating example is the issue of fear. Through an increasing emphasis placed on the social construction of emotions, such individual experiences of fear is also related to the sociocultural response to death, and not only considered as an individually produced feeling. For example, the "sequestration of death" is described as an important aspect of social life in late modernity (Mellor & Shilling, 1993). This phenomenon is seen as a consequence of the

biomedical dominance and implies that death has become privatised and lacks legitimation in the public sphere (Giddens, 1991; Mellor & Shilling, 1993). It is further argued to contribute to explain the *"intense confusion, anxiety, and event terror which are frequently experienced by individuals before signs of their own mortality"*(Mellor & Shilling, 1993: 414). Such suggestions illustrate how sociology identifies a link between wider cultural systems and individual emotions.

Both Barbalet (1998) Williams (2000b) and Turner and Stets (2005) emphasise the importance of addressing emotions in sociological inquiry. Turner and Stets find the late emergence of emotions in sociology remarkable "*in light of the fact that emotions pervade virtually every aspect of human experience and all social relations; experience, behaviour, interaction, and organisation are connected to the mobilisation and expression of emotions"*(Turner & Stets, 2005: 1). According to Turner and Stets, emotions are the "glue" binding people together and generating commitments to large-scale social and cultural structures. Williams (2000b) describes emotions as the "functional prerequisite" for social order and social action and consider them as *"specific ways of being in the world"* (Williams, 2000b: 562). In the prolongation of this acknowledgement, emotions are considered a fundamental for how we "do" illness. For example, a belief in the ability of medicine to heal the ill body, may be considered as grounded in the fear that we can experience in times of illness, as well a rational commitment to the medical conceptualisation of the disease.

There is considerable disagreement within the sociological tradition about how individuals relate to wider cultural systems in the construction of emotions, and also to which degree emotions are socially constructed (Freund, 1990; Williams, 2000b). While the first debate is crucial in this thesis, the latter is not particularly addressed. In accordance with later contributions on this field (Barbalet, 1998; Turner & Stets, 2005; Williams, 2000b), I consider emotions as socially constructed, without excluding the influence of biology.

The inclusion of emotions in sociological studies of health and illness is fundamental for the effort in this study to understand how multiplied possibilities to exchange information and to engage in disembodied communication are responded to by women who are diagnosed with breast cancer. In the next section, I return to the debate on the relevance of the biomedical model approach in the lay construction of illness.

2.1.2 The sick-role concept and its successors

The critical thoughts against Parsons' sick-role concept had their origin in symbolic interactionism, which emerged as the leading perspective within the sociological tradition during the sixties, and in which the macro-perspective of Parsons was replaced by a more micro-oriented focus. In contrast to Parsons, this position acknowledges that the "societal reaction" to illness is open to a certain scope of negotiation. Normative evaluation ensuring a person's status and identity as ill is conceptualised as *fluid adaptation* to a situation *rather than standardised application* (my emphasis) of fixed rules. This constitutes links with the social order understood as "negotiative order" (op cit).

Within the interactionist paradigm, illness and disability is considered as a challenge to life style and identity. The general line of the argument is that the patient negotiates as much normality as can be mustered; normalisation is introduced as a basic strategy. An important point in this line of thoughts is that destruction of self can not be avoided. Accordingly, consequences of illness-related incapacities are depicted as self-loss (Gerhardt, 1989). This focus on a return to something "normal" illustrates some common dimensions with the Parsonian sick-role.

With his description of illness as a "biographical disruption" (Bury, 1982), the British medical sociologist Michael Bury stood out in these efforts to describe the illness experience (Pierret, 2003). This concept was introduced in 1982 and takes as a point of departure that illness, and particularly chronic illness, is a kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted. According to Bury (1982), chronic illness involves a recognition of the worlds of pain and suffering, possibly even of death, which are normally only seen as distant possibilities or the plight of others. It is however important to note that the sick-role is not fundamentally questioned as a position that is irrelevant or "forced" on the individual from this point of view. The tradition is rather part of the efforts to develop and clarify the sick-role concept (Pierret, 2003).

In her historical and intellectual overview of medical sociology, Uta Gerhardt describes the raise of both a phenomenological and a conflict-paradigm in medical sociology (Gerhardt, 1989). In contrast to what she describes as the interactionist paradigm introduced above, these positions are directing their attention to the "limited" value of the biomedical model and the accompanying sick-role from a lay point of view, while they at the same time offer a different diagnosis of how pervasive this frame is in the construction of illness. This is crucial for the view on self-help strategies that can be derived from these positions.

Transferred to the contemporary debate, it can be argued that phenomenological and the conflict-oriented arguments are reflected in terms of respectively "post-modern" and "post-structural" descriptions of illness (Williams, 1999). In the further descriptions of these paradigms in medical sociology, I will mainly stick to the post-modern and post-structural characteristics. My point is that crucial ideas in the phenomenological paradigm form the basis for post-modern readings of illness, while crucial ideas in the conflict-paradigm are reflected in post-structural readings of illness.

By drawing these lines, the risk of oversimplifying the development in medical sociology is apparent. This will for example be traceable in my outline of post-modern and post-structural readings of emotions. Within the early sociological literature on emotions, the different positions were described as respectively "social-constructivistic" and "positivistic"

(Kemper, 1981), in which the first can be argued to include both post-modern and post-structural readings. In their more recent contribution, Turner and Stets divide existing sociological theories on emotions into seven loose clusters (Turner & Stets, 2005). They describe a cluster of dramathurgical and cultural theories, of ritual theories, symbolic interactionist theories, symbolic interaction with a psychoanalytic focus, exchange theories, structural theories and evolutionary theories.

In this thesis, I describe the clusters that Turner and Stets (op cit) describe as dramathurgical and cultural theories on emotions on one hand, and structural theories on the other, as underpinnings of respectively post-modern and post-structural readings of health and illness. I will not enter into a detailed argumentation on the grade of correspondence between the positions. I am further aware that the divide between post-modernism and post-structuralism is blurred and that post-structuralism even is considered as one of many schools in post-modernism (Alvesson & Sköldberg, 2000). Again, my aim is to outline some main points of view in the sociological descriptions of health and illness, not to enter a fine-grained discussion of the concepts that are used.

I consider the post-modern and the post-structural positions as crucial premise providers for a debate on how online self-help groups can respond to the needs of women with breast cancer. In the following, post-modern readings will be argued to illustrate a potential in online self-help groups, while post-structural readings are connected to formulate a more sceptical position in relation to this potential. However, a main argument in this thesis is that in spite of their differences, post-modern and post-structural readings of illness have a common point of departure in the notion that medical thought represents an "outsider position" to the subjective illness experience. This term was introduced by Peter Conrad in 1987 (Conrad, 1987; Gerhardt, 1989). According to Gerhardt, Conrad identifies "outsider perspectives" with a medical or social theoretical perspective, in contrast to what he considers as the lay point of view. According to Conrad, Parson's idea of sick-role avails to no ”insider perspective”. In a later publication, Conrad argues that *”such concepts (the sick-role) are essentially ‘outsider’ perspectives on the experience of illness”* (Conrad, 2005: 130).

The common point of departure of post-modernism and post-structuralism is also commented elsewhere (Alvesson & Sköldberg, 2000). According to Alvesson and Sköldberg, a number or writers direct attention to their common denominators, such as the general questioning attitude, for example to the Enlightenment tradition which frames medical knowledge. As indicated previously, the conceptualisation of outsider and insider perspectives on illness that underpin these positions has been questioned (Bury, 1982; Crossley, 1998; Williams, 1999). While the limitations of the sick-role as a reflection of the illness experiences remains as a crucial point of departure, its position as an insider-aspect of illness is not fundamentally questioned. A crucial contribution from this investigation is a demonstration of the relevance of these contributions.

2.2 Descriptions of the outsider position of the biomedical approach

In this section, I outline the views that take the “outsider-position” of the biomedical approach as a point of departure in the construction of illness in further detail.

Within the phenomenological paradigm and the following post-modern readings of illness, considerable attention is paid to demonstrate the local and situational construction of illness. From this point of view, I argue that the outsider-position of the sick-role is positioned as irrelevant. As commented above, my argument is that such views frame the enthusiastic response to self-help groups and to be reflected in the broader governmental orientation towards the consumer-oriented new health care user.

By making this connection, it is important to be aware that post-modern readings of illness and the phenomenological paradigm thereby are linked to the neo-liberal ideas that characterises contemporary welfare states. This can appear as a too hasty made connection; the phenomenological paradigm did originally rise as an apolitical position (Gerhardt, 1989). According to Gerhardt, phenomenology further became the epitome of anti-elitist theorising in the euphoria of revolutionary spirit after 1968, and in spite of its lack of political intentions, it was ascribed a revolutionary impact in sociology. Throughout the seventies, it remained a metaphor for leftist standpoints. However, Gerhardt writes in 1989 that the paradigm tends to be deemed as politically non-leftist and connected to the "New Right". In the mid-eighties, Bury presents a corresponding comment, directing attention to the raise of alternative medicine and the challenge towards scientific medicine: "*It is ironic that those 'radicals' advocating alternative medicine find themselves reproducing the self-same values (consumer choice and producer competition) which underpin the major structures of contemporary capitalist society"* (Bury, 1986: 162). One reason for this assumed connection to neo-liberal ideas might lie in the view on biomedicine as one out of several approaches to health that is characteristic for this paradigm. It adjusts for the much referred image of the health care consumer who does not accept expert views on face value.

Within the conflict paradigm and the following post-structural readings of illness, considerable attention has been paid to demonstrate the pervasiveness of the biomedical frame and how the lay construction of illness is subordinated to this frame. This position can be argued to underpin the scepticism that is expressed towards the governmental focus on empowerment and which was described in the introductory chapter. As will be outlined in more detail later in this chapter, this scepticism is due to the individual responsibility that is underscored within the biomedical approach.

2.2.1 Post-modern readings; the irrelevance of the biomedical approach

Post-modern readings of illness reject the "suffering self" and the work towards normalisation which is a crucial part of the interactionist paradigm and which represented the first efforts to develop and clarify Parsons' sick-role concept. From a post-modern point of view, *"issues such as biographical disruption and the search for meaning and legitimacy, merely serves to 'fabricate' a subject who is effectively 'trapped' within her/his 'pained' body and is required to 'adjust' or 'adapt' to the limitations this engenders*" (Williams, 1999: 802). The anatomical body is not the "carapace" of the self. If the self does inhabit such an interior location, then this is seen as a consequence of discourse. Discourses within the medical and human sciences then, do only contribute to particular views on the pained "Body Without Organs" (op cit).

The American sociologist Arthur Frank's contributions serve to illustrate the assumed irrelevance of the biomedical approach and the modern sick-role in further detail (Frank, 1995; Frank, 1997). In his book, *"The wounded storyteller. Body, illness and ethics"*, Frank (1995) describes three storylines that are available to ill people in late modern societies. These are the story about restitution which was introduced in the introductory part of the chapter, the quest-story and the story about chaos. The storyline about restitution has the basic storyline *"Yesterday I was healthy, today I'm sick, but tomorrow I'm healthy again"* (Frank, 1995: 77). As described, Frank equates this story with the modern, or Parsonian sick-role, and in spite of its dominant position, he emphasises its irrelevance as self-story, or reflection of the subjective illness experience.

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. It is not only a condition that is to be "passed", as signalled by the modern sick-role and the restitution story. Quest stories meet suffering head on; they accept illness and seek to use it. As such, an image of the individual hero often emerges. Quest stories further tell us that learning the integrity of suffering is central to the boom (Frank, 1995). Published stories are often stories about quest and reveal an image of the individual hero. According to Frank (op cit), and also commented by Seale (2002), quest stories are often seen in media portrayals of ill people. Giving the quest status as a self-story, or reflection of the subjective experience, Frank is aware of the risk of these stories of presenting the burning process as "too clean" (Frank, 1995: 135). However, he emphasises their ability to illustrate the "potential consciousness" of the illness experience (Frank, 1997) and which might be best equated with the inspiration from role-models, which is a crucial aspect of the gain provided by self-help groups (see for example Yaskowich & Stam, 2003).

The story about "chaos" is argued to be as anxiety provoking as the restitution story is preferred (Frank, 1995). 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. According to Frank, there is need to create a space for these aspects of the illness.

It is important to be aware that Frank (1995) describes these stories as "listing devices", or "ideal types". He underscores that people tell their own unique stories, but argues they compose these stories by adapting and combining narrative types that culture makes available. Ideal types provide a reflexive medium, a language, for talking about what is particular in real bodies. Actual tellings further combine the different types, which is also an important point to have in mind. Few stories about illness are without elements of chaos. The point made by Frank however, is that the dominance of the restitution story needs to be challenged in order to support people in doing their illness in accordance with their subjective experience.

In his article from 1997, Frank continues this line and argues that serious illness calls for the ill person to “rise to the occasion” and to become successfully ill. He argues that the process of becoming successfully ill begins with resisting the biomedical rhetoric and accepting that the problems are not going to go away. However, through the preference for the “restitution story”, or the entrance into a modern sick-role, in many of the social relationships in which ill people are engaged, Frank considers the return to health as the single moral expectation of the patient, and the physician is to facilitate that return (Frank, 1997). He considers this as being close to a denial of the moral life of ill persons and calls for greater attention to this aspect. Frank emphasises the importance of ill people acting as persons who suffer and to a less degree fulfilling external expectations about restitution. Then, being “successfully ill” and rise to the occasion is not only a potential, but a lived reality.

It is on this backdrop the irrelevance of the medical model emerges and further a critique of symbolic interationism becomes visible. For example, Frank (1997) introduces his article about illness as a moral occasion as following: *“Is medical sociology prepared to cast off its Parsonian origins and begin to take seriously what has been scrupulously avoided: the moral life, and the moral agency, of people being seriously ill?”* (Frank, 1997:131). He still acknowledges that his notion of being successfully ill - and related to this context, efforts to adjust for this process - places another imposition on the ill. He further comments that Parsons’ positive contribution was to assert that patients are not responsible for their diseases. However, his argument is that those who are suffering already are bearing a considerable burden in finding out not only what do do, but who to become to live with the consequences of the illness. It is here that biomedical approach and the Parsonian sick-role has little to offer.

Illness as a local and situational accomplishment

As indicated previously, post-modern readings of illness, such as Frank's (1997) call for ill people being successfully ill, are here linked to crucial ideas in what Gerhardt (1989) has described as the phenomenological paradigm in medical sociology. I use her overview in order to sum up and clarify the position further.

According to Gerhardt, the closeness of this tradition to symbolic interactionism was soon acknowledged. Throughout the seventies various attempts were made to demonstrate that no irreconcilable cleavage existed between the two micro-approaches, particularly in the light of their both focusing upon face-to-face interaction rather than structural norms and values. However, in contrast to symbolic interactionism, the phenomenological position does not adopt the idea of the sick-role, and offers then a critical view on the self-loss that is characteristic for the interactionistic view (Williams, 1999). Illness is frequently not distinguished from crime. Both are viewed under the perspective that it is the *same* social processes which make for their intersubjective construction.

One idea that is crucial within the phenomenological view, and which is of considerable importance for the discussion in this thesis, is the local and situational focus on health and illness. The phenomenological paradigm attempts to show that social systems, such as the socio-cultural response to illness, are but the outcome of continuous processes of accounting and accomplishing whereby individuals take interpersonally monitored decisions (Gerhardt, 1989). Competence as an agent of moral conduct and social control, in turn, constitutes the essential presupposition of membership in society. This focus is reflected in the above description of illness as a moral act (Frank, 1997).

Gerhardt (1989) considers the basic idea in phenomenology regarding illness is that it drastically diminishes a person's moral status. Illness, as latent absence or impending reduction of moral quality of the person, constitutes trouble and is liable to invite normalisation efforts. Ill people use repair strategies guaranteeing as much normality as the sick person’s family and friends may feel necessary to function as an intact membership group. Illness belongs to a broad category of disturbing occurrences (accidents or achievements) which breach the taken-for-granted peace of everyday routines. It constitutes trouble, because it may break the trust of others. Peoples’ moral status is not only linked to the intellectual character of the individual, but also to the physical (Album, 1996).

However, even though illness is considered as situational managed from a phenomenological point of view, it still invites the discretionary use of official routines in dealing with it (Gerhardt, 1989). One of these routines is the use of an expert. Medicine, as well as the law, fulfils the function of re-establishing trust where trouble has proved unmanageable among those immediately concerned. According to Gerhardt however, medical issues never occupy as much of the forefront of phenomenology’s concerns as problems of medical practice are core matters for structural functionalism and mental patients’ plight spurs on symbolic interactionism. Doctors actions are frequently disregarded, or mentioned as only one among many sources of medical help, as illustrated in the presentation above.

Phenomenology places considerable emphasis on the fact that trouble, as well as trust, are related to modes of speaking about them. This is another idea that is crucial within this paradigm, but which is paid less attention in this thesis. Biological processes behind the burden of illness are not mentioned (Gerhardt, 1989), or becoming an implicit, rather than explicit theme (Williams, 1999). Medical help is further perceived as organised in a linguistic domain and knowledge frame of its own. The socially constructed dimension of illness represents a crucial point of departure for most contemporary sociologists, while there is a debate on the degree to which such processes illuminate the emergence of illness (Williams, 2000b). As indicated previously, I consider this debate as too fine-grained for the aim of this thesis.

My argument here is that the situational focus of this perspective offers a sociological frame for the notion of the consumer oriented health care user and for the enthusiastic view on technology. As commented in chapter one however, it is important to be aware that the phenomenological paradigm should not be used to defend technology optimism in its “pure” expression, such as described by Wynn and Katz (1997). It seems more likely to argue that it rather forms an important basis for research that emphasises the ”technology-in-action” (Timmermanns & Berg, 2003), which also ascribe considerable emphasis to the influence of technology.

Within post-modern readings of illness, emotions are considered as situational dependent. This “plasticity” of emotions is further outlined below.

Situation-dependent emotions

A post-modern approach to emotions can be illuminated by the description of emotions that is offered by the American sociologist Arlie Hochschild (1979). Hochschild has mainly applied her theoretical framework on occupational roles and marital roles (see, for example Hochschild, 1983), but it has also been applied in research on the illness experience and patient roles (Exley & Letherby, 2001; McKenzie & Crouch, 2004; Williams, 2000a; Williams, 2000b).

In her essay from 1979, Hochschild proposes an emotion-management perspective. She argues that the individual often works on inducing or inhibiting feelings so as to render them “appropriate” to a situation (Hochschild, 1979). She postulates that societies reveal an emotion culture consisting of a complex set of ideas about what people are supposed to feel in various types of situations. This culture is composed of emotion ideologies about appropriate attitudes, feelings, and emotional responses in basic spheres of activity. In any specific context of activity, there are two basic types of norms. One type is feeling rules, which specify the emotions that individuals should feel and experience in a situation, as when one is supposed to feel sadness at a funeral or happiness at a cocktail party. The second type of norm is display rules, which specify when and how the overt expression of emotions in a situation is to occur, such as crying at a funeral and laughing at a party.

According to Hochschild, when individuals follow these display rules, they are engaging in surface acting, which involves changing one's outward appearance and behaviour so that they are consistent with normative expectations. One example is to "put on a happy face" to sustain an encounter where display rules require they should feel happy (Hochschild, 1979; Turner & Stets, 2005). Hochschild (1979) proposes that for many situations, people must engage in *emotion work* or *emotion management* to maintain a presentation of self that conform to emotion ideologies, feeling rules and display rules. She pays particular attention to situations in which cultural scripts force people to engage in behaviour that arouse negative emotions. When displayed feelings repeatedly must depart from inner feelings, she argues that self-estrangement, alienation, and feelings of inauthenticity are likely to emerge. It is in these situations that emotion work will be evident. This description gives associations to arguments about an isolating experience of breast cancer, see for example Broom (2001), McKenzie and Crouch (2004) and Høybye et al (2005), and to Frank's (1997) call for sociology to be aware of the moral act of being ill.

Hochschild has been particularly inspired by Goffman, see for example Goffman (1974), Goffman (1967) and Goffman (1959). Within this perspective, interaction is considered as guided by a script written by culture. It is however important to note that within this view, culture is not a straight jacket, although it is constraining, all actors are given some dramatic licence in playing a role. Impression management and strategic behaviour are important keywords for her description (Turner & Stets, 2005). There is still a disagreement on the consciousness given to the actor in Hochschild's work. In a comment to this proposal, Turner and Stets (2005) argue that this emotion management is not simply emotional control or suppression in a Goffmanian sense. It can include this, but it also includes changing the type of emotion one is feeling. In acting, actors hope to feel and experience the emotion that their gestures are supposed to signal. According to Turner and Stets (2005), Hochschilds adopts elements of Erwin Goffman's analysis, while adding a critical edge that is more reminiscent of Marx' view on alienation. For Hochschild, they argue, individuals often engage in strategic performances that are not gratifying. Cultural scripts often impose requirements on persons that are stressful, if not alienating (Turner & Stets, 2005).

Other authors (Album, 1993; Kemper, 1981) locate her work in a tradition that holds that there is a great plasticity to human emotions because emotions are largely disconnected from biology. In addition, the "licence" given to actors gives associations to the local and situational focus which is crucial within post-modern views. This focus is important for my categorisation of her work within a post-modern frame.

2.2.2 Post-structural readings: the dominance of the biomedical approach

Post-structural readings of illness are in accordance with post-modern readings in their view on the illness experience as socially constructed and on biomedicine as a language on health and illness on its own. They deviate from post-modern readings in their emphasis on the pervasiveness of the biomedical approach in peoples' construction of illness. A situational focus is maintained, but macro-structures within situations are accounted for and the agency of social actors, or "licence to play a role" is toned down. It might be argued that it is not the "local" competence described by Frank (1997) that is in focus, but rather the work to do illness in accordance with dominating views.

The emphasis placed on domination and subordination

As argued in the introductory part of the chapter, I consider crucial ideas of what Gerhardt (1989) describes as the conflict-oriented paradigm in medical sociology as fundamental in post-structural readings of illness. In its origin, the conflict paradigm emerged out of an increased interest in how social contradictions abide during the seventies (Gerhardt, 1989). Social interaction is understood in terms of domination and subordination. During the seventies, it emerged as an alternative to the preoccupation with harmony as the essence of social order, which had been dominating in sociology. Harmony between social forces was considered as a product of stifled conflict, and conflict was not confined to the political but extended to all realms of life. This position fully embraces the topics of ideology, domination and inequality to understand society as a web of conflict production. Inequality in society documents the fact that conflict is suppressed by those who are in power, and kept latent through means of intimidation and indoctrination (op cit).

Through the raise of the conflict paradigm, Gerhardt argues that Marx was revitalised as one of the classical theoreticians in sociology, but his work is taken to signify a point of departure rather than a credo (Gerhardt, 1989). In the renewed version, this Marx-inspired perspective extended its focus from different access to material goods to unequal conditions of consciousness in society. The powerless would be assumed to go along with the dominants' world view and suppress their own regarding power and equality because of false consciousness due to ideological indoctrination. From this, the "medicalisation of life" thesis emerged, in which one of the central aspects is the tendency to perceive the aetiology of social problems in individualistic terms and to "depoliticise" social problems (Strong, 1979; Williams, 2001). According to Williams, this thesis took on altogether new dimensions from the early 1980s, in the guise of Foucault's contributions. Foucault is rather apolitical in his approach to power, but processes of domination and subordination is still emphasised in his theoretical framework (Cuff et al, 1992).

In the mid-eighties the conflict-perspective was described as ”the” leading perspective in medical sociology, and considerable attention was paid to deconstruct or to demystify medicine (Gerhardt, 1989). Gerhardt comments that many sociologists feel justified in taking an anti-medicine view, because they are convinced that the medical profession is far too entangled with the upper classes to do all it could be for the benefit of the powerless. The class conflict extends to medicine insofar as the medical profession is part of the ruling class whose ideologies doctors willingly or “blindly” impose upon their patients.

According to Gerhardt (1989), the firm belief regarding illness within this paradigm is that inequality is one of the major sources of suffering in modern society and it is from this point of departure illness is described. Inequality is again an expression of covert or overt social conflict. Social factors characterising the individuals’ position in society are understood to define a degree of general susceptibility to disease to which is each group is prone. Both the biological and the social side of illness are now seen as interrelated such that physiological lesions are traced to antecedent conditions characterising the social situation of the patient. These conditions can be both psychosomatic - such as anxiety, hopelessness and helplessness – and sociosomatic – such as environmental factors and behavioural factors as industrial hazards, smoking, excessive alcohol consumption, which again is related to peoples’ social status. Within this view, the individual is seen as an incumbent of multiple roles or statuses each of which may carry a risk of or susceptibility to sickness or premature death (op cit).

Gerhardt (1989) further makes the point that in this awareness of domination and subjugation, knowledge is explicitly included. No longer is science excluded from the sociologist’s gaze identifying relativity of seemingly objective discoveries, and the notion of ideology became prominent in these neo-Marxistic thoughts. Medical science and technology were critically approached, and the focus on social interest in knowledge production was pervasive (Knorr-Cetina, 1982; Sismondo, 1993).

Compared to post-modern readings of illness, medical conceptualisations are still ascribed a more crucial role in peoples' experience of illness, and is further argued to lead to a suppression of their subjective experience (Gerhardt, 1989). Through the adoption of this view and the critical approach to medicine, medical sociology extends the clinical gaze into areas hitherto excluded from the realm of medicine. Social relationships as well as life styles become relevant for medicine because they prove to be important aspects or precursors of illness. That medical practice is accepted by the public as seemingly effective and efficient in dealing with health matters must be traced to domination over the working-class population, but also to other subordinated groups in society (op cit). As an example, feminist authors have connected the biomedical approach to a masculine world-view, aiming to further illustrate the subordinated position of women with breast cancer (see, for example Pitts, 2004; Potts, 2000).

In this feministic literature we see the revised version of the medicalisation thesis that emerged through the Foucauldian insights, and in which clinical gaze is seen as entering peoples' everyday life (Rose, 1999). Included in this view is a more critical approach to a potential circulation and consolidation of heroic stories about illness than was expressed by Frank (1995). An extension of the individualisation that is characteristic within the biomedical paradigm is seen in the circulation of such stories. On this backdrop, a critical view is also offered on the activity on the Internet (Broom, 2001; Pitts, 2004). While hoping for liberation of suppressed aspects of the breast cancer experience, there is a fear that these aspects are further suppressed.

To sum up then, the influence of macro-structures - both in material and intellectual/symbolic forms - is emphasised in this perspective. Relatively few theories are still developed on how social structures determine the arousal and flow of emotions (Turner &

Stets, 2005), but it can be argued that the issue of vulnerability is crucial and of particular importance to illustrate a post-structural view on the potential in online self-help groups. I turn to this below.

Emotions and vulnerable positions

The work of Jack Barbalet (Barbalet, 1998) gives an intake to describe the influence of social position in the construction of emotions. What is important to note about Barbalet however, is that he offers some critical comments to the exclusion of biology that lies inherent in the post-structural perspective. The reason to describe his framework within the post-structural "umbrella" is that it takes account for the influence of social position that is crucial in post-structural readings of illness.

Barabalet (1998) argues that emotions arise from macrostructural processes as they impinge upon individuals in micro-encounters. Important for the discussion in this thesis is that his work is argued to enter into a body of research that emphasises how emotional energy is sustained across situations (Williams, 2000b), as he directs considerable attention to those who have the emotions, or more precisely, their social position. This is not accounted for in a similar manner within post-modern readings of illness.

From this viewpoint then, accumulations of positive and negative emotional experiences, including feelings of pride or shame, mesh more or less with broader patterns of structured dis-advantage, power, status and prestige across historical time and space (Williams, 2000b). Differing modes of emotional being then are different felt ways of feeling empowered or disempowered. In his contribution to how emotions can be approached from a macro-perspective, Williams comments that *"More precisely, a person's social position and status will determine the resources they have at their disposal in order to define and protect*

(…) the boundaries of the self, and to counter the potential for invalidation by powerful and significant others" (op cit: 568).

Through feministic authors as Sontag (1979)and later Broom (2001), Potts (2000) and Pitts (2004), such ideas have been made present in breast cancer research. Broom, for example, describes the experience of breast cancer as a four-way intersection which she considers as a move towards specifying how *"socio-cultural fears about death, disease, sexuality and femininity converge to isolate and silence women who are diagnosed, to frame their choices and experiences, and to shape their stories"* (Broom, 2001: 249). Though such analysis', the vulnerable position of women with breast cancer is emphasised.

An interesting point in relation to the potential role of self-help is that Barbalet (1998) considers emotions as physiological states that influence on how people act. These states sometimes become conscious feelings and at other times remain subliminal or unconscious. For example, a feeling of vengefulness can arise and indicate that "basic rights" to form meaningful social relationships and cooperate with others are threatened. According to Barbalet, those who feel their rights have been violated will then seek to gain power in order to realise their rights. As these emotions are experienced collectively in response to their exposure to similar structural conditions, emotions prompt individuals into collective actions that can alter macro-structures.

The critical point then, is the consciousness about such feelings. Based on this perspective, it can be argued that the consciousness about dominating and subordinated positions was salient in the self-help movement during the seventies, at a time when their political content was salient (see for example Kickbush, 1989). Sociologists who committed themselves to the conflict-oriented view then considered self-help groups as important tools for a collective uprising towards the dominant medical perspective. Self-help groups were closely linked to the efforts of regaining power for lay perspectives on health and illness

(Withorn, 2005). According to Withorn, the feminist movement was particularly active, beginning to explore and share a growing criticism of the medical “knowledge” about women’s bodies.

Worries about a too “weak” consciousness about a subordinated position, and thereby the power to make a change, can be argued to underpin the expectant approach to the contemporary focus on self-help groups within post-structural readings of illness. A Norwegian study on women with chronic pain (Werner et al., 2004) might serve as an illustrative work in this tradition. These authors described the women’s descriptions of themselves as a gendered work of credibility as woman and as ill. They argued that the interviewed women negotiated a picture of themselves that fits with normative, biomedical expectations of what illness is and how it should be perceived or lived out in “storied form”. However, behind these stories about own strength, the authors further argued that they heard “whispering voices” that signalled rejections of the stereotype medical account of the crazy, lazy, illness-fixed or weak woman patient. Transferred to Barbalet’s terms, it might be argued that the consciousness about the suppression of their lay point of view was not solid enough to be transformed into a resistance to the dominant view. As such, worries about a further circulation of socially desirable stories about restitution or new wisdom come into the foreground, see for example Broom (2001) and Pitts (2004).

It is however important to have in mind that the categorisation of outsider and insider perspectives that forms the basis for both post-modern and post-structural readings of illness has been questioned. I use these insights to formulate a third perspective on the potential role of online self-help group in breast cancer rehabilitation.

2.3 Reconsidering the insider aspects of the illness experience

As indicated in a previous part of the chapter, the idea of the outsider-position of the biomedical approach in lay construction of illness is less prominent within the interactionist perspective on illness. For example, the Parsonian sick-role is not fundamentally questioned as a position that is irrelevant or "forced" on the individual. Instead, it is considered as part of a broader spectre of roles that the individual enters through his or her illness trajectory. The idea of deviant identity is further not adopted, and normal identities are understood as the sole worthwhile reference points of patients' self-image. This point of view has been particularly made visible by Bury's conceptualisation of illness as a biographical disruption. However, as indicated in the beginning of this chapter, this perspective came under increasing attack through post-modern and post-structural readings of illness.

Offering a kind "modernist defence" to the post-modern and post-structural critique, Williams (1999; 2000a; 2000b) argues that the arguments offered by the post-modern and post-structural positions have something of a hollow ring into to it in the context of pain and sickness, disability and death. When the "chips are down" he argues, *"when illness throws our taken-for-granted assumptions about our bodies and selves into critical relief, modernist medicine may indeed seem preferable to the 'deconstructive spirit' of post-modernism"* (Williams, 2000a:47).

One of the premises of this position is that illness as a biological fact is distinguished from illness as a social reality. The dual nature of illness is emphasised. In its origin, this premise gave rise to the criticism raised against the medical model. In this context however, it represents a way of distinguishing the interactionist model from the more radical stances of post-modern and post-structural readings of illness. The argument was underscored by Michael Bury in his article about illness as a "biographical disruption" from 1982. Bury acknowledged that the deep involvement of medicine in reorganising the disruptive experiences of chronic illness inevitably involves issues of social control, and that it is important that medical sociology sees to explore this. But to *"suggest, as some writers do, that the experience of pain, illness and even death, can be faced without recourse to such codes is patently false"* (Bury, 1982:179). According to Bury, this thesis remains sociologically naïve. He argues that the assessment of medicine's role as a symbolic system, in *facilitating*, as well as *constraining* understanding and action (my emphasis), is jeopardised by the continuance of a one-sided portrayal of medicine's negative influences in much sociology.

Bury defended his position towards authors who paid considerable attention to medical domination and the "medicalisation of life" thesis. According to Bury, the fact that people may not experience the processes that are alleged to be taking place is either ignored or not taken as damaging. Bury argues that separation of disease from self is a powerful cultural resource. To be able to hold the disease "at a distance" assists the claim that one is a victim of external forces. *"To do anything less is to fully accept the burden of responsibility"* (Bury, 1982:173). In a similar vein, Crossley (1998) illustrates how HIV-positive individuals reject "obligation" elements of the traditional sick role, at the same time as she argues that this rhetoric of empowerment co-exists uneasily alongside a number of presupposed sick-role-like tendencies.

In this exploration, the reconsideration of the insider-aspects the illness experience is taken further. It will be traced in an exploration of the relationship between socially desirable doings of illness and the lay perspective, which is an underpinning theme in the articles from this study, and which I consider as influential for the potential role of online self-help groups in breast cancer rehabilitation.

Methods and Methodology

As described in the introduction, this exploration of the potential role of online self-help groups in breast cancer rehabilitation is conducted through an action research approach. It included establishment and management of an online self-help group. Action research enters into the domain of applied research and has two central concerns – improvements in practice and increased knowledge and understanding. Action research is distinctive in the sense that the researcher also has a double role as both implementer and as evaluator of the change (Finne et al., 1995; Olsen & Lindøe, 2004). Its focus is on enhancing learning processes to support an organisation's or a community's capacity to solve pertinent problems (Finne et al., 1995). This study intended to contribute to the efforts to diminish the "empty space" that has been present in cancer care (The Ministry of Health and Social Affairs, 1997).

3.1 The study

The study was initiated by the Norwegian Center for Telemedicine (NCT). NCT is a centre of competence on telemedicine and ehealth, which gathers, produces and disseminates knowledge about telemedicine services and whose aim is to ensure the integration of telemedicine services. The centre is ascribed a role as a "national centre of competence" on telemedicine by the health care authorities in Norway. It is located within the professional health care system, more precisely as a division within the University Hospital of Northern Norway. The activities on the centre are partly funded through public resources and partly through external funding. Research on health care users' needs for and experiences with ICT, or e-health, represents one area of activities that are undertaken. I was engaged in the year 2000 to take part in these research activities.

The idea of exploring further the potential role of online self-help groups for breast cancer patients arose during the spring 2001. At this point of time, online self-help groups received increasing attention as a promising tool for improving health care (see for example Burrows et al., 2000), and we considered it as an important area for further research on ehealth services. As described previously, cancer patients - and particularly breast cancer patients – had already positioned themselves as active users of existing services on the Internet and were encountering challenges related to the diagnosis that made them to a potential target group for a broader focus on online self-help services.

The study has been conducted in collaboration with the Norwegian Cancer Society (NCS) and the Norwegian Breast Cancer Society (NBCS). NCS is a non-profit non-governmental organisation that works to reduce the incidence of cancer, to increase the recovery rate and to increase quality of life for those who are diagnosed with cancer. The organisation further gives financial support to research on cancer. In Norway, the voluntary sector functions as a “prolonged arm” of the professional sector, and NCS represent one of the crucial actors in this work (Thuen & Carlsen, 1998). The NBCS is an independent organisation, but is affiliated to the NCS, for example by sharing administrative resources. Of importance here is that their websites were part of the internet-based services that was offered by the NCS. For example, the NBCS could not decide on their own whether the organisation could establish online self-help groups for women with breast cancer. Both the NCS and the NBCS responded positively to the question from NCT about designing a study that could provide more insight into the potential of online self-help groups in breast cancer rehabilitation. In co-operation with representatives for all three organisations, I administered the process of designing the study and managed the further progress when a funding for the study was acquired. The funding was given from The Foundation for Health and Rehabilitation.

Online health services were not considerably developed when we started to work with the study (2003), and there was a great need for clarifications of how we could ensure that juridical and ethical aspects were accounted for when establishing an online self-help group. The ethical considerations are outlined in the final part of this chapter.

The online self-help group was accessible during 15 months - between late October 2003 and the beginning of March 2005. I come back to a further description of the informants and the activity in the group later in the chapter. The NCS withdrew as active participator in the study in April 2004. They considered the response to the service to be modest and decided not to implement online self help groups as part of their ordinary services at that moment of time (attachment 9). After this decision, my dialogue with NCS about a further development of the service was not maintained. Their withdrawal took place about 6 months after the group was established and at a point on which it was actively used by a small group of participants. However, my communication with the Norwegian Breast Cancer Society was maintained for a longer period.

Below, I present the action research framework in further detail.

3.2 The action research framework

In the introduction to this chapter, I described action research as an approach that focuses on enhancing learning processes to support an organisation's or a community's capacity to solve pertinent problems (Finne et al., 1995). The method has its origin in the pragmatism of John Dewey and the research conducted by the "Chicago-school" during the 1930s and 1940s. The term "action research" was introduced by the social-psychologist Kurt Lewin, as a model for generating knowledge about, and change, social systems (Hansson, 2003).

After being introduced by Lewin, the ideas of action research were particularly taken further by the Tavistock Institute in London (Cullen, 1998; Reason & Bradbury, 2006a). This institute was originally established (in 1920) to research and develop treatments for the range of “neurotic disabilities” encountered in the First World War, but began during the latter stages of the Second World War to orient itself towards wider social problems outside the area of mental health. According to Cullen (1998), the work in this institute was reflected in characteristics as the social engagement of social science, the future orientation of this engagement, with a commitment to innovative practices. The application of “action research” became the main methodological vehicle for social engagement. After the early medico-military work, this trademark was brought to organisational change and to sociotechnical innovation in the coal, petrochemicals, and automobile industries (op cit).

The “Tavistock- researchers” further cooperated with Norwegian researchers to develop the framework further. The “climate” for sociotechnical changing processes in working life was better in the Scandinavian context than in Britain, in which the relationship between industrial leaders and the workers was more tensed. Active participation in changing processes became in the forefront in these activities, while the research remained more in the background. The sociotechnical ideas for changes in working life then spread to Sweden and other countries and back to the United States (Hansson, 2003). Action research did get a foothold in Norway, and the activities conducted at both the Institute of Social Research in Industry in Trondheim and the Work Research Institute in Oslo have contributed to a maintenance of these activities during the latter decades.

Generally spoken, the turn to action research has often evolved as a response to widespread non-utilisation of evaluation findings and the desire to create forms of evaluation that would attract champions who might follow through on recommendations with meaningful action plans (Lincoln, 2001; Morrison & Lilford, 2001; Reason & Bradbury, 2006a). Lincoln comments that in those instances where research has clearly impacted policy, those to whom the policy is directed, or the stakeholders, have rarely been consulted regarding how their needs might be met. Consequently, policies are frequently viewed as misdirected by stakeholders and as wasteful and useless by both founders and taxpayers alike. Through dialogue, action research tries to bridge this gap between researchers and stakeholders (Lincoln, 2001).

At the same time, rationalist objective science has grown rapidly in international prominence during the last decades. This growth has taken place as a means of ensuring that health care professionals provide effective and efficient care and that public health interventions are demonstrably effective before they are funded and implemented by governmental authorities (Lambert et al., 2006). This framework now plays a fundamental role in many national health systems, not only in guiding clinical practice but also in shaping research agendas, formulating policy and allocating financial resources (op cit). Randomised controlled trials (RCT) represent the "gold standard" within this paradigm to improve practice and have become paradigmatic for medical knowledge production. Roughly spoken, RCT tell us if something "works" or not, and the focus is on the *outcome* of the evaluation (op cit). Potential weaknesses of RCT studies are however commented (Lambert et al., 2006). According to these authors, patients' views on what "works" often differ from those of researchers and practitioners, and particular tensions arise in attempting to combine, or balance, evidence-based approaches to health care with the views and preferences of patients receiving health care. Sandelowski (2004) further argues that proponents of evidence-based practice note the importance of including patients' preferences and values in treatment decisions while also directing attention to critics who argue that these have yet to be discernibly included in the evidence-based practice process. Such contributions underscore a need to consider alternative evaluation approaches when exploring the potential of new treatments or rehabilitation services. In accordance with these comments, Morrison and Lilford (2001) argue that the shortcomings of the rationalist scientific approach begin to come to light, because of the adoption of overly simple models of how, for example, doctor, patient and treatment interact. According to Morrison and Lilford, the appropriate response to this is to see how these models can be developed or replaced by others that are better able to take account of the complexities. In recent years, action research has again received increased attention in western welfare states as a potential approach to develop health care (Cullen, 1998; Khanlou & Peter, 2005; Morrison & Lilford, 2001)

The prominent position of the rationalist science in health care and the emerging critical voices is important to assess in this effort to describe the use and position of action research in health care. However, beside an emerging critical attention to conventional approaches in health care development, a further backdrop for an increased receptivity for action oriented studies lie in the changed illness pattern in western societies. For example, through the transition from acute to chronic illnesses there are increasing demands for health care for more complex medical conditions over prolonged periods (Bury, 2001; Cullen, 1998; Lupton, 1997; Ziebland, 2004). Management and care have superseded treatment and cure (Gerhardt, 1989) and has made the context of treatment and rehabilitation more complex. Further, Cullen (1998) directs attention to the increasing utilisation of sophisticated technologies, among them information technologies, to respond to these pressures. According to Cullen, governments and health care providers are exploring ways in which the administrative and organisational structure of health care can be adapted to reduce costs while maintaining or improving quality of care, also acknowledging that the users of health care are getting more informed and make increased demands. Cullen proposes that there is an organisational re-engineering that provides the spaces and contexts in which action research can re-invent itself (op cit).

3.2.1 Doing action research

Morrison and Lilford (2001) describe five tenets of what they consider as an "idealised" action research approach; their first point is the *flexible planning tenet*, which implies that the detailed content and direction of a research project are not to be determined at the outset. These take on a definitive shape only as the work progresses and are kept continuously under review. The second point is the *iterative cycle tenet*. Research activity is to proceed on a cycle of a)considering what the problem to be researched is, b)proposing action to solve the problem, c)taking action, d)learning lessons from the results of that action, e)reconsidering what the problem is in the light of those lessons, and so back to b) and through the cycle again as many times as necessary. Each phase involves consultation with all interested parties. The third point is the *subjective meaning* tenet. The situational definitions and subjective meanings that those directly implicated in the problem being researched attach to it must be allowed to determine the content, direction, and measures of success of a research project. As a forth point, Morrison and Lilford propose the *simultaneous improvement tenet*. A research project must be set out to change the problem situation for the better in the very process of researching it. This tenet means that action research is sometimes seen as a way of intervening to solve an organisational problem as well as an approach to research. Their fifth and last point is *the unique context tenet.* A research project must explicitly take into account the complex, ever-changing, and hence unique nature in which the project is carried out.

My role as implementer in this study became particularly obvious in efforts to ensure an optimal function of the online self-help group. These efforts are traceable through two main activities. First, I intended to facilitate use of the service and to ensure a supporting community in the group. Second, these efforts to ensure an optimal function included an immediate use of data. The experiences were continuously assessed and incorporated into the further development of the actual service. The challenges and advantages related to the double role of the action researcher are further discussed in the forth article of this thesis.

Action research is conducted at several fields and in different forms. One way of conceptualising a strategy for conducting action research is to divide it into a first-, second- or third person inquiry (Ladkin, 2007; Reason & Bradbury, 2006b). Third person research aims to create a wider community of inquiry between people who may not have face-to-face contact, but who share a common interest. Ladkin comments that Participatory Action Research (PAR) is a good example of third person research practice. In second-person inquiry, an issue of common concern or interest between people in a small group is in focus. First-person inquiry is inquiry into how the researcher her or himself makes choices, frames experiences and behaves (op cit). According to Ladkin, critical subjectivity is a key component of each of these strategies, but is perhaps most apparent in first-person inquiry. This study falls into the category of third-person research, due to the aim of facilitating a “doing” of breast cancer that is helpful for women who are diagnosed with the illness.

Before I turn to a methodological positioning and the implementation of this study, I will make some further clarifications of the action research framework.

3.2.2 Possibility or aspiration?

One point that calls for some comments is how the five tenets of action research should be realised for the categorisation of a study as action research. As indicated above, Morrison and Lilford describe the five tenets as idealised action research. These authors emphasise that their use of the expression “idealised action research” can be understood in one of two ways. Taken in the first way, pieces of actual research would be assessed against the ideal and regarded as not proper action research if they fully did not exemplify the key tenets. Taken in the second way, the idealised version would be seen as an abstraction, to which actual pieces of research, in all their variety, might seldom if ever conform. Morrison and Lilford intend idealised action research to be read in the second of these two ways – as an abstraction, which opens up for a more flexible use of the framework at a technical level.

Similarly, in her summary of a workshop on the experience of putting action research theory into practice, Ladkin (2007) refers to repeated comments from the researchers about not being sure that they had been doing action research. Ladkin argues that this speaks to the fact that there is no right way of doing action research: *"Instead there is the intention of the researcher, coupled with a commitment to rigorous reflection end experimentation with new understandings or behaviours, which are the hallmarks of this approach"* (op cit: 479). She argues that perfect action research cannot exist, and suggests that action research must be seen as an aspiration rather than a possibility. But she also argues that it is in this striving towards an ideal of collaboration, working towards an articulation of the self's frame for perceiving, or committing to reflection and action - that the researcher embraces something of the essence of what it is to be human working towards the betterment of human conditions.

For my own sake, these reflections facilitated some of questions that have emerged during the run of this study and which have made me ask myself the question whether I was doing "real" action research.

3.2.3 A family on its own?

Even though production of knowledge is crucial also in action research, several action researchers have been engaged in describing the approach as different from traditional ways of doing research (Morrison & Lilford, 2001; Reason & Bradbury, 2006b). In their "Handbook of Action Research" Reason and Bradbury (2006b) describe action research as a family of appproaches, a family which sometimes argues and falls out, whose members may at time ignore or wish to dominance others, yet a family who *"sees itself as different from* *other forms of research"* (op cit : xxii). They rest this argument on a strong value orientation and that action research is research with, rather than on practitioners.

The wider purpose of AR, in the terms described by Reason and Bradbury (2006b) and their co-authors is to contribute through the acquired practical knowledge to the increased well-being of human persons and communities, and to a more equitable and sustainable relationship with the wider ecology of the planet of which we are an intrinsic part. According to Reason and Bradbury (2006a), action research starts with everyday experience and is concerned with the development of living knowledge. A primary purpose is to produce knowledge that is useful for people in the everyday conduct of their lives. Human persons are agents who act in the world on the basis of their own sensemaking. These authors see it as a practice for the systematic development of knowing and knowledge. Action research is based in a rather different form from traditional academic research – it has different purposes, is based in different relationships and has different ways of conceiving knowledge and its relation to practice. In effect then, action research is argued to bypass the traditional, constructed separation between research and application (op cit).

On the other hand, there are other authors who de-emphasise the difference between action research and other forms of research (Lilford et al., 2003; Lincoln, 2001; Morrison & Lilford, 2001). They rather find it reasonable to consider it as part of a broad critique of social science which exposes the seeming inability of social research to provide incontrovertible answers to persistent social problems (Lincoln, 2001). Research becomes a form of activism, and legitimises its activity in a moral commitment, which is not unique for action researchers in contemporary social science. This will be outlined further later in the chapter. According to Morrison and Lilford, action researchers need to reconsider their critical stance toward "mainstream" research. They argue that for example arguments framed in terms of epistemological distinctions between action research and other methods resolve into the well worn arguments about such issues as reliability/validity, positivism/relativism inherent in the research used, not in action research per se. These efforts to include the use of action research framework into ongoing methodological debates in the social sciences are taken as a point of departure for this study. In the next section, I turn to a clarification of its methodological frame.

3.3 Methodological frame

Broadly defined, action research has been part of, or at least sympathises with, a post-positivist social constructivist paradigm in the social sciences (Ladkin, 2007; Lincoln, 2001), within which the critique against positivistic science has been the main characteristic. These thoughts have provided dissolution of the term “objective” knowledge and have questioned the superior status of scientific knowledge compared to its everyday forms. However, as commented previously, a more precise starting point for action research is found in the American pragmatism. This approach advocated a “naturalistic” approach to research, taking as a point of departure the complexity of social life. Instead of beginning with abstractly defined concepts, research should start by learning at first hand about the ways different situations are experienced by those involved in them (Cuff et al., 1992; Mortensen, 1997). Influenced by the thoughts of George Herbert Mead, pragmatism emphasised the ways in which knowledge is the product of human inquiry and therefore is conditioned by the problems that human beings address and the reasons they have for addressing them.

It might still be argued that action researchers, at least in the sociological domain, orient themselves away from the deconstructive approach that has been so salient during the last decades, and which has been provided by post-modern and post-structural perspectives (Alvesson & Sköldberg, 2000). Reason and Bradbury comment that *“while postmodern/ poststructuralist perspectives help us immensely in seeing through the myth of the modernist* *world, they do not help us move beyond the problems it has produced"* (Reason & Bradbury, 2006a: 6). They find postmodern and poststructural thoughts as helpful, but also as limiting. They further argue that we need to find a way of acknowledging the lessons of the linguistic turn while not ignoring the deeper structures of reality, and propose that a more creative and constructive worldview can be based on a metaphor of *participation.*

Although Reason and Bradbury and their co-authors are eager to underscore a theoretical "promiscuity" within the action research framework, it is difficult to not place emphasis on its close connections to critical theory and a conflict oriented approach to social interaction (see chapter 2). In their outline of a participatory world view, Reason and Bradbury emphasise its function as both a political statement, as well as a theory of knowledge (Reason & Bradbury, 2006a). According to the authors, this world view asserts the importance of liberating the muted voices of those who are held down by class-structures and neo-colonialism, by poverty, sexism, racism and homophobia. These reflections resonate with other contributions who consider action research as "normative" (Malterud, 1995) and as being sensitive to the issues of power (Ladkin, 2007). It illustrates further its link to a conflict-oriented approach. As indicated above however, their metaphor of participation goes beyond the "linguistic reduction" (Alvesson & Sköldberg, 2000) that is offered by post-structural thoughts, and which is salient in the conflict-oriented approach as it often appears in the contemporary debate.

The focus on liberation of "muted voices" has still been experienced as challenging by researchers in the field who are concerned about the scientific value of the research made. According to Argyris and Schön (1989), action research faces a challenge finding its position between *rigor* and *relevance* (Argyris & Scön, 1989; Malterud, 1995). Rigor refers to the requirements of "normal science", while relevance is connected to the commitment to the everyday reality of those being studied. Argyris and Schön argue that the challenge is to define and meet standards of appropriate rigor without sacrificing relevance. Through the example studied they illustrate how alternate explanations are not considered and that the researchers miss an opportunity to demonstrate the kind of rigor appropriate to action research. Their point is that the authors do not try to construct and test plausible alternatives to their hypothesis; *"Indeed, they do not treat it as a hypothesis at all, but as an obvious interpretation of the data of the case"* (op cit: 618).

I consider the contribution from Argyris and Scön (1989) as a reminder of realising the participative approach within a frame of sensitiveness toward the particular context being studied. As I will argue below, this awareness is particularly important when deploying the action research framework in complex late-modern contexts. It is for example argued that the idea of human liberation and the good life, which is so crucial within a participatory world view, has become problematic in the late-modern culture and that it needs some reconsideration (Guneriussen, 2004).

3.3.1 Doing action research within the complexity of late-modern societies

In his description of four different sociologies and call for a commitment to what he describes as a "public sociology", Burawoy (2004) argues that it is important to find the balance between being critical and being dogmatic within the critical realm of sociology. Action research conducted as "third-person" inquiry can be argued to belong to this critical realm.

On one hand, the awareness towards power is crucial. Taking Foucault and a post-structural approach as a point of departure, Cullen (1998) directs attention to the complex form that power can take. Cullen argues that in the evolution and application of "engaged social science" which is characteristic for action research, one can find an ingrained ambivalence. Using the work in the Tavistock Institute as example, he argues that both the work toward egalitarianism in the Tavistock Institute and its engagement in industries also can be seen as driven by necessity (from "above") as well as an engaged social scientific ethos. Relating this to contemporary developments of health care, he directs attention to the efforts to increase self-management and control by consumers that is realised by action research. Cullen foresees a democratisation of health care through this activity. At the same time, he also argues that it can have the effects of contributing to the control of social groups by extending the medical gaze rather than propagating a new form of societal and organisational change. It is here the "awareness to power" needs to be present. In this context, it means that the warnings of disempowerment that are offered by post-structural readings of illness (see chapter two) are incorporated in the approach to the empirical field of research.

On the other hand, there is also need for a "sobriety" within the critical paradigm (Alvesson & Sköldberg, 2000). Alvesson and Sköldberg argue that followers of critical theory distance themselves from and engage themselves in battle with existing institutions and authorities – which, for these theorists, exist to be opposed. Another warning is offered by Klawiter (2004). Relying on Foucault's concept of "regime of practices" (Foucault, 1987), Klawiter develops the term "disease regime" as a way of conceptualising the structural shaping of illness experiences. Foucault is rather apolitical in his approach to power and considers it as an autonomous force. It is certainly wrong to think of power as the means by which one social group controls others in its own interests (Cuff et al., 1992). In accordance with critical theory however, the dominance of institutions is emphasised.

Drawing on the insights of the Foucauldian tradition, Klawiter states that her concept of disease regime departs from this tradition's totalising view of power. She finds that both Foucault himself and scholarship in this post-structural tradition tends to portray regimes of public health and medicine in rather totalising terms. One of her arguments is that *"even* *though Foucault repeatedly claims that 'where there is power, there is resistance', he focuses his own analysis on power, not resistance"* (Klawiter, 2004: 850).

In line with such arguments, the Norwegian philosopher and sociologist Willy Guneriussen makes an effort to formulate a new foundation for critical theory (Guneriussen, 2004) , or a normative point of departure, in the late-modern culture. In his article, *"uncertain foundations – the prospects of a (new?) critical theory"*, Guneriussen replaces the idea of a universal theory of human liberation and the good life with an approach that aims to contribute to a "balanced" modernity in which none of the modern forces are allowed to run wild. According to Guneriussen, this discourse will be motivated, not by a big project of final liberation, but by a more modest wish to contribute to the defence of a balanced and necessarily tension-ridden modernity.

My argument here is that such contributions, here exemplified by Alvessson and Sköldberg, Burawoy, Klawiter and Guneriussen, can provide a broadened methodological basis for the action research framework and its awareness towards power and domination. This might pave the way for the "reflexive interpretation" that is called for by Alvesson and Sköldberg (2000) as an appropriate position for the qualitative researcher. It is my argument then that awareness towards the "dogmatic danger" of conflict-oriented approaches, can represent crucial tools in the work to find a point of departure for undertaking action research within late-modern complex societies. Related to this study, in which the initial point of departure is to facilitate the emergence of the active and involved health care user, the framework contributes to an awareness of a potential ideological dominance that can be extended by the establishment of online services, as well as resistance towards overdoing this aspect.

However, while this analytical device hopefully provides considerable insight into complex situations, the question still remains how useful such context-bounded insight can be in a broader societal context. As described previously, usefulness is one of the important aims of action research, in the sense of aiming to produce insight that can be relevant for people in their conduct of everyday life. The usability still needs to be outlined in further detail, and is addressed in the next section

3.3.2 The usability of context-bounded data

The usability of the context-bounded insight offered by qualitative research, such as this action-oriented study, is exposed of increased critical attention within health care research (Sandelowski, 2004), also within the Norwegian context (Frich, 2007). According to Sandelowski, this renewed urgency to demonstrate its utility is the result of several converging trends in health care research. These trends include the elevation of practical over basic knowledge as the highest form of knowledge, the proliferation of qualitative health research studies, and the rise of evidence-based practice as paradigm and methodology for health care.

However, usefulness has different meanings within different frames. Within a quantitative research frame, usefulness derives from the generalisability of findings from study samples to populations not studied but deemed to be like those samples. Within grounded theory, which has been the most widely used qualitative interpretive framework in the social sciences (Alvesson & Sköldberg, 2000), analytic generalisation and theoretical transferability are the bases for utility. However, grounded theory has come more under debate as post-modern and post-structural approaches have paid critical attention to the authority of the researcher. Within action research, usability has been related to the undermining of oppressive structures and the degree to which liberatory/emancipatory goals have been achieved (Sandelowski, 2004). As such, it might be argued that the answer of usefulness depends on the frame within which the research is undertaken, which might not be a satisfactory answer to people outside the academic world.

Attempting to offer a more concrete response to the demands of demonstrating usefulness, Sandelowski (2004) argues that Estabrook's (1999) description of research utilisation as instrumental, symbolic and conceptual is a useful frame to examine the various meanings of use of qualitative research. I will present these in some further detail.

Instrumental utilisation

Instrumental utilisation is the concrete application of practice to research findings that have been translated into material forms, such as clinical guidelines, care standards, appraisal tools, pathways and intervention protocols. These forms are then put into practice and evaluated with specific groups of patients in specific practice settings to achieve specific outcomes. In instrumental utilisation, the utilisation of findings is the ultimate goal of empirical/analytical research (which may include qualitative and quantitative inquiry) and of the evidence-based practice paradigm that favours this form of research (Estabrooks, 1999; Sandelowski, 2004).

Instrumental utilisation has not been the main objective for qualitative research. A common view, in particular within the medical domain (see for example Frich, 2007) has been that the main contribution from qualitative research on this level is to deepen the understanding of a social phenomenon and to identify aspects of the phenomenon that can be incorporated in a quantitative design and further assessed – before they are considered as usable within a practical setting. As will be shown, some experiences from this study are defined as point of departure for further quantitative investigation.

However, champions of qualitative research have increasingly turned their attention toward showing how qualitative research findings can be of material and measurable use in practice and that they can be valued for their contribution independent of quantitative methods (Sandelowski, 2004). To my point of view, this depends on the support that can be related to such findings in the literature on the particular issue. For example, as most studies of online self-help groups have shown high drop-out rates (Eysenbach et al., 2004), it might be argued that experience of the helpful function of such groups among their users needs further support before implementation.

Symbolic and conceptual utilisation

According to Sandelowski (2004), conceptual and symbolic utilisation appears as the most important objectives of qualitative research (see also May, 2005). It means that that the research serves as a persuasive or political tool to legitimate a position or practice (symbolic) or that it contributes to a change in the way users think about problems, persons, or events (conceptual) (Estabrooks, 1999; Sandelowski, 2004). Commenting conceptual utilisation, Sandelowski argues; *"for individuals with personal experience of a target event, qualitative research findings offer a mirror that allows them to look back on and reframe their experience. Whether revealing or reflecting, in conceptual utilisation, the action happens in the user who is newly informed or enlightened (…). Conceptual utilisation may be a precursor to instrumental utilisation as users develop the capacity to articulate the changed experience and to translate it into more observable or material form"* (Sandelowski, 2004: 1372).

An illustrative example of research that is of conceptual value has been offered by Arthur Frank (1997), in his proposal of using written stories, or first-person accounts of illness experience, as "data" within a sociological context. According to Frank, such explorations of what he describes as the “potential consciousness” of illness have the value of imaging new parameters of response to the fundamental questions about self and identity that follows a serious illness diagnosis. As indicated previously, this aim is important for action research, seeking to provide people with appropriate tools to reframe their situation. Symbolic utilisation also represent an important aim, but might as a successor to conceptual utilisation.

Through these final reflections on the usefulness of qualitative research, I leave the description and positioning of the action research frame and turn to a further outline of how this particular action oriented study was undertaken.

3.4 Implementing the study

3.4.1 Recruitment

Recruitment of participants to this online self-help group started in October 2003 and new members were welcomed during the whole study period. In Norway, 20 000 women are living with a breast cancer diagnosis, and close to 3000 are diagnosed with breast cancer every year (Kåresen et al., 2004). All women who had been diagnosed with breast cancer and could communicate in Norwegian could participate in the study. Those who were interested had to sign a written consent before entering the study. Information about the study was mainly distributed through the Norwegian Cancer Society and the Norwegian Breast Cancer Society.

A few members signalled their interest for the group at an earlier point of time. The study was referred to in the member’s bulletin of the Norwegian Breast Cancer Society already in December 2002. We had planned to start of the group during the spring 2003. However, as I will outline further in the final section about ethical considerations, we later entered a detailed discussion with The Regional Committee for Research Ethics which was not foreseen at this point of time. Because of this process we had to delay the further recruitment of participants. However, through this early announcement, I established a valuable contact with two experienced users of online self-help group. These women became important conversation partners during the process of developing the service, for example by contributing to the development of directions for use of the group that was described earlier in the chapter.

The active efforts to get participants to the study were mainly concentrated to a short period of time during the autumn 2003. The study was mentioned in one of the national newspapers (Aftenposten) in the beginning of October and in a member bulletin that was sent to all members in NCS in November. In addition, information about the study was distributed as an email newsletter from the NCS in the beginning of October. Information about the study and the possibility to participate was further available at the home-page of the NBCS during the whole study period.

Further active efforts to recruit new members were conducted during the autumn 2004. It is important to note that this took place after the NCS had withdrawn from the study, but at a point of time on which my contact with NBCS was maintained. Active users of the group experienced that the group was very important for them and considered lack of knowledge about the service as a reason to what the NCS considered as a modest response. They tried to recruit new members on their own initiative, hoping to demonstrate that there was an interest of online services among women with breast cancer. Among other efforts, they distributed information about the group on the annual meeting for young women who are diagnosed with breast cancer in October 2004, which was arranged by the NBCS. The NBCS did further distribute information about the study to new members in the organisation during the autumn 2004. On the whole, 192 information letters were distributed.

During the study period, at total of 51 women diagnosed with breast cancer conveyed their interest of the self help group and received the preliminary information. Forty women returned written consent indicating their intention to participate and received a password. Twenty-nine women were registered as participants in the study during the autumn 2003, 4 were registered during the spring 2004 and 7 during the autumn 2004.

3.4.2 Material

When returning their written consent, the participants were asked to complete a questionnaire. Further data were obtained by means of participant observation of the written activity in the group and through qualitative interviews. I have scarce knowledge about two of the participants. They did not return the questionnaire, did not leave any messages in the group and were not contacting me on a more informal basis. They were either not contacted for interview.

Questionnaire

The questionnaire asked for information about sociodemographic variables, time for the surgical intervention, their social network and their experiences of the Internet, the health care system and the breast cancer patient organisation. Twenty-eight of the forty women returned the questionnaire. I obtained equivalent information about another ten participants through more informal contacts, for example e-mails or shorter telephone calls which were motivated by practical issues. The majority of the participants were under treatment or had newly finished treatment when they entered the group. Those under treatment were both women who were treated for primary breast cancer and women who were treated for recurrence. A minority had been reported fit for some years when the group was established. As a whole this was a group of well-educated women: most of them had formal education after secondary school. The majority reported that they had a strong social network and experienced themselves as comfortable with the Internet. Their experience was related to searching for cancer information and to ordering travels and reading newspapers. One of the participants in this group had experience from a face-to-face based self-help group, five others from other online self-help groups for breast cancer patients and one had participated in an online group for another health problem.

The written activity in the group

During the period of access (from November 2003 to March 2005), a total of 1114 messages were left in the group. This makes an average of 2,5 messages each day the group was accessible. Among these were 80 “moderator messages” written by me, while 1034 were written by the participants. I did not engage in topics that were related to the illness, but took part in conversations about practical issues and about the directions for use. This is more closely described in article two. The group was closed one week during Christmas 2003 and three weeks during the summer 2004.

The total number of 1114 messages posted in this group were distributed on 127 conversional topics, or “threads”, which is the term used to describe the activity in newsgroups on the Internet and which refers to the comment-response style in which one person makes a statement, another person comments and then another person comments, perhaps on the comments on the second person (Denzin, 1999). Thirty of the 127 threads contained only one message, 74 contained 1 to 10 messages, 10 contained 11 to 20 messages, and 13 threads contained more than 20 messages. Personal illness stories represented the threads which were most actively addressed. The initiators used them for further update on their situation, to which the others responded. Sometimes, if the initiator had not written any messages in the group for a while, she was also ”called for” under these threads. One of these contained 92 messages. Threads that addressed coping strategies and diet were also extensive. Those who addressed the illness, side-effects and treatment, or more practical issues, did constitute several, but shorter threads.

Interviews

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 defined eleven participants as active users of the group, mostly because of their stable presence during most of the study period (nine), but also because of a shorter, but enthusiastic presence (two). I did gradually become aware of a high tendency to not participate or to withdraw from the group. I defined twenty-nine women as non-users. Either they did not participate at all (eleven) or they disappeared from the group after they had posted some messages (eighteen). The disappearance of the latter was confirmed when they were contacted some months after their last message. In order to explore this phenomenon, I deliberately recruited a large number of non-users for interviewing. It is however important to be aware that this “exact” number of participants is referred to in order to give some reference to the use-pattern of the group. Few of the participants left a “black-white” impression of their experience.

On the whole, 25 participants were interviewed; 8 users and 17 non-users. Fourteen interviews were conducted face-to-face (40 to 110 minutes) and 11 through telephone (20 minutes to one hour). The choice to use the telephone was mainly a result of practical considerations, such as the geographical distance.

3.4.3 Analysis

The core question asked in this study is what role that can be ascribed to the multiplied possibilities to exchange information and the disembodied context that is offered by an online self-help group in breast cancer rehabilitation. From this point of departure, the material presented above is approached through an issue-focussed analysis. Such analyses are concerned with what can be learnt about specific issues, events or processes (Weiss, 1994). The support provided, the significance of the disembodied context and the relevance of online self-help groups in breast cancer rehabilitation were presented as concrete issues for further exploration in this study.

Three dimensions of the material are ascribed analytical significance during the work with the material. The first is the *accounts* that are given by the women about the experiences with the group and their need for support. Such accounts were given in the questionnaire, in the postings in the group and in the interviews and represent a main source for illuminating the issues under study. Within the frames of an issue-focussed analysis, various themes are identified and illustrated with quotes from across the data-set (Bury, 2001). For example, in article one, the support provided by the group is analysed. Accounts from participants who chose to leave the group still contributed to the identification of its supportive function. Furthermore, the attractiveness of the online group is addressed in the third article. In this analysis, accounts from active users also contributed to the identification of constraints to group participation. As indicated above, few participants left a "black-white" impression of their experience. Within the frames of an issue-focussed approach, some respondents might further contribute more to the analysis, and others less (op cit). This is the case also in this study.

The term "account" is used about the women's expressions in order to indicate that these are more than a disclosing of an internal state, but also part of the women's ongoing identity-work (Radley & Billig, 1996). It means that situated claims and justifications are taken account for when analysing the expressions, such as the research-frame of the conversation with me and the presence of other women in a similar situation when writing to the group. Emphasising the situational influence and the identity-work in relation to others, Radley and Billig argues that *"In offering views, people are also making claims about themselves as worthy individuals, as more or less 'fit' participants in the activities of the social world"* (op cit: 221). This situational emphasis, and particularly the justification that might be involved in peoples' accounts on illness, is given considerable attention in the discussion in this thesis. The focus on justification is particularly traced within post-structural readings of illness (see, for example Werner et al., 2004).

The situational focus is however toned more down in other proposals of how to approach peoples' expressions about illness. Maintaining the awareness towards elements of self-presentation, Mathieson and Stam (1995) locate the identity work that is conducted in a more consistent subject, or the particular individual who is experiencing the illness. Their point of departure is the biographical disruption or *"the way through regimens of treatment, changing bodies and disrupted lives"* (op cit: 284) that must be encountered by the ill person. Within this frame, tellings of illness are *"the vehicle for making sense of, not an illness, but a life"* (op cit: 284). To my opinion, this contribution serves as a reminder of not overdoing the situational focus when interpreting the women's accounts. The tension between these interpretations of the accounts given represents an important backdrop for the discussion in this thesis.

A further dimension of analytic significance is the *comment-response* style that formed the threads in the group. The topics that were introduced and the response to these topics offered an intake to reveal the views on what breast cancer is and how to live with it that were given priority in group communication. More precisely, I divided each of the 127 threads into sequences of talk, for example a question or an update that were responded to by other members in the group. This approach resonates with other descriptions of Internet conversional life (Denzin, 1999), who describes Internet life in moderated and non-moderated groups as cyclical.

On the whole, I identified 292 sequences of talk within the whole number of threads. Through this focus on sequences, I could categorise the activity in the group independent of the threads. The threads were mainly constituted by the participants in the group. At several occasions, they addressed similar issues under different threads. By identifying sequences of talk, I could link related sequences together independent of the thread they "belonged" to, for example those which addressed the impact or handling of the cancer. Through this work, the coping-response style on issues as the impact of the cancer and how they handled it could be identified. This focus does particularly contribute to illuminate the significance of the disembodied context and whether it can facilitate the emergence of a broad spectre of illness experiences.

The importance of considering such aspects, or the form of interaction was first commented by Goffman (1967; 1974). What is interesting to note in this context, is a proposal of how focus groups can contribute to illuminate this dimension (Warr, 2005). She refers to Agar and MacDonald (1995), who discussed interactional styles featured in focus group discussions. Making a distinction between "insider-oriented" and "outsider"-oriented discussions, these authors argued that focus groups tend to elicit insider-oriented talk rather than outsider-oriented explanations. Insider-oriented data allow researchers to glimpse the processes of sense making within groups. Outsider-oriented data include instances in which participants address the moderator/researcher to explicate an opinion or position.

The online group studied here was not a focus group. For example, it was established as part of a study, but was also initially planned to exist as a group beyond the research period. In addition, my role as researcher was less salient within this group than it would have been in a focus group. However, the fact that the interaction in this group was research-initiated and observed by a researcher makes a comparison relevant. The proposals of an insider-orientation in focus-groups underscore the value of taking the comment-response style in the online self-help group into account during the analysis. The tension between a situational focus and the individual who is trying to "make sense of a life" is also made visible in the interpretations of the comment-response style in the group.

A third dimension that is used to illuminate the issues explored in this thesis is *the use of the group*. My argument is that this focus reveals further insight into how group participation is included in the conduct of the everyday life of these women. It contributes to illuminate the relevance of group participation in different situations. What is of particular value is that I was in contact with some of the participants during most of the study period (15 months). For some, the situation changed from being under treatment for breast cancer to being declared "free of symptoms". Another two participants experienced that the cancer spread. Through this long-lasting contact, I was offered particular insight into how the group was approached in different situations that the individual participant found herself into. Situational and more subject oriented approaches are made visible also in my interpretation of the use of the group.

3.4.4 Ethical considerations

As indicated earlier in the chapter, the onset of this action oriented study raised ethical considerations. Both The NCS and The Regional Committee for Research Ethics expressed worries about the risk for negative health effects for the participants in the study, due to potential misinformation about medical treatments and the risk of psychological reactions when participants were confronted with each others stories. These discussions resulted in an agreement between the initiators of the study to keep the activity in the group under active surveillance during the study period. In addition, we established a reference group which consisted of members from both NCS and NCT. Members of this group could be contacted if there were problems related to the communication in the group.

Before upstart we also worked out directions for use of the group. These were available on the website when the participants logged in to the group. Two experienced users of online self-help groups, who conveyed their interest for participating in the study at an early point of time, were involved in the formulation of these directions. As a result of our discussions with the NCS and The Regional Committee for Research Ethics about the risk for negative effects of group participation, a request of warning others if they were addressing difficult issues was included in these directions. The influence of this manoeuvre on the group conversation is further outlined and discussed in article two and four.

I further entered a role as “hostess” of the self-help group. In addition to my efforts to ensure an optimal function of the service, this role included an administrative responsibility and a controlling function that was conducted in accordance with the clarifications made towards the Norwegian Cancer Society and The Regional Committee for Medical Research Ethics. I controlled the content of the postings in the group every day.

During the study period, I had frequent contact with the study participants. This was of a more informal type and did mainly take place by use of telephone and email. As described in article three, several of the participants did not use the group, and I contacted them in order to ask if there were any practical problems related to their use of the group. I consequently used the telephone at these occasions, because use of email was not included in the design of the study. There is further a security risk connected to the use of email that is not encrypted (The Ministry of Governmental Administration and Reform, 2001), and which I wanted to avoid. However, several of the women used email when they wanted contact with me, and I responded to email contact that was initiated by them.

In action research, the borders between the role as researcher and implementer of a program are sometimes blurred (Khanlou & Peter, 2005). When I noted that there were several participants who did not write postings in the group, I contacted them and asked if there were any practical problems related to their participation that I could help them with, or if there were other reasons for their absence. In these situations, I intended to increase use of the service. This might imply a risk for “pushing” the participants to use the service. I did however underscore to those who were contacted that I wanted to know if they had any practical problems and that it was important that they used the group in accordance with their own needs. I did further underscore that our main aim was to obtain more knowledge about how such groups could function and that it was valuable to also gain more knowledge about why some participants did not leave postings in the group. The example still illustrates how the aim of facilitating use and the responsibility of ensuring the ethical frame of the study can come into conflict at some occasions. These are further described and discussed in article four.

I did receive a few emails in which some study participants regretted that they had not used the group. Again, I answered that it was important to eliminate practical challenges related to group participation, but that it was important that they used the group in accordance with their own needs.

In addition to ethical considerations that relate to my behaviour directly towards the participants in the study, ethical aspects that relate to the practice of social research are further raised when parts of the data material (i.e. the communication in the group) is available on the Internet and might potentially be accessed by people from outside. In this study, we were aware of this risk. Beside the use of passwords, the email address of the study participants, and the IP-address of their computer, was not logged when they left postings in the group (for a further description, see attachment 3). Further, the participants were requested to not give too much background information about themselves. Some had nick-names within the group, but most preferred to use their first name. I did further advice them not to refer to the name of their doctors and the hospital on which they were treated. This advice was not followed consequently. Particularly those who were treated at "big" hospitals, such as Ullevål University Hospital or the University Hospital of Northern Norway did mention the name of their hospital and sometimes their doctors. I chose to not comment the flow of such information. It did not happen at many occasions, and I felt that I could enter a too "controlling" role through such acts. Through the customs of the group, the participants were further requested to not refer to details about names, hospitals etc.

The communication in the group was also available to all study participants in written form and might further raise ethical considerations to the practice of social research in this context (Bloor et al., 2001). Bloor et al discussed the use of virtual focus group in research, which can be comparable to the group studied here. In such contexts, information about the origin of a computer transmitted message is for most users almost impossible to remove, which makes it more difficult to guarantee confidentiality to research subjects. The authors comment that *"Traditional procedures for storage of data and anonymising participants are complicated in a medium where a record of the original data is routinely available to others who have participated in the research – members of a virtual focus group all receive a copy of the posting"* (op cit:85). Through the technical arrangements and our request of being careful with disclosing identifiable details, we worked to reduce the risks related to the research conducted in this study. The material was further treated in accordance with the directions from the Norwegian Social Science Data Services.

Presentation of articles

Four articles are included in the thesis. Three of them contribute to the debate on the potential role of online self-help groups in cancer care, while the fourth offers a more detailed discussion on the challenges and possibilities of using the action research framework in the development of online self-help services. This latter article is based on the experiences made in this study and a corresponding study of an online self-help group for adolescents with mentally ill parents.

4.1 Article 1: Approaching the role of the Internet: Experiences from an online self-help group for women with breast cancer

In this first article, I analyse the support provided by the online self-help group and enter the debate on the potential role of Internet use in health care. Within the sociological context, this debate has been taken forward by “enthusiastic” and “contingent” responses. These different responses are grounded in different approaches to the context of Internet use. The first perspective has proposed a radical role of Internet use. It relies on notions a departure from the “modern” Parsonian patient role among users of health care in the late modern society and on the emergence of a more pluralistic approach to health. I argue that this perspective is influential in health care and describe it as crucial for the upstart of this study. The second position has toned down the radical role of the Internet, by revealing that Internet use takes place in a context of more mixed illness practices.

Three issues were recurring when the women who had participated in the group reflected on the support provided: group participation gave them an increased sense of control in the treatment process, it provided hope and a space for “illness talk”. I argue in the article that this material does illustrate how the Internet can have a decisive function, in the sense that group participation provided hope for a qualitative rich life in a situation of spread.

On the whole however, my argument is that the analysis illustrates how the support provided by the group was framed somewhat differently and contributed to reveal a more mixed context of illness practices than underpins the enthusiastic responses. It became particularly visible in the reflections on how group participation provided an increased sense of control and a space for illness talk. The analysis revealed that a biomedical orientation, subordination to the doctor's view and a protection of close environments were constitutive for the role of the online self-help group. A crucial argument in the article is that a commitment to a 'modern' patient role needs more attention in the further debate on the potential role of the Internet in a cancer context. I conclude that the material illustrates further the need for a contingent response to the role of the Internet.

4.2 Article 2: A space for suffering? Communicating breast cancer in an online self- help context.

The second article directs attention to the disembodied context on the Internet and explores further the liberating influence of online communication. The point of departure is the "emotion work" that seriously ill people are argued to conduct in their established relationships and in which they affirm socially desirable stories about restitution and new wisdom. The question asked is whether the online group offers a space for suffering, or aspects of the cancer experience that often are suppressed elsewhere. While directing attention to a space created for the disruptive impact of cancer in the anonymous context, my main argument is that socially desirable elements are further circulated also in this context. These were not about restitution, but about taking control in a burdening situation in which life is never going back to normal. This impression is particularly related to the support and emphasis placed on individual strength. I discuss why the interaction in the group contributes to affirm an image of the cancer hero and my main argument is that it should also be considered as a necessary and voluntary process, and not solely as an alienating practice which is emphasised in much literature. This argument draws on literature in medical sociology that places emphasis on how illness threats the "natural attitude" and the necessity of distancing this threat. The importance of being in control among well educated women is suggested as another condition of possible influence. As such, the scepticism towards the focus on individual control within the online self-help context is toned down.

4.3 Article 3: The challenge of fitting in: non-participation and withdrawal from an online self-help group for breast cancer patients

In this article, I discuss the use of the online self-help group. Similar to what is commented in studies of face-to-face based self-help groups, we experienced in this study that several of the women who conveyed their interest for the group and received a password, chose not to participate or withdrew from the group after writing some postings. My main argument in the analysis is that an adherence to the restitution story - or the patient role that commits to the biomedical model on health and illness - constituted an important background for why several study participants chose to not participate or to withdraw from the group. I further argue that this adherence to the restitution story can be in accordance with the subjective illness experience in a broader range of situations than suggested by many sociological authors, as it appears to be related to a need to be in touch with "normality" and by role-conflicts in the women's life.

A further argument that is emphasised as influential on non-participation and withdrawal, is also that the group was experienced as an arena for successful coping. It did not emerge as an alternative in periods of feeling bad and in which both the entrance into the restitution story or the heroic story was experienced as too constraining. On the whole, the material leaves the impression that online self-help group participation is relevant in a lesser range of situations than was expected at the upstart of the study. This latter observation gives further support to the contributions that question assumptions about an increased space for the "bleaker aspects" of the illness experience in online self-help groups.

4.4 Article 4: The double-minded action researcher

Article four is a reflection on the use of action research in this study and on another action oriented study that was initiated by the Norwegian Centre for Telemedicine. It is written in co-operation with a sociologist and colleague, Marianne Trondsen. In the article, we reflect on advantages and challenges of conducting action research with the intention to improve health care, directing particular attention to the researcher as implementer of the program studied. The work to ensure an optimal function of the group and immediate use of data are outlined and discussed. Based on our analysis, we argue that action research can facilitate both an increase in knowledge, but also a greater sense of ownership among those who are intended to benefit from the program. On the other hand, we also argue that a potential conflict between the researcher's pursuit of data, and ethical considerations, still became apparent in the contexts studied. Bearing these challenges in mind, we still conclude that action research offers an important contribution to the further development of health care services.

Discussion and implications for further research

In this study, the subject of investigation is the potential role of online self-help groups in breast cancer rehabilitation. The core question asked is what role that can be ascribed to the multiplied possibilities to exchange information and the disembodied context that is offered by an online self-help group in breast cancer rehabilitation. More precisely, the support provided, the significance of the disembodied context and the relevance of online self-help groups has been addressed. This chapter offers a concluding discussion on how these questions are illuminated by the material.

As indicated in chapter one, an "enthusiastic" view on the potential role of online self-help groups framed the onset of this study. There were promising reports on how the Internet and online support groups helped people to cope better with their health problems (Eysenbach, 2000; Ferguson, 2000). Further, assumptions about the emergence of a more active and involved health care user indicated that adjustments for self-care could be relevant on a more general basis (Coulter & Magee, 2003). Linking these to the sociological debate, I have argued that these expectations spring out of post-modern readings of illness, meaning that the irrelevance of the "modern", or Parsonian, sick role represent an important point of departure (Frank, 1995; Frank, 1997). It implies that considerable influence is ascribed to the multiplied possibility to exchange experiences and the disembodied context that is offered by online self-help groups. Within the sociological tradition, this view is particularly developed through the work conducted by Michael Hardey (Hardey, 1999; Hardey, 2001; Hardey, 2002a; Hardey, 2002b). I have described these contributions as illustrations of perspectives that place emphasis on the technology-in-action (Timmermanns & Berg, 2003).

For some of the participants in this study, the online self-help group had an important function, which is outlined in article one. This finding gives some resonance to the enthusiastic response, for example that the group facilitated a doing of illness that deviated from what these women experienced as possible in their established social relationships and that was more in accordance with their needs. My main argument has still been that the online self-help group was introduced in a context of illness practices that were of a more mixed character than what is accounted for within the enthusiastic response. On the whole then, the study becomes part of a "contingent and embedded" response to the Internet (Nettleton et al., 2005), through which the context of use is brought into focus, and the independent influence of the possibilities offered by the Internet is toned down. Peoples' approach to the Internet is considered to be contingent upon their health needs and pertains to particular conditions (op cit). Such contributions are also described as a "second-age" of Internet studies (Haythornthwaite & Wellman, 2002; Nettleton et al., 2005).

It is however important to be aware that a focus on the technology-in-action and an independent role of the technology is not completely succeeded by a social essentialistic perspective through this turn (Timmermanns & Berg, 2003). I find it more reasonable to consider the different perspectives on technology as a continuum and that this study enters into a body of literature that contributes to downplay the role of the technology without excluding its influence.

Having these clarifications in mind, the turn from an enthusiastic to a contingent response to the potential role of online self-help groups in breast cancer rehabilitation is outlined below.

5.1 Moving from an enthusiastic to a contingent approach

As indicated, the main contribution from the analysis is that the post-modern readings of illness which underpins the enthusiastic response to the Internet receives critical attention. However, I will start with a description of the elements of the material that gave resonance to the enthusiasm and to the underpinning assumptions of a departure from a modern - or Parsonian - way of doing illness among ill people.

5.1.1 The contribution from the online self-help group

This online self-help group was actively used and highly appreciated by a group of study participants. These were mainly women who were under treatment for the disease, and particularly women who were diagnosed with spread. In article one, I analysed the support provided by the group. I argued that group participation contributed to the adoption of a consumer-identity in the communication with health care professionals, by giving the women a sense of control. I further argued that group participation provided hope for a qualitatively rich life in a situation of spread, helping the women to redefine this situation into a situation of meaning. This was helpful both for those who were diagnosed with spread, but also for women who feared that they later could find themselves in this situation. Women in the group who had experienced spread of the cancer became role-models for others A third argument was that group participation could contribute to break a sense of isolation that was particularly experienced by those with spread and that emerged in situations in which they communicated with other women with breast cancer. In a broader perspective, these experiences from the study demonstrated how the online group facilitated a doing of illness that deviates from the story about restitution, for example through the provision of a space for communicating details about spread and negative illness courses.

The facilitation of alternative ways of being ill through group participation was illustrated in more detail in article two. In this article, I directed attention to the interaction in the group and argued that it signalled receptiveness for the disruptive impact of the illness, exemplified by an agreement among the women of facing an insecure future, communication about marital problems and the experience of being amputated after mastectomy. I will later argue that this influence of the online group was not radical in light of the suggestions of a transforming role of the Internet, but this argument does not totally exclude the impression of a facilitation of alternative ways of doing illness. On the whole then, the study can be argued to give some resonance to proposals of the Internet as a new, unique and global space in which people can rewrite or reconstruct their narrative (Hardey, 2002b). It is particularly important to note how it provided a space for acknowledging the insecure future, which can contribute to challenge the "sequestration of death" that is argued to be pervasive in late modern societies and which can give little meaning to people who are diagnosed with spread of cancer.

What aspects of the online self-help group were crucial for the support provided then? On the whole, the facilitated access to other women with spread and their experiences and knowledge appeared as particularly crucial for the helpful function of this group. As argued in article one, it gives associations to a point made by Walther (2004), that the Net is not only about what you get, but also who you get. The social networks provided by the Internet may differ radically from those of offline life, such as the constitution of a network of women who have experienced spread of breast cancer. The helpful function of the group towards women who had experienced spread is worth to note. More people now live longer with cancer (Cancer Registry of Norway, 2007). In this material, those who were diagnosed with spread also participated in "normal" activities, such as entering into a role as an active mother or grandmother. Some were even capable to continue their professional work, at least in periods. As such, people who are living with their incurable condition are getting more "visible". At the same time, this material indicates that few positions seem to be available for them as persons who are incurable ill. I will later argue that these women also expressed a need to not make the "illness dimension" of their life too dominating, but their approach to the online group still signal a discrepancy between the positions available and their needs. It does particularly direct attention to how this group is approached by patient organisations as the Norwegian Breast Cancer Society. It appears that it was within this context, or at other arenas they could access other people with similar prospects, that these women were ready to make visible and address a broader spectre of their illness experience. However, at gatherings organised by the Norwegian Breast Cancer Society, they experienced that their responsibility to not create fear among newly diagnosed women limited their possibility to do so. As such, the alternative network provided by this online self-help group is made particularly visible.

The helpful function of the disembodiness on the Internet appeared as more mixed. The anonymity of the Internet was not particularly emphasised among these women, while the written communication was commented as advantages (see article one), which is previously brought into focus in psychological literature (Pennebaker & Beall, 1986) and also in ethnographical studies of online communication (Høybye et al., 2005). It is further interesting how the flexibility of the Internet was commented on by some of these women, as an increased possibility to talk about the illness when the need was apparent and not at a particular point of time which is the case in face-to-face based groups. The flexibility was also commented in article one. On the whole then, the increased possibility to access other women in a similar situation and the flexibility offered by the Internet appeared as important for the helpful function of this group.

However, the departure from the modern sick-role that is assumed to underpin the helpful function of online self-help groups was less pervasive among these women than suggested by the proponents of post-modern readings of the illness experience. One example is the emphasis placed on the social isolation that is experienced by women with breast cancer and which represents an important frame for the enthusiasm directed towards the facilitating role of online self-help groups. Among the participants in this study, the sense of isolation was particularly traced when women with spread were in the company of newly diagnosed women. The sense of being “unwillingly” isolated in other relationships, such as the family, friends and working colleagues was not expressed clearly. It does not imply that this experience was not present, but as argued in article one, several women also expressed that they wanted to tone down their illness in these relationships. This experience questions the emphasis placed on a burdening suppression of the brutal aspects of the breast cancer experience among some authors in the sociological breast cancer literature (Broom, 2001; McKenzie & Crouch, 2004). Taken further, the assumptions of “alienating processes” (Hochschild, 1979) and the “vulnerable position” (Barbalet, 1998) of women with breast cancer which appear to underpin this literature might need to be more critically assessed.

Further, for women with spread who were participating and appreciated the online group, the liberating role of the group was also related to the experience of being better able to protect their close environments towards the brutal impact of the disease. The group made the women able to make a “divide” between the arenas in which the illness was addressed. This dimension of group participation downplays the impression of a health care user that is leaving the modern sick-role and gives an extended perspective on the helpful function of the online self-help group. This observation is interesting because it can contribute to deepen the understanding of why participants in self-help groups usually have a normal social network (Levy & Derby, 1992), and that self-help group participation rather functions as a supplement to existing networks than replacing lacking social networks (Thuen & Carlsen, 1998). In this particular example, the alternative space created by the online self-help group implied that the difficult aspects of the disease were further removed from the established social networks (see article one). The voluntariness of these practices will be addressed later in the chapter.

These latter points direct critical attention to the broad rootedness of a post-modern response to illness that underpins the enthusiastic response to the Internet. They bring some nuances to the assumed need to reconstruct the illness narrative and what the need for an alternative space can contain. Below, I continue this critical attention to post-modern readings of illness by describing two crucial experiences from the study. First, I illustrate how the online group was not “exploited” by its users as foreseen by the enthusiastic response to the Internet, see for example Hardey (1999) and Ferguson (2004). Second, group participation appeared to be relevant in fewer situations than assumed by these authors.

5.1.2 Not exploiting the possibilities as expected

One reason for arguing that the possibilities provided by the Internet were not exploited as suggested in the enthusiastic contributions is a reliance on a biomedical frame among those who used the group. In relation to the treatment of the disease, the attention of these women was directed at being medically ”updated”. As a result, the adoption of a consumer-identity, which I have described previously, took place within a biomedical frame. It tones down the impression of Internet use as a challenge to medical dominance which is suggested by enthusiastic contributions (Burrows et al., 2000; Hardey, 1999; Hardey, 2001; Hardey, 2002b) and directs attention to the pervasiveness of this frame which is also commented by other authors (Fox et al., 2005; Nettleton et al., 2005).

Within a broader debate, a constitution of the empowered and medically updated cancer patient also gives resonance to a “media convergence thesis” that has been offered in analysis’ of the activities on the Internet (Nettleton et al., 2005; Seale, 2005). The media convergence thesis suggests that the Internet in the field of health is beginning to show increasing similarities with conventional mass media, with the consolidation of their web presence by powerful interests that influence people’s experience of internet health information (Seale, 2005). According to Seale, representations of health and illness in popular web sites are less fluid than suggested by the hyperbole about internet-facilitated democratisation of medical knowledge.

In article one, I demonstrated how the biomedical orientation appeared as quite “rooted” among the women who participated in the group. The dominant position of the doctor did further appear as “natural”. For example, the efforts to challenge medical authority that was noted by Broom (2005) in his study of prostate patients was not noted among these women. The role of the Internet in this context therefore appeared to be constituted within the frame of subordination to medical dominance, which gives some insight into why the possibilities offered were not exploited as assumed. It further contributes to raise critical attention towards a radical departure from the compliancy that characterises the modern patient role, and which is taken as a point of departure by the enthusiastic responses to Internet use (Hardey, 1999; Hardey, 2001) .

In article two, I further argued that the communication about how to handle the illness followed a narrow line. While the group signalled receptiveness for the disruptive impact of cancer, self-realisation, being able to face the realities and management of fear became emphasised in the exchanges of how the situation could be handled. The difficulties of handling the situation, such as the experience of meaningslessness and uncontrollable fear, were further not woven into the communication. Scattered efforts to communicate about these aspects were not responded to with recognising comments that could contribute to extend the space for a “less successful” handling of the situation. It is such experiences that constitute the impression that the possibilities offered by the Internet were not exploited as expected in the enthusiastic literature. In accordance with previous studies of face-to-face based support groups for cancer patients (Coreil et al., 2004; Ussher et al., 2006), I argued that an image of the individual hero emerged through the exchanges. As such, it can be argued that the interaction in the group contributed to the further circulation of a socially desirable story about breast cancer.

However, the emerging image of the illness experience in this group was less about the hero who wins a self-willed victory over the cancer, or the "warrior who beats the enemy by her own will" that is commented in the critical literature (Broom, 2001; Pitts, 2004). The story that was constituted does rather give associations to the "memoir" described by Frank (1995) in his outline of different versions of quest-stories. In such stories, trials are not minimised, but told stoically, without flourish. The impression of stoicism, rather than being in a war, was salient among these women, and particularly created through the common acknowledgement of the insecure future which was described in article two. Similar to the story about the cancer patient who wins a victory over the cancer however, the message of being in control of the situation was salient, for example through the focus on *"extending life in breadth, not only in length"*.

In this material, an experienced obligation to be considerate emerged as an important background for what I consider as a limited space offered for a less successful handling of the cancer. For some, it appeared important to not "force" 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 'safe' terms about the heavy thoughts that should never win, or not responded to at all. It was outlined in article two. 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 final point is that the involvement and control that was introduced and supported in the group was not openly challenged. As further outlined in article two, some of the women who were active contributors to this image still said in the interview that it might had been too dominating, or that they could have presented themselves as "more vulnerable" than they did.

My main argument in the analysis was that it might be necessary to also consider this interactional pattern as a necessary and voluntary process. This argument will be outlined later in the latter part of the chapter. However, these experiences do also direct attention to other dimensions. As I discussed in article two, it is necessary to pay critical attention to the directions of how to behave in the group and how this might influenced the comment-response style. The question can be raised whether the interaction in the group was “outsider-oriented” (Agar & MacDonald, 1995) and addressed me as moderator and researcher. A further point that could have some influence was the organisation and leadership of the group, which was also commented in article two. It can be argued to illustrate a need for an active awareness towards the interaction in the group, not only towards an acceleration of negative processes that early emerged as an issue in this field (see for example Waldron et al., 2000), but also towards the constitution of an overly successful handling of the situation. In article four, me and my co-author Marianne Trondsen outline and discuss our roles as “hostesses” of the online self-help groups studied. We place emphasis on our point of departure in an effort to adjust for mutual support and to enter a discrete role as hostesses of the groups. As such, the constitution of a cancer hero through the exchanges in this group could have been more actively counteracted. However, as commented above, I also argue that this process can be considered as both necessary and voluntary for the women who were involved.

5.1.3 When the possibilities are not used

Similar to previous experiences in studies of self-help groups, both face-to-face based (Luke et al., 1993) and online groups (Eysenbach et al., 2004), we experienced that the majority of the participants chose to not participate or to leave this online self-help group for women with breast cancer. I explored this observation in article three. As outlined in the article, the need to protect one self against painful details about possible illness courses and need for positive information emerged as one reason to not participate or to leave the group. Stories about spread were introduced to the group quite early in the study period. Some of the newly diagnosed participants expressed “receptiveness” for this information, but others experienced such details as difficult to manage. They felt that they had to protect themselves against them and “get something positive”. As argued in the article, this orientation towards encouraging information is commented in previous research on women who are diagnosed with breast cancer (Giese-Davis et al., 2006).

Such experiences raise the question whether it is necessary to pay more attention to the information needs among newly diagnosed women, and that they might not have an “unlimited” need for information. At the same time, this suggestion is perhaps mainly directed to the prominent image of the information seeking health care user that is crucial in the public debate. During my work with this study, I learned that an awareness of this aspect was present among health professionals who worked with cancer patients (Roaldsen, 2008).

The group was further considered as too “illness-focused” by some of the participants. There was another content in the exchanges in the group than they were looking for. The communication was characterised of “being in” the illness, for example through the focus on treatment and illness courses or the experience of how the illness interrupted the normal life. Those who felt that the group was too illness-focused gave an impression of being on their way out of the disease and wanted to exchange information and experiences that were related to their way back to normal. As such, several exchanges about breast cancer were experienced as irrelevant or not suitable. It is worth to note that the experience of not being ill enough for the group also was expressed by women who entered the group at a time of their illness in which they could be expected to be heavily “into” the disease. As described in article three, one entered the group about six months after the diagnosis and three months after her tumour was removed. Her experience of not being ill enough for the group emerged quite early after she had entered the group and her participation became sporadic after being quite active during the first weeks. She wrote her last message about three months (after she entered the group), which was about nine months after she was diagnosed with breast cancer. The example illustrates how the resistance towards entering a story about restitution story about illness also can be lacking among some women who are diagnosed with breast cancer.

This example illustrates that it is necessary to have in mind that a breast cancer diagnosis does not in itself construct a sense of "being in the same boat" as other women who are diagnosed with the disease. There is need for more work to identify the situations in which potential users of such services feel that they share a common problem. The material also raises the question whether more information-based services could have been sufficient for some of these women. Among those who felt they were not ill enough, information about prostheses and courses for cancer patients represented topics they wanted to hear more about.

It is however important to be aware that the willingness to adopt the identity as "ill" and enter into the kind of "illness talk" that characterised this group can be changed. Nettleton et al (2004) argue that 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. As described in article three, one woman was pregnant during the upstart period of the group and felt that she did not fit in. She gave an impression of being on her way "out" of the disease. When she was diagnosed with spread, she entered the group and wrote to the others that she experienced it as very important. The example illustrates how a resistance towards "illness talk" not necessarily is related to particular individuals.

Further, an adherence to conventional norms about how to behave did not only appear to influence on how the group was exploited, as described in the last section, but also on whether the group was used. As described in article one, this adherence became visible because some women felt that they could not find a legitimate position in the group. Some felt it was difficult to present their “happy” stories, or they were afraid to “complain” to women in a clinically worse situation. The group was also experienced as an arena for “successful coping” among some of the women, which restricted further the issues that could be addressed in the group and therefore the situations in which it was used. As argued previously, it is reasonable to argue that a clearer leader function in the group could have influenced on the exchanges. The crucial function of leadership in self-help groups, either they are face-to-face based or online, is further commented by other authors (Lieberman & Russo, 2001; Till, 2003). My further argument will be that such conventional exchanges can have voluntary aspects, but does not eliminate the need for a further focus on the leadership of online self-help groups.

A last condition that emerged as a constraint to group participation was the organisation of everyday life, which was also outlined in article three. 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 with using an internet-based program for life-style changes over time was explained by the inability of integrating use of the service into everyday life (Anhøj & Jensen, 2004). Such findings link to research that proposes that the organisation of everyday life might be of crucial influence for how people conduct health care activities (Frohlich et al., 2001).

5.2 The commitment to socially desirable ways of doing illness

To sum up then, I have argued that there are elements in this material that give resonance to an enthusiastic view on the potential role of online self-help groups in breast cancer rehabilitation. However, a more modest utilisation of the increased possibilities for exchanging information, and of the disembodied communication, than assumed by the enthusiastic responses still remains as a main experience from this study. It is on the backdrop of this experience that a turn from an "enthusiastic" to a "contingent" response to the potential role of online self-help groups has taken place in this study. During the above discussion, I have argued that it is necessary to pay attention to the organisation and leadership of this online self-help group as being influential for the impression of a modest utilisation of these possibilities. My further argument is that this experience is related to a rootedness of socially desirable ways of doing illness that is not accounted for within the enthusiastic response. This argument is outlined below.

As commented in chapter two, authors who have focused on how people do their illness are making a divide between storylines that are preferable in the late-modern western culture and those which are difficult to hear and accept as part of "reality" (Broom, 2001; Frank, 1995). Desirable stories are stories about restitution or new wisdom (quest), while those that are less preferable are stories about the insufficiency of medicine, about suffering and meaninglessness. As described in chapter two, an underpinning assumption in post-modern readings of illness is that ill people need to raise to the occasion and be "successfully ill" (Frank, 1997). From this perspective, entering the role as a hero in their own life can be part of this process of being successfully ill. But there is also a call for a broader recognition of the less desirable, or chaotic, aspects of the illness experience in the way illness is lived out (Frank, 1995).

The discussion in the last sections above has demonstrated a commitment to socially preferable stories in the way the women in this material live out their illness springs, and that this commitment framed the approach to the group. The underpinning discussion in the articles has been how a commitment to socially desirable stories relates to the lay perspectives on illness. My main argument has been that that there might be insider-aspects of this commitment that need to be further considered and that will be of importance for the further debate on the potential role of online self-help groups in breast cancer rehabilitation. In the final part of this discussion, my arguments are resumed and further outlined.

5.2.1 Socially desirable appearances and the lay perspective

In chapter two, I presented two sociological approaches to the illness experience that take account for a commitment to socially desirable ways of doing illness. On one hand, there are post-structural readings of illness in which this commitment reflects subordination to dominating views on health and illness among people who are ill. It thereby directs attention to the expectant approach to the empowerment strategy and the health political focus on self-help. The reason is that this focus can be argued to open up for a further consolidation of socially desirable ways of doing illness.

However, a commitment to socially desirable ways of doing illness is also accounted for among authors who tone down the outsider position of the medical approach to illness (Crossley, 1998; Williams, 1999; Williams, 2000a; Williams, 2000b). These contributions open up for considering this commitment as also being part of the lay experience of illness, and that it might be less directly connected to processes of domination and subordination. It contributes to raise critical questions towards the governmental focus on self-help, but through this view, the link between the focus on self-help and the expansion of symbolic power is toned more down. Rather than being considered as a tool for liberation, or as contributing to a consolidation of symbolic power, their influential role comes into question.

This argument is outlined below. I direct attention to three dimensions that serve to illustrate a correspondence between socially desirable doings of illness and lay perspectives. These are the *ambivalence* that is argued to characterise late modern societies (Bauman, 1991), a *consistency in self-presentation* and the work to maintain *ontological security* when living with a serious illness. By arguing that these three dimensions represent an important backdrop for how the women in this study approached the self-help group, I also underscore how emotions frame the orientation towards health care among seriously ill people. My further argument is that the two latter points contribute to call for a further reconsideration of the relevance of the modern sick-role.

Ambivalence

The ambivalence that is argued to characterise late-modern societies (Bauman, 1991) is one dimension that needs further consideration in an effort to illuminate the commitment to socially desirable stories among women with breast cancer. In his emphasis on this dimension, Bauman (1991) describes the character of contemporary societies as one in which people acknowledge the impossibility of achieving secure, final, unambiguous order with respect to knowledge about society and themselves. Peoples' lifeworlds have become fragmented and pluralized and people identify with many different roles. Based on her study of consumers handling of environmentally related food risks, Halkier (2001) further suggests that ambivalence in consumption practices needs to be addressed through an acknowledgement of the sometimes conflicting roles that people hold.

Bauman is considered as being among the authors who describes a decentred subject and a post-modern social order (Harste, 1997). However, the attention paid to chaos and conflicting roles is scarcely reflected in previous contributions that offer post-modern readings of illness (Frank, 1995; Frank, 1997; Hardey, 2002b). A focus on ambivalence might add an important dimension to this literature.

In this discussion of the correspondence between a commitment to socially desirable doings of illness and the lay perspective, this focus is particularly interesting as an alternative to how this commitment can be read within a post-structural frame. For example, post-structural readings of illness can find resonance in this material, in the sense that it was possible to trace a distance between how these women lived out their illness and their subjective experience. There were elements in this material that gave associations to "whispering voices", which were introduced by Werner et al (2004) in their study women with chronic pain. One of these is traced through the identified constraints on group participation that were outlined in article three, in which the organisation of everyday life was argued to influence on group participation. This constraint was illustrated through the story of a woman who was one of the active users of the group, but who disappeared during the last part of the study period. When interviewed, this woman told med how she gradually resumed her normal obligations as employer, as spouse and as a mother, which can be considered as an entrance into a restitution story about illness. She still expressed an attraction to the group and a need to also linger with the disruptive impact of the disease. Her point was that she found it difficult to combine this need with the resumption of her normal functions. It is possible to describe her need to linger with the disease as a "whispering voice" that was suppressed in her entrance into her normal life.

A further example of such tensions is traced in the story told by another woman in article one. I described a woman who experienced that her quality of life was reduced by taking a medication that is given to prevent recurrence and spread of the disease, and which is now included in the treatment of some categories of breast cancer in Norway (Tamoxifen).

This woman expressed that her quality of life was more important to her than the number of years she could possibly "win" through taking this medicament. However, she did not stop taking the medication before it was approved by her doctor. Also in this example, a "whispering voice" can be identified through the communication of a considerable burden related to the compliance to a standardised treatment-regime, at the same time as the decision to stop taking the medication needed to be approved by a professional. In one sense, this woman can be argued to subordinate her own needs to the medical focus on cure. Suggestions about a consolidated dominance and subordination of lay perspectives which are offered by post-structural readings of illness can then be argued to be of relevance.

My main argument, and which I have also argued in the articles, is that it is necessary to account for such affirmations of restitution and subordination to the medical view as an active and "voluntary" choice and that these examples illustrates the ambivalent position that individuals in the late modern society can find themselves into. As described in article one, the entrance into the restitution story counteracted this woman's need of also lingering with the disruptive impact of the illness. On the other hand, it made her able to function adequately in other roles that were important for her. In the second example, the subordination to the doctor's advice liberated this woman for adopting an overwhelming responsibility for a potential negative progress of her disease, which appeared to be important for her at the same time as she wanted to maintain her quality of life.

Consistency in self-presentation

Another dimension that I want to emphasise in my suggestion of a correspondence between a commitment to socially desirable ways of doing illness and the lay perspective is a consistency in self-presentation. The decentred subject has been a crucial point of departure for sociological research during the last decades. Both post-modern and post-structural perspectives build on and develop a critique of the idea of an individual subject into new directions (Alvesson & Sköldberg, 2000). According to Alvesson and Sköldberg, these directions *"run counter to the tradition which, it is said, sees the conscious, autonomous, holistic and delimited individual as the bearer of meaning and as an active and "active" subject around which the social world evolves"* (op cit: 164). Instead, the human subject is decentred, considered as an effect rather than the origin of social and discursive processes. In this thesis, these points of view have been illustrated through the situastional focus that is emphasised both in post-modern and post-structural readings of illness. Alvesson and Sköldberg further argue that there are good grounds in empirical research for paying serious attention to this decentred subject, for example by arguing that the subject is particularly sensitive to discursive variations. I illustrated the importance of taking account for this sensitivity in article two, in which the influence of the disembodied context on the Internet was further explored. I argued that a socially desirable story about the individual hero was constituted through the interaction in the group and indicated that this both could be related to the directions of how to behave in the group and to the women's position as strangers to each other.

However, Alvesson and Sköldberg (2000) also direct attention to criticism in which the importance of decentring the subject is argued to be over-emphasised. On the other hand, a reliance on the individual has been crucial in symbolic interactionsim. Or, said differently, the critique against the idea of the individual subject has been less radical within symbolic interactionism than in post-modern and post-structural perspectives. Symbolic interactionists do also emphasise that individuals carry multiple identities tied to specific roles and contexts. But a fundamental assumption within this perspective is still that they also carry a more general self-conception. To some degree, identities must be consistent with the more general self-conception, and the various identities must often be reconciled with each other –

especially when the identity for one context comes into conflict with that of another (Turner & Stets, 2005).

In my further reflections on the constitution of a socially desirable story about breast cancer in the online self-help group in article two, I directed attention to expressions among the participating women which indicated that their controlled and "stoic" behaviour in the group was not deviating from what they considered as "being themselves". My argument is that such expressions illustrate a greater consistency in peoples' appearances than is accounted for within post-modern and post-structural perspectives, and that it contributes to raise some questions towards the independent role of the disembodied context on the Internet.

Maintenance of ontological security

An important point of departure for the micro-sociological perspectives that emerged in sociology during the sixties was how that social actors act within the frames of a taken-for-granted reality (Album, 1996; Gerhardt, 1989). This viewpoint and had its origin in the work of Schütz (Schutz, 1967), who argues that the principle of taken-for-granted world of routine activities based on assumptions of calculability and controllability is the epitome of rationality in everyday life (Gerhardt, 1989). At its most fundamental level, these activities serve to preserve trust and confidence in our existence (Album, 1996), or what is also described as maintenance of ontological security (Giddens, 1991).

There is further an agreement upon that in most cases, this crucial function of the routine activities and normality is normally not reflected upon. They are undertaken more or less unconscious. However, when being ill, *"our self-concepts are put into pressure"* (Album, 1996: 130), because the control over the body is threatened. When this control over the body is broken down, our ontological security is threatened, and this threat becomes particularly salient when diagnosed with a life-threatening illness.

The threat towards ontological security that is caused by serious illness can be argued to be uncontroversial within sociology. However, it is argued that sociology has been concerned almost exclusively with concerns of life, rather than with the subject of death (Mellor & Shilling, 1993). This comment was given 15 years ago. It is further argued that death has increasingly entered the public sphere (Jacobsen, 2002). It might still be argued that this "universal parameter in which social and individual life is constructed" (Mellor & Shilling, 1993: 411) is scarcely accounted for in sociological analysis.

However, in his study patient interaction in hospital, Dag Album (1996) addressed this issue. Among the people studied, there were several people with cancer. Album directs attention to the emphasis placed on "ordinariness" and the mundane interaction between these patients and. He relates this emphasis to their "vulnerable selves". Ordinariness became something "sacred".

In this thesis, I take Album's argument further, by directing attention to an emphasis placed on normality and relating this to the maintenance of ontological security. In article one, I argued that the protection of a "normal" appearance in their established relationships could be approached as a self-willed choice by the women with spread who were active users of the group. In article two, I suggested that a focus on ontological security could locate a self-willed dimension also in the reluctance to open up for the chaotic aspects of the illness experience in the group. In article three, I further argued that this focus serves to locate an orientation towards normalisation into another context than considering it as a suppression of crucial aspects of the illness experience. On the whole then, I find it reasonable to argue that maintenance of ontological security represented an important frame for how this online self-help group was approached, and that it needs to be accounted for in the further debate on the potential role of online self-help groups.

5.3 Conclusion

The aim of this study was to obtain more knowledge about the potential role of online self-help groups in breast cancer rehabilitation. Based on the material, I have argued that the group studied here provided a sense of increased control in the treatment process, that it helped the participating women to create meaning in a marginal situation and that it helped them to protect their close social environments. Such support played a decisive role for some of the participants in this study, and the group as particularly important for women who had been diagnosed with spread. The increased possibility to access other women in a similar situation emerged as the most important dimension of the online self-help group.

On the whole however, the main argument in this thesis is that the radical expectations that were salient at the time of the upstart of this study are not affirmed. For example, in spite of the experienced benefits among the women who were using this online self-help group, the support provided in the group did not give indications of a transformed doctor-patient relationship. A tentative suggestion would rather be that the group made the women better able to support the doctors. Further, the disembodiness on the Internet did not represent an alternative context in the sense that hidden and silenced aspects of the illness experience were made more visible, they were rather treated alone or in other relations. A final point is that group participation became relevant in a smaller range of situations than might be expected on basis of the literature available on the breast cancer experience. I have argued that a commitment to normalisation and a "return back to normal" represented an important backdrop for how this group was approached. The action-oriented framework of this study became particularly helpful in order to reveal this latter point.

I have further argued that notions of subordination to nominating norms of how to do illness should be extended by alternative perspectives in the interpretation of these practices. As such, it can be argued that the material does not give considerable support to worries about a burdening focus on individual responsibility that is extended by the availability of online self-help groups for women with breast cancer. I have suggested that a consistency in self-presentation, maintenance of ontological security and the conflicting roles that people in late modern societies can identify with, are dimensions that also need further attention in the debate. These dimensions can be argued to give further insight into how the exchanges in the online self-help group constituted a socially desirable image of breast cancer, or how group participation became relevant in a lesser range of situations than expected when the group was started. They need attention in further efforts to provide insight into the potential role of online self-help groups for women with breast cancer.

Relating these experiences to a broader context and to the expectations of a changed health care user, my argument is that more attention needs to be paid to how the changing processes take place. They raise the question how the emergence of the “active and involved” new health care user relates to the conflicting roles that people hold, and further to the work to maintain ontological security that can frame people’s life with a serious illness. Based on the experiences from this study, more knowledge about these questions will be of importance for the health care authorities in their work to respond to the changed health care user. What might be of crucial importance is to gain further knowledge of the form these changing processes takes within the context of chronic illnesses in which the life-threatening aspect of the illness is less salient than in cancer. This will provide important insight into the potential role of online self-help groups on a more general level.

I have further argued that there is need to pay more attention to the organisation and leadership of online self-help groups in order to obtain more knowledge about their potential. In this study, it is reason to assume that our decision to include all women with breast cancer into one group did prompt some of the withdrawal from the group. A divide between women who had experienced spread and those who had not could have been a more optimal solution.

In addition, a more active facilitator-role could further have encountered processes that can threaten the cohesion of the group, for example by being aware and active towards the image of breast cancer that was constituted in the group. An important experience from this study is that the action-research framework became helpful in the exploration of how to enter the role as facilitator of an online self-help group.

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Articles