Intervention to Enhance Empowerment in Breast Cancer Self-Help Groups

Nursing Inquiry

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Abstract

As arduous psychological reactions and loss of control almost inevitably represent a challenge for women diagnosed and treated for breast cancer, a participatory intervention study was initiated that aimed to enhance empowerment in breast cancer self-help groups. Women newly diagnosed with breast cancer were invited to participate. The intervention encompassed three professionally led self-help groups running sequentially, each group for approximately four months. Each group of 5-7 participants met weekly. Several empowerment strategies were initiated by two professional facilitators, aiming to promote empowerment processes and to manage stress. The participants experienced group participation as both empowering and as a valuable source of support, and although the group processes developed very differently, a strong sense of fellowship developed in all three groups. The discussion highlights the findings in relation to several theoretical perspectives including social capital, social cohesion, risky agreements, helper-therapy and power/empowerment. We conclude that empowerment strategies that are implemented in professionally led breast cancer self-help groups can contribute to participant empowerment and function as an important source of re-discovery and confirmation of the participants' strengths and abilities.

Keywords: breast cancer, empowerment, health promotion, patient participation

Introduction

Being diagnosed and treated for breast cancer is almost inevitably accompanied by feelings of loss of control, powerlessness, fear of disability and deteriorated health, and deep apprehension about one's own mortality (Nelson 1996; Oktay 1998; Rustøen et al. 2000; Montazeri et al. 2001). Disempowerment may also originate from dependency on caregivers, from asymmetric power relations between professionals and patients, and from that one's life is planned around treatment calendars over which the patient has little or no control (Thuen and Carlsen 1998; Schou and Hewison 1999; Sainio et al. 2001). Thus, one of the great challenges is the struggle to regain a sense of control over one's life (Havik 1989). Peer- or professionally led self-help groups are amongst the interventions that have been tried and tested, to help women cope in the recovery phase of breast cancer.

The essence of self-help groups is the provision of mutual aid and support provided by peers (Borkman 1999). Research shows that self-help groups also may promote empowerment (Gray 1997; Sharf 1997; Mok and Martinson 2000; Ussher et al. 2006), but none of the studies whose evidence suggest this included intervention specifically to enhance empowerment. In a previous paper we have described learning as empowerment processes in a study of breast cancer self-help groups in which an explicit empowerment intervention was conducted (Stang and Mittelmark 2008a). Recapitulating the results briefly, four types of learning were evident: consciousness-raising, acquisition of objective knowledge, learning from others' experiences, and discovery of new perspectives in life and in oneself. The study participants themselves judged that the self-help groups' explicit focus on empowerment made a valuable contribution to their recovery. In another previous paper, we describe positive and negative aspects of social connections in these groups, in particular social support and interpersonal stress (Stang and Mittelmark 2008b). However, few traces of interpersonal stress were found, most likely due to the implementation of the empowerment perspective and subsequent precautions taken to avoid additional distress. We concluded that 'best practice, for those who manage self-help programmes of all types, may be to arrange for empowerment to be an explicit aspect of the intervention, guided by professionals with training in group facilitation and knowledgeable about the facilitation of empowerment in particular' (Stang and Mittelmark 2008a). Therefore, this paper presents the detailed empowerment intervention and an analysis of participants' experience of the intervention. The

intervention was based on the following understanding of the empowerment construct and empowerment processes.

Empowerment

The idea of empowerment, rooted in the social action ideology of the 1960s and the self-help perspectives of the 1970s, represents a paradigm shift emphasising rights and abilities rather than deficits and needs (Kieffer 1984; Gibson 1991). Critical theory, a foundation of social action, assumes that people are capable of critical self-reflection including awareness of limiting conditions constricting the potential of human realization and of which conditions are necessary for developing participatory competence (Habermas 1999). Main tenets of critical theory are promotion of critical reflection, consciousness-raising, enlightenment and emancipation, as well as the promotion of equity and social justice and engaging oppressive social structures (Tones and Green 2004), tenets also emphasised in Freire's (1972) emancipatory theory. Critical theory is often associated with improving the living conditions for underprivileged groups, among which Kuokkanen and Leino-Kilpi (2000) include women and patients.

Tones and Green (2004) claim that 'to be healthy is to be empowered' (10) and argue that empowerment is the main raison d'être of health promotion. The essence of empowerment is gaining mastery and control in life, exemplified by Rappaport's (1984) classic definition of empowerment as 'a process: the mechanism by which people, organizations, and communities gain mastery over their lives' (3). Empowerment reflects both intrapersonal and interpersonal aspects reflected in Gibson's (1991) definition of empowerment as 'a social process of recognizing, promoting and enhancing people's abilities to meet their own needs, solve their own problems and mobilize the necessary resources in order to feel in control of their own life' (359). Empowerment processes as they are usually conceptualised are multifaceted, multileveled and influenced by context (Schulz et al. 1995). Consequently, empowerment will take different forms for different people, organizations and settings (Rappaport 1987). Thus, there has been called for empowerment research in different contexts and settings (Zimmerman 1995).

Empowerment research is needed especially in medical care settings, where experts provide care to novices and power imbalance follows inevitably. The development of competence and

confidence is regarded as crucial to make one's voice heard when interacting with persons more powerful than oneself (Kieffer 1984; Gibson 1995). This is relevant especially where power imbalances disfavour underprivileged groups (Freire 1972), and the ill, being dependent on others for essential services and support (Stang 1998). When a group works purposefully to enhance the empowerment of all its members, empowerment processes are set into motion at both the group and the personal/psychological levels. According to Zimmerman (1995) psychological empowerment has three components: 1) intrapersonal, 2) interactional, and 3) behavioural. The intrapersonal component refers to self-perceptions including domain-specific perceived control, self-efficacy, motivation to control, perceived competence and mastery. The interactional component refers to the individual's cognitive understanding and learning about one's environment, including a critical awareness and the mobilizing of resources to exert control, to gain environmental mastery. The behavioural component refers to actions taken to directly influence outcomes, like joining a self-help group. In practice, these components may be hard to distinguish in the activities of a self-help group, since individually and collectively, members would be expected to engage all three components. Tones and Green (2004) underline that the distinction between personal/psychological and community empowerment may to some degree be artificial, as empowerment at different levels may be inextricably intertwined.

Finally, empowerment outcomes are mostly positive and appreciated, but the possibility of negative outcomes does exist. Responsibility overload is one example of a negative empowerment outcome (Gibson 1995), and Gray et al. (2000) stress the need to avoid this outcome in breast cancer self-help groups. Counteracting negative outcomes and group processes was thus an aim of the empowerment intervention used in this study.

Study aims
The aim of this paper is to document the intervention in sufficient detail so that it could be closely replicated by others in non-research settings, and to present an analysis of participants' experience of the empowerment aspects of the intervention in particular.

The intervention

The participants

The women who participated in this empowerment intervention, were ethnic Norwegians living in the southern part of Norway, and were undergoing or recovering from treatment of breast cancer. The study's 18 participants were from 38 to 58 years old. Most of the women had a total amputation of the breast, but there were variations in severity of disease and treatment.

All women except two (who were unemployed) were fulltime employees, but most of them were on sick leave while participating in the self-help groups. Eight women had higher professional education either from college or university, and one had her own business. Eight were single (divorced or never married), and all except one had children (young, adolescents or grown up). All lived in urban areas and were from the same county. All the women were from the middleclass.

The facilitators

Facilitator 1 – the first author – was an assistant professor in nursing with specialist competence in empowerment and coaching, and experienced as group leader. She was the research project leader, and responsible for group organisation and logistics and implementation of the empowerment intervention.

Facilitator 2 was a professional group leader and a psychiatric nurse with specialist competence in coaching and family therapy. She was engaged to assist the first author to promote a free dialogue among the participants, and to counteract negative group processes and further strain in women who already had stressful experiences to deal with.

The establishment of the groups

Each group was comprised of the two facilitators and participants with newly diagnosed breast cancer and having undergone surgical treatment. Each group had 5-7 members. Four participants pre-terminated participation. Initially, the groups were supposed to run sequentially meeting weekly for about 90 minutes each session for approximately four months. However, according to the advice from group one, the frequency of weekly sessions were re-arranged for group two –

weekly sessions the first two months and thereafter (approximately) every second week. This arrangement was however difficult to implement for the third group due to unforeseen reasons.

Conducting the groups

The group sessions were held in the local Norwegian Cancer Society's meeting room, furnished like a private living room. Refreshments were served at every session. In order to avoid responsibility overload, the participants had no responsibility for organising the meetings. All sessions were organised the same way, conducting 'rounds-around-the-table' which means that all participants were provided with the same opportunity to speak. At the first session in each group, mutual agreement on group norms was achieved, including the norm of reciprocal confidentiality. Further, empowerment theory was briefly presented, highlighting empowerment as an enabling strategy consisting of: (1) enhancing sense of control, competence and autonomy; (2) stimulating and mobilizing strength, resources and abilities; (3) reduction of stress and powerlessness. Empowerment continued to be addressed as a main perspective of the self-help group process throughout the whole intervention.

At each session the facilitators invited the women to describe how they were doing, and what occupied them mentally or physically at present. The participants were encouraged to discuss themes they perceived as important, and they were the main providers of themes discussed, supplemented by themes suggested by the facilitators. The participants were asked to reflect on how their ordinary coping-strategies could be mobilised in their current life-situation. They were also asked what they regarded as their strengths and resources, and how these could be useful in managing the strains and psychological reactions following the trajectories of treatment and recovery. The rationale was to promote their awareness about own strengths, to promote learning from each others' coping reservoirs, and to foster their 'abilities to meet their own needs, solve their own problems and mobilize the necessary resources in order to feel in control of their own life' (Gibson 1991: 359). As such, the participants' intrapersonal component of psychological empowerment (Zimmerman 1995) including self-perceptions of self-efficacy, motivation to control and perceived competence and mastery, was stimulated. Further, autonomy as a key tenet of empowerment was emphasised as a basic value and they were stimulated to reflect on power

issues and distributing of power among group participants and facilitators – e.g. did the facilitators dominate the group or did may be some of the participants do so?

Halfway through the intervention period, an evaluation was conducted in each group. The halfway evaluation was mainly undertaken to ensure satisfactory and well-functioning group processes. These evaluations included discussions of group processes with the aim of trying to improve group processes in the coming sessions. The intention was also to further stimulate critical reflection and consciousness-raising (Freire 1972), and to avoid 'limiting conditions constricting the potential of human realization' (Habermas 1999) which might emerge in such groups.

Ethics

The project was approved by the Norwegian Regional Ethics Committee for Research.

Results

A brief summary of the focus groups interviews

The data indicate that in all three groups, the empowerment perspective became an important inspiration, not only with regard to the recovery trajectory, but also in other arenas of life. Empowerment seemed bolstered by the sense of fellowship fostered by the heterogeneous (however accidental) group compositions. The groups provided a sense of security and of being understood which was very much appreciated by the participants, and in all three groups heterogeneity was regarded as both advantageous and challenging. One participant said: 'I think it is very good that we are different as persons because it provides different perspectives on themes discussed. I think it is great!' In this way heterogeneity was perceived as positive by broadening the perspectives of the discussions. However, heterogeneity was also perceived as challenging and somewhat negative, exemplified by one of the youngest women who asserted that she would have preferred a more homogeneous group in the respect of group members having small children.

What I missed were other mothers with small children like myself. I think I would have felt it as advantageous to share experiences on how to deal with this facing the children. So, age and motherhood should be assessed when compositing such groups.

The group processes

The guinea pig – group one

The group process of group one did not progress as expected before the halfway evaluation. One participant said:

> The reason why the process did not moved on was probably because two participants joined in later, and thus we had to repeat ourselves a lot. If we all had started at the same time, it probably would have functioned somewhat differently.

Thus, one may argue that all participants preferably should participate from the start and attend all meetings, but some of the participants argued otherwise:

> It's of course an advantage if everyone can participate from the start, but then one has to wait until after the chemotherapy and that may be a bit too late.

> It's in the beginning when getting the diagnosis and undergoing treatment that you're the most vulnerable and have the most urgent need to talk and to get information. As such you'll also feel secure by knowing that you'll have somebody to talk with in the nearest future.

> I really appreciated that they joined in, because they experienced the same treatment trajectories as I did. It was quite relieving as nobody can understand what it's like unless they have been there themselves.

The halfway evaluation revealed that the group discussions were perceived to be lacking somewhat in structure, and that the participants wanted the facilitators to ask them further questions as they sometimes found it difficult to think of themes themselves. Consequently, the

structure was tightened up and more in-depth questions were asked, and the group discussions improved to the participants' satisfaction. From being somewhat reserved, the participants now disclosed personal experiences in a way they had not done earlier.

Facilitator 2 played the active role during group one discussions, and facilitator 1 – the researcher and empowerment 'expert' – had a somewhat withdrawn and indirect facilitating role. She did participate and contributed in group discussions, but she mainly acted as an educator and supervisor for facilitator 2 outside group meetings, especially regarding empowerment promotion. This was assumed to be the best facilitating style when planning the project, but since it emerged as a somewhat artificial arrangement, this facilitating style was reconsidered and changed for the next two groups, and facilitator 1 thereafter played an active facilitating role.

Smooth running – group two
Group two was the group that ran most smoothly with respect to group climate, logistics and organisation. Factors playing a role in group two's success were: a) the advice from the first group on how to organise the group – starting with weekly sessions in the first period (approximately two months) and thereafter, sessions every second or third week, and b) the experience from group one regarding group facilitation and implementation of empowerment perspectives. One participant having a serious prognosis said:

> Participating in this group has fulfilled my expectations on being empowered and in control because when I joined the group I had no control at all. Even my physician said: You are coping better than others in the same situation. I will say, much better than others with the same prognosis.

Although the participants were very different as persons, a strong sense of fellowship emerged at a very early stage and the group climate was characterised by kindness, willingness to speak openly by sharing personal experiences, mutual support and concern, a lot of humour and laughter making serious matters manageable, and a commitment to promote each other's strengths and abilities. One participant even felt committed to continue participation though she at times felt that participation was straining and somewhat unnecessary because of her adequate

ordinary network support. She stayed on however, afraid that her withdrawal could result in group dissolution (also expressed as a concern by one of the others). However, when the group terminated meetings she said: 'We came here of our free will – it's nothing automatic about it. If you didn't think it was important, you wouldn't have participated.'

A month before group cessation the group climate was remarkably lowered because one participant's condition deteriorated, or rather, deterioration was confirmed by the oncologists. She was certain that this information was withheld in early phases of her disease. Irrespectively, this message caused worries in the others (included the facilitators) thinking of her well-being and her prospective death, which was likely to occur within a year. The knowledge of this serious prognosis also caused deep worry in one of the other participants about her own prognosis, wondering if her doctors withheld information. In spite of this, the participants' sense of humour and mutual support and commitment never failed, and they managed to cut the sharpest edge of the despair.

The bumpy process – group three
At the halfway evaluation some of the participants of group three reported the group climate as being depressive. One participant said: 'For a while I felt that we depressed each other. And that was the fear I had when we started.' A plausible reason explaining a depressive group climate was probably too much attention paid to negative aspects and not so much focus on empowerment perspectives as intended. Thus, facilitator 1 re-enforced the empowerment perspective and implemented strategies focusing on strengths and resources instead of difficulties and burdens. At the time of group cessation, the participants reported satisfaction. One participant said:

> I think the process has been bumpy. Several times very few showed up, and suddenly someone you feel connected to disappears. I had expected more intensive use of empowerment strategies to promote our strengths. However, I think it gradually improved.

Three prominent factors are plausible to explain why the process was characterised as 'bumpy'. Firstly, irregular attendance intruded continuity. As irregular attendance was more common and included more participants than in the two other groups it may have had greater negative effect in group three. Even if irregular attendance mainly occurred because of treatment side-effects, it influenced the group process negatively, especially when the obligation to notice absence – a consented standard – was not followed. Consequently, unpredictability and some insecurity occurred. Another factor explaining the bumpy process was two participants terminating their participation before the planned end of group activities, and as a consequence, a feeling of loss or abandonment occurred in the others. The third, and maybe the most important reason why the group process was perceived as bumpy, was presence of silent participants (the same as those who pre-terminated participation), who did not share personal experiences as expected. This induced distress in the others. Tape-recorded meetings, field notes and telephone-calls reveal that in particular one of the silent participants felt strained by the obligation to speak in the presence of the whole group of six. Even when facilitator 2 tried to urge them to speak about themselves, they hesitated. Only in one exceptional session with only three participants present did the silent participants speak openly about themselves.

Even if the process of group three was perceived as bumpy, the participants reported satisfaction and a strong sense of fellowship by the time of group cessation. Unlike the other groups, the four remaining participants had the intention of group continuation without the facilitators.

The promotion of empowerment dialogue in all three groups
As described above, several approaches were implemented to promote the empowerment dialogue. Here, the empowerment dialogue will be further elaborated with examples from the groups.

As described above, a brief presentation of empowerment theory was given at the initial group session and continuously focused thereafter, which indeed stimulated the participants' awareness of their strengths, abilities, resources and coping strategies. This approach also included the facilitators' emphasis on the participants' strengths in situations where the participants did not recognize them as such. Soon, the participants adopted the facilitators' approaches and eagerly

used them to support and encourage each other. For example, one participant emphasised another participant's sense of humour as a strength worthwhile coping and of great importance for the group's climate. She said:

> I very much need your humoristic sense of seeing things as I'm the serious kind. Being so formalistic I had great fun of your humoristic approach. That's what I need!

Yet another approach was to inspire the participants to re-consider what they perceived as (unsolvable) difficulties or weaknesses by changing their perspectives and looking at them from a new angle – e.g. when depressed mood and straining psychological reactions occurred, and the facilitators asked whether this state of mind was only to be considered as negative. Consequently, the discussions re-focused on how strains and difficulties like breast cancer may enrich life. The purpose was not to minimize their experiences of straining conditions and psychological reactions related to a life-threatening disease, but rather to demonstrate that these experiences may offer a new meaning to life. Some participants pointed to this aspect of disease and treatment-experiences themselves, and one of them said: 'It's almost horrible to say, but I think it has been a very rich period. In a way I don't know if I would have been without it because it gave me so much!'

Especially one participant who empowered herself by taking control and making choices from the very day she was diagnosed, emphasised that the disease and subsequent treatment as a challenge rather than a threat, even though she had a more serious prognosis than most of the others. She said: 'Of course I took advantage of my knowledge, so I just took control. I decided where to be treated and what I wanted to listen to or not.' This woman's proactive style in combination with the facilitators approach of including and not excluding strains made the other participants more easily recall histories in their own lives where coping with problems was superior. In this way, they became conscious of their previous coping strategies and strengths, and those feeling powerless and depressed when starting in the groups told that they had regained their strengths. After only a few sessions, one participant told another: 'I can see how you have improved and recovered from the state of depression and powerlessness since the group started.' This was obvious to us all and confirmed by the participant, and she further told us she had taken up

previous activities and almost gave her sister a shock when they met at a café unexpectedly. She believed that this was a consequence of group discussions on how to manage arduous psychological reactions related to cancer as a life-threatening disease, combined with the support and encouragement offered in the group. This was not the only example, but characteristic for participants like her, struggling to regain a foothold in life after being diagnosed with breast cancer.

Yet another approach to promote empowerment was the exercises introduced by facilitator 2. She asked the participants to present a poem, a song or other types of presentations that illustrated: 1) their state of mind during recovery, or 2) one outstanding experience or situation of a person who cared for them either in early childhood or later. Some participants presented poems giving them peace of mind or poems that illustrated a state of mind they aspired to, for example a sense of security, calmness or feeling strong. Other examples of presentations were self-made paintings or essays, and oral presentation of things or phenomena of great value to them. In exercise 2, performed in group two, the facilitator gave each participant a piece of clay from which they created an experience or situation described above. The exercises promoted elaborated discussions of who they were as persons and how to mobilize intrapersonal and interpersonal resources and strengths stimulating their awareness or consciousness.

The empowerment intervention in this study had four elements:
1. Facilitator 1 educated facilitator 2 about empowerment and self-help group theory;
2. Facilitator 1 established and implemented three self-help groups in which the subject of empowerment was discussed regularly, initiated by both facilitators, and gradually, by the participants;
3. At the initial group session facilitator 1 educated the participants about empowerment theory;
4. Promotion of empowerment was initiated by elaborating the participants' strengths, sometimes by re-consideration of their initial opinion of phenomena or how they perceived own psychological reactions. Also, facilitator 2 promoted empowerment by initiating exercises by asking the participants to present a poem, a song or other types of presentations that illustrated their state of mind during recovery.

Discussion

In the discussion below the group processes and the promotion of the empowerment dialogue will be assessed and discussed in relation to associated theory.

The group processes

Social capital and social cohesion

One of the most prominent findings in the analysis of the group processes was the participants' perception of a strong sense of fellowship. This fellowship was expressed in the form of mutual support and care, and the sharing of information and experiences, which can be comprehended as social capital, defined by Bourdieu (1986, 248) as 'the aggregate of actual or potential resources which are linked to […..] membership in a group'. Of the four forms of social capital depicted in Carpiano's (2006) Bourdieu-based model of social capital, social support (a source to draw upon to cope with daily problems) and social leverage (e.g. help people to get access to information) were the most evident in the data from these groups (Stang and Mittelmark 2008a; Stang and Mittelmark 2008b). The concept 'social cohesion' in Carpiano's (2006) model which includes patterns of social interaction and values (e.g. network formation, trust and ties) 'from which social capital can be formed… and used for action' (3), also illustrates the essence of the participants' fellowship, as they perceived the groups as places of refuge, offering them an alternative to burdening their ordinary networks with all their concerns, and sympathetic persons to speak with regularly who 'understood' without in-depth explanations.

Social capital and empowerment

The mutual sharing in these groups also illustrates exchanges of favours and obligations which are tenets of social capital (Banks 1997). According to Banks (1997), the more people involve themselves in exchanges of favours and obligations, the more social capital individuals will have at their disposal. Also, individuals' control over events of interest to them will enhance when areas of exchange expand, as they will have less difficulty finding help when needed, or in giving services in exchange. In this study, the self-help groups added to the participants' ordinary networks, and as such, being a member of these groups expanded the participants' opportunities to exert control over matters of interest – especially the disease and subsequent treatment including psychological reactions, but also in other areas of life as well.

One important tenet of empowerment theory is that people experience a sense of control over matters they perceive as important (Gibson 1991), and as such, the social capital – actual and potential resources, and exchanges of favours and obligations – that was generated in these self-help groups contributed to the promotion of empowerment. By introducing the empowerment perspective including enhancement of the awareness of own strengths, abilities and resources, and by offering support and care for each other, a pathway to empowerment processes was created. As Campbell and MacPhail (2002) argue: 'communities that are high in social capital are most likely to provide contexts for the identity and empowerment processes involved in health-enhancing behaviour change' (337). We will argue that our three groups were high in social capital, however most evident in group two as the group process of group two ran more smoothly than in the other groups.

There are nuances worth mentioning. Some participants chose to pre-terminate participation, two after only one meeting, one approximately halfway, and one close to cessation. The first two probably never impacted the fellowship (social capital and social cohesion) in group two in any sense, as they never really joined the group. The other two, however, did to some extent affect the development of fellowship in group three, but mainly negatively, as they – the silent members – did not manage to share own experiences and adapt to the fellowship. By mainly being silent they induced stress in the others, which had a negative impact on the development of trust and ties – the foundation of social capital. However at time of cessation the four remaining participants reported that they experienced a strong sense of fellowship. The reason was not merely that the silent members pre-terminated. It was perhaps more the effect of a re-emphasis on the empowerment perspective in later group sessions.

Group one also experienced some problems related to the development of social capital. Before the halfway evaluation, repeated introductions, as new members joined in at sessions subsequent to the first session, and a lack of structure, delayed development of trust and ties. However, at the time of group cessation the participants reported a strong sense of fellowship.

Finally, social connection is mostly addressed as positive, but it also has its negative aspects, including interpersonal stress. As described in another paper (Stang and Mittelmark 2008b),

interpersonal stress in this study was not prominent compared to the findings in the only previous study investigating negative group experiences in any depth (Galinsky and Skopler 1994). Thus, we concluded that this empowerment intervention focusing on coping strategies, strengths, resources and abilities, as well as stress reduction, had a positive effect in preventing interpersonal stress. It also indicates that the empowerment intervention and the social support emerging in these groups contributed positively, albeit varying, to the development of social capital.

Risky agreements

Social capital comprising interpersonal trust, norms of reciprocity and social engagement may foster beneficial outcomes like health (Carpiano 2006). According to Banks (1997) trust and norms create the basis for the development of bonds or ties which allow people to enter into risky collective agreements. In these groups, the risky collective agreement is represented by sharing experiences, as the participants were strangers before the groups started. For a few participants, this agreement seemed to be too risky and they either chose to keep silent and not follow the obligation of sharing and/or pre-terminated participation.

The helper-therapy

Self-help group participants often benefit from giving help, known as the helper-therapy principle (Banks 1997). Giving help may increase levels of perceived interpersonal competence and social approval from those being helped, and thus, it may derive satisfaction and improved self-esteem. Albeit variations, all participants in this study seemed to benefit from both giving and receiving help, but especially one participant who willingly shared her profound knowledge and who became the others' role model in proactive behaviour style, benefited mostly from being the helper due to her unimpaired sense of control. Group participation, she emphasised, did confirm that she coped well and that her contribution was valuable to the others, and as such became valuable to her.

Divergent group processes

Why did the group processes emerge differently? Obviously, group one was 'the guinea pig' as it was the first time for implementing the empowerment strategies and the cooperation between the

facilitators was newly established. Lessons were learned and deficiencies were corrected, and group two functioned successfully. However, group three did not become the successful duplicate of group two as was expected. Did the non-directed group compositions have a greater impact in group three than in the two other groups? In this study, group composition based on those who volunteered, was the only option as the number of available participants was relatively small. Strict selection and group composition criteria could have jeopardized the project. Another important reason for non-directed group composition is that self-help groups should be inclusive rather than exclusive for all individuals wanting to attend such groups, reflecting the democratic aspect of empowerment (Gibson 1991). Thus, the challenge is to balance potential tensions emerging from participants' different attitudes and behaviours, and to create a tolerant group climate. In the case of group three, the facilitators might have improved the group process at an earlier stage by implementing evaluation of the group process also before the halfway evaluation.

The promotion of empowerment dialogue

Making their voices heard

The empowerment strategies conducted were implemented to promote the participants' sense of control in an arduous life-situation. In their ordinary daily-life before illness struck, these women coped well, but to most of them the disease represented a threat, challenging their ordinary coping abilities. In encounters with health care professionals, the professionals' contributions to treatment and care are mainly regarded as valuable and necessary, but professionals prioritizing curing diseases do not always adequately meet the women's needs for assistance to cope with the psychological reactions following the disease and subsequent treatment. Newly diagnosed with breast cancer, women may find it difficult to ask for such help, and thus, the women may have had difficulties in letting their voices being heard (Gibson 1995). Consequently, the medical discourse becomes dominant in encounters with health professionals. According to Habermas' theory this may be characterised as the system colonising the life-world (Habermas 1999; Andersen 2007) whereas the system and its management mechanisms based on a technical and purposive rationality, reduces the need for communication, and simultaneously, expels the communicative rationality which creates the basis for communication. Thus, the individuals' opportunities to express their experiences are being expelled as well. As the health care system continually develops more advanced technology including diagnostic systems, the patients'

possibilities to communicate their needs may be further reduced, and the power imbalance between the health care professionals and the patients may expand in disfavour of the patients.

The rationale for the establishment of self-help groups was to create a forum for communicative interactions, like sharing experiences. This empowerment intervention and these self-help groups can therefore be seen as a 'power resistance' against the system and the dominant medical discourse, as the self-help groups aimed at promoting participants' sense of control and emancipation. Also, structuring the dialogues as rounds-around-the-table – giving all the same opportunity to speak and share experiences – was implemented to promote equality and equity, and to eliminate domination. This can be aligned with Habermas' (1999) concept of the ideal speech situation based on communicative rationality and referring to the way people interact to create intersubjectivity through a dominant free conversation.

The basic approach of this empowerment intervention differed from typical support group approaches in that it made the subject of empowerment an explicit and major aspect of the group dialogue. It stimulated an open and ongoing discourse about empowerment, and thereby raised the salience of disempowerment/empowerment to a higher level than is typical in support groups.

Professional dominance or 'flies on the wall'
In this study, several empowerment strategies were used to promote participant empowerment. But did these strategies, like the introduction of empowerment theory, promote professional dominance rather than promoting participant empowerment? Did the professionals 'dominate the room' (Bourdieu 1996) or did the participants have the same opportunities for influence? The study results suggest that the participants were given opportunities to make their voices heard, and that the empowerment strategies contributed positively as intended. The study results also reveal that the participants experienced being empowered and that they regained their strength and sense of control in life (Stang and Mittelmark, 2008a). According to the participants, they regarded themselves as the true group members, and the facilitators as 'flies on the wall'. As such the professional contribution and influence did not emerge as dominant to the participants. Also, the participants emphasised the necessity of professional guidance of the discussions, securing a structure giving all participants the same opportunity to speak. They also emphasised the

facilitators' contributions in presenting other perspectives to the discussions than they did themselves. These strategies prevented what one participant called ordinary 'girls-talk', meaning an unstructured dialogue jumping from theme to theme, which they regarded as insufficient to promote critical reflection and growth.

Empowering each other

The empowerment strategies described, focusing on the participants' abilities, strengths and coping-strategies mainly counteracted powerlessness and depressed emotions, and as the participants regained their strengths and sense of control in life, it is reason to believe that this empowerment intervention was successful. However, the professional contribution was not the only reason for this. The participants' contributions were as important as the facilitators' as the participants adopted the empowerment strategies introduced by the facilitators, and their contribution of developing mutual trust, comfort and care, as well as the mutual sharing of experiences and information, were of paramount importance. One example of this was the transmission of optimism and a proactive style of action, features which may be regarded as the ability to recognize alternatives and to act upon them, compatible to the tenets of psychological empowerment (Zimmerman 1995) and participatory competence (Kiefer 1984). For the majority of the participants the reciprocity described above along with the empowerment strategies conducted, this study emerged as an effectual mechanism to release the ability to vent emotions and to discover or rediscover strengths and coping-strategies, and also to adopt new attitudes and proactive styles. Also, most participants showed the ability to take charge and to let their voices being heard (Gibson 1995) in encounters with health care professionals and in other settings as well.

Lessons learned, limitations and future recommendations

In this research project, we learned that an explicit empowerment intervention may be a powerful agent to promote participant empowerment and help participants to regain control, to make necessary changes to improve their lives during recovery and after, and to promote their relationships to family, friends, colleagues and health professionals. We also learned that self-help group interventions probably are not suitable for all individuals as some may be overloaded

by others' stories, be embarrassed by disclosing their emotions in the company of others, or be unable or unwilling to join in group discussions.

For future empowerment interventions we, recommend the following. Group size should not extend beyond five to six members, nor is a smaller group size recommendable. The duration of a self-help group can be time-limited and still be effective. This study indicates that group duration of about four months may be sufficient, with a frequency of weekly sessions in the first period of six to eight weeks, and thereafter every second week. Sessions should not extend beyond 90 minutes, at maximum two hours, as the sessions otherwise will be too exhaustive. The use of a comfortable and home-like meeting place with easy access, and the serving of refreshments are recommended. We also recommend reaching early, mutual agreement on group norms, including a reciprocal obligation to treat discussions with confidentiality. Further, rounds-around-the-table is recommended to provide all the participants with the same opportunity to speak and to prevent dominance by some members.

In empowerment interventions, the facilitators ought to be knowledgeable as group facilitators, and in particular, knowledgeable of empowerment facilitation. A brief introduction of empowerment theory seems to be a very important element in an explicit empowerment intervention, as is a continuous focus on the empowerment perspective. As empowerment strategies includes stress reduction, necessary precautions to prevent further stress and negative experiences should be implemented. Finally, we recommend that discussions about group processes should be undertaken early in the intervention and to be continued on several occasions thereafter.

Conclusions

This intervention study of professionally led self-help groups shows that empowerment strategies can contribute to participant empowerment. The empowerment strategies were important for re-discovery and confirmation of the participants' strengths and abilities, and albeit variations, also for their sense of control in life. The study results revealed that empowerment strategies can not fully guarantee that negative group processes will not occur. It is not possible to know how the circulation of power amongst the participants was altered by the empowerment intervention. That

would have required a study design in which the groups proceeded for an initial period without the empowerment intervention, then for a period with the empowerment intervention. Such a design was not considered.

For future intervention studies we recommend implementation of the same or similar empowerment strategies, but simultaneously to be aware of the need to change the agenda for conducting evaluation earlier in the process to address potential problems. Since facilitating group processes and implementing empowerment strategies is complex, we recommend facilitators of such groups should have training in group facilitation and to be knowledgeable about empowerment strategies in particular.

Acknowledgements

References
Andersen H. 2007. Jurgen Habermas. In: *Klassisk og moderne samfundsteori,* eds H Andersen and LB Kaspersen, 367-389. Copenhagen: Hans Reitzels Forlag
Banks E. 1997. The Social Capital of Self-Help Mutual Aid Groups. *Social Policy* 28 (1): 30-38
Borkman TJ. 1999. *Understanding Self-Help/Mutual Aid: Experiential Learning in the Commons*. New Brunswick: Rutgers University Press
Bourdieu P. 1986. The Forms of Capital. In: *Handbook of Theory and Research for the Sociology of Education,* ed JG Richardson, 241-258. New: Greenwood Press
Bourdieu P. 1996. *Symbolsk makt. Artikler i utvalg.* Oslo: Pax Forlag AS.
Campbell C and C MacPhail. 2002. Peer education, gender and the development of critical consciousness: participatory HIV prevention by South African youth. *Social Science & Medicine* 55 (2): 331-345

Carpiano RM. 2006. Neighborhood social capital and adult health: An empirical test of a Bourdieu-based model. *Health & Place doi:10.1016/j.healthplace.2006.09.001*

Freire P. 1972. *Pedagogy of the Oppressed.* New York: Herder and Herder

Galinski MJ and JH Schopler. 1994. Negative Experiences in Support Groups. *Social Work in Ambulatory Care,* 20 (1): 77-95

Gibson CH. 1991. A concept analysis of empowerment. *Journal of Advanced Nursing* 16: 354-361

Gibson CH. 1995. The process of empowerment in mothers of chronically ill children. *Journal of Advanced Nursing* 21: 1201-1210

Gray RE, M Fitch, C Davis and C Phillips. 1997. A qualitative study of breast cancer selfhelp groups. *Psycho-Oncology* 6: 279-289

Gray R., M Fitch, C Davis and C Phillips. 2000. Challenges of participatory research: Reflections on a study with breast cancer self-help groups. *Health Expectations* 3: 243-252

Habermas J. 1999. *Kraften i de bedre argumenter.* Oslo: Ad Notam Gyldendal

Havik OE. 1989. En generell modell for psykologiske reaksjoner ved somatisk sykdom: Hvordan kan vi best forstå og ivareta pasienters psykologiske behov? *Nordisk Psykologi* 41: 161-17

Kieffer, C.H. 1984. Citizen Empowerment: A Developmental Perspective. *Community Mental Health Review* 3: 9-36

Kuokkanen L and H Leino-Kilpi. 2000. Power and empowerment in nursing: three theoretical approaches. *Journal of Advanced Nursing.* 31(1), 235-241

Mok E and I Martinson. 2000. Empowerment of Chinese Patients With Cancer Through Self-Help Groups in Hong Kong. *Cancer Nursing.* 23(3): 206-213

Montazeri A, S Jarvandi, S Haghighat, M Vahdani, A Sajadian, M Ebrahimi and M Haji-Mahmoodi. 2001. Anxiety and depression in breast cancer patients before and after participation in a cancer support group. *Patient Education and Counselling* 45(3): 195-198

Nelson JP. 1996. Struggling to Gain Meaning: Living with the Uncertainty of Breast Cancer. *Advances in Nursing Science* 18 (3): 59-76

Oktay JS. 1998. Psychosocial Aspects of Breast Cancer. *Lippincott's Primary Care Practice* 2 (2): 149-159

Rappaport J. 1984. Studies in empowerment: Introduction to the issue. *Community Mental Health Review* 3:1-7

Rappaport J. 1987. Terms of Empowerment/Examplars of Prevention: Toward a Theory for Community Psychology. *American Journal of Community Psychology* 15 (2): 121-148

Rustøen T, A Wahl and C Burchardt. 2000. Changes in the Importance of Quality of Life Domains After Cancer Diagnosis. *Scandinavian Journal of Caring Science* 14: 224-231

Sainio C, Eriksson E, and S Lauri. 2001. Patient Participation in Decision Making About Care. *Cancer Nursing* 24 (3): 172-179

Schou KC and J Hewison. 1999. *Experiencing Cancer. Quality of life in treatment.* Buckingham: Open University Press

Schulz AJ, BA Israel, MA Zimmerman and BN Checkoway. 1995. Empowerment as a multilevel construct: perceived control at the individual, organizational and community levels. *Health Education Research* 10 (3): 309-327

Sharf B. 1997. Communicating Breast Cancer On-Line: Support and Empowerment on the Internet. *Women & Health* 26 (1): 65-84

Stang I. 1998. *Makt og bemyndigelse – om å ta pasient og brukermedvirkning på alvor.* Oslo: Universitetsforlaget

Stang I and MB Mittelmark. 2008 a. Learning as an empowerment process in breast cancer self-help groups. *Journal of Clinical Nursing,* doi: 10.1111/j.1365-2702.2008.02320.x

Stang I and MB Mittelmark. 2008 b. Social Support and Interpersonal Stress in Professional-Led Cancer Self-Help Groups. *International Journal of Mental Health Promotion,* 10(2), 15-25

Thuen F and B Carlsen. 1998. Selvhjelpsgrupper. Hva kjennetegner dem, og hvorfor har de vokst frem? *Tidsskrift for Samfunnsforskning* 1: 28-48

Tones K and J Green. 2004. *Health Promotion. Planning and Strategies.* London: SAGE Publications

Ussher J, L Kirsten, P Butow and M Sandoval. 2006. What do cancer support groups provide which other supportive relationships do not? The experience of peer support groups for people with cancer. *Social Science & Medicine* 62 (10): 2565-2576

Zimmerman MA. 1995. Psychological Empowerment: Issues and Illustrations. *American Journal of Community Psychology* 5: 581-599