

**Being in the same boat:
An empowerment intervention in breast cancer self-help groups**

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To the memory of my mother

Ring the bells that still can ring
Forget your perfect offering
There is a crack in everything
That's how the light gets in.

From Anthem by Leonard Cohen

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LIST OF PAPERS

Paper I

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ABSTRACT

Background: Health is not merely the absence of disease – health also encompasses mental and social wellbeing, illustrating the term positive health. Empowerment, including promotion of sense of control and mastery in life, is a key tenet in the field of health promotion and is regarded as a state of positive health. While there is a growing body of empowerment theory and research, there is a further need for context-based knowledge of empowerment. Many women diagnosed with breast cancer experience heavy demands in the trajectories of disease and recovery, and struggle to regain a state of positive health. They also sometimes experience that their burdens are amplified by the lack of support from professional health workers and their ordinary networks of family and friends. Thus, interventions like self-help groups may fill in the gap to promote empowerment and health as they aim to provide mastery through mutual support and learning.

Aim: The overall aim of this study was to promote participants' empowerment, and to develop and investigate the empowerment intervention of professionally led breast cancer self-help groups, and thus, to contribute to the development of context-based theoretical and practical knowledge of empowerment.

Design and methods: Building on this foundation, an empowerment intervention study of three sequentially running professionally led breast cancer self-help groups was undertaken. The research design was inspired by participatory action research (PAR) and a co-operative inquiry perspective. The participants were involved as equal and active partners within the self-help groups but not in any of the scholarly parts of the study. The intervention included implementation of the empowerment perspective aiming to promote participants' strengths, abilities, resources and sense of control. Halfway evaluations were conducted to discuss and potentially change group processes. In total, eighteen women recovering from breast cancer participated, of which four pre-terminated participation. Two professional facilitators, the researcher and a hired professional group leader, mediated the group discussions. Data were collected through multistage focus group interviews and participatory observation. The multistage focus group interviews, conducted at the first and last group session of each group and six months after the last session, constituted the main data. The focus group interviews aimed to explore and gain insight into participants' empowerment processes and outcomes, as well as into any social support and interpersonal stress emerging within the self-help groups.

Qualitative data analysis was conducted by using the analytic tools a) meaning categorisation; b) meaning condensation; and c) structuring of meaning through narratives.

Findings: The data analysis revealed learning as an empowerment process including four subcategories: 1) consciousness-raising; 2) objective knowledge; 3) model learning; and 4) discovery of new perspectives about life and about oneself. The analysis further revealed both positive and negative aspects of social support. Among the positive experiences were a strong sense of fellowship, respect and acceptance, humour and laughter, and relief from not burdening family and friends. The negative experiences that occurred were mostly caused by group logistics and organisation, and a 'bumpy' group process in group three before the halfway evaluation. The analysis demonstrated that there were few elements of interpersonal stress in this study. Mutually shared experiences and the implementation of the empowerment perspective promoted an awareness of the participants' strengths, abilities and resources which stimulated them to take action to make improvements in their recovery process as well as in life in general. Participation and sharing experienced broadened the participants' horizons and promoted their self-awareness, positively contributing to expand their coping strategies.

Conclusion: The study results revealed that empowerment strategies can not fully guarantee that negative group processes will not occur, but the findings document that the positive experiences overshadowed the negative experiences. The findings document that, for the majority of participants, the empowerment intervention promoted their empowerment processes and that the empowerment strategies were important for the re-discovery and confirmation of the participants' strengths, abilities and resources, and for their sense of control in life. The findings further document that the empowerment perspective and intervention, and the information and insight gained from participation, were regarded as a valuable contribution to recovery.

1 INTRODUCTION

1.1 *The focus and purpose of the study*

This dissertation is based on two recognitions: 1) the stated need to further develop contextual-based empowerment theory by conducting research studies; and 2) the needs of women recovering from breast cancer to overcome subsequent stress and vulnerability and to regain control of their life. For nearly two decades I have studied and contributed theoretically to the literature of empowerment theory. During this time, I have learned of an increasing number of women diagnosed with breast cancer. Thus, I galvanised my commitment to address both issues by conducting an intervention study of professionally led self-help groups to facilitate empowerment processes in women recovering from breast cancer.

The main purpose of the study, which also is the core of empowerment (Rappaport 1984, Gibson 1991), was to promote strength, coping abilities and reduce stress so that the women who participated were able to either maintain or to regain control of their lives, in general and in the trajectories of treatment and recovery. Accordingly, as social support – a tenet of self-help groups – seems to contribute to better objective health status (Spiegel et al. 1989, Hall et al. 1994, McLean 1995), while interpersonal stress may have the opposite effect (Rook 1998, Aanes 2005, Mittelmark et al. 2004, Bancila and Mittelmark 2005), a complementary research objective was to investigate the presence of social support and interpersonal stress in these groups.

In recent years, interest has grown in the use of self-help groups to stimulate empowerment processes in women with breast cancer (Gray et al. 1997, Gray et al. 2000, Sharf 1997, Mok and Martinson 2000, Ussher et al. 2006), but, to my knowledge, no intervention study has been presented in the literature in which the subject of empowerment in cancer self-help groups has been an explicit theme, including an introduction to empowerment theory and promoting participants' awareness of empowerment issues. Further, there is a considerable body of research on social support, also in combination with different kinds of support groups, but apparently, only one study (Galinsky and Schopler 1994) has examined the phenomenon of negative experiences in such groups in any depth.

1.2 Health, empowerment and health promotion

The WHO's (1946, p. 2) famous definition of health claims that:

“Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. The enjoyment of the highest attainable standard of health is one of the fundamental rights for every human being without distinction of race, religion, political belief, economic or social condition.”

For women undergoing treatment and recovering from breast cancer fighting infirmity and disease is of course of paramount importance. But for these women, as for all ill people, health is also a question of regaining mental and social wellbeing. Many women diagnosed with breast cancer struggle to regain a state of positive health regarding the mental and social aspects, sometimes amplified by the lack of support from professional health workers, family and friends (Landmark 1999, Montazeri et al. 2001). From this perspective, interventions like self-help or support groups may fill in the gap to promote empowerment and health.

Empowerment is regarded essential to health. Tones and Green (2004, p. 10) even claim that “to be healthy is to be empowered”. They further argue that empowerment is the main *raison d'être* of health promotion. Within nursing, the interest in the empowerment concept probably originated from WHO's definition of health promotion (Gibson 1991), depicted in the Ottawa Charter for Health Promotion (WHO1986) as:

“a process of enabling people to increase control over, and to improve, their own health. To reach a state of complete physical, mental and social wellbeing, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities. Therefore, health promotion is not just the responsibility of the health sector, but goes beyond healthy life-styles to wellbeing.”

Health promotion is often orchestrated by initiating specific population programmes, but also small-scale interventions like the use of intimate groups – e.g. self-help groups as in the

present study – are emphasised as adequate efforts to achieve empowerment (Wallerstein 2006).

1.3 Breast cancer

Breast cancer represents the most common cancer disease among women in Norway and other countries in the western world, with an incidence of 2673 per year of female breast cancer in Norway in 2006 (Cancer Registry of Norway 2007a). To date, no significant knowledge of the causes of breast cancer exists, but risk is seemingly related to heritage, hormones, height, weight and socio-economic conditions (Cancer Registry of Norway 2007b). Approximately five to ten per cent is considered to be related to heritage, while hormonal conditions such as early menstruation debut, late primipara (giving birth for the first time), childlessness and late menopause seem to increase the risk of breast cancer.

1.3.1 Breast cancer patients' vulnerability and powerlessness

When receiving a diagnosis and undergoing treatment for breast cancer, many women experience vulnerability in the form of feelings of uncertainty, anxiety, depression, anger, loss of control (powerlessness), fear of treatment, impaired sense of femininity and apprehension about survival (Oktay 1998, Rustøen et al. 2000, Montazeri et al. 2001). Also, women with breast cancer may experience extraordinarily heavy personal and social demands and challenges throughout the trajectories of illness and treatment, as well as face difficult decisions about one's own treatment and care (Loveys and Klaich 1991, Milburn 1996, Nelson 1996).

Feelings of powerlessness – loss of control – may also frequently follow from, or may be exacerbated by, the dependency on others that serious illness produces, in synergy with the sick role induced by asymmetric power relations between professionals and patients (Thuen and Carlsen 1998). This may be amplified when health professionals are not sufficiently aware of the ways their patient-related behaviour and style of interaction may contribute to a patient's sense of loss of control (Havik 1989, Montazeri et al. 2001). There is also some research that indicates that the routines of treatment contribute to feelings of powerlessness, when virtually all aspects of one's life must be planned around treatment calendars, over which the patient has little or no control (Milburn 1996, Havik 1989, Schou and Hewison 1999, Sainio et al. 2001).

Additionally, patients lacking ready access to information about the disease and the treatment may feel anxiety and helplessness over their ignorance (Sainio et al. 2001). Undoubtedly, coping with breast cancer and its treatment is among the most significant challenges a women can face.

1.4 Breast cancer self-help groups and empowerment

A small body of research provides grounds for optimism that cancer self-help groups can indeed empower their members (Gray et al. 1997, 2000, Sharf 1997, Mok and Martinson 2000, Ussher 2006). Self-help groups are viewed as a suitable vehicle to promote empowerment as well as being a source of mutual aid and support (Borkman 1999). Thus, self-help group participation may offer a valuable contribution to help women to cope with the stress and vulnerability associated with breast cancer (Montazeri et al. 2001, Adamsen 2002, Chatwin and Tovey 2004, Docherty 2004, Michalec 2005).

As being diagnosed and treated for breast cancer represents a great challenge to the women affected, it was of paramount importance to prevent further strains on the women participating in the self-help groups in the present study. Therefore, these groups were led by two facilitators, a professional group leader and me, the researcher, who endeavoured to keep an enabling and facilitating style compatible with the values of empowerment.

2 EMPOWERMENT

As empowerment was the basic theoretical perspective of this doctoral dissertation and the guiding principle of the study, the presentation of empowerment theory extends the presentations of the other theoretical perspectives of this study. Consequently, empowerment theory is exclusively presented in this chapter. The other theoretical perspectives are presented in chapter 3.

2.1 *History and ideology*

The idea of empowerment, rooted in the social action ideology of the 1960s and the self-help perspectives of the 1970s, represents a shift of perspective or paradigm, emphasising rights and abilities rather than deficits and needs (Kieffer 1984, Gibson 1991). The social action referred to here can be traced back to critical theory originating from the Frankfurt School¹ established in Germany in the beginning of the 1920s (Ramsay 2007). Habermas, the second generation representative of the Frankfurt School who further developed critical theory, was one of the intellectual sources of inspiration for the radical student movement in the 1960s, and as such, Habermas was an important contributor of the social action ideology in the 1960s. He did however distinctively contradict the ideology of the most militant parts of the student movement (Andersen 2007).

Critical theory is based on the assumption that people are capable of critical self-reflection, meaning that human beings are able to reveal veiled ideologies and distorted communication occurring in specific historical and social contexts. In this way, critical self-reflection can enhance the awareness of limiting conditions which constrict the potential of human realization and also the awareness of which conditions are necessary for developing participatory competence (Habermas 1999). Thus, the main tenets of critical theory are the promotion of critical reflection, consciousness-raising, enlightenment and emancipation, as well as the promotion of equity and social justice and engaging the prevailing social structures which are seen by critical social researchers as oppressive structures (Tones and Green 2004). Furthermore, critical theory is often associated with improving of the living conditions for the

¹ The name Frankfurt School originated from the German Institut für Sozialforschung (IfS) in Frankfurt, Germany. The name Frankfurter School came into existence in the 1960s when critical theory from IfS for the first time was officially applied and discovered by the radical student movement (Ramsay 2007).

underprivileged, commonly described as oppressed groups, among which Kuokkanen and Leino-Kilpi (2000) include women and patients.

Likewise, Paulo Freire, “probably the best-known advocate of a radical, libertarian approach to education for social change” (Tones and Green 2004, p. 229), presented his emancipatory theory in which ‘conscientization’ – translated as ‘critical consciousness-raising’ – was the main purpose aiming to counteract poverty, powerlessness and oppression (Freire 1974). ‘Conscientization’ refers to: “learning to perceive social, political, and economic contradictions and to take action against the oppressive elements of reality” (Freire 1972, p. 19). In his work, Freire was especially concerned with the living conditions of the underprivileged and oppressed groups in South-America. He asserted that powerlessness and alienation are the consequences when individuals act as objects in relation to their environments rather than being subjects able to act upon and influence their own lives (Freire 1974). Freire (1974) further asserted that powerlessness occurs as a result of a person’s passive acceptance of oppressive cultural conditions as if they were eternal truths, or because people surrender to ‘the culture of silence’ meaning that they remain silent instead of protesting against social, economic or political injustices.

Although empowerment is historically rooted in social action ideology (Gibson 1991), it has also been asserted, especially from representatives of conservative political ideologies, that empowerment implies that the responsibility for one’s life and health lies with the individual itself (Skelton 1994). Simultaneously, they argue that the society’s responsibility for collective welfare services should be reduced. This ideology, however, does not correspond with the ideas of health promotion policy, advocating collective actions like fighting poverty, social inequalities and social inequities, which also implies social and structural changes based on collective responsibility. This is especially important for underprivileged or marginalized groups as they often do not have the competence and/or the necessary resources to escape their poverty and wretchedness or to fight their temporary or permanent incapability.

2.2 Definitions and characteristics

The essence of empowerment is gaining mastery and control in life, exemplified by Rappaport’s (1984, p.3) classic definition of empowerment as: “a process: the mechanism by

which people, organizations, and communities gain mastery over their lives.” Another often cited definition was provided by Gibson (1991, p. 359) defining 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.”

Empowerment is characterised as a learning process in which critical reflection and consciousness-raising are considered core factors to improve people’s coping abilities and participatory competence (Kieffer 1984). Empowerment thus incorporates growth and potential through stimulating and mobilizing resources, enhancement of energy and reduction of stress (Gibson 1991).

Empowerment is regarded as a process and an outcome (Gibson 1991). Consequently, empowerment may be seen as both a terminal and an instrumental value, meaning that being empowered is synonymous with (positive) health and that empowerment is a means to achieve (positive) health (Tones and Green 2004). However, although empowerment outcomes are mostly positive and appreciated, the possibility of negative outcomes does exist. Responsibility overload is one example of a negative empowerment outcome (Gibson 1995) and therefore important to avoid (Gray et al. 2000).

The individual’s autonomy and rights to choose are essential tenets of empowerment. This is also true in health care settings, and it is tautological that one’s informed involvement in mutual decision-making requires that one has access to, and can comprehend, essential information (Rodwell 1996). Medical patients cannot seriously participate in treatment decision-making if the information they receive is insufficient in either amount or quality (Sainio et al. 2001). Optimal empowerment is not, however, a simple function of how much information one has. More important is one’s right to decide the amount and kind of information received, and the right to express autonomy by authorizing others to make decisions (Sainio et al. 2001, Milburn 1996, Nelson 1996).

Empowerment is multifaceted, multileveled and context-based, implying individual, organizational and community levels of analysis and practice (Schulz et al. 1995). Consequently, empowerment will take different forms for different people, organizations and

settings (Rappaport 1987). Empowerment is therefore referred to as a dialectic concept (Gibson 1991). For this reason, it is also necessary to conduct empowerment research in a wide range of contexts and settings (Zimmerman 1995). From a nursing perspective, it is important to explore the meaning of empowerment in contexts where people meet heavy demands in their lives and when their sense of control is threatened.

Finally, although empowerment is divided into different analytical levels, Tones and Green (2004) point out that the distinction between e.g. individual and community empowerment may to some degree be artificial, as empowerment at different levels may be inextricably intertwined. As individual empowerment was the major aim of this project, and the intervention did not include social action in terms of collective action, the focus of the presentation below is therefore empowerment at the individual level. It is, however, necessary to underline that self-help groups are regarded as small communities and the establishment of such group may be seen as a first step toward community empowerment (Laverack 2004). However, since collective social action was not the purpose of the study, and since the self-help groups were an organizational arrangement to promote individual empowerment and potential personal action, the self-help groups in this study can hardly be seen as the start of collective action.

2.3 Individual, psychological and personal empowerment

Empowerment at the individual level can be labelled as individual, psychological or personal empowerment. 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 her study of personal empowerment in mothers of chronically ill children, Gibson (1995) found that personal empowerment comprised four phases: 1) discovering reality, including acceptance of the situation and realizing unchangeable aspects of the situation; 2) critical reflection, referring to the awareness of own strengths, abilities and resources; 3) taking

charge, reflecting a proactive and cooperative, but not subordinate, manner in health care settings; and 4) holding on, reflecting a sense of personal control and power even during changing and challenging circumstances. The basic driving force of the empowerment processes in Gibson's study was frustration originating from the consequences of the children's diseases and the sometimes problematic cooperation with the health care professionals. Gibson's study illustrates self-empowering processes and outcomes; however, these were sometimes facilitated by supportive relations with others.

Mok et al.'s (2004) study reveals that individual empowerment among Chinese patients participating in cancer self-help groups in Hong Kong implied three major processes: 1) a motivational process, including strategies such as commitment, responsibility and obligation to the family, an attitude of still existing hope and religious or cultural beliefs; 2) seeking mastery over illness, including strategies of acquiring information, skills and knowledge related to disease and treatment, alternative medicine and diet therapy; 3) a process of transformational thoughts, including strategies of accepting the unchangeable, letting go, goal for each day, positive thinking, believing that suffering has an end and a limit, looking at life from a holistic perspective, setting alternative goals and downward comparison. The consequence of the first process was finding meaning in life. The consequence of the second process was acquiring skills and knowledge. And finally, the consequence of the third process was acceptance of illness, perceiving harmony in self and with the illness, and peace at heart.

2.3.1 Participatory competence

Zimmerman's account of psychological empowerment resembles the concept of participatory competence described by Kieffer (1984, p. 31). He defines participatory competence as:

“the combination of attitudes, understandings, and abilities required to play a conscious and assertive role in the ongoing social construction of one's (...) environment. It is essentially an enabling evolution which implies the establishment of self as subject, or author, of one's own history.”

Kieffer (1984, p. 31) further presents three major aspects of participatory competence:

“(a) development of more positive self-concept, or sense of self-competence, (b) construction of more critical or analytic understanding of the surrounding social and

political environment, and (c) cultivation of individual and collective resources for social and political action.”

In Gibson’s (1995, p.1208) study, participatory competence was redefined as: “the ability to be heard by those in power”. On the background of her study results Gibson asserts that even if some of the participants of her study did not attain participatory competence, they still achieved a sense of personal empowerment. Participatory competence is thus regarded as a desired, but not necessarily an attainable outcome of empowerment processes (Gibson 1995).

2.4 Power

Empowerment includes counteracting powerlessness and promotion of social justice by redistribution of power within relationships, communities and societies (Gibson 1991, Tones and Green 2004). Power, being the root of both empowerment and powerlessness, is in Weber’s (1947, p.139) classic definition described as: “the probability that one actor within a social relationship will be in a position to carry out his own will despite resistance”. Consequently, power exercise can take different forms, both including and excluding dominance or coercion. Power exercise has thus the inherent capacity to both empower and disempower.

Sometimes, power redistribution implies that the powerful have to lose power so that those having less or no power can gain it, characterized as a ‘win-lose’ situation, also meaning that to gain power one has to seize it from another (Laverack 2004). This also illustrates what is described as ‘zero-sum power’ which means that there is only a certain amount of power within a society, often associated with political and economic influence and status subsequently following from wealth and income (Laverack 2004).

Power redistribution may however take on a different form, especially when power is not regarded as a finite entity – e.g. as a certain amount of wealth within a society at a certain time. Power can instead be viewed as infinite and expanding, and equating ‘win-win’ situations based on the idea that if some, either a person or a group, gain power, everybody else also gains it (Laverack 2004). Examples of ‘win-win’ situations within power redistribution are sharing of knowledge, skills, care and trust as these are aspects of power existing in social relationships (Hernes 1975, Laverack 2004). And for the promotion of empowerment, development of competence, knowledge and confidence is regarded crucial to

make one's voice heard, especially when interacting with persons who are more powerful than oneself (Freire 1974).

Power exercise within the perspective of empowerment implies cooperation, fellowship and mutual respect, but also a commitment to struggle against discourses and paradigms which represent domination and coercion, as well as oppressing norms and practices (Freire 1974, Rappaport 1984, Ryles 1999, Kuokkanen and Leino-Kilpi 2000). Empowerment is thus compatible with the notion of 'power to' (Hokanson Hawks 1991, Stang 1998) which emphasises cooperation, reciprocal respect and acceptance as well as mutual determination of means and goals. This stands in contrast to the notion of 'power over' being compatible to paternalism, also incorporating coercion, dominance and competition (Hokanson Hawks 1991). 'Power-over' is often associated with economic and political dominance, or it can be a form of social dominance following from social class, gender, education, ethnic background, age, physical or mental ability, and sexual preference, all tending to structure 'power-over' relations (Laverack 2004).

Laverack (2004, p. 36) describes three aspect of power: 1) 'power-from-within'; 2) 'power-over'; and 3) 'power-with'. 'Power-from-within' is described as "an experience of 'self', a personal power or some inner sense of integrity or 'truth' ", which is also aligned with individual, personal or psychological empowerment. 'Power-with' resembles 'power-to' as the essence of 'power-with' is to increase people's strengths and abilities "rather than to dominate or exploit them" (Laverack 2004, p. 39). 'Power-with' also incorporates a transformation of 'power-over', a transformation which only succeeds when submissive individuals have gained enough strength and power enabling them to exercise their own choices and decisions.

Laverack's description of 'power-over' mainly resembles Hokanson Hawks' concept, but Laverack (2004) also includes the notions of exploitation and hegemony. Exploitation is described as: "the indirect power to control people's choices through economic relations, in which those who control capital (primarily money) also have control over those who do not" (Laverack 2004, p. 38). Hegemony which tends to be internalized and invisible, and thus, taken for granted, is described as: "the ability of a dominant group to control the actions and behaviours of others by intense persuasion" (ibid). Freire (1974), Foucault (1994) and Bourdieu (1996) all addressed hegemonic power. Freire, as described above, asserted that in

fighting hegemonic power and to avoid ‘the culture of silence’, it was necessary to develop ‘critical consciousness’ among the oppressed and underprivileged groups. Foucault (1994) addressed hegemonic power as a form of power which exists everywhere in our daily lives and is thus subtle in its form. Foucault further asserted that the only form of resistance was to live one’s life in concealment from the authorities (Laverack 2004). And finally, Bourdieu (1996) asserted that hegemonic power tends to be restored by taking on other forms even when the structures of society are changed or reorganized to promote the opportunities and power of underprivileged groups.

Hegemony, exploitation, coercion, dominance and competition inherent in the notion of ‘power-over’ is, as emphasised earlier, not compatible to empowerment as this kind of power exercise easily induce powerlessness in those not being in the position of power, unless there is a successful transformation to ‘power-with’.

2.5 Powerlessness

The essence of powerlessness is the sense of not having or losing control. Powerlessness is a state of being disempowered and can be characterised as either situational or permanent (Stang 1998). Miller (1984, p. 118), who asserts that powerlessness is genuinely situational determined, defines powerlessness as: “a perceived lack of control over a current situation or immediate happening”. The enduring form of powerlessness which is characterised as permanent state of powerlessness (Stang 1998) is defined by Seeman (1959, p. 784) as: “the expectancy or probability held by the individual that his own behaviour cannot determine the occurrence of the outcomes, or reinforcements, he seeks”. The state of permanent powerlessness is also associated with learned helplessness (Seligman 1975), a stable personality trait (Miller 1984), or as a generalised expectation of external control (Rotter 1966). A rich body of research has revealed that burdened and demanding life conditions such as poverty, discrimination, oppression, unemployment, problematic school situation, learning difficulties, deteriorating family conditions, disabilities, illness and hospitalization, often induce powerlessness which may have serious consequences for life and health (Seeman and Evans 1962, Seeman 1963, Miller 1984, Roy 1984, Havik 1989, Oberle 1992, Seeman and Lewis 1995, Jørgensen 1996, Nelson 1996, Rustøen et al. 2000).

Although most psychological reactions related to illness are temporary and incidental (Havik 1989), individuals often experience heavy demands in life when acute and serious illness

strikes. When being hospitalised, diagnosed with a serious disease, as well as undergoing subsequent treatment, patients can experience psychological reactions and a lack of control being similar to a sense of crisis or regressive reactions (Havik 1989). The intensity of such reactions is however dependent on each person's resources, abilities and coping capacity. Counteracting powerlessness and other psychological reactions is, thus, of paramount importance.

3 OTHER THEORETICAL PERSPECTIVES

3.1 *Self-help groups*

The term self-help can be understood in different ways. One understanding is that self-help is an individual's own efforts to fulfil his or her potential and to improve one's living conditions. Another perspective of self-help which is relevant for this study, includes both helping oneself as well as helping one another, the latter is also characterised as mutual aid (Borkman 1999).

A self-help group is a form of social technology structuring social relations between people having the same problem (Borkman 1999). A self-help group is also called 'a sharing circle' characterised by horizontal peer relationships and participants sharing primary experiences through narratives or storytelling. Borkman (1999) asserts that self-help groups can offer a liberating meaning perspective as the participants are able to define – based on their own primary experiences – what is of importance to them and not what society or people outside the group may consider to be correct or true. To generate a liberating meaning perspective, Borkman further asserts that the self-help group participants must be willing to develop intimacy and to establish a group dialogue based on critical reflection. In this way, the liberating meaning perspective and the horizontal peer relationships of self-help groups can contrast e.g. the hierarchical relationship between laypeople and health care professionals, often dominated by the professionals' perspectives, knowledge and discourses. And furthermore, such asymmetric relations often leave the patients without the possibility to find solutions to problems not stemming directly from the disease and subsequent treatment. As Avery and Nyhof-Young (2003, p. 38) account for:

“It is easier to determine a patient's individual needs, identity, motivation, and competencies in a group than it is in the physician's office or a busy clinic. (...). In the nonthreatening environment of the support group, women with breast cancer can begin to recognize, articulate, and act on their needs.”

Solidarity, equality, support and help, reciprocity, mutual learning and knowledge development through experienced-based dialog are considered important tenets of self-help groups (Bottomly 1997, Thuen and Carlsen 1998, Borkman 1999, Adamsen 2002). In recent years, interest has grown in the use of self-help groups to investigate and stimulate

empowerment processes (Gray et al. 1997, 2000, Sharf 1997, Mok and Martinson 2000, Ussher et al. 2006), and peer social support has been regarded as a mechanism to assist women in coping with the stress associated with breast cancer (McLean 1995, Samarel et al. 1998, Montazeri et al. 2001, Adamsen, 2002, Chatwin and Tovey 2004, Docherty 2004). According to Gray et al. (2000), participant empowerment and democratic decision-making are important features of self-help groups. Further, Mok and Martinson's (2000) study of cancer self-help groups reveals that social support and mutual learning rooted in participants' experienced-based knowledge can make a foundation for empowerment processes and outcomes.

Compositions of self-help groups vary in relation to aims and arrangements, but there exist these commonalities: a) voluntary participation; b) small size and informal constitution; c) face-to-face contact (though internet based groups are developing); and d) mutual help and support to attain a certain aim, such as the satisfaction of common needs, the conquering of common problems, or the promotion of desired social and/or personal change (Sharf 1997, Thuen and Carlsen 1998, Borkman 1999, Klemm et al. 2003).

Self-help groups can either be self-governed or assisted by professionals, and when professionally led, the role of professionals may vary (Gray et al. 1997, Thuen and Carlsen 1998, Smeardon 2001, Adamsen 2002). Sometimes the professionals merely help start the groups or function as consultants, in other cases they act as facilitators or leaders all along. Professional involvement seems paradoxical in the self-help concept, especially when considering the power issue (Thuen and Carlsen 1998, Borkman 1999, Gray 2000). Yet, professional assistance has become more common and may contribute positively when the nature of involvement is based on the idea of solidarity and equality (Adamsen 2002). In a comparative study of the effectiveness of peer-led and professionally led support groups for family caregivers, Toseland et al. (1989) found that participants in a professionally led group improved slightly more in psychological functioning and personal change compared to participants in a peer-led group. The participants in the peer-led group however, had more positive changes in informal support networks than those in the professionally led group. Another study of newly diagnosed cancer patients revealed significantly better psychological functioning and coping styles in participants of a professionally led support group than in participants of a non-interventional group (Bottomley 1997).

3.1.1 Learning in self-help groups

As described earlier, empowerment is characterised as a learning process including critical reflection and consciousness-raising. Likewise, learning is considered an essential activity in self-help groups as mutual sharing of experiences and information can increase the participants' knowledge and awareness (Borkman 1999, Mok 2001, Avery and Nyhof-Young 2003).

Learning in self-help groups is described by Borkman (1999) as the cycle of experiential-social learning which refers to the process of how a self-help group participant learns from and with peers. The cycle is based on ideas of experiential and social learning theories and consists of four phases: (1) gain information and interpret within one's worldview; (2) reflect: is the idea applicable to me?; (3) try out the new idea in daily life; and (4) assess consequences of using the new idea. However, Borkman underlines, this model is an analytic tool and the phases will probably not be so distinct in practice. Nevertheless, it may be helpful to understand the process of learning in self-help groups.

Based on shared experiences, the cycle of experiential-social learning including assessment and interpretation of new ideas as presented here often leads to change or expansion of the individual participant's preliminary worldview. Avery and Nyhof-Young (2003, p. 43) emphasise:

“Talk is an important form of action for women with breast cancer, and shared personal stories are a powerful means of learning about the experiences and needs of others. Through talk, patients with breast cancer can find their voice among the voices of others and develop a language representing their health experiences. Through supportive talks with others, patients can reflect in their activities, their reasons for acting as they do, and their future actions. Public discussion in the group slows down action so that participants can reflect on, critically interpret, and change tacit understandings that motivate their actions.”

The process of learning by listening to and critically reflecting upon shared experiences is also characterised as vicarious experience through modelling (Bandura 1986). This means that each participant acts as a model for the co-participants when articulating experiences as well

as attitudes, beliefs and actions as this may portray and inspire the others to consider and adopt alternative perspectives and ways of acting and coping.

3.2 Social support

Social support is a core tenet of self-help groups. In the literature, social support has been conceptualised and measured in various ways (Williams et al. 2004). Among several definitions of social support House's (1981, p. 39) classic definition describes social support as:

“an interpersonal transaction involving one or more of the following: (1) emotional concern (liking, love, empathy), (2) instrumental aid (goods or services), (3) information (about the environment), or (4) appraisal (information relevant to self-evaluation).”

A number of dimensions along which social support has been conceptualised are: “(i) time (short or long term) and timing (when); (ii) relationships and social ties (structure, strength, type, nature); (iii) supportive resources (emotional, material, skill or labour, time, cognitive, information, feedback); (iv) intentionality of support; (v) impact of support (positive or negative); (vi) recognition of support need; (vii) perception of support; (viii) actual support; (ix) satisfaction with support; (x) characteristics of recipient; and (xi) characteristics of provider” (Williams 2004, p. 947). Based on a review of occupational stress literature Buunk and Hoorens (1992) describe four different perspectives of social support. The first perspective includes the degree of one's social integration or the size and structure of one's social network, in which health is promoted by provision of stable and rewarding roles, by promoting healthy behaviour, by deterring the individual from unwise behaviour, and by maintaining stable functioning in times of rapid change. A second perspective includes the availability of relationships which provide love, intimacy or esteem, and as such may act as buffers against stress. In the third perspective, social support is presented as the perceived assumption that others can be relied on when needed, and that this mere perception per se reduces stress. This is also called the perceived helpfulness view. The fourth perspective of social support primarily refers to the actual helpful actions of others, and does not, like the three foregoing perspectives, include a stress preventive aspect.

Research reveals that self-help groups and support groups are valuable sources of social support for women with breast cancer (McLean 1995, Gray et al. 1997, Mok 2001, Avery and Nyhof-Young 2003, Docherty 2004, Stang and Mittelmark 2008 b), and that participants of cancer support and self-help groups have significantly lower levels of depression and anxiety (Montazeri et al. 2001, Zabalegui et al. 2005). Results from several studies further show that support and self-help group participation foster additional positive outcomes as: (i) increased sense of community and belonging; (ii) feelings of unconditional acceptance and ‘being understood’; (iii) reduced isolation; (iv) increased knowledge of cancer and subsequent treatment; (v) provision of alternative perspectives, hope and spiritual support; (vi) the opportunity for healing laughter; (vii) more adaptive coping styles; (viii) improved quality of life and psychological well-being; and (ix) empowerment (Bottomly 1997, Gray et al. 1997, Montazeri et al. 2001, Adamsen 2002, Avery and Nyhof-Young 2003, Docherty 2004, Zabalegui et al. 2005, Ussher et al. 2006, Stang and Mittelmark 2008 a, Stang and Mittelmark 2008 b).

3.3 *Interpersonal stress*

Social support can also have a dark side, as when well-meant support attempts backfire or when support is offered in an inept way that may do more harm than good (Rook 1988, Henriksen 2001). These are amongst the most benign examples of negative social exchanges, which Rook (1988) defines as actions (including verbal) that people perceive as misdeeds or transgressions and that cause distress. This includes both acts of omission and acts of commission. Mittelmark et al. (2004, p. 7) conceptualise interpersonal stress from a social psychological perspective, as: “a transactional, cognitive process involving appraisal and not completely satisfactory coping, to resolve dissonance among cognitions about significant other(s)”. Problems such as minor squabbles and brief disagreements are excluded from this definition. Interpersonal stress, viewed this way, is a relatively chronic aspect of one’s life, that may involve conflict (but often does not), and is serious enough to cause rumination and distress. Examples include feeling close to someone who needs help, but not knowing how to help, receiving the ‘wrong’ kind of support from some close, and not being able to meet expectation or demands from someone who is close.

Social exchange theory, in which equity theory is regarded the most influential, refers to peoples expectations of giving and receiving beneficial support in social relationships (Buunk and Hoorens 1992). Negative affective reactions are likely to occur if the assumed flow of

exchange of support is disturbed; either by not receiving the expected support, or by not being able or not willing to return support, or when the received amount of support is more favourable than the support one is able to give in return. In equity considerations, the type of relationship is also important. Interestingly, equity seems to be the most important in business relationships and less important in intimate relationships even though:

“a large number of studies have shown the importance of a global perception of equity for satisfaction in personal relationships, and that people with disabilities attempted to maintain reciprocal supportive relationships” (Buunk and Hoorens, 1992, p. 448).

Giving more support than receiving may lead to feelings of unfairness and resentment, while the opposite may lead to feelings of guilt and shame.

Self-help groups are meant to provide arenas for the exchange of social support, but they can also be arenas that generate strain, including interpersonal stress, as seen in a relative small number of studies (Galinsky's and Scopler 1994, Slevin et al. 1996, Gray et al. 1997, Mok and Martinson 2000, Mok 2001, Avery and Nyhof-Young 2003). However, only two of these studies give examples of negative experiences which can be characterised as substantial interpersonal stress. In Galinsky's and Scopler's (1994) study these include: (i) disruptive members; (ii) inappropriate behaviour; (iii) over-dependence; (iv) interpersonal conflicts; (v) violated confidentiality; and (vi) failure to follow group norms. In Mok's (2001) study interpersonal stress are revealed to be (i) a perceived pressure to conform to group demands; (ii) feelings of being overwhelmed or uncomfortable; and (iii) feelings of being useless in the group.

3.4 Study aims and research questions

The overall aim of this study was to promote participants' empowerment, and to develop and investigate an intervention of professionally led breast cancer self-help groups, and thus, to contribute to the development of context-based theoretical and practical knowledge of empowerment which has been called for by researchers in this field. The following research questions guided this intervention study:

Research question 1: What are the characteristics of empowerment processes in professionally led breast cancer self-help groups when an intervention is made to promote empowerment?

Aim: Explore and gain insight and knowledge on empowerment processes in professionally led breast cancer self-help groups.

Research question 2: What kinds of social support and interpersonal stress occur in the professionally led breast cancer self-help groups?

Aim: Explore and gain insight and knowledge on social support and interpersonal stress occurring in professionally led breast cancer self-help groups.

Research question 3: What are the characteristics of the group processes in professionally led breast cancer self-help groups influenced by an empowerment intervention, and do these processes differ from one group to another?

Aim: Explore and gain insight and knowledge on how group processes occur and are influenced by an empowerment intervention in professionally led breast cancer self-help groups.

4 METHODS

This project is based on research conducted *with people* rather than *on people*. Collaboration was a key consideration as the development of meaning and knowledge was based on the participants' and the researcher's common efforts and interactions. A qualitative and interventional approach was chosen since the nature of the project was to initiate and promote empowerment processes, and to explore participants' experiences related to empowerment processes, social support and interpersonal stress in self-help groups.

4.1 *Scientific position*

The underlying philosophical, ontological and epistemological assumptions of this project are based on the ideas of critical theory and empowerment, mainly embedded in the research paradigm labelled as the participatory paradigm (Lincoln and Guba 2000), or the advocacy/participatory paradigm (Creswell 2003). Adherents to this paradigm hold participation as a political imperative (Reason 1998), and emphasise that inquiries undertaken in the context of this paradigm have a political agenda (Creswell 2003). Key tenets of this paradigm emphasise an action agenda for change in, and improvement of, the lives of the people participating in the research projects, centred on empowerment (Creswell 2003). The ontological position is that reality is regarded as participative, and that subjectivity-objectivity is "co-created by mind and given cosmos" (Lincoln and Guba 2003, p.168). Human beings are regarded as active agents "with emerging capacities for self-awareness and self-direction" (Reason 1998, p. 150), but they are simultaneously heavily dependent on community and participation with others. In this view, participation is regarded as an epistemological imperative (Reason 1998). Knowledge is created in a community of people who are not separated entities, but inextricably related to one another. This is also true for researchers. Unlike the positivist perspective that places the researcher in an outside position, separated from the subject of research, and that regards knowledge as objective and true when critically tested, the participatory paradigm places the researcher in a reciprocal position with the community, in which knowledge is co-created (Reason 1998). In this perspective, co-created knowledge and findings are based on "critical subjectivity in participatory transaction with cosmos", and knowledge is experiential, propositional and practical (Lincoln and Guba 2000, p. 168). As Reason (1998, p. 160) writes:

“A participative epistemology articulates a way of knowing and acting which is both grounded in our experiential presence in the world and honours the human capacity of sense-making and intentional action.”

In this study, ontological and epistemological issues are reflected in the intervention, based on the ideas of empowerment and self-help, in which reflection and consciousness-raising through dialogue, among equally collaborative partners, aimed at promoting mutual learning and development of meaning and knowledge. At one level, meaning and knowledge gradually emerged through the interactions between the participants and the facilitators, and through the participants’ mutually sharing experiences, perspectives and thoughts, cautiously promoted by the facilitators. At another level, the epistemological imperative of participation was not met, as the researcher (facilitator 1) developed meaning and knowledge by conducting data analysis and interpretation without the collaboration of the participants.

4.2 Design

The research design of this study is inspired by participatory action research (PAR) and a co-operative inquiry perspective, a design suitable for implementing the ideas of the participatory paradigm. This perspective is one of several variations within the action research ‘family’ which covers diverse strategies from emancipatory inquiry to positivist field research (Reason 1998). The concept of action research has three central components: action, research and participation (Greenwood and Levin 1998). Action research is further characterised by the intention to forge social change (particularly for marginalised groups), through the intention to improve the participants’ capabilities to more efficiently control their own goals, and to promote their abilities to do so continuously. The primary focus of PAR and co-operative inquiry is the creation of knowledge-for-action, contrasting research in which the primary aim is to create knowledge-for-understanding (Hummelvoll 2008a). The idea of generation of knowledge-for-understanding in participatory research is not a contradiction, but it is given a subordinate position. In participatory research, knowledge develops through a cyclic process of action and reflection, central to which is the enhancement of people’s abilities to critically investigate reality and their own knowledge in order to position themselves to influence their environment and to promote their performance in life (Reason 1998, Kemmis and McTaggart 2000).

In participatory research, knowledge is created through a co-generative dialogue, in which community participants are active and equal partners, and not merely consultants from whom the researcher collects data. Together, the participants with the insider's perspective and the researcher with the outsider's perspective on the topic in question, create a new, context-based local theory or framework based on their former frameworks, which are different, but considered as equal and mutual important (Elden and Levin 1991). Participatory research is fundamentally emancipatory and aims to transform theory as well as practice, both equally important for the improvement of the participants' life conditions in particular local settings (Kemmis and McTaggart 2000). Unlike mainstream research, the focus of PAR and co-operative inquiry is not so much the methods used, but is rather the researcher's attitudes and the locally defined priorities and perspectives wherein participant's influence and power are essential features (Hummelvoll 2008a). The degree of participant involvement may vary from periodic/sporadic involvement to full participation, the latter meaning involvement from the initial design to the presentation of results, and taking action for social change that is stimulated by the research (Whyte et al. 1991, Hummelvoll 2008a). Regardless of the level of participant involvement, researchers working in the framework of PAR and co-operative inquiry "attempt to make qualitative research more humanistic, holistic, and relevant to the lives of human beings" (Denzin and Lincoln 2000, p. 376).

In this study, full participation in all phases of the project was not accomplished, and was not aimed for. Instead, periodic participant participation and influence on the research process were implemented as main features in the self-help groups' functioning, and in the multistage focus group interviews. The multistage focus group interview, further described below, is an appropriate data collection method when one seeks the participation inherent in empowerment work and the participatory paradigm. This research project was initiated by the researcher without participant involvement, and the researcher was solely responsible for planning the project and initiating the self-help groups, being advised by academicians and health care professionals only. The participants did not participate in group management and logistics, in data collection preparation, in data analysis and interpretation, nor in the formal dissemination of the results. However, the self-help groups were the very foundation for development of meaning and knowledge in this study, and the participants were active and equally collaborative partners from the start to the termination of the self-help groups. The participants influenced and decided group activities, and they were also the main providers of themes discussed in the groups. Thus, the meaning and knowledge emerging in the self-help

groups were heavily influenced by the participants as co-creators, and the participants' role in this process was of paramount importance. The self-help groups, being the foundation for the development of contextual-based knowledge as well as promoting empowerment processes, may also be characterised as communities of inquiry (Reason 1998).

Three central principles characterise communities of inquiry (Reason 1998). Firstly, the group constitutes a clear framework which is reciprocally accepted as the foundation for group activities. In this study, the framework consisted of mutual agreement on group norms to regulate group activities, and mutual acceptance of empowerment as the main perspective.

Secondly, when constituting communities of inquiry, it is essential to articulate "a future form of desirable relationship to which group members can aspire" (Reason 1998, p.155). This desirable form must however always be loose and open for definition and re-definition. This may contradict clarity since a firmly defined goal cannot be fully defined. On the other hand, it opens a gap between the clarity of the present and the undefined future which "stimulates the imaginative capacities of the participants" (Reason 1998, p. 156). In this study, relationships and group activities were discussed and defined in the beginning and later discussed and sometimes re-defined at the following group sessions, at the halfway evaluations and at the focus group interviews.

The third principle relates to the establishment of a process of learning and inquiry. According to Reason (1998), this process is somewhat paradoxical as it simultaneously "defines boundaries and opens a space in which creativity is demanded" (Reason 1998, p.156). Under such circumstances liberating leadership and facilitation is necessary, and the facilitators must be willing and able to manage contradictions and "to articulate a vision of a future state and invite others to reach toward it with them" (Reason 1998, p.156). The participants in this study were presented the vision of empowerment, and were invited to create knowledge and meaning according to this vision in the context of breast cancer self-help groups. We, the facilitators, made intentional efforts to implement a liberating, facilitating style by including 'rounds-around-the-table', by critically reflecting upon our roles and by encouraging the participants to be the main providers of themes discussed.

The establishment and conduct of the self-help groups represented the action part of this study, and critical reflection was promoted through group dialogues. The cyclic process of

action and reflection in this study took place within the self-help groups and was promoted by the researcher's presentation of empowerment theory at the first session of each group, so that not only the researcher, but also the participants and the other facilitator were reflective and aware of empowerment issues in the group discussions, and in the reflective process.

Because practice is a prominent part of the cyclic process of reflection and action, the participants gave a brief introduction of their life history and their disease and treatment experiences at the first session. As such, important aspect of both theory and practice were exposed and illuminated for further scrutiny along the way. The cyclic process of collective self-reflection was further reinforced by the halfway evaluations conducted in each group, focusing on group processes and empowerment issues. These evaluations included meta-discussions meant to elevate the discussions and reflections to a higher level of abstraction. The way the self-help groups were organised was – on a broader level – a step taken to promote the cyclic process of action and reflection. An additional element in the cyclic process was that running the groups sequentially gave the facilitators and the participants the opportunity to critically consider the functioning of the previous group when planning for the next group.

Returning to the issue of degree of participation in PAR, some claim that full collaboration in all phases of the study is an obligation, while others assert that full participation in all parts of the research project is not necessary (Low et al. 2000, Reason 1998). The competencies of academics and laypersons are different, and full participant collaboration is therefore sometimes unrealistic and not always practical or manageable for the participants (Low et al. 2000, Etowa et al. 2007). In cases where full participant collaboration is not achievable, it is important to address power issues. Power imbalances may easily be the consequence of the dominant position of the researcher(s). However, equally important is the participants' condition and capabilities, especially when people are dealing with life-threatening diseases like breast cancer and when experiencing straining psychological reactions. Under such circumstances the value of participant involvement in academic tasks must be weighed against the imperative to avoid adding further burdens to an already burdened life. Participants' restricted participation does not necessarily mean that the participants are being overruled by the researcher(s); it can also be the result of a conscious effort to avoid responsibility overload for participants who are in a vulnerable life situation. As Gibson (1995) emphasises, the results of empowerment processes are mainly positive, but negative

results like responsibility overload do occur. Of course, the answer is not that researchers should exclude ill persons from participating in PAR studies. Instead, researchers should be particularly considerate when conducting PAR projects together with people dealing with life-threatening diseases and straining – and sometimes exhausting – treatment regimes. The alternative, excluding ill people from PAR studies, would be deeply regrettable because empowerment and social and personal change is as important for these people as it is for others.

The above discussion brings to the fore the question, is this study correctly located under the umbrella of PAR? The position taken is that the study may be regarded as a modification of PAR leaning towards co-operative inquiry, though others might claim that studies like this are of the top-down PAR genre (Low et al. 2000). Others have suggested that Advocacy Research (AR) is a more appropriate label when conducting research with disenfranchised society members and when participation is problematic and requires too much from both participants and researchers (Etowa et al. 2007). In our study, the participants were not disenfranchised society members. Rather, they normally were competent and resourceful persons, but their capacity to be fully collaborative partners was reduced due to their need to deal with heavy demands following the trajectories of illness and treatment. The scholarly parts of this study were definitely dominated by the researcher, but not in an exploitative manner. According to the participants' reported experiences, researcher dominance was not a feature in these self-help groups. One participant's statement illustrates this: "I felt that we were the group and you (the facilitators) were more like flies on the wall".

4.3 *The intervention*

The intervention, referred to above as the 'action', encompassed the establishment, organisation and conduction of the three sequentially running professionally led self-help groups.

4.3.1 Preparing the intervention and establishing contact with collaborative partners

In the preparation phase of the project during autumn 2001, an application for recruitment of women undergoing treatment for breast cancer as participants for the self-help groups was sent to a regional hospital in southern Norway. A meeting with the chief surgeon at the hospital was then held. Thereafter, a meeting with the chief surgeon in the section of breast cancer was arranged and topics like different sampling selection criteria, establishing contact

with nurses as recruiters, and information-meetings for these nurses were discussed. The next step was establishing contact with the head nurses at the surgical ward, and at the surgical and oncological outpatients' department to select nurses to be engaged in the recruitment process. Only nurses with dedicated responsibility for women undergoing treatment for breast cancer were selected. Thereafter, five meetings with different groups of selected nurses, the chief surgeon in the section of breast cancer and the head nurses were arranged to inform them about the research project, including the plan for the establishment of the self-help groups and the empowerment intervention. Empowerment theory was briefly introduced, and the recruitment process, the sampling criteria and how to organise and coordinate the recruitment were discussed.

The researcher also contacted and collaborated with the nurses at the local Norwegian Cancer Society (NCS). The nurses at the centre represented co-operative partners for the researcher during the intervention, and they offered a room and other facilities at the centre to the groups. The nurses attended one group session for each self-help group to briefly inform them about the NCS, and about the facilities they could offer.

4.3.2 The recruitment process

An invitation letter and additional verbal information about the project was given to eligible women by the nurses engaged to recruit participants. The women were asked to participate either at the surgical outpatient department when undergoing the two-week post-discharge examination, at the oncological outpatient department when undergoing chemotherapy, or they were recruited from outside the hospital. Including women from outside the hospital was feasible and necessary, because fewer than the usual numbers of women were diagnosed with breast cancer during the first months of 2002 (in the particular region in southern Norway where the study took place). The surgical ward was excluded as an arena for recruitment. The invitation letter stated that the project would emphasise an empowerment perspective and tenets of empowerment were briefly described.

The women willing to participate mailed an informed consent form to the researcher, who then contacted each participant by telephone to provide further information about the project and the starting date of the self-help group.

4.3.3 The participants

The participants in this study were 18 women from 38 to 58 years old and recovering from breast cancer. Most of the women had a total amputation of the breast, but there were variations in severity of disease. Most of them had chemo and/or radiation therapy when participating in the groups and some received hormonal medication. Just a few did not get any follow up therapy at all, either due to medical appraisal or according to the woman's own wish. 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.

4.3.4 The facilitators

Facilitator 1 – the first author – was an assistant professor in nursing with specialist competence in empowerment and coaching, and experienced as a group leader. She was the research project leader, and responsible for: i) group organisation and logistics; ii) implementation of the empowerment intervention; iii) data collection through focus group interviews and participatory observation; and iv) dissemination of the study results.

Facilitator 2 was a professional group leader engaged to assist the researcher 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 professional group leader was a psychiatric nurse with specialist competence in coaching and family therapy.

4.3.5 The establishment of the groups

Each group was comprised of the two facilitators and participants with newly diagnosed breast cancer and also 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, for approximately four months. However, according to the advice from group one, the frequency of weekly sessions was changed for group two, which had 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. One reason was the time of the year. Like the first group, group three started during spring season, and in this period of time, several holidays occur. Other

reasons were irregular attendance and the researcher's doctoral program re-scheduled, causing cancellation of one meeting each. Unfortunately, we did not succeed to re-schedule the meetings as we did for the first group. Thus, not only did the ideal frequency of meetings fail in group three, the group also had fewer meetings than group two. Therefore, group three, like group one, had one additional meeting after the summer holidays.

4.3.6 Conducting the groups

At the initial session, the first focus group interview was conducted, and the participants recounted their experiences of being diagnosed with and having breast cancer, and additionally, they gave a brief presentation of their life story. At the next session, the researcher gave a brief presentation of empowerment theory, and the participants continued to share experiences subsequent to breast cancer disease and treatment, and other personal matters. All sessions were organised in a way that provided each participant with the same opportunity to speak. 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 further encouraged to discuss themes and perspectives they perceived as important. Halfway through the intervention period, an evaluation was conducted in each group. 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. The participants had no responsibility for organising the meetings.

4.3.7 Implementation of the empowerment perspective

The empowerment presentation highlighted empowerment as an enabling strategy consisting of: (1) enhancing a sense of control, competence and autonomy; (2) stimulating and mobilizing strength, resources and abilities; and (3) reducing stress and powerlessness. Empowerment continued to be addressed as a main perspective of the self-help group process throughout the group trajectories. The empowerment intervention consisted of the following five activities:

1. Facilitator 1 educated facilitator 2 about empowerment and self-help group theory, and regular meetings were held to supervise facilitator 2 on empowerment issues and how to implement empowerment in the group processes.
2. Facilitator 1 established contact and obtained cooperation of the chief surgeon in the breast cancer section and nurses (who recruited participants) at the regional hospital,

informing them about the project, and educating them about empowerment and self-help group theory.

3. 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.
4. At the initial group session, facilitator 1 educated the participants about empowerment theory.
5. The promotion of empowerment was initiated by highlighting the participants' strengths, sometimes by re-consideration of their initial opinion of phenomena or of how they perceived own psychological reactions. Also, facilitator 2 promoted empowerment by initiating exercises in which the participants presented a poem, a song or other types of presentations that illustrated their state of mind during recovery.

4.4 Data collection

Data collection was conducted through focus group interviews and participatory observation. As participatory observation is part of PAR, it is not described as a particular data collection method in this study. The focus group interviews provided the main study data while the observation data provided a basis for comprehension of the culture, the relationships and the processes within the groups. Each group was interviewed three times: at the first and last meeting, and half a year after group cessation. Semi-structured interview guides were used, allowing the participants to speak openly about the topics discussed. The interviews were audio taped and transcribed verbatim. All meetings in between focus group interviews were audio-taped (but not transcribed) to keep a record of background data, and field notes having the same purpose were written after the meetings. Data collection occurred from March 2002 to February 2004.

Focus groups are especially useful when knowledge about social and psychological issues and behaviour are requested and when the aim is to investigate knowledge and values shared by cultural groups (Brataas 2001). Focus groups allow the researcher to observe collective interactions within the groups, and the method is also useful when the aim is to investigate the participants' attitudes, experiences and beliefs, and when the researcher wants to investigate how knowledge is created and used in particular cultural contexts (Madriz 2000).

Until 1981, marketing was the only discipline reporting any frequent use of focus groups, but since then, focus group research has been widely used in research (Fern 2001). Today, there exists an array of focus group research, and Fern (2001) argues that each researcher may adjust the focus group design to fit the particular research task of his or her project.

Accordingly, Fern also advocates some departures from traditional focus group techniques.

4.4.1 Multistage focus groups

Multistage focus groups are one such departure from the traditional method. Commonly, several focus groups are established within the research project and each focus group meets only once. With multistage focus groups on the contrary, only a few focus groups are established and several meetings with each group are arranged over a period of time, these are also characterised as ‘longitudinal groups’ (Morgan 1997, Hummelvoll 2008a). While ordinary focus groups are used to create knowledge based on the participants’ opinions of particular topics, multistage focus groups move beyond that (Høye and Severinsson 2008). One benefit of multistage focus groups is that bonds between the members are built through disclosure of individual biographies and preferences, and thereby, a sense of shared history develops. Morgan (1997, p. 69) further argues that multistage focus groups “raise a variety of issues that do not occur in the typical ‘one-shot’ use of focus groups”. According to Hummelvoll (2008a, p. 5), multistage focus groups may be a suitable method to investigate knowledge dialogues focusing on experiential material, dialogues which may provide “possibilities to ‘elevate’ the participants’ experiences to a higher level of abstraction”. As such, the knowledge gained may have substantial relevance beyond the particular context in which it is created, a form of transferability or generalization.

In this study, the focus groups and the three self-help groups had identical composition. As such, these groups simultaneously represented multistage focus groups and communities of inquiry. In theory, the main difference is that while the feature of multistage focus groups is creating knowledge through dialogues, communities of inquiry also incorporate the notion of action (Hummelvoll 2008a). In this study, the aim was to incorporate knowledge creation and action in one and the same group, and this proved feasible.

Three separate interview guides were composed for each of the three interviews. The third interview guide, however, also included the main questions from the second interview guide

for the purpose of investigating any changes in the participants' comprehensions of group participation half a year after group termination.

Facilitator 2 acted as co-moderator in all interviews by taking notes for a résumé. This résumé was presented at the end of the interview to ensure whether the résumé correctly reflected the discussions during the interview and the participants had the opportunity to agree or disagree with or make adjustments to the résumé's content.

4.5 *Qualitative analysis*

For the purpose of analysing data systematically, qualitative analysis was conducted. The data were analysed with the primary intention of exploring and interpreting the participants' individual empowerment processes. According to Halkier (2006), the processing of data from focus group interviews needs to be carefully considered whether the analytic unit is the content (the individual expressions) or the group interactions, or both. In this study, both the individual and the group constituted the analytic units. However, as individual empowerment processes were the primary focus of this study, the individual, or rather individual expressions, constituted the main analytic unit. Overall, the groups were of relatively minor significance as analytic units, but the group level of analysis was important when analysing the group processes that are reported in article III.

4.5.1 *Analytic tools*

Analysis was conducted using different analytic methods (Kvale 2001), consisting of: a) meaning categorisation; b) meaning condensation; and c) structuring of meaning through narratives (for sequences of the analytic process, see Attachment IV). The analysis started by reading and re-reading the transcribed interviews to capture a general view of the interview data (Kvale 2001). This was followed by a systematic process of *meaning categorisation* (Kvale 2001), through the clustering of the participants' expressions that seemed to reflect the same underlying meanings. Each category was then condensed to bring out its essential theme by extracting rather comprehensive expressions into a few sentences, described as *meaning condensation* (Kvale 2001). Seen retrospectively however, the meaning condensation process in this study emerged as less important as the essential themes also were easily captured directly from the categories.

To capture essential elements of empowerment, the analysis was continued by a reconsideration of data and the categories, revealing three empowerment processes: learning, social support and personal change. The data and the categories related to learning were then reconsidered, revealing four aspects or sub-themes of learning as an empowerment process: 1) consciousness-raising; 2) objective knowledge; 3) model learning; and 4) discovery of new perspectives about life and about oneself, as reported in article I. As personal change appeared to be an intertwined part of the empowerment processes, or rather, as outcomes of the empowerment processes, personal change was not processed or presented as an independent topic. Thereafter, the data and the categories related to social support were reconsidered. Several positive and negative aspects of social support were revealed, accompanied by an analysis of the negative experiences of social support to extract aspects of interpersonal stress, all presented in article II. A detailed description of the group processes and the empowerment intervention are the subject of article III.

Finally, a systematic process of clustering the individual expressions within each category was conducted to explore and interpret individual empowerment processes, characterised as *structuring meaning through narratives* (Kvale 2001). In this study, the narratives were not fully analysed as narratives with regard to sequence of time, the social dimension or the course of action. The narratives were rather used to enrich the comprehension of each individual's story as observed in the groups, and thus allowed a better illumination and understanding of the individual empowerment processes. An important methodological limitation of the study is that individual interviews were not conducted. As limited project resources did not allow for both focus group and individual interviews, focus group interviews were prioritised. The rationale for this was that the focus group interview provided a social context in which individuals could reflect on their own and on others' experiences in and outside the group, such that the 'conversation' generated by the focus group interview might stimulate individuals to engage in deeper reflection about their own experiences and feelings, than they might be able to achieve in individual interviews. The trade off was the possibility that individuals might refrain from expressing themselves frankly about group processes, and about other group members.

4.6 Study quality

In both qualitative and quantitative research, researchers seek to establish research rigor through strategies for verification of knowledge (Kvale 2001). As qualitative research departs

from the positivistic ideals of accurate and objective knowledge proclaiming to represent the world as it is, some qualitative researchers prefer to replace the traditional concepts of reliability, validity and generalizability with other concepts like relevance, trustworthiness, transferability, authenticity or confirmability (Denzin and Lincoln 2000, Thagaard 2003, Wennberg and Hane 2005). Other qualitative researchers like Kvale (2001) and Halkier (2006) prefer to use the traditional terms, but re-conceptualise them for qualitative research. These re-conceptualised terms will be used in this dissertation.

4.6.1 *Reliability and validity*

The degree of reliability in qualitative research is in large part a function of the degree of transparency achieved regarding the methods used to produce, analyse and interpret data, so that the research quality can be assessed by others (Halkier 2006). In this way, reliability is also a salient part of research validity, since validity in qualitative research relies on communicating and revealing the research project step by step (Halkier 2006). To achieve research reliability and validity, the researcher needs to critically examine each single part of the study and carefully examine how these parts are connected, including a critical assessment of the arguments used when choices are made and when developing the research design – and make this explicit to others (Kvale 2001, Halkier 2006). Reflexivity and self-correction is essential, not only at the end of the research process, but included as an integral part from the very beginning (Alvesson and Skjoldberg 2000, Kvale 2001, Malterud 2001, Vinje 2007). Halkier (2006) asserts that in focus group research, validity is achieved when the researcher succeeds in revealing the process to others, and by arguing analytically and convincingly, so it can be accepted by others.

Validity in qualitative research is further elaborated in relation to language, dialogue and participant utility. As Kvale (2001) underlines, knowledge verification in qualitative research is based on the understanding that knowledge is contextual, personal and related to society, rooted in daily living and local experiences. Thus, language and dialogue are essential for knowledge generation, as it is for the knowledge verification process. Especially important is the nature of the dialogue representing the context in which knowledge is to be understood. Therefore, one needs to critically examine how, why and with whom the dialogue takes place, also referred to as communicative validity (Kvale 2001). *How* refers to power issues and proclaims an ideal of no social dominance in the argumentative process. *Why* refers to the aim of creating true knowledge through dialogue and the criteria for achieving such knowledge

through consensus. *Who* refers to the questions: Who are communicating with whom? And who are regarded as legitimate partners in the dialogue wherein knowledge is generated?

This is in line with Halkier (2006) who asserts that further enhancement of validity in focus group research is achieved through inclusion of minor validity strategies all along the research process and by making the strategies explicit. Such strategies, by way of examples, may include the assessment of the number of focus groups involved, the number of participants in each group, who the participants were, how they were recruited, where the focus group interviews were situated, and how the focus group interviews were conducted – including the structural level of the interviews and group moderation, the interview guide and what kind of equipment was used.

Communicative validation reflects agreement through dialogue. Pragmatic validation however, goes further by also including action as part of the knowledge verification process (Kvale 2001). In pragmatic validation, knowledge verification is an evaluation of the practical value for those involved. This is also referred to as face validity (Kemmis and McTaggart 2000). When participant utility and benefits are achieved, the claim of face validity is met. This may, however, be at the cost of research rigor, especially in action research, including participatory action research, if more immediate gains in face validity get priority (Kemmis and McTaggart 2000). However, as Kvale (2001) asserts, the validation process must not be too rigorous, as this may jeopardize creativity and even lead to invalidity because of distrust in the face value of the research statements, interpretations and actions.

In order to establish reliability and validity in this study, I have attempted to provide a detailed presentation of each study part, the relation between these parts and the arguments used for the choices made. In this way, I hopefully have made a web of interrelated and intertwined research parts that emerge as reasonable and coherent, so that the reader will find a sensible and comprehensive thread leading from the scientific position to the dissertation of the results and the conclusions. In regard to conducting focus groups (here also self-help groups), communicative validity refers to an explicit and detailed description of the establishment and implementation of the groups, and the arguments used when choices were made. In order to follow the notion of communicative validity of focus/self-help groups, these aspects of the work are described in detail: the recruitment process; the number and size of the groups; the approaches applied to establish and conducting the groups; the facilitators' roles;

the emphasis on establishing a dialogue based on respect and equity; the implementation of the focus group interviews as an integral part of the knowledge generation process.

Another approach to achieve validity in this study was to systematically present and critically discuss methods, findings and data interpretations with academic colleagues and researchers (also from other professions) at research seminars, workshops and conferences all along the project period. This approach aims to obtain interpretive insight and to assure the interpretations' trustworthiness (Kvale 2001).

In the literature on qualitative research, the researcher is often recommended to include the participants in the validation process by letting the participants read and give feedback on the transcriptions (Kvale 2001). In this study, however, participant involvement in the validation process was different as participant involvement was represented by minor validation strategies incorporated during the intervention trajectory. One such strategy was the implementation of a halfway evaluation which was mainly undertaken to ensure satisfactory and well-functioning group processes. However, integral in an evaluation process is also the confirmation of whether the generation of knowledge and meaning is coherent with the intervention's intention, which in this study meant to create and implement knowledge about empowerment and social support. For example, participants in group three reported that this intention was not fully realised, and thus, the facilitating style was changed to improve the empowerment processes (see Paper III). As such, knowledge generation 'got back on track' to accomplish the study's intentions. Another validation strategy was the participants' opportunity at the second focus group interview to offer recommendations for organising and facilitating the next group. As such, the participants could influence 'the action' of this study directly, both at the halfway evaluation and at the second focus group interview. And, not least, in this way the participants could influence participant utility, referred to as pragmatic validation. A third validation strategy was the implementation of the third interview half a year after group cessation in which questions from the second interview were included in order to investigate whether the participants' experiences and interpretations of group participation had changed.

Participant involvement in validation efforts in this study did not aim to validate the data categorisation and interpretation, but to validate the knowledge generation. The main reason for not involving the participants in the analytic process was to avoid responsibility overload

in a straining and challenging life situation. A forth and last strategy of validation is the résumé which was written by facilitator 2 as part of the focus group moderation process. When the interviews were completed, facilitator 2 presented the résumé so that the participants could agree or disagree whether the résumé reflected the content of the discussions during the interviews and eventually make necessary adjustments. This is also described as a suitable validation process by Wennberg and Hane (2005).

Finally, research validity is also related to interview transcriptions (Kvale 2001). The spoken language is different from the written language, and verbatim interview transcriptions are therefore not copies of the spoken language but rather abstractions of it. When reading transcriptions, the spoken language may therefore seem odd and incoherent (Kvale 2001). As Kvale (2001) further says, when using citations to exemplify findings it is often necessary to make the text more fluent and appropriate, also to avoid participant embarrassment when reading the published end result. However, research validity may be at risk if the original meaning of the spoken language is lost or detached. In this study, verbatim transcriptions were processed for the purpose of making the language fluent and coherent. During this process, I carefully considered the original meaning by reading the verbatim transcriptions closely and also sometimes by listening to the tapes. Another pitfall for violating validity in this study is that all citations were translated from Norwegian to English as the findings were to be published internationally. English is my second language and thus it makes the translations even riskier. However, the translated citations were validated by other academic colleagues, and not least, the citations were also validated by my adviser and collaborative partner in the analytic process, who is a native speaker of English and has Norwegian as a second language.

4.6.2 Generalizability

In qualitative research, generalizability in terms of statistical generalizability is replaced by analytical generalizability, as knowledge is regarded as contextual, diverse and complex, instead of universal and precise as in the positivistic tradition (Kvale 2001). As was the case for reliability and validity, analytic generalizability is achieved when the researcher conducts a thorough examination of the research process and makes this process, including the arguments used, transparent and explicit so that not only the researcher, but also the reader can judge for her- or himself whether the knowledge is relevant to another setting (Kvale

2001). As already mentioned, I have attempted to attend to these issues as carefully as possible.

According to Wennberg and Hane (2005) generalisation or transferability (the term they prefer) of results from focus group interviews can be provided by relating the interview material to theories, reasoning and discussions known by the associates in the research field in which the findings are published. As such, the researcher attends to generalisation by elaborating the interview material to higher levels of abstractions which is familiar to the reader. This is in line with Malterud (2001) who says that rather than being facts assessed as applicable for a population at large, the findings from qualitative studies are assessed for their applicability as descriptions, notions or theories within a specific setting.

In the papers included in this dissertation, I have attempted to discuss and relate the interview material to relevant theories and discussions in the fields of empowerment, self-help groups, breast cancer, social support, interpersonal stress and PAR. By revealing my interpretations of the relationship between the interview material and these theories, I hopefully have made it possible for the readers in these fields to recognise the reasoning from familiar theories and discussions within the presentations and interpretations of the focus group interviews in this study.

4.6.3 Self-reflexivity and the researcher's role

In qualitative research, it is salient to carefully consider the researcher's role and the impact the researcher has on the research process and the knowledge generation (Kvale 2001). It is thus important that the researcher makes her or his prejudices conscious and explicit, as they otherwise would unduly and covertly influence the research process, including data collection, analysis and interpretation. Prejudices and more or less conscious feelings, originating from one's own life story and social and cultural background, can blind the researcher or make the researcher take things for granted (Fog 2001). Thus, fostering researcher self-reflexivity is important (Alvesson and Sköldberg 2000).

In order to develop researcher self-reflexivity and to conduct critical self-examination, I have frequently written reflexive field notes during self-help group participation. By doing so, I have fostered an internal discussion and critical introspection of my own feelings and reactions to what was happening. I also frequently had discussions with facilitator 2 to get

feedback on my assessments and interpretations, as well as my performance as a researcher and group facilitator. Not least, I encouraged the participants to discuss both mine and facilitator 2's performance, perhaps especially emphasised when conducting the halfway evaluation and focus group interviews as part of a systematic investigation. However, seen retrospectively, I must admit that self-reflections probably were too harsh when I chose to moderate my involvement as a facilitator in the first period of group three, out of fear of being too dominant. Unfortunately, this resulted in less emphasis on empowerment before the halfway evaluation.

Self-reflexivity was further fostered in frequent discussions with colleagues and researchers from different fields. The topics for these discussions were my participating and facilitating style in the self-help groups, and the way I conducted all parts of the research process. This included critical examination of how questions were formulated and why, what kind of questions I proposed and how I responded to the answers or the stories told. Other topics taken up were how I managed to validate participant expressions, what kind of feelings emerged in me, and how this affected my behaviour.

The researcher's role is influenced by cultural aspects and the degree of similarities and differences in social and cultural background between the researcher and the participants. This is not merely a source of blindness, but also an important source of connectedness with the participants, and thus a source for establishment of trust (Fog 2001). The participants in this study, being white, ethnic Norwegian women ranging from 38 to 58 years of age, their social, cultural, economic and occupational background, their different social roles, like being a woman, mother, daughter and sister, and their daily-life experiences, are in many respects similar to my own roles and background. Perhaps the greatest differences between us were that I was not diagnosed and treated for breast cancer, and that I was the researcher, in charge of the project, which gave me a dominant position, a position I consciously tried to minimise.

Finally, since I as the researcher, consciously influenced the knowledge generation process, and thereby influenced the participants' attitudes and behaviour, it was important to explicitly and critically examine the reasons for my actions and the choices I made. This was a process in which I invited the participants and others to assist, as described above.

4.7 Ethical considerations

Kvale (2001) discusses three ethical principles which are necessary to address when conducting research with human participants. These include participation by informed consent only, the right of anonymity and confidentiality, and careful consideration of consequences for the participants. These principles have been addressed to some degree in section 1.3.1, 4.2, 4.3.2, 4.3.4 and in the three papers. The principles will be further discussed in this section in which the ethical principles of beneficence, non-maleficence and justice are reflected upon (Hummelvoll 2008b).

4.7.1 Informed consent

In all research projects informed consent means that the participants are provided with full information about the project and participation consequences, including possible advantages and disadvantages (Kvale 2001). Informed consent is based on the principle of autonomy which is reflected in the notion that participants must agree voluntarily to participate in the study and that they have the absolute right to withdraw from the project at any time (Christians 2000). Since explorative studies (common in qualitative and participatory action research projects) may produce new knowledge that influence study aims and plans during the process, and thus can be changed, it can be difficult to fulfil the obligation of providing full information at the beginning of the project (Kvale 2001, Hummelvoll 2008b). This is also relevant for participant reactions subsequent to participation, as they cannot always be foreseen. To attend to these matters, the alternative is to have an ongoing dialogue discussing the project aims and plans, as well as participants' reactions in order to meet the obligation of full information. In this study, such dialogues were implemented (described earlier) and the participants were active partners when changes were made. One example was the agreement to conduct the third focus group interview which was not intended from the start.

A possible ethical problem related to informed consent regarding the participants in this study may have occurred when being asked to participate by nurses who were more or less involved in their treatment regimes. Critical reflection on dependency caused by helping relationships is important as it may influence the participants' willingness to participate. Receiving help and care can make one feel obliged to do something in return or induce fear that the quality of care and treatment can be affected negatively if one chooses not to participate. Thus, dependency might influence the informed consent and reduce the participants' autonomy (Hummelvoll 2008b). However, the participants in this study emphasised that their main

reason for participation was the positive prospects of self-help group participation including the focus on empowerment issues. Thus, it is reasonable to conclude that dependency of the nurses had minor effects on their autonomous choice.

4.7.2 Confidentiality

In this study, anonymity was ensured by using pseudonyms and by describing personal experiences in a way so that no one outside the groups could recognise the participants or their stories. Further, the facilitators were committed by a moral and legal obligation to maintain confidentiality, and the participants were encouraged to establish a moral and reciprocal, but not legal, confidentiality, meaning that the participants were not to give any information received about each other to anyone outside the groups. In order to attend to the right to privacy and the right to receive respect of personal integrity (Hummelvoll 2008b), the participants were encouraged to be particularly considerate about the information they revealed about themselves and their personal lives so that they would not feel uncomfortable or embarrassed. None of participants reported any violation of these rights.

4.7.3 Consequences

Both positive and negative consequences need to be critically considered in order to fulfil the ethical obligation of research (Kvale 2001). The implementation of empowerment as the main perspective in this study was an intended and desired outcome or consequence, also reflecting the essential tenet of PAR and the ethical principle of beneficence (Hummelvoll 2008b). Since the essence of empowerment is promotion of autonomy, all interventional steps taken to achieve empowerment in this study were also steps taken to promote autonomy. One must however take into account that not all people want to be empowered or act autonomously. But since the participants were informed both in writing and orally about the main intention of this study, the participants had the option to decline participation when asked. This might have been a reason for participant pre-termination, but that is a question lacking an answer due to the right to withdraw without explanation. Thus, as a researcher I could not ask for anything else than what they actually gave as reasons for pre-terminations. Another step taken in this study to promote participant utility, were the efforts made to promote social support and to avoid straining experiences from self-help group participation. As described in the articles, all these intentions were mainly achieved.

The study proposal was submitted to the Norwegian Regional Ethics Committee for Research and the Norwegian Social Science Data Services for approval, which was received (see Attachment I). Beyond that, precautions were taken to avoid further strain on the participants due to their involvement in the study. One such precaution was the engagement of facilitator 2 whose primary task was to assist the researcher to promote a group climate characterised by reciprocal respect, trust, care and support. Another precaution was facilitator awareness and consideration to notice possible participant reactions that needed more attention than self-help group support could provide, and if necessary, the facilitators would help the participants to get access to further help or therapy. Such assistance was given during the intervention period. As a researcher with particular responsibility to attend to participant vulnerability and wellbeing, described in the Helsinki Declaration (WMA 2002), I also made several telephone calls and sent messages when participants seemingly needed further support. In the case of the one participant having disease recurrence, I also sent postcards and a poetry book for encouragement and comfort.

One ethical concern occurs when considering research consequences. When discussing findings of interpersonal stress in article II, one participant's behaviour was described as somewhat disturbing or annoying. Retrospectively, there is reason to critically consider if this offended the participant's right of protection when the research findings were published. However, neither the participants nor the readers will know who this person was, but reading this might induce strain in the participants if they are self-referring and think: Was this me? Thus, this may be an example of an ethical dilemma occurring when participant perspectives are less regarded than research and knowledge development (Kvale 2001).

Finally, power issues are central in this study and essential for ethical consideration. These issues were discussed in previous sections, but will also be taken up later in the general discussion.

5 FINDINGS

5.1 *Paper 1: Learning as an empowerment process in breast cancer self-help groups*

This study draws on data collected from three professionally led breast cancer self-help groups that held sessions in the period from March 2002 until February 2004. In total, eighteen women participated, however, four stopped participation before the scheduled end of the intervention. Some of the findings and interpretations from the qualitative analysis of the focus group interviews addressed research question one in article I: “What are the characteristics of empowerment processes in professionally led breast cancer self-help groups when an intervention is made to promote empowerment?” The aim of this paper was to explore how an empowerment intervention influenced participation in the self-help groups, and if and how it could promote participant empowerment processes. The analysis revealed empowerment as a learning process having four components: 1) consciousness-raising; 2) acquisition of objective knowledge; 3) learning from others’ experiences; and 4) discovery of new perspectives about life and about oneself. Although presented as sequentially following each other, these four elements constitute an intertwined and cyclic process (see figure 1).

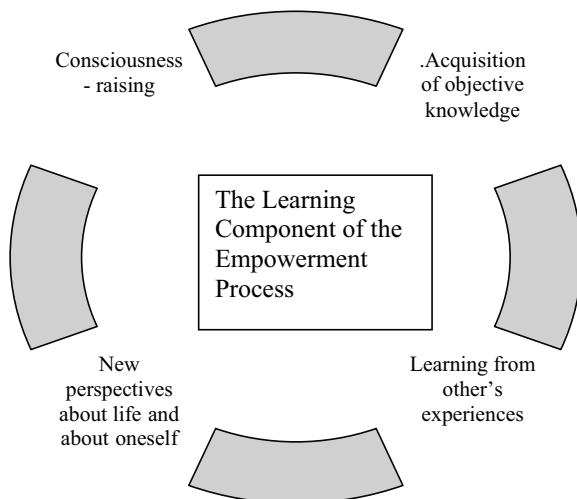


Figure 1 The Learning Component of the Empowerment Process

According to the participants, the sharing of experiences and the implementation of empowerment as an overall perspective promoted an awareness of their own resources and strengths which they doubted they could have achieved on their own. This awareness influenced the participants to take action in their recovery process and several succeeded in translating the essence of empowerment to make changes in other arenas of their lives as well. Learning from others, both in respect to objective knowledge and from what others did or did not do, was regarded as valuable by the participants. They also expressed that participation broadened their horizons and self-awareness, which contributed positively to their coping strategies. Unlike previous studies investigating empowerment processes in self-help groups, this study included an explicit empowerment intervention. Although learning processes were observed in a few of these other studies, empowerment was not emphasised as such. The results of this study revealed that the empowerment perspective and intervention, and the information and insight gained from participation, were regarded as a valuable contribution to recovery.

5.2 Paper 2: Social Support and Interpersonal Stress in Professional-Led Breast Cancer Self-Help Groups

The purpose of this paper was to address research question two: “What kinds of social support and interpersonal stress processes occur in the professionally led breast cancer self-help groups?” Drawing upon data collected from the three breast cancer groups, the qualitative analysis revealed several positive and negative social interaction experiences. In previous research, positive experiences are frequently illuminated and reported, but negative experiences from self-help or support groups are infrequently reported, especially considering negative experiences in the form of interpersonal stress. The positive social interaction experiences found in this study were: 1) sense of fellowship: a sense of being a team based on mutual understanding and support; 2) getting a lift: downward comparison gave relief; 3) acknowledgement of emotions: approval and recognition of disclosed emotions; 4) a place of refuge: the group was considered as a place providing space, acceptance and a sense of security; 5) humour and laughter: social glue, providing relief from pressure and stress; 6) relationships with family, friends and colleagues: group participation affected these relationship positively as it decreased the pressure on ordinary networks; and 7) relationships with health professionals: the participants became more pro-active in their relationships with health professionals. The negative social interaction experiences were: 1) diversities: heterogeneity due to age, marital status, etc., and personal abilities to express emotions; 2) the

prospect of death: the expected death of a group member; 3) irregularities: irregular attendance at group sessions and members who stopped participation before scheduled end of group; 4) group cessation: induced loneliness and stress in a few members; and 5) listening to the stories of other members: sharing experiences were mostly regarded as positive, but simultaneously it induced stress in some group members. The participants' overall experience of self-help group participation was positive even if some negative experiences did occur. The participants felt strongly that they had a sense of fellowship which provided them with valuable support and care, characterised as 'being in the same boat'. Downward social comparison regarding the prognosis of the disease was another source of positive experiences for the participants having a good prognosis. For the participants having a poor prognosis upward social comparison was a source of psychological distress.

In this study, the self-help groups generated little interpersonal stress (problems in relationships), mostly caused by silent members who were not able or willing to properly disclose their own experiences and emotions, which induced stress in the active members. In addition, based on the observation data, one participant's unsuccessful acts of care and empathy was a possible source of interpersonal stress, for the others as well as for the participant herself, as it seemed she was simultaneously included and excluded from the fellowship. The conclusion of this paper was that the implementation of the empowerment perspective emphasising participant strengths and resources, and the precautions taken to avoid interpersonal stress and negative group experiences, were mainly successful, as the participants considered participation as highly valuable, and for most participants the positive experiences overshadowed the negative experiences. However, if individual interviews had been conducted, it is possible that other aspects of interpersonal stress would have been disclosed, because such delicate topics might have been difficult to express in front of the others.

5.3 *Paper 3: Intervention to Enhance Empowerment in Breast Cancer Self-Help Groups*

In paper III, we addressed research question three: "What are the characteristics of the group processes in professionally led breast cancer self-help groups influenced by an empowerment intervention, and do these processes differ from one group to another?" The aim was to present in detail the empowerment intervention and to explore the group processes of three professionally led breast cancer self-help groups occurring from March 2002 to February

2004. Drawing on data collected from focus group interviews and participatory observation, the qualitative analysis revealed that all participants appreciated group participation, however, three different group processes occurred.

In group one – ‘the guinea pig’ – the halfway evaluation revealed that there was somewhat of a lack of desired structure and that the group process did not progress as expected due to repeated introductory presentations as new members joined two and three weeks after the starting day. As the facilitators succeeded to improve the structure and the group process, the participants reported satisfaction with the group process at group’s cessation.

Group two – ‘smooth running’ – was the group which ran most smoothly with respect to group climate, logistics and organisation. Following advice from group one, group two had weekly meetings in the beginning, and thereafter approximately every second week. Also, the facilitating style and the implementation of empowerment issues were improved due to the experience gained from group one. The strong sense of fellowship, emerging earlier in this group than in the others, was characterised by kindness, openness, humour and laughter, and mutual support focusing on each others’ strengths and abilities. However, the group climate was remarkably affected in the last month due to one participant’s deteriorated condition. Even then, the participants never failed to support each other and they held on to their sense of humour.

Group three – ‘the bumpy process’ – had a somewhat depressed atmosphere before the halfway evaluation. Irregular attendance due to treatment side-effects had some influence, but more dominant were the silent members who were not willing or able to share experiences, and who also generated a sense of loss when they stopped participation before the scheduled end of the intervention. Another dominating factor was that there was much focus on negative issues. When the empowerment perspective was re-enforced after the halfway evaluation and probably also because the silent members left the group, the group process improved. Group three participants even wanted to continue the group by themselves after cessation. The negative experiences mainly stemmed from group organisation and logistics, and only rarely from interpersonal stress. This suggests the value of intervening systematically to strengthen group processes as well as empowerment processes.

6 GENERAL DISCUSSION

The findings of this study are presented and discussed in the three papers. Therefore the discussion here focuses on overall perspectives based on an integration and synthesis of findings. An assessment of the study's quality is further elaborated in light of quality assessment criteria for PAR studies. Methodological issues, practical implications and an agenda for future research are also discussed.

6.1 *The empowerment intervention*

The model, Figure 2, below depicts the major elements of the study intervention and the processes whereby it influenced individual's empowerment. It integrates the findings of the three papers and illustrates central parts of the following discussion.

6.1.1 *Participants*

As Figure 2 indicates, the participants' contributions to the group processes are their experiences and reactions of being diagnosed and treated for breast cancer. Being diagnosed with breast cancer is followed by a diversity of psychological reactions, more or less adverse. Some of the participants in these self-help groups experienced reactions similar to reactions of crisis, others were scarcely affected. Some were afraid and felt uncertain, or felt depressed and powerless. Some were pessimistic about their prognosis while others demonstrated a fighting spirit and a proactive style, and thus showed few signs of adverse psychological reactions. A few – the silent members – felt uncomfortable with sharing their experiences and feelings, which indeed affected the other participants and the group processes.

The participants experienced themselves as very different as people and the only issue they really felt was commonly shared, was having and being treated for breast cancer. However, their reactions of being diagnosed with breast cancer and their treatment regimes differed. Consequently, the individual members of each group provided different and unique inputs, which affected the group processes and dynamics of the three groups differently.

6.1.2 *Facilitators*

The facilitators also provided inputs to the group processes. The facilitators' contributions were however the same for all three groups, namely our facilitating skills and our professional competence. However, apart from both being nurses and skilled as group facilitators, our

professional competences had different origins. Facilitator 2 is a psychiatric nurse and family therapist, and I, facilitator 1 and the researcher, am an assistant professor with special competence in health promotion and empowerment.

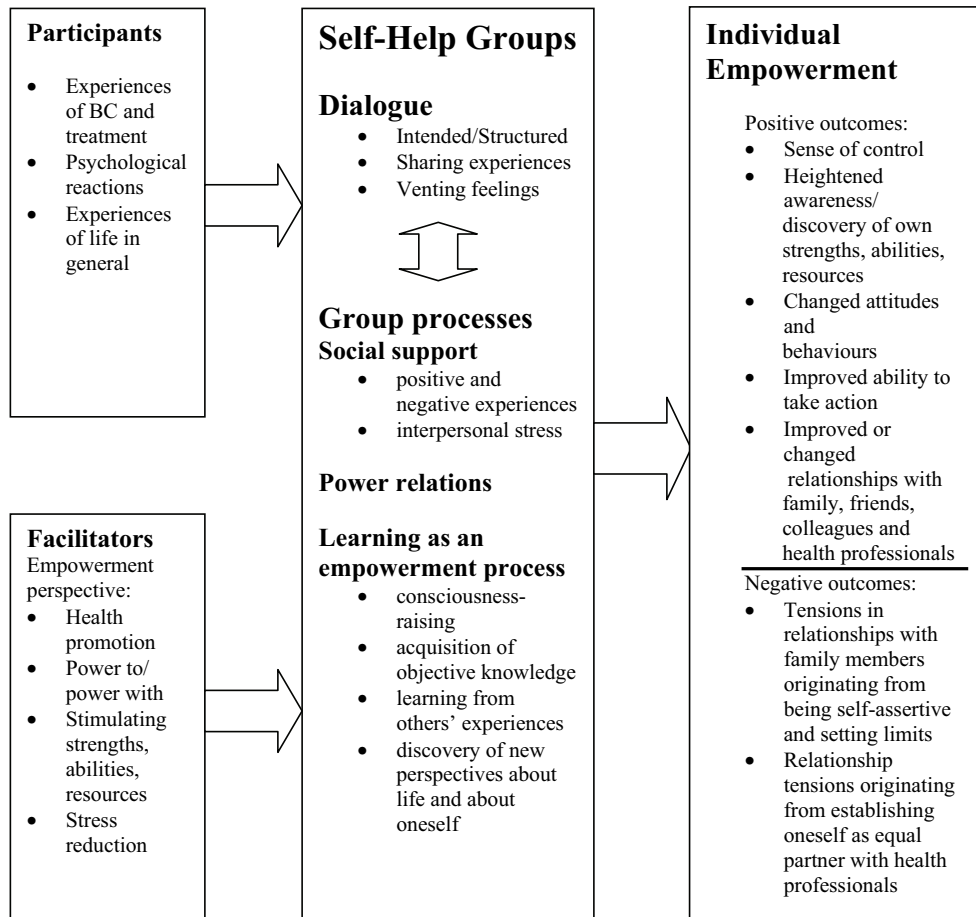


Figure 2
Model of an Empowerment Intervention in Professionally led Breast Cancer Self-Help Groups

Also, as we, like the participants, are different as people, and as we to some extent had different facilitating roles, we influenced the groups differently. However, as emphasised above, our inputs were the same in all three groups, only influenced and somewhat changed

by the fact that our empowerment facilitating skills developed during the courses of the groups, and that we were also influenced by the different group compositions.

6.1.3 The dialogue

Within the groups, the intertwined and cyclic processes of social support, power relations and learning as empowerment were influenced by the dialogue, and vice versa. The dialogue was given structure by conducting the discussions as rounds-around-the-table which provided all the participants with the same opportunity to speak and to listen. The way the dialogue was organised influenced the sense of equality and respect, and thus the group processes. As sharing experiences was a prominent feature of the rounds-around-the-table, mutual learning was promoted, and as trust and confidence developed during the course of the group meetings, the content of the dialogue became increasingly intimate. As such, the dialogue and the group processes were influenced reciprocally.

In this study, the dialogue-facilitating role was not rotated among all group members. Thus, group facilitation was not ‘fully democratic’ (Heron and Reason 2001). Nevertheless, organising the dialogue the way we did addressed essential features of democracy and authentic collaboration, as all participants were given equal opportunity to speak. Freeing the women from the responsibility of dialogue facilitation was perhaps better for their wellbeing - in terms of stress reduction and avoiding responsibility overload which are important aspects of empowerment – than facilitator rotation would have been.

The findings revealed that all participants perceived that they had same opportunity to speak about themselves in an equal and satisfactory way. The participants were also main providers of the themes that were discussed. Although one participant at group cessation expressed the view that she had missed discussion on some themes, she said that the reason for this was probably that these themes become relevant late in the course of recovery (for example, sexuality and relationships to men).

As the aim of this study was to promote participant empowerment, also understood as participant ‘power-from-within’, it was important to promote equality and to avoid dominance, professional or lay, in the group discussions. Therefore, the facilitating style and the dialogue were based on the perspective of ‘power to’ or ‘power with’. The rationale for implementing empowerment was to create a liberating meaning perspective – a perspective that offers people with straining conditions an alternative opinion or perspective on

themselves and their situations, and “a constructive way of dealing with their problems” (Borkman 1999, p.115). The findings of this study revealed that, on the whole, the implementation of the empowerment perspective was successful and promoted participant empowerment processes. The degree of success was not uniform, however, as in the case of group three, in which empowerment processes were somewhat delayed.

The empowerment perspective, the rounds-around-the-table and the emphasis on the participants as main providers of discussion themes, were mechanisms to promote empowerment and power-from-within. By emphasising the participants’ strengths, abilities and resources, by giving them equal opportunities to speak, and by emphasising that it was them and not the facilitators who were the main providers of themes to be discussed, the intention was that power be distributed to the participants. Evidence that this was achieved is found in the participants’ expressions that it was they who composed the groups, and that the facilitators were only ‘flies on the wall’.

6.1.4 Social support and its affect on participant empowerment

As illustrated in Figure 2, social support was an essential group process. However, as revealed in the findings presented in Paper II, social ties had both positive and negative aspects which affected the empowerment processes in these self-help groups. This is further elaborated below.

The positive aspects of social support revealed in this study were: a) sense of fellowship; b) getting a lift; c) acknowledgement of emotions; d) a place of refuge; e) humour and laughter; f) relationships with family, friends and colleagues; and g) relationships with health professionals. The sense of fellowship, reflecting the experience of being in the same boat and the sharing of a joint destiny, was regarded as most valuable by the participants. It nourished the growth of mutual trust, confidence and respect, and thus positively affected the development of the empowerment processes. Conversely, the empowerment processes such as learning from others or discovering new perspectives about life and about oneself, positively affected the participants’ sense of fellowship.

The groups, providing positive experiences as a place of refuge and humour and laughter, contributed to stress reduction, and thus empowerment. According to the findings in Paper II, the participants felt relief from not having to burden their ordinary networks of family and

friends with all their concerns. Further, the groups provided someone to speak with regularly, who 'understood' without in-depth explanation. The group also represented a place of refuge and promoted empowerment, as group participation helped coping with problematic matters in relation to their networks of family, friends, colleagues, and health professionals. Another element of the group as a place of refuge was that group participation offered mutual empathy and care, which contributed to the enhancement of self-affirmation and thus empowerment, quite the opposite effect of interpersonal stress (Aronson et al. 1995), described in Paper II.

Humour and laughter was of paramount importance for empowerment processes. Not only did humour and laughter provide stress reduction, they also contributed to strengthen the sense of fellowship. For one participant in particular, the aspect of humour and laughter contributed to the discovery of her own strength. Partly due to the other participants' comments, she discovered that her sense of humour was a most valuable personal strength. Her sense of humour made her able to cope with problematic issues, and in this way, she also became a role model to the others. As such, the aspect of humour and laughter was empowering, in particular for this woman, but also to the others. Indeed, this woman's sense of humour was a most valuable source of the smooth-going process of group two (see Paper III).

Some of the other aspects had paradoxical influence as they were experienced simultaneously as both positive and negative, such as sharing of experiences. Mutually shared experiences promoted participant empowerment as it stimulated learning. On the other hand, mutual sharing of experiences also induced distress in some of the participants, and thus counteracted empowerment and was probably a reason for pre-terminating group participation.

Mutual sharing of experiences also prompted downward and upward social comparisons. Downward, self-enhancement comparison is a mechanism to regulate emotions when experiencing threat (Buunk and Hoorens 1992). In this study, downward social comparison was characterised as getting a lift, meaning that the participants felt relieved by having a better prognosis than some of the others. Downward social comparison contributed to stress reduction and was thus a source of empowerment. On the other hand, a few participants made upward social comparisons clearly increasing their level of distress and cultivating a sense of envy towards the participants having a better prognosis (see Paper II). The distress induced by upward comparisons counteracted empowerment processes.

The negative experiences related to social ties counteracted empowerment processes, because they induced distress. The negative social experiences were mainly caused by group organisation and logistics issues, or were caused by illness and treatment side effects, and by one participant's prospected death. There were, however, few traces of interpersonal stress in this study (see Paper II) compared to the findings in Galinsky's and Scopler's (1994) study. The most prominent causes of interpersonal stress were the silent members in group three, whose silence impacted the sense of fellowship and the promotion of empowerment processes negatively.

It can be concluded that all aspects of social support influenced participant empowerment processes either positively or negatively. However, for most participants the positive experiences of social support outweighed the negative experiences, and thus, social support emerged as salient for the promotion of empowerment in these breast cancer self-help groups.

6.1.5 Power relations and its affect on participant empowerment

In Figure 2, power relations represent another essential aspect of the group processes. According to Foucault (1994), power exists in all relationships, and as power is closely related to empowerment, there is a need to investigate and discuss the influence of power in an empowerment intervention study. Power issues related to professional power or dominance within the self-help groups were discussed earlier, and need not be addressed here. However, participant dominance, or participant power imbalances in the self-help groups, has not yet been addressed, and this subject is taken up next.

According to Lehoux et al. (2006), one has to go below the surface of group interactions to reveal subtle power forms or power forms which may be taken for granted. Lehoux's et al.'s (2006) findings are related to focus groups, and their findings describing how participants positioned themselves in their groups are highly relevant for this study. Social dynamics unfolding in focus groups can influence the knowledge creation processes, and thus, it is necessary to reveal such influence (Lehoux et al. 2006). Lehoux et al. (2006) investigated differences in participant influence and dominance by dividing the participants into two groups – the knowledgeable and the advice-seekers. In their groups, some participants adopted dominant roles and positioned themselves as experienced and knowledgeable, or they were positioned as such by the others. Or opposite, some participants positioned themselves

as vulnerable or in need of support, or were positioned as such by the others. The participants did however shift their positions according to the flow and content of the discussions.

In the present study, it was obvious that the participants also adopted positions as knowledgeable, or as advice-seekers, but the essential question is 'how did this influence the group interactions?' Here, in particular the knowledgeable will be addressed because they are potentially those who can dominate a group. In two of the groups, two participants positioned themselves as experienced and knowledgeable regarding topics of disease and treatment. They were both nurses, and due to their professional attitude and their knowledge they were also positioned as knowledgeable by the others. Additionally, they had a pro-active style showing that they took control in life even in the demanding phase of disease and recovery. When discussing medical questions, the other participants positioned themselves more as advice-seekers than as knowledgeable. However, unlike some of the knowledgeable in Lehoux et al.'s (2006) study, the knowledgeable in this study did not act dominantly. The group climate, as described in the papers, was characterised by tolerance and friendliness.

With regard to other themes, there were few signs of members who positioned themselves as knowledgeable. The only occasions were when two participants positioned or were positioned as knowledgeable in the discussions of death. One of them was Karin who expected to die within a year, and the other was the one who felt that she was a source of the depressed climate in group three. Neither of them acted dominantly, but they might have had much influence on this particular discourse, as their strong and unique stories may have prevented others from "adding something that would be perceived as too trivial compared to the first story shared" (Lehoux et al. 2006, p. 2094). One important reason why these participants never became dominantly knowledgeable might be that the knowledgeable also disclosed their vulnerability and their adverse experiences.

Lehoux et al. (2006, p. 15) emphasised that: "not all participants' contributions receive support and some participants are more influential in the shaping of a common ground". A common ground can also be understood as a discourse defined as "a pattern of talking and writing or visually representing an event, object, issue, individual or group" (Tones and Green 2004, p.18). As already mentioned, the knowledgeable participants in this study might have impacted the group discourses more than the others, but unlike most knowledgeable participants in Lehoux et al.'s (2006) study, none of the knowledgeable in this study

dominated all group discussions, and most often all contributions from all the participants were supported. The groups' climates were tolerant and almost no themes presented were regarded as unimportant or inappropriate. Of course, disagreements might, as in Lehoux et al.'s (2006) study, have been veiled by the use of humour and laughter or other mechanisms, either to end a discussion or to change the topic of a discussion. However, no support for this possibility emerged from the data or from the repeated listening to the tape-recordings of the meetings.

There is one important difference between this study and Lehoux et al.'s (2006) study. The participants in this study may have developed a different attitude to one another as they did not see each other only once, but several times during a period of four months. Likewise, it is reasonable to believe that the introduction of empowerment and the structured dialogue effectively suppressed potential domination by any participant. Thus, the groups in this study were probably more similar with one of the groups in Lehoux et al.'s (2006) study, a group which was characterised by a stronger sense of commonality than the other groups and wherein few signs of dominance were revealed. Even if the knowledgeable participants in this study displayed their medical knowledge or their challenging concerns about death, it was done in such a way that it was appreciated or mostly accepted by the others.

The conclusion seems to be that participant dominance and power imbalances mainly were avoided in this study, and that the knowledgeable participants contributed to the empowerment processes.

6.1.6 Learning as an empowerment process

The third group empowerment process depicted in Figure 2 is learning, with four components: a) consciousness-raising; b) acquisition of objective knowledge; c) learning from others' experiences; and d) discovery of new perspectives about life and about oneself. Learning was heavily influenced by the two other processes described above. These three processes were not sequential, but occurred as intertwined and cyclic processes.

Consciousness-raising emerged from shared experiences and feelings, from being reminded of one's own strength, abilities and resources, and from the implementation of the empowerment perspective. Acquisition of objective knowledge emerged as a result of the mutual sharing of knowledge of breast cancer and subsequent treatment. As one participant said, she had no clue

about the various stages of the disease and treatment regimes before she joined the group, even though she had previously received information on her disease and her treatment regime from health professionals. Learning from each other's experiences promoted coping with the different demands and challenges these women met. They learned from what others did, as well as from what others might have done, but did not do. Discovery of new perspectives about life, and about self, emerged from the richness of perspectives and themes presented in the groups, fed by the participants' differences as persons and their different experiences.

6.1.7 Individual empowerment – the outcome of the empowerment processes

Individual empowerment as showed in Figure 2 illustrates the positive and the negative outcomes of the empowerment processes in these self-help groups. The findings, documented in the papers, revealed that the participants experienced a heightened awareness of their own strengths, abilities and resources. This was promoted, for example, by asking the participants to discuss previous coping strategies, by doing different exercises, and by giving each other positive feedback.

The findings also revealed that the participants managed to change or improve their attitudes and behaviour, for example by an improved ability to be self-assertive and to set limits, and to establish more equal relationships with health professionals. The participants also demonstrated an improved ability to take action. The findings further revealed improved relationships with family, friends and colleagues, as the groups gave relief from burdening these ordinary networks with all their concerns. Some participants also established themselves as more equal partners in encounters with health professionals, which were considered as an improvement by the participants, but not always by the professionals.

However, even if positive outcomes are the essential aim, negative outcomes seem to be inevitable. In this study, although empowerment was promoted by setting limits and being self-assertive in family relationships, it sometimes simultaneously induced relationship tensions. Likewise, as indicated above, establishing oneself as an equal partner in relationships with health professionals also could induce relationship tensions. In particular, one participant experienced equality as positive while her physician did not. Nevertheless, as reported by the participants, relationship tensions and also distress originating from negative aspects of social support were overshadowed by the positive outcomes of the empowerment processes and group participation.

6.2 Health promotion and the empowerment intervention

This study is unique in that it sought intentionally and explicitly to enhance its participants' health and well-being by addressing their capacity for empowerment. It is in this sense a health promotion intervention, even in its context of the struggle with breast cancer and the very difficult process of treatment and recovery. Health promotion aims to empower people to control their own health, by mobilizing and stimulating their strengths, abilities and resources, thus increasing their ability to solve problems and to cope with the challenges of living (WHO 1986, Rappaport 1984, Gibson 1991). In health promotion interventions, empowerment is often cited as the overarching aim, but is less often addressed explicitly in the features of the intervention. As reviewed in the three papers, much of the research on breast cancer self-help groups mentions empowerment, but as far as it can be ascertained, this study is the first to mount an explicit empowerment intervention in breast cancer self-help groups.

Therefore, the central issues stimulated by this dissertation are these: To what degree did the empowerment intervention work? What were the essential processes through which the empowerment intervention affected the participants? Is an explicit empowerment intervention to be recommended to others who arrange and conduct such interventions? How might future empowerment intervention in breast cancer self-help groups be improved?

Question two is addressed above as the processes of social support, power relations and learning as an empowerment process. As the model also depicts the outcomes of the empowerment intervention, question one is also partly addressed above. Before question one is further elaborated and answers are given to question three and four, the appropriateness and the quality of study methodology must be addressed, especially since health intervention study designs are usually experimental or quasi-experimental designs, and not a PAR design as in this study.

6.3 Study design and study quality

6.3.1 Experimental and quasi-experimental designs

Intervention research addresses not only the question 'did the intervention work', but also questions about intervention processes, acceptability, participant satisfaction, amongst many other aspects. No study design is suited to answer all these types of questions (Bradbury and Reason 2001, Pettecrew and Roberts 2003). The most significant strength of the experimental methodology is its ability to rule out plausible rival hypotheses about causes of observed

outcomes. However, this requires a level of control that blinds the investigators and the participants to important details of the study. The idea to empower participants is inconsistent with the experimental design, in which participants are blocked from all knowledge of the conditions of their participation. In a double-blind clinical trial, both the 'subjects' and the research staff are kept as ignorant as possible of the details of the trial, with just one (or very few) senior scientists understanding the whole picture.

6.3.2 Participatory action research

Other research designs are available for empowerment intervention research, namely the participatory action research (PAR) design. As described above, this is a family of designs including co-operative inquiry. Within the family of PAR designs, participant involvement ranges from those in which participants are the senior collaborators involved in every aspect of the research, to the approach of this study, in which the researchers are the senior collaborators and the participants are only involved as senior collaborators in the knowledge generation process within the self-help groups (Turnbull et al. 1998). PAR is not the ideal design to rule out plausible rival hypotheses, but it is the ideal design in which to develop and investigate an empowerment intervention.

PAR has been used with good results in a variety of health intervention studies including: community-based substance abuse intervention for young mothers (Baldwin et al. 1999), an early mothering project to promote learning and empowerment in birth women (Barrett 2001), transforming evaluation of nursing students' clinical practice (Hills 2001), community development in a charitable HIV/AIDS organization (Lindsey et al. 2001), community-based life enhancing interventions related to workplace violence, wound management practice and chronic illness (Koch et al. 2002), community-based diabetes intervention for improvement of health (Horowitz et al. 2003), health education campaigns for the prevention of cervical cancer (Lam et al. 2003), internet-based empowerment intervention to improve access to health information (Masi et al. 2003), psychosocial intervention for women with breast cancer (Angell et al. 2003), intervention to improve nutritional resource environment (Sloane et al. 2003), intervention to reduce childhood asthma (Parker et al. 2003), intervention to identify Chinese immigrants at high risk for osteoporosis (Lauderdale et al. 2003), community-based diabetes support and education (Greenhalgh et al. 2005), developing rehabilitative handling practice in caring for patients following stroke (Mitchell et al. 2005), intervention to improve black women's health in rural and remote communities (Etowa et al. 2007), HIV/AIDS youth

project (Flicker 2008), community development to overcome social exclusion (Titterton and Smart 2008), and intervention to improve communication in psychiatric care (Vatne and Hoem 2008). Thus, the present study is certainly not ground breaking in using a co-operative inquiry design.

6.4 Assessment of study quality

From some viewpoints, studies in which laypersons are involved as collaborators may be seen as unscientific. However, in their review study of more than sixty community-based participatory research studies Viswanathan et al. (2004, p. 5) found that: “There was little evidence to indicate that high-quality scores in community collaboration are associated with low-quality research scores”. Participatory designs can be employed with a high degree of rigour, but they must be assessed with different standards than the standards of positivist science.

There exists no widely agreed quality standards for evaluating studies within the PAR family, but some quality standards are available against which to assess the quality of a participatory intervention study (Bradbury and Reason 2001, Petticrew and Roberts 2003, Viswanathan et al. 2004). Since it seems impossible “to articulate a set of all embracing standards of quality criteria” (Cassell and Johnson 2006, p. 806), one must choose a set of quality standards that is compatible to the epistemological and ontological positions of the actual study. Therefore, PAR studies need to be assessed in regard to quality standards which reflect the paradigms and the philosophies underpinning PAR study designs and the subsequent core assumptions about ontology and epistemology (Bradbury and Reason 2001, Cassell and Johnson 2006).

This empowerment intervention study, which is embedded in the ideas of PAR and co-operative inquiry, critical theory and empowerment, must therefore be assessed in accordance with the tenets of this philosophical tradition and with quality standards which reflect the participatory paradigm and the philosophical ideas of these theories. As Bradbury’s and Reason’s (2001) qualitative standards are more in line with the philosophical underpinnings of this study than those suggested by others, the assessment of quality of this empowerment intervention study will follow Bradbury’s and Reason’s quality standards. Thus, the five quality standards addressed below are: a) quality as relational praxis, b) quality as reflexive-practical outcome, c) quality as plurality of knowing, d) quality as engaging in significant work, and e) emergent inquiry towards enduring consequence.

6.4.1 *Quality as relational praxis*

Essential aspects of this quality standard are addressed when asking “whether the action research group is set up for (eventual) maximal participation?”, “whether opportunities are used to allow all to feel free to be fully involved?”, “whether decisions are made on the principle that the best decision is one that maximizes participation?”, and “whether especially less powerful people are helped by their experience of participation in inquiry?” (Bradbury and Reason 2001, p. 450).

In the current study, the ideal standard of full participation in all study parts from the planning phase to disseminating the results is not met, as the participants were only senior collaborators within the self-help groups. The reason for not involving the participants in the academic parts of the study was to avoid responsibility overload in a situation where the participants faced heavy demands following breast cancer. Full participation in scholarly tasks would most likely have amplified their burdens and as such been unethical. As shown in Gibson’s (1991) study of mothers with chronically ill children, responsibility overload was a negative outcome of empowerment processes. Therefore, the decision in this study was to avoid activities which could have added to the participants’ burdens, even though it affected the ideal of full participation.

However, within the self-help groups full participation was established by organising a structured dialogue which intended to foster the democratic ideal of equality and the same opportunity to speak. Participants reported that they experienced equality and non-dominance, and that it was them that comprised the groups. In sum, even if the participants were not involved in scholarly tasks, they experienced themselves as equal and senior collaborators within the self-help groups, including participation in planning the future groups. The silent participants did however demonstrate that full participation was somewhat unsuccessful in the third self-help group, as they failed to establish themselves as equals, hesitating to disclose their experiences. Thus, the silent participants did not only inhibit their own possibilities of full participation, their behaviour also affected the group process.

When assessing “whether especially less powerful people are helped by their experience of participation in inquiry?” (Bradbury and Reason 2001, p. 450), the findings to some degree demonstrate this. One example was the participant who established herself as an equal partner in the encounters with her physician. She learned from the others that they had taken tests

which she had not been offered. Thus, although the physician got angry with her, she claimed that these tests should be taken in order to increase her confidence in being cured from breast cancer. Another example was the participant who started to do things alone which she never had done before, for example going skiing and going to the cinema. These examples illustrate how group participation stimulated the participants so that they enhanced their sense of power in relationships with others and in freeing oneself from dependency on others.

The conclusion of this assessment is, that although the participants were only senior collaborators in the self-help groups and not involved in the study's scholarly tasks, it was probably the best decision in order to avoid responsibility overload and an unethical study design. This demonstrates how complex and difficult full participation can be when conflicting factors must be taken into consideration.

6.4.2 Quality as reflexive-practical outcome

This quality standard refers to whether the practical outcome of the research is important or not. Action researchers should ask whether or not people involved in the study act differently as a result of the inquiry – “Is the work useful/helpful?” (Bradbury and Reason 2001, p. 448). However, whether the research is useful and helpful is not a straightforward question. One might distinguish between technical, practical and emancipatory outcomes, which has to be explored reflexively by those involved in the study and “which in turn informs the relational process” (ibid). Action research requires cycles of action and reflection, and the reflexive process is emphasised as equally important as the action part to promote useful and helpful outcomes. Importantly, researchers have to ask “whether the research is ‘validated’ by participants’ new ways of acting in light of the work?”, and ideal participant statements are “that was useful – I am using what I learned!” (Bradbury and Reason 2001, p. 451). Thus, participatory research is not solely a question of adding to the body of theoretical knowledge, it is also (and is sometimes even more) important to add to practical knowledge to enhance the practical benefit of the research. As Cassell and Johnson (2006) assert, PAR studies should be assessed to find out to what extent interventions have transformative potential.

The results reveal that the study was useful and helpful. The study promoted mutual learning with respect to objective and experience-based knowledge. It fostered increased self-awareness and enhanced the participants’ abilities to take action and to set limits in relationships with others. Group participation also promoted changes in attitudes, as in the

participant who succeeded in transforming pessimism to optimism by learning from the other participants' optimistic ways of being. This demonstrates how "the research is 'validated' by participants' new ways of acting in light of the work" (Bradbury and Reason 2001, p. 451).

As the implementation of the empowerment perspective stimulated an enhanced awareness of strengths, resources and abilities, empowerment became a positive factor not only in the recovery phase, but also in other areas of life as well. Also, being with peers was relieving, as the others understood without in-depth explanations. The groups were regarded as places of refuge as the participants felt free to speak openly, without worries about burdening family and friends. As such, group participation was an antidote to loneliness and depression. The groups provided space for the participants' life-world to unfold (Habermas 1999) as well as promoting social capital (Bourdieu (1986) (see Paper III). Not all participants experienced the same degree of usefulness and helpfulness, and for the drop-outs, the study was not experienced as useful and helpful at all. However, most participants gave multiple signs that they would agree with the claim "that was useful – I am using what I learned!" (Bradbury and Reason 2001, p. 451).

The quality of outcomes has to be explored reflexively together with the participants (Bradbury and Reason 2001). In this study, the participants joined the facilitators in the reflexive process, at the halfway evaluation and at the second and third focus group interviews. This reflexive process fostered actions – illustrating cycles of reflection and action as an important feature in action research. However, as concluded in Paper III, more frequent evaluation and meta-discussions on group interaction might have inhibited problematic group processes and as such, further strengthened the reflexive-practical outcome of this study. On the other hand, the continuous dialogue in the self-help groups can also be regarded as minor cycles of reflection and action, as the participants' continuously reflected on their own beliefs, attitudes and behaviour, which promoted consciousness-raising and subsequent actions taken to make changes in their lives.

The conclusion of this assessment is that this study to a large extent was useful and helpful, and that practical and emancipatory outcomes were achieved. Group participation including cycles of reflection and action contributed to consciousness-raising, learning and empowerment although this might have been improved. In sum, it can be asserted that the study reached an acceptable level of quality as reflexive-practical outcome.

6.4.3 *Quality as plurality of knowing*

Action research is not limited to conceptualised or intellectualized forms of knowledge, but incorporates extended forms of knowledge or epistemologies as valuable sources of insight and understanding (Bradbury and Reason 2001). Thus, action researchers need to ask how different forms of knowledge have been drawn on or were allowed to surface in the study, and “how they have informed the ways in which the work itself is presented?” (Bradbury and Reason 2001, p. 448). Therefore, this issue refers to three different quality assessment issues: a) quality through conceptual-theoretical integrity, b) quality through extending our ways of knowing, and c) quality through methodological appropriateness.

Quality through conceptual-theoretical integrity

Quality through conceptual-theoretical integrity refers to that knowledge achieved in PAR studies can be conceptualised in theoretical terms (Bradbury and Reason 2001). This theorising is anchored in people’s experience, and theory can be practical and useful to the community of inquiry if described in understandable terms. However, as knowledge derived from action research is context-based and commonly originates from profound knowledge of one case, the challenge is how to generalize this knowledge to other contexts or settings. The solution suggested, is that researchers within the same research field can consider the usefulness of the previous study by ‘seeing as if’ and consider if the previous study can illuminate their own situation (Bradbury and Reason 2001), or “whether or not the previous knowledge makes sense in a new context” Greenwood and Levin (2000, p. 98).

This study illuminates learning as an empowerment process. In this section, a further validation and assessment of study quality will be conducted by considering this learning aspect in light of theory of empowerment at the individual level. The rationale for doing so is to find out whether the study findings are congruent and compatible with associated theory, and if so, research validity is improved (Tones and Green 2004). Also, this makes a theoretical generalization possible. The experiences referred to below are only examples employed to consider theoretical compatibleness and congruence. Thus, the intention is not to present as many different participant experiences from as many different participants as possible.

Learning as an empowerment process and associated empowerment theory

For Karin, whose empowerment story is presented in Paper I, group participation was a vehicle to regain sense of control in the recovery phase which sustained throughout the terminal phase of her life. This can be understood as *domain-specific control* which is an element of the *intrapersonal* component of psychological empowerment (Zimmerman 1995). Karin demonstrated a reawakened *motivation to control* and that her experience of *self-efficacy*, her *perceived competence* and *mastery* emerged throughout group participation, all being elements of intrapersonal empowerment (Zimmerman 1995). Karin, encouraged by the group, eagerly sought the knowledge she needed from different sources, the group included, illustrating *acquisition of objective knowledge* – representing the second component of *learning as an empowerment process* (see Paper I), and *acquiring skills and knowledge* described as part of individual empowerment by Mok et al. (2004).

When learning from another participant's story about how much she and her colleagues regretted that one of their colleagues would not meet them after being diagnosed with cancer, Karin gained insight of the importance of re-establish contact with her ex-colleagues. This exemplifies *consciousness-raising* – the first phase of learning as an empowerment process (see Paper I) – which aligns *critical reflection* in Gibson's (1991) model of personal empowerment and *critical awareness* as an integral part of interactional empowerment in Zimmerman's (1995) model.

In the terminal phase of her life, Karin became the 'head commander' in her life which illustrates the *interactional* and the *behavioural* components of psychological empowerment (Zimmerman 1995). This also illustrates the third phase – *taking charge* – in Gibson's (1991) model of personal empowerment. Accordingly, the fourth phase – *holding on* – in Gibson's model was obtained as Karin endured the challenges of relapse and prospected death without feelings of powerlessness and despair. Karin achieved participatory competence which is described as "an enabling evolution which implies the establishment of self as subject, or author, of one's own history" (Kieffer 1984, p. 31), illustrated by repeating from Karin's empowerment story: "She regained her strength sufficiently to what needed to be done – her way."

Not only Karin, but most participants in this study achieved empowerment, albeit varied and related to different aspects of life. This illustrates the dialectic characteristic of empowerment.

For one participant in particular, *positive thinking* – described by Mok et al.’s (2004) as a component of *acceptance of illness, perceiving harmony in self and with the illness, and peace at heart* – was most important. She was inspired and learned from the others’ proactive and positive attitudes, and thus she succeeded to change her negative attitude and fear of relapse, to optimism and hope for the future. She experienced what Mok et al. (2004) describe as a *motivational process*, or Zimmerman’s (1995) *motivation to control* in the intrapersonal component of psychological empowerment. The *motivational process* is an element in Mok et al.’s (2004) component of individual empowerment: *finding meaning in life*, which also includes *an attitude of still existing hope*, which this participant experienced by adopting the others’ positive attitudes. It also illustrates that she achieved *interactional* and *behavioural* empowerment (Zimmerman 1995), as well as demonstrating ‘the cycle of experimental-social learning’ (Borkman (1999), as she critically considered the others’ behaviours and attitudes, and got the understanding that this was adequate for mobilization of her own resources to reach a state of mastery.

As accounted for in paper II, families were valuable to all participants. They improved their family relationships due to group participation, and learned from each other how to manage problematic family issues, especially matters caused by illness and treatment, but also ordinary daily life problems. Mutual sharing of experiences helped them to take action and gain mastery in their relationships with their partners, their children, their parents, their elderly mothers in particular, other family members, as well as friends, colleagues from work and health professionals. The documented improvement of these relationships reflects *learning from others’ experiences*, the third component of *learning as an empowerment process* (Paper I), and *commitment, responsibility and obligation to the family* – an element of *finding meaning in life* in Mok’s et al.’s (2004) model. Consequently, as they became able to improve their relationships, also their environmental understanding was improved – reflecting the *interactional* component of psychological empowerment (Zimmerman 1995). As this learning also included action, it simultaneously illustrates the *behavioural* component of psychological empowerment (Zimmerman 1995), as well as participatory competence (Kieffer 1984).

One participant demonstrated that she was empowered in all aspects of psychological empowerment (Zimmerman 1995) before she joined the group. For her however, the helper-therapy principle (see Paper III) further stimulated *mobilization of her resources* and re-

enforced her *self-efficacy* (Zimmerman 1995) because she realized that her knowledge and proactive style made her valuable as a role model for the others. She did, however, emphasize the value of group participation as such, and that the sense of fellowship was of utmost importance to her. Yet another participant explicitly emphasised the sense of fellowship by describing how group participation made her feel full of power when going home from the meetings. This, in accordance with several other aspects described in this section, shows that social support was salient and also a catalyst and a driving force of *learning as an empowerment process* in this study, like frustration was in the model of personal empowerment in Gibson's (1991) study.

As the empowerment processes observed in this study are compatible to previous theory and research in the field, it is reasonable to assert that a high degree of success was achieved. Finally, the assessment shows that the empowerment findings of this study add to the existing body of empowerment theory. As such, quality through conceptual-theoretical integrity is achieved.

Quality through extending our ways of knowing

The second issue within this quality standard, quality through extending ways of knowing, refers to the ideal that action research incorporates several epistemologies and knowledge forms (Bradbury and Reason 2001). These knowledge forms can be experimental, aesthetical or presentational, representational, or as described above, theoretical-conceptual. The main issue is thus to assess how the different forms were used or allowed to surface in this study, and how different knowledge forms can stimulate creativity in the knowledge generation process. For example, aesthetical knowledge can bring about insight and understanding which is not easily available otherwise (Bradbury and Reason 2001).

In this study, different forms of knowledge were employed in the knowledge generation process in which experimental-based knowledge was the foundation and the very core of creating meaning and knowledge. That is, without the knowledge originating from sharing experiences there would not have been a foundation for any other knowledge forms. For example, the conceptual-theoretical knowledge described above was based on the lived experiences which unfolded during the courses of the self-help groups. In this study, aesthetical and presentational knowledge in the form of poems, writings, songs and clay modelling were introduced to promote empowerment. By doing these exercises, unconscious

material came to the surface which hardly would have happened otherwise. Clay modelling was exceptional in this regard, as it enabled the participants to unveil emotions related to either being cared for – or the opposite.

Quality through methodological appropriateness

The third issue within this quality standard, quality through methodological appropriateness, concerns the question “Why certain methods are chosen, how well they have been pursued and whether they are indeed congruent with the participative orientation of the action research work?” (Bradbury and Reason 2001, p. 449). Therefore, researchers must ask “whether they have drawn on the different methodological traditions appropriately and creatively in the context of their own work” (ibid). There is no doubt that the research part in participative research studies is important for the quality of the outcomes. Based on their review of several community-based participative research (CBPR) studies, Viswanathan et al. (2004, p. 5) state:

“Among the limited number of fully evaluated, complete interventions that were identified, the stronger or more consistently positive health outcomes generally were found in the higher quality research designs. This should convince CBPR research partnership to pay adequate attention to the “R” component of CBPR.”

Thus, assessment of methodological appropriateness is necessary and is also a part of addressing research validity.

Within PAR, this study is most correctly labelled co-operative inquiry, in which the collaboration between researcher and the participants can be regarded as a community of inquiry (Reason 1998). The essence of a community of inquiry is to set up a framework for collaboration based on joint agreements on how to arrange group activities and interactions, and how to foster learning and social change based on equality, mutuality and non-dominance. This mutually agreed framework must be flexible in order allow changes and re-definitions which are necessary to promote creative learning processes. In this study, learning and the knowledge generation process were based on mutually agreed group activities and norms, continuously considered and re-arranged in cycles of reflection and action, also reflecting the principle of participation. In addition, implementation of the empowerment perspective served to promote participant empowerment by developing each participant’s strengths, resources and abilities. As such, no preliminary standards can be fixed, as

empowerment processes requires openness to different aspects of importance in different people's lives. By choosing co-operative inquiry as the research design of this study, the tenet of participation was given high priority and further attended to by establishing the communities of inquiry as self-help groups.

Previous research has shown that self-help groups not only can provide mutual support and learning, they also can be appropriate for the promotion of empowerment (Gray et al. 1997, 2000, Sharf 1997, Borkman 1999, Mok and Martinson 2000, Ussher 2006). On this background, self-help groups were chosen as a method of participation and action in this study, aiming to promote empowerment and social support for women recovering for breast cancer. Importantly, the self-help groups were chosen as an arena for creation of context-based empowerment knowledge, in which the participants were senior collaborators. In this study, arrangements were made to provide equality and non-dominance based on democratic values, which also are essential tenets of PAR and empowerment. Further, the self-help groups in this study ran sequentially in order to improve each subsequent group's arrangements and organisation, such that one group's participants and the facilitators influenced the next group. This arrangement represented a genuine example of action research.

As the self-help groups were constituted as communities of inquiry, it was natural to choose a data collection method which is compatible with the tenet of participation inherent in both self-help groups and PAR. Consequently, multistage focus group interviews were chosen as the main data collection method. As there was hardly any difference between the structured dialogue established in the self-help groups and the dialogue used when collecting data in the focus group interviews, this was beneficial in both instances, as the participants did not have to act differently when the groups switched from being self-help groups to become focus groups. Another benefit is that multistage focus groups, like self-help groups, provide the opportunity to generate knowledge over a period of time, contrary to ordinary focus groups which only meet once. Consequently, the implementation of identical composition for the self-help groups and the multistage focus groups in this study was successful as the two arrangements were reciprocally supplementary. Further, as both methods emphasis a high degree of participant involvement, they are both "congruent with the participative orientation of action research work" (Bradbury and Reason 2001, p. 449).

The conclusion of this assessment is that participation as the key principle of PAR was attended to in all the methods chosen in this study. According to the findings, the participants experienced the groups as their own, only facilitated by the professionals. The participants did not experience facilitator or participant domination, and they reported that they had equal opportunities to speak and take part in the group discussions. As such, the intention of full participation in the self-help groups was achieved in this study.

6.4.4 Quality as engaging in significant work

To grasp the essence of the forth quality standard one has to ask: “So why are we doing this work?” and “Why this way?” (Bradbury and Reason 2001, p. 449). A study must be properly done, but this is not enough if the study is not of real importance to those affected by the study. Thus, together the researchers and the participants must ask whether the study is valuable and worthwhile, and whether it has importance beyond the generation of scientifically interesting answers. To attend to valuable and worthwhile aspects in life for those involved in the study, researchers should ask if the study “calls forth a world worthy of human aspiration” and strive to actuate ideal participant expressions such as: “Work is inspiring” or “The work helps me live a better life” (Bradbury and Reason 2001, p. 449).

The immediate answer to the question above “So why are we doing this work?” is that this empowerment intervention study aimed to improve the lives of the women recovering from breast cancer in the midst of their struggle with the heavy demands of disease and treatment. The key aspect of an empowerment intervention study like this is to promote consciousness-raising and to strengthen the participants’ sense of control so that they are able to take action and make desirable changes to improve their lives. Although the participants experienced varied outcomes, self-help group participation was regarded as so important that they would highly recommend others to participate in such groups. The conclusion of this assessment is that the participants experienced the study as making a significant contribution to the quality of their lives.

6.4.5 Emergent inquiry towards enduring consequences

This fifth quality standard refers to “thinking through the developmental quality of our work through its history and into the future” (Bradbury and Reason 2001, p. 449). Participatory action research which is aimed at change and transformation develops over time. Consequently, one can not just go to some group or community and ‘do it’, “but rather the

work evolves (or does not) through mutual engagement and influence” (ibid). Further, one must ask if the research is viable in the longer term even after the initiating researcher has withdrawn from the study. Ideal expressions from people involved in emerging and enduring work are “This work continues to develop and help us” or, “Can we use your work to help develop our own?” (Bradbury and Reason 2001, p. 449).

As described above, group participation had, with some variation, a positive effect on the participants. Although participation also included some negative experiences, these experiences were overshadowed by the positive for all the participants except for the drop-outs. This study did not only evolve as useful and helpful during the course of the self-help groups, it also had enduring consequences for the participants. As reported by the participants at the third focus group interview a half year after group cessation, the positive outcomes of the empowerment intervention continued to have a positive effect. One example was the participant transforming pessimism into optimism. She had, in the period of six months after group cessation, re-scheduled her working hours allowing her and her family to travel more often and do things they appreciated. At the time of the third focus group interview, she expressed a high degree of life satisfaction. Another enduring consequence of this study was that the participants in the third group wanted to continue the group after the facilitators had withdrawn.

This study also has the potential for enduring consequences at the organisational level. Interest in self-help work, in particular self-help groups, is growing in Norway, and as a researcher I was invited to the Organisation of Breast Cancer Survivors and to the local Norwegian Cancer Society to inform them about this intervention study, as at the time of this writing, these organisations were about to establishment breast cancer and other cancer self-help groups. This does not mean that this study has immediate, concrete enduring consequences at the organisational level, it merely points to its potential to influence these organisations’ future work, illustrating this PAR ideal: “Can we use your work to help develop our own?” (Bradbury and Reason 2001, p. 449).

The conclusion of the assessment of this quality standard is that the intervention continued to help the participants after group cessation and that it has a potential to influence future work at the organisational level. For the participants, the empowerment perspective focusing on strengths, resources and abilities, combined with social support and the sense of fellowship,

became important contributions to recovery phase and life after. In sum, the assessment of the quality of this study shows that in many aspects, an acceptable level of these quality standards was achieved.

6.5 *Limitations and methodological considerations*

Several methodological limitations have been addressed in the papers and earlier in this dissertation. However, to keep a record of them, a brief review is given here.

Firstly, not conducting individual interviews may have narrowed the insight and comprehension of negative experiences, particularly interpersonal stress, as the participants could have been afraid of jeopardizing participant and facilitator relationships, or hurting someone's feelings. Likewise, additional triangulation of data collection approaches like conducting standard measures of empowerment processes, may have strengthened the validity of the study, as well as provided an even better insight into individual empowerment processes. Not least, it could perhaps more clearly have revealed differences between participants' empowerment processes. Additional triangulation in regard to data analysis might also have been enriching and elevated insight into power issues in particular. Eventual subtle power forms or dominance, beyond those which have already been discussed, could possibly have been discovered if, for example, a discourse analysis had been conducted, in addition to the other analysis approaches used.

Now, we return to an issue touched on earlier, that the PAR study design has important strengths, but also weakness, compared to the experimental design. In particular the PAR design performs poorly in ruling out plausible rival hypothesis about why observed effects have occurred. Thus it is necessary to consider plausible causes of the empowerment outcome, other than the empowerment intervention itself. Quite aside from participation in an empowerment self-help group, having a life-threatening disease and facing subsequent challenges may cause consciousness-raising and discovery of new perspectives about life and about oneself, including strengths and capabilities leading to increased empowerment. Also, support from their ordinary networks of families, friends and colleagues, as well as health professionals' support, might have contributed independently to the participants' well-being and capacity to cope with heavy demands of disease and recovery, and thus affected their empowerment. Likewise, for some participants, a strong religious belief might have been an important source of regaining strength. Not least, merely sharing experiences and supporting

each other without the empowerment intervention and the influence of the facilitators might have been empowering.

Indeed, the study findings indicate that these plausible causes of empowerment did operate in the cases of the women in the three groups. However, the findings certainly document that the empowerment intervention also promoted the participants' empowerment processes. The remaining questions are these: Which element or elements, either one or more of those just mentioned or the empowerment intervention, affected each participant the most? What variations existed between the participants in this respect? Without standard empowerment measurements, a satisfactory answer can hardly be given.

The balance of considerations taken up in this chapter suggests that the empowerment intervention was successful, in that participants, except the dropouts, seem to have experienced some degree of empowerment over and above that which might have been expected without the empowerment intervention. When conducting interventions like this, one obviously wishes for complete success in all parts of the intervention. In this study, the unsuccessful parts were in particular the dropouts and the group process in group three which turned out to be 'bumpy' before the halfway evaluation. However, important insight can be gained from these 'failures'. One such insight is that self-help groups are not always the right answer for becoming empowered, but for individuals who can cope with sharing adverse as well as positive experiences, this study reveals that self-help groups can be most valuable.

Finally, several considerations of the study design are taken up in Chapter 4, including a discussion of whether this study should be labelled as participatory action research or not. Without returning to that discussion, I will here focus on the one genuine element of action research in this study. Advice from one group was used as an important basis for planning and implementing the next group, and in this sense, the participants were included as co-researchers in this particular process of environmental change.

6.6 Recommendations for empowerment intervention in self-help groups

Based on the experiences from these professionally led breast cancer self-help groups and the assessment presented above, this kind of systematic empowerment intervention is recommended to others who arrange and conduct self-help groups. By conducting a systematic empowerment intervention, it seems the chances of accomplishing participant

empowerment are more likely than in interventions without an intended empowerment approach. When empowerment theory is systematically and explicitly introduced, and the empowerment perspective is continuously focused on, participant awareness of their own strengths, resources and abilities are more easily encouraged.

Based on feedback from the participants and the facilitators' experiences, it is highly recommended to pay close attention to group logistics and organisation. According to the participants the group size should not extend beyond five to six members, nor is a smaller number recommendable. Suitable group duration is approximately four months, with weekly sessions in the first period and thereafter session held every second week. The length of the sessions should not extend beyond one and a half to two hours, as the sessions otherwise will be too exhaustive. It is also important to attend to facilities like a comfortable and homelike meeting room, refreshments and easy access. Establishment of mutually agreed group norms, including a moral and reciprocal obligation of confidentiality, is of paramount importance.

In empowerment interventions, the facilitators have to be, apart from being skilled as facilitators, knowledgeable of empowerment facilitation. Training in empowerment facilitation is recommended. The facilitating style should include a 'power to'/'power with' approach to promote participant 'power-from-with-in'. Likewise, 'rounds-around-the-table' should be conducted to provide the participants with the same opportunity to speak and listen, and thereby prevent participant dominance. A brief but formal introduction of empowerment theory is necessary as is a continuous focus on empowerment issues during the course of the self-help group. Precautions to avoid stress and negative experiences must also be implemented, including telephone calls to participants who are struggling or referrals to other kinds of support, like individual therapy, when needed.

The involvement of two professional facilitators was not particularly cost beneficial. In this study, two facilitators were considered necessary, especially since this was the debut of this kind of intervention, and because it was uncertain whether the researcher could manage facilitating the groups without assistance. For future interventions however, better cost benefit is attainable by using one instead of two facilitators. This facilitator must however be knowledgeable of both group facilitation and empowerment facilitation. Another option is to teach laypersons empowerment group facilitation, and use a training-of-trainers model to develop a cadre of facilitators who might even work on a volunteer basis. However, when

laypersons act as facilitators, the use of two facilitators is recommended, as they would certainly benefit from partnership, as we did in this study. It is also recommended that lay facilitators seek supervision from skilled facilitators until they reach a certain level of skill and experience.

When planning similar interventions, it is important to prevent responsibility overload and increased distress. Based on the experience of the ‘bumpy’ process in group three, it is recommended that group evaluations be conducted more than once during the course of a group, since relatively frequent discussions about group interactions may prevent adverse group processes. Finally, based on the participants’ advice, it may be wise to arrange separate groups for younger women with small or younger children, as these women may face problems that women with adult children do not face.

6.7 Concluding remarks

Further research on empowerment interventions in self-help groups is clearly warranted. As the first study to examine the effects of an explicit empowerment intervention in breast cancer self-help groups, the study has made a contribution to the field of health promotion, but it has also illuminated ways in which future research on this subject may be improved. First, data and method triangulation is called for, including different data collection methods and different data analysis approaches. In particular, standard empowerment measurements are important, to get better insight into the development of individual empowerment processes. Also needed is a methodology that can better assess the contributions to empowerment of the broad range of treatment and recovery experiences, of which exposure to an empowerment intervention is just one aspect. Finally, the findings of this study may be relevant for other types of self-help groups, and it is hoped that this study will help stimulate more research on breast cancer self-help groups, but also empowerment intervention research in other self-help group contexts.

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