

**Psychological distress, coping and social support
in the diagnostic and preoperative phase of breast cancer**

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Scientific environment

The PhD candidate has been employed as an associate professor (førstelektor) at the University of Bergen, Faculty of Health and Social Sciences, Department of Nursing (Anaesthetic Nursing, Postgraduate Study). At the end of the research period the PhD candidate was part of the research group at the Centre for Care Research West Norway.

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Abstract

Aims: The main aim of this thesis was to describe the psychological distress, coping and social support among women in the diagnostic and preoperative phase of breast cancer using quantitative and qualitative approaches in sequence. This included descriptions of relationships between demographic variables, social support, anxiety, coping and defence strategies among women with suspected breast cancer, as well as in-depth descriptions of the women's experiences after having received a breast cancer diagnosis, including their coping strategies and experiences of social support while awaiting primary surgery. The theoretical frameworks were theories about coping (Ursin 1988, Lazarus 1999), social support (Weiss 1974) and nursing (Adaptation Model, Roy 2009, and Uncertainty in illness, Mishel 1988).

Material and methods: In the quantitative study data were collected by self-administrated questionnaires from 117 women who had undergone a breast biopsy. The questionnaires concerned: the Social Provisions Scale, the State-Trait Anxiety Inventory, the Utrecht Coping List and the Defense Mechanisms Inventory. In addition, data regarding age, level of education, employment, marital status and household status were collected. Data were collected in the qualitative study through individual semi-structured interviews with 21 women with newly diagnosed breast cancer the day before surgery. The interviews were analysed according to Kvale's qualitative meaning condensation method.

Findings: The results in Paper I showed that patients reported elevated levels of anxiety and high levels of social support. The anxiety was most strongly and negatively related to "instrumental-oriented coping", followed by "cognitive defence" and unrelated to "defensive hostility". Contrary to expectations, anxiety was unrelated to "emotion-focused coping" and social provisions. Social provisions were somewhat related to "instrumental-oriented coping", but sparsely related to "emotion-focused coping", unrelated to "cognitive defence" and partly negatively related to "defensive hostility". In Paper II the results showed that social support was positively related to "instrumental-oriented coping", and "emotion-focused coping" and unrelated to "cognitive defence" and "defensive hostility". Higher education levels were related to a greater use of "instrumental-oriented coping", while lower education levels, being unemployed and being single/divorced/widowed were related to a greater use of "cognitive defence". Educational level was the most important contributor to social support.

“Attachment” and education were the most important contributors to “instrumental-oriented coping”, with education being the strongest predictor.

A qualitative study was performed in order to gain in-depth understanding on how anxiety was experienced, on how social support was experienced and used, and on the coping strategies that were used to deal with the situation.

In the qualitative interview study, Paper III, the themes identified were feeling healthy but having to adapt to disease, waiting, uncertainty, having to inform others and existential awareness. Having to wait was experienced as frightening, painful, long and difficult but also necessary. Some expressed apprehension because they could not do anything about their situation. Others emphasised that it was good to have some time between diagnosis and surgery to become personally prepared and spend time with loved ones. Informing others of the diagnosis was a great burden for most of the women. Social networks could both give and need support. In Paper IV the prominent themes within coping were revealed as step-by-step, pushing away, business as usual, enjoying life, dealing with emotions, preparing for the worst and positive focus. The women were very aware of the threat of death, but at the same time were hopeful and optimistic. In general, they wanted to be treated as usual. Pity and compassion could increase their feelings of fear and vulnerability. Emotions were dealt with either by openness or by holding back. In Paper V themes revealed in connection with social support were available support, information and advice, care, having confidants, and balancing distance and closeness. Knowing that both family and healthcare professionals were available and caring gave a sense of security. Professional information and a professional contact with whom they could talk personally were essential. Social support gave strength, but too much could be experienced as difficult and frightening. The women needed a balance between distance from and closeness to their social network.

Conclusions: While awaiting a breast cancer diagnosis, “instrumental-oriented coping” and “cognitive defence” were connected to low anxiety. Social support and “emotion-focused coping” did not in themselves help to reduce anxiety. Patients who coped best had a reasonably good education and received social support from relationships characterised by “attachment”. Women who used a defensive hostile coping style tended to receive poor social support. While awaiting breast cancer surgery, the women used most energy handling their

uncertainty about the future and the severity of their cancer. Having to inform others was experienced as a lonely burden of being obliged to both inform and offer consolation. Avoiding being overwhelmed by emotional reactions was a major goal in the women's coping strategies. Keeping the diagnosis at some distance helped. The women's coping strategies displayed similar patterns but diverged on some points. Social support was an important resource for women with breast cancer but could be a double-edged sword as the networks' offered support could sometimes be a burden. Healthcare professionals were considered to be an important source of social support. By being aware of women's individual needs and different coping strategies, nurses and other healthcare professionals can improve their support to help women cope in this vulnerable situation.

Keywords: breast cancer, anxiety, uncertainty, coping, defence, social provisions, social support, social network, demographics, patients' experience, preoperative phase, diagnosis, surgery, healthcare professionals, nursing, questionnaires, interviews.

List of publications

Drageset S. & Lindstrøm T.C. (2003) The mental health of women with suspected breast cancer: the relationship between social support, anxiety, coping and defence in maintaining mental health. *Journal of Psychiatric and Mental Health Nursing* 10, 401-409.

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1. Introduction

Despite the fact that few women undergoing a breast biopsy have cancer and that survival rates are increasing, the diagnostic and preoperative phase has been identified as stressful (Montgomery & McCrone 2010, Vahdaninia *et al.* 2010, Ando *et al.* 2011). How women appraise the diagnostic process and their diagnosis affects both their immediate experiences and the post-surgery adaptation (Boehmke & Dickerson 2006, Van Esch *et al.* 2011, Iwatani *et al.* 2012). Coping strategies used during the diagnostic and preoperative phase of breast cancer have been found to be indicators of psychological adjustment after surgery (Schou *et al.* 2005a, Gall *et al.* 2009, Silva *et al.* 2012). Social support plays a key role in how women who are awaiting or have received a diagnosis adjust to the prospect of living with breast cancer and its treatment (Liao *et al.* 2007, Von Ah & Kang 2008, Alqaissi & Dickerson 2010, Blow *et al.* 2011). Based on these assumptions the overall purpose of this study was to describe the psychological distress, coping and social support among women in the diagnostic and preoperative phase of breast cancer by using quantitative and qualitative approaches in sequence to improve our knowledge in order to enhance coping and to offer individualised support to these women in this vulnerable and important period.

1.1 Breast cancer

Breast cancer is the most common cancer in women worldwide (World Health Organization 2011). In Norway it is the most common cancer diagnosis in women aged 25 to 69 (Cancer in Norway 2009) and constitutes 34% of all cancers in women aged 25 to 49 years old. It affected 2,745 women in 2009, representing 22% of all female cancers, and mainly affects women over 50 (Norwegian Breast Cancer Group 2011). Approximately one in ten women in Norway will develop breast cancer at some time in their life (Cancer in Norway 2009).

In Norway incidence rates have steadily increased over the last decades. However, the most recent five-year period (2005-09) is the first one showing a decline. At the end of 2009 there were 35,966 women diagnosed with breast cancer in Norway (Cancer in Norway 2009, Norwegian Breast Cancer Group 2011). Breast cancer is the leading cause of death among woman worldwide (World Health Organization 2011) and the second leading cause of death in Norway. In 2009, 671 women died of breast cancer in Norway. The mortality rate in

Norway is decreasing – this reduction is thought to be due to earlier detection and improvement in treatment (Cancer in Norway 2009). The prognosis of breast cancer is strongly dependent on the stage of the disease – for the period 2005-09 the five-year relative survival rate where the disease is confined to the breast (stage 1) is 95.3% compared to 18.8% if there is a clear spread at diagnosis (Norwegian Breast Cancer Group 2011). The long-term survival rate among diagnosed patients aged below 50 is actually lower than for diagnosed patients aged 50-59. This is partly due to more aggressive tumours in the younger age groups, and partly due to the effects of screening on the older groups (Cancer in Norway 2009). However, it is known that breast cancer patients have a clear excess mortality of more than 20 years after diagnosis (Norwegian Breast Cancer Group 2011).

The Norwegian Breast Cancer Screening Programme invites all women between 50 and 69 years of age to have a mammography (X-ray examination) of the breasts every two years. Approximately four in every 100 of the participants are recalled for further examinations, of which about one in seven of those who are recalled have changes that need to be treated (Cancer in Norway 2009).

When breast cancer is suspected – as a result of findings by mammography, symptoms or other reasons – three elements are included in the “triple” investigation: clinical breasts/axillaries’ examination, mammography and/or ultrasound scan and fine-needle aspiration cytology (FNAC) and/or core needle biopsy or excision biopsy. Breast magnetic resonance imaging (MRI) is used in addition to mammograms and ultrasound in complex cases. The standard treatment for breast cancer is surgery, chemotherapy, hormone therapy and radiotherapy (Norwegian Breast Cancer Group 2011).

2. Theoretical framework

The theoretical framework for this thesis consists of theoretical perspectives on psychological distress and theories about coping, social support and nursing.

2.1 Psychological distress

According to Montgomery and McCrone's (2010) quantitative systematic review conducted to define the manifestations that characterise psychological distress during the diagnostic phase of suspected breast cancer, there are many potential conceptual definitions of psychological distress. In this review psychological distress was found in many studies to be defined in more general terms such as: emotional upset, tension, confusion, depression and intrusion. Anxiety was found to be the most specific manifestation that characterises psychological distress, being present to varying degrees in every woman screened for its presence. However, the most common conceptual definition of psychological distress found in this review was described by Potter (2007) as an affective cognitive and behavioural response to a crisis-precipitating event perceived as threatening and manifested by anxiety and depressive symptoms. According to one definition of distress in cancer, distress is defined as "a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis" (National Comprehensive Cancer Network, Guidelines Version 3, 2012, DIS-2).

2.2 Coping

Various definitions and theoretical positions exist regarding coping and defence (Olf 1991, Franks & Roesch 2006) and different coping theories have been applied in breast cancer research. Lazarus' (1999) theory of appraisal, stress and coping, and Ursin's (1988) theory of cognitive-behavioural coping were used as theoretical frameworks in Papers I, II and IV.

Historically the term “coping” has a much briefer history than that of “defence” (Lazarus 1999). The concept of defence stems from psychoanalytic theory and was introduced by Sigmund Freud (1856-1939) who described defence mechanisms as being used by the ego to defend itself against anxiety by repressing unacceptable internal impulses. The concept was further developed by Anna Freud (1979) who claimed that the ego uses defence mechanism not only to protect itself against unacceptable internal impulses but also against external threats. Other authors later regarded defence as not only different from coping but as varyingly harmful (Olf 1991). Vaillant (1971) regarded defences as being more or less beneficial. He described four sets of defences, classified as primitive or mature. Haan (1977) discriminates 10 dimensions with coping and defending as opposite poles, i.e. the defence of repression has as a coping counterpart suppression, which is a conscious restraint of emotional expression. More adaptive psychological aspects of defence were later elaborated. Lazarus and Folkman (1984) adopted a cognitive approach to defence where defences were regarded as part of the coping process.

According to Lazarus and Folkman (1984, p. 141), coping can be defined as “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person”. An individual’s appraisal or perception of a situation determines the stress associated with it and the behaviours directed at managing the stress. Psychological stress occurs when an individual appraises an event as taxing or exceeding resources and endangering well-being. Lazarus (1999) assumed a process of appraisal to occur between stressors and effect. The appraisal process consists of: a) “primary appraisal”, where the individual appraises the internal and external environment in terms of harm/loss, threat or challenge and which is shaped by the individual’s beliefs, values and goals; b) “secondary appraisal”, which refers to a cognitive-evaluative process, focusing on what can be done about a stressful person-environment relationship; and c) “reappraisal”, where the efficacy of the coping strategies is evaluated. “Reappraisal” may influence stress and emotion and give new meaning. Hence, coping is a process not a trait (Lazarus 1999). Antecedent conditions of primary appraisal, such as time in our life circle and experiences in life, together with personal and social resources, are woven into the primary appraising process.

Lazarus (1999) has identified two major types of coping strategies. “Problem-focused coping” is behaviour aimed at solving the problem or situations such as obtaining relevant information about what to do, and “emotion-focused coping” which is behaviour aimed at regulating the emotions related to stress, i.e. by avoiding thinking about the threat or reappraising it without changing the realities of stressful situations. “Emotion-focused coping” also covers various defensive and avoidant strategies. “Problem-focused coping” and “emotion-focused coping” influence each other throughout a stressful situation – they can both facilitate and impede each other. Coping strategies may change over time, as coping strategies adopted early in the adjustment period can become less effective as time progresses and alternative coping strategies may be adopted (Lazarus & Folkman 1984, Lazarus 1999). Lazarus makes no prediction about the effects of coping and does not discriminate between defence and coping (Lazarus 1999).

Coping defined as “positive response outcome expectancies” (Ursin 1988) is developed within a cognitive-behavioural tradition (Bolles 1972) and stress research (Ursin & Hytten 1992). Coping defined as a “positive response outcome expectancy” (Ursin 1988) means a generalised positive attitude to one’s own capacities to handle the stressful situation, independent of the particular strategy used. The essential element is the acquired *expectancy* of being able to control the situation. The perceived control is the underlying theme in this concept of coping. It is the expectancy of being able to cope that is the essence, not the objective possibility of having control. Response outcome expectancies are learned based on experienced outcomes of coping efforts. The response outcomes are defined as either positive (coping), negative (hopelessness) or uncertain (helplessness) (Levine & Ursin 1991). This is formulated in the cognitive activation theory of stress (CATS), where the stress response is regarded as an essential and necessary physiological response (Ursin & Eriksen 2004, 2010) – necessary for handling challenges or threats to the organism. Sustained arousal occurs only when a coping solution is not found or attempted. Sustained arousal may lead to illness and disease (Ursin & Eriksen 2004, 2010). In situations such as receiving a breast cancer diagnosis “solving the problem” is beyond the possibility of the individual and one is dependent on help from “medical expertise” to “solve the problem”. In such a situation the individual has no control over the main problem but the individual may perceive control over other aspects such as facing threatening information step by step to alleviate stress and keep anxiety at a tolerable level.

According to this view, coping is regarded as distinct from defence in the sense that coping efforts are based on a reasonably correct perception of reality, whereas defence is based on perceptive or cognitive distortions of reality (Haan 1977, Ursin 1988). Within this tradition, coping is regarded as effective in solving problems and reducing activation and anxiety, whereas defence is not – at best it may have a “palliative” or “postponing” effect, but it does not solve any problems. Defensive strategies are found to cluster together and to be negatively related to mental health and anxiety (Eriksen *et al.* 1997, Eriksen 1998). Expectancy of positive outcomes from actions (coping) is, however, associated with the use of certain types of coping strategies, particularly the more active problem-focused strategies. In this tradition, coping strategies were first categorised as problem-, emotion- and avoidance-focused coping (Olff 1991). To test these categories, a factor analytic study was performed to obtain an empirically-based classification (Eriksen *et al.* 1997). Two coping styles, “instrumental-oriented coping” and “emotion-focused coping”, and two defensive styles, “cognitive defence” and “defensive hostility”, were identified. “Instrumental-oriented coping” reflects an instrumental, active coping style and positive expectancies of the coping efforts. “Emotion-focused coping” involves seeking social support, expressing emotions and the use of palliative responses. “Cognitive defence” involves a variety of strategies such as denial, repression, principalisation, reversal and comforting cognitions. “Defensive hostility” includes turning against the object, projection and aggressive behaviour. These four styles have been consistently found to be related to different problem solving and health consequences (Eriksen 1998). An instrument, CODE (Eriksen *et al.* 1997), was constructed based on this factor-analytical study. “Instrumental-oriented coping” and “emotion-focused coping” are related to Lazarus’ (1999) problem- and emotion-focused coping, but defensive strategies are separate from these. The instrument CODE (Eriksen *et al.* 1997) was chosen to measure coping and defence in the present survey study (Papers I and II).

Ursin’s (1988) definition of generalised coping as a personality trait or disposition meaning a “generalised positive outcome expectancy” is related to other concepts developed within different traditions: “internal locus of control” (Rotter 1966), “self-efficacy” (Bandura 1977), “hardiness” (Kobasa 1979), “sense of coherence” (Antonovsky 1987) and “resilience” (Luthar *et al.* 2000).

2.3 Social support

The concept of social support has been defined and operationalised in different ways and is frequently suggested to be important in maintaining mental health (Cobb 1976, Monat & Lazarus 1991, Lazarus 1999) and in adjusting to breast cancer (Holland & Holahan 2003, Helgeson *et al.* 2004). Social support is a multidimensional concept and is generally conceptualised from a quantitative-structural perspective of social networks, such as numbers of persons and formal relationships with them, or from a qualitative–functional perspective of social support, such as the perceived content and availability of relationships with significant others (Helgeson 2003, Nausheen *et al.* 2009). The qualitative–functional support refers to the quality or function served by the structural support components, and is mainly divided into the provision of instrumental, emotional and informational support (Helgeson 2003, Finfgeld-Connett 2005). Two theories of social support, the “direct effect” and the “buffering” theories, have been proposed to explain how support influences health and well-being (Cohen & Wills 1985). The former theory maintains that support is beneficial to health and well-being regardless of the amount of stress people are experiencing. The latter reflects the belief that support buffers against the adverse effects of stressors under conditions of high stress. Several studies have examined the “buffer” effect of social support during times of stress among women with breast cancer (Bloom *et al.* 2001, Kornblith *et al.* 2001, Gremore *et al.* 2011). These studies generally conclude that social support from family and friends is associated with a better adjustment to disease.

Weiss’s (1974) theoretical framework for social support incorporates the major components of most current conceptualisations of social support (Cobb 1976, Cohen & Wills 1985) and was therefore chosen for the survey study (Papers I and II). Weiss’s theory of social provisions represents a multidimensional view of social support, laying out six different social components or provisions, each of which is associated with a particular type of relationship. “Attachment” is provided by relationships from which the person gains a sense of emotional closeness and security; the absence of such relationships may result in loneliness and emotional isolation. “Social integration” relates to being an integral part of a group, and the lack of this may result in loneliness or social isolation. “Reassurance of worth” is provided by relationships in which the person’s skills and abilities are acknowledged, and the absence of this may lead to low self-regard. “Opportunity for nurturance” represents a sense of

responsibility for the well-being of others. “Reliable alliance” stems from relationships in which the person can count on assistance under any circumstances, and the absence of this may result in a sense of vulnerability. “Guidance” is provided by relationships with trustworthy individuals who can provide advice and expertise, and its absence may cause a feeling of uncertainty and anxiety. According to Weiss (1974), each provision provides a particular form of social support and all provisions are needed to feel adequate support, although different provisions may be more or less crucial under different circumstances. Several provisions may be obtained from the same person. An instrument, the Social Provisions Scale (SPS)(Cutrona & Russell 1987), was developed from this theory and was used in the present survey study (Papers I and II).

2.4 Nursing

The Roy Adaptation Nursing Model (Roy 2009) describes people, both individually and in groups, in terms of holistic adaptive systems that cope with internal and external environmental stimuli through processes of adaptation. This nursing model identifies the adaptation of patients as a critical phenomenon (Polit & Beck 2012) and is related to the theory of Lazarus (1974). Roy’s Adaptation Nursing Model was found to be an appropriate nursing model to be used in this thesis, in Paper IV. According to Roy (2009), there are four subsystems within the human system: physiological-physical, self-concept-group identity, role function and interdependence. The physiological-physical is concerned with the basic needs required to maintain physical and physiological integrity. The self-concept-group identity deals with people’s perception of their physical and personal selves, including emotions. The role function response is concerned with people’s performance of role activities on the basis of their positions within society. The interdependence mode deals with development and maintenance of satisfying affectionate relationships with significant others. These subsystems constitute adaptive modes that provide mechanisms for coping with environmental stimuli and change.

Environmental stimuli categorised as focal, contextual and residual activate the coping processes and the regulator (physiological) and cognator (cognitive and emotional) subsystems of the individuals, which in turn produce behavioural responses relative to the four modes. These responses can be either adaptive, thus promoting the integrity or wholeness

of the human system, or ineffective and not contributing to the goals of the human system. Ineffective responses are not necessarily inappropriate responses, but rather responses that signal a need for nursing intervention. According to the Roy Adaptation Model (Roy 2009), health is a state and a process of becoming integrated and whole. It is a reflection of adaptation, i.e. the interaction of the human adaptive system and the environment. Roy (2009) defines the goal of nursing as the promotion of adaptive responses in relation to the four adaptive modes. The Roy Adaptation Model in nursing is frequently used in breast cancer research (Samarel *et al.* 2002, Henderon *et al.* 2003, Zeigler *et al.* 2004). In this study the focal stimulus is what immediately confronts the individual, such as receiving the diagnosis of breast cancer. Contextual stimuli are factors that contribute to the focal stimulus such as marital status and waiting for surgery. Residual are unknown environmental factors that may affect the individuals with breast cancer.

The theory “Uncertainty in illness” (Mishel 1988, 1990, Bailey & Stewart 2006) is perhaps the most comprehensive nursing theory about uncertainty. According to Mishel and Braden (1988), uncertainty in illness occurs in a situation in which the individual is unable to assign definite value to events and/or is unable to predict outcomes accurately. In the illness experience uncertainty has four forms: ambiguity concerning the state of the illness, complexity regarding treatment and the system of care, lack of information about the diagnosis and seriousness of the illness, and unpredictability of the course of the disease and its prognosis (Mishel 1988). Mishel (1988, 1990) attributes the underlying stress-appraisal coping-adaptation framework of the original theory to the work of Lazarus and Folkman (1984). The theory explains how patients cognitively process illness-related stimuli and construct meaning in these events. This theory is frequently used in breast cancer research (Mishel *et al.* 2005, Gil *et al.* 2006, Liao *et al.* 2008). Mishel’s theory of uncertainty was therefore chosen as an appropriate nursing theory to be used this thesis, in Paper III.

The concepts of this theory consist of three major themes: antecedents of uncertainty, cognitive appraisal of uncertainty, and coping with uncertainty (Mishel 1988, 1990). The antecedents of uncertainty include the stimuli frame (symptom pattern, event familiarity and congruence between expected and actual illness-related events), cognitive capacities and structure providers. The stimuli are influenced by cognitive capacity (information-processing ability) and structure providers such as education level, social support and healthcare

providers. According to this theory, uncertainty can be appraised as a danger or as an opportunity. If uncertainty is appraised as a danger – such as receiving a cancer diagnosis – coping efforts are employed to reduce this uncertainty. When uncertainty is appraised as an opportunity – such as “not knowing is better”, for example avoiding seeking healthcare despite the presence of symptoms of serious illness – coping efforts to maintain the uncertainty are implemented. If the coping strategies are effective adaptation occurs (Mishel 1988, 1990).

3. Research on psychological distress, coping and social support in connection with breast cancer

This chapter gives a summary of previous research on psychological distress, coping and social support associated with breast cancer. The summary of previous research within each of these themes is divided into two parts. Firstly, within each of these two parts previous research related to women with suspected breast cancer will be presented, followed by a presentation of previous research related to women with breast cancer. Some of the studies include cases of both suspected and confirmed breast cancer diagnosis.

Broad searches have been conducted in the main categories of psychological distress, coping and social support. The literature presented in this chapter has been sourced from the electronic databases Medline (Ovid), PsychInfo (Ovid) and Cinahl (Ebsco). Searches have been updated several times during work on the thesis. During the searches relevant subheadings were included. Unfortunately, there is no consistent term use in the literature and this posed a particular challenge in the literature searches. Reading reference lists have been an essential technique in identifying relevant literature concerning these phenomena.

3.1 Research on psychological distress in connection with breast cancer

Although the majority of women with symptoms of possible breast cancer have benign breast disease, the diagnostic phase of breast cancer has been identified as stressful, characterised by increased perceived stress, uncertainty, anxiety, fear and mood disturbance (Northouse *et al.* 1995, Deane & Degner 1998, Poole *et al.* 1999, Lebel *et al.* 2003, Demir *et al.* 2008, Liao *et al.* 2008, Montgomery & McCrone 2010, Montgomery 2010, Blow *et al.* 2011, Steffens *et al.* 2011). Previous studies have also revealed that psychological distress prior to diagnosis was higher in patients who had high trait anxiety, suppression of anxiety, medical history, many life stress events and subjective symptoms (lumps, pain, abnormal nipple discharge or a deformed nipple) (Ando *et al.* 2009, Montgomery & McCrone 2010). It has been reported that anxiety and/or depression assessed prior to diagnosis were significant predictors of psychological distress after breast cancer diagnosis (Ando *et al.* 2011, Van Esch *et al.* 2011, Iwatani *et al.* 2012). De Vries *et al.* (2009) found that trait anxiety could influence depressive symptoms from the period before diagnosis to six months after diagnosis. Previous studies

have shown that women with benign breast symptoms experience similar levels of anxiety and other psychological distress as those with breast cancer during the period from the initial discovery of symptoms up to receiving a definitive diagnosis (Woodward & Webb 2001, Witek-Janusek *et al.* 2007, Iwatani *et al.* 2012). However, anxiety levels have been reported to be significantly higher before diagnosis than afterwards, peaking just prior to biopsy (Witek-Janusek *et al.* 2007, Liao *et al.* 2008) and remaining elevated two months despite the diagnosis (Witek-Janusek *et al.* 2007). Schnur *et al.* (2008) found that women awaiting lumpectomy are more distressed than women awaiting biopsy. After diagnosis, anxiety levels and emotional stress have shown to fall more quickly in women with benign disorders. For women diagnosed with cancer the emotional stress is reported to intensify or sustain after receiving the diagnosis (Woodward & Webb 2001, Liao *et al.* 2008, Blow *et al.* 2011).

Various factors increase psychological distress and anxiety, including demographic characteristics. Findings concerning the association between demographics, anxiety and stress in the diagnostic phase of breast cancer have been conflicting. With regard to age, higher age is found to be related to higher levels of anxiety and uncertainty (Novy *et al.* 2001, Liao *et al.* 2008). However, it has also been reported that age was unrelated to anxiety and distress (Deane & Degner 1998, Olsson *et al.* 1999, Ando *et al.* 2009, Montgomery & McCrone 2010). Younger women in particular have been found to report more anxiety and distress (Chen *et al.* 1996, Seckel & Birney 1996, Cunningham *et al.* 1998, Steffens *et al.* 2011). However, some of these studies suffer from methodological weaknesses. Chen *et al.* (1996) included only women below 65 years of age, Seckel and Birney (1996) had only 30 respondents, and the studies of Cunningham *et al.* (1998), Deane and Degner (1998) and Steffens *et al.* (2011) were retrospective.

Similar discrepancies exist in previous studies regarding the influence of education on anxiety, distress and uncertainty among women with suspected breast cancer. Higher levels of education have been associated with less anxiety and distress (Lauver & Tak 1995, Northouse *et al.* 1995, Andrykowski *et al.* 2002, Montgomery & McCrone 2010) but have also been reported to be unrelated to anxiety (MacFarlane & Sony 1992, Deane & Degner 1998), while women with less education tended to report greater distress (Liao *et al.* 2008, Steffens *et al.* 2011).

Several studies have reported that receiving the diagnosis of breast cancer is a traumatic experience (Cordova *et al.* 2007, Mehnert & Koch 2007, Taleghani *et al.* 2008) and may cause various emotional reactions such as feelings of chaos, uncertainty, anxiety, hopelessness and despair (Montazeri *et al.* 2000, Zabora *et al.* 2001, Landmark & Wahl 2002, Bertero & Chamberlain Wilmoth 2007, Fu *et al.* 2008, Shaha *et al.* 2008, Al-Azri *et al.* 2009), and mostly anxiety and depression (Montazeri 2008). It has been reported that the prevalence of anxiety and depression at the time of diagnosis is significantly related to anxiety and depression one to two years after diagnosis (Burgess *et al.* 2005, Den Oudsten *et al.* 2009, Vahdaninia *et al.* 2010, Van Esch *et al.* 2011) and is even common several years after diagnosis and treatment (Lueboonthavatchai 2007, Montazeri 2008). Some women are reported to have post-traumatic stress disorder symptoms a long time after treatment (Kornblith *et al.* 2003, Mehnert & Koch 2008).

According to several studies, stress can be caused by the waiting time during the diagnosis and treatment journey (Paul *et al.* 2011), by waiting for healthcare (Fogarty & Cronin 2008) and by the preoperative waiting time for breast cancer surgery (Oudhoff *et al.* 2004, Schnur *et al.* 2008). The highest level of distress reported among breast surgery patients is on the day before surgery (Ryburn 2003). Uncertainty remains a major stressor that influences women's experiences during the breast cancer trajectory (Shaha *et al.* 2008). It has been reported that the women suffer uncertainty at different stages in the process: before diagnosis (Demir *et al.* 2008, Liao *et al.* 2008, Montgomery 2010), before surgery (Montgomery & Bovbjerg 2004, Schnur *et al.* 2008, Drageset *et al.* 2010) and concerning the future following surgery (Wade *et al.* 2005, Doumit *et al.* 2010). Bertero and Chamberlain Wilmoth (2007) found that many patients with breast cancer are afraid of the disease's recurrence and have to live with "uncertain certainty". Poor comprehension of information from the hospital and limited knowledge about cancer and its treatment add to the patients' uncertainty (Gaudine *et al.* 2003, Saares & Suominen 2005, Shaha *et al.* 2008) and to their existential concerns (Landmark *et al.* 2001, Logan *et al.* 2006, Bertero & Chamberlain Wilmoth 2007). Anxiety increases particularly in situations where uncertainty and existential threat exist (Giske *et al.* 2009, Remmers *et al.* 2010, Blow *et al.* 2011).

3.2 Research on coping in connection with breast cancer

Previous studies have reported that adaptive coping strategies used by women before diagnosis have been found to be predictive of psychological adjustment after breast cancer surgery (Stanton & Snider 1993, Gall *et al.* 2009). However, it has been reported that coping efforts have varying effects. Chen *et al.* (1996) found that coping through active confrontation of uncertainty prior to the diagnosis of breast cancer has been associated with better psychological adjustment, whereas avoidant coping strategies have generally been reported to have detrimental effects (Stanton & Snider 1993, Lebel *et al.* 2003) but have also been suggested to reduce anxiety (Styra *et al.* 1993, Heckman *et al.* 2004).

With regard to demographic variables and coping with a threatened or actual breast cancer diagnosis, more maladaptive coping strategies have been found to be connected to low levels of education in women recalled after mammography screening (Olsson *et al.* 1999), to low age in women with newly diagnosed breast cancer (Compas *et al.* 1999, Epping-Jordan *et al.* 1999), or to both of these variables in survivors of breast cancer (Wonghongkul *et al.* 2000). In contrast, age has been reported to be unrelated to coping in a study of women before and after breast cancer diagnosis (Stanton & Snider 1993). Adaptive coping has been reported to be connected to older women with suspected breast cancer referred to clinical mammography (Mehlsen *et al.* 2009). Low age was found to be connected to adaptive coping in women with breast cancer (Schnoll *et al.* 1998).

The emotional reactions following a breast cancer diagnosis place extraordinary demands on women's coping abilities (Landmark *et al.* 2008, Al-Azri *et al.* 2009, Blow *et al.* 2011). It has been reported that coping strategies used during the preoperative phase of breast cancer have been found to be indicators of psychological adjustment after surgery (Degner *et al.* 2003, Schou *et al.* 2005a, Jadouille *et al.* 2006, Silva *et al.* 2012). Active acceptance at diagnosis is found to predict better adjustment during the first year (Stanton *et al.* 2002, Roussi *et al.* 2007). Defensive strategies reduce distress at three months but increase the fear of cancer recurrence at one year (Stanton *et al.* 2002). However, defensive avoidance-oriented coping, a helpless/hopeless coping style combined with pessimism or passive acceptance and resignation, predicted a poor psychological adaptation one to three years later (Stanton *et al.* 2002, Hack & Degner 2004, Schou *et al.* 2004).

3.3 Research on social support in connection with breast cancer

Different components of social support are regarded as useful, depending on the specific stress experienced (Weiss 1974, Billings & Moos 1981, Cohen & Wills 1985). Social support has been suggested to be an essential resource for coping (Lazarus 1999) and a positive coping resource in the diagnostic phase of breast cancer (O'Mahony 2001, Liao *et al.* 2007, 2009, Montgomery & McCrone 2010), and as being important in explaining differences in women's coping mechanisms (Fridfinnsdottir 1997). Previous studies among women with suspected breast cancer have reported that those who received good social support reported less emotional distress and anxiety and more adaptive coping responses (Deane & Degner 1997, Woodward & Webb 2001, Liao *et al.* 2010, Blow *et al.* 2011). However, social support has been reported as positive in the period around the breast biopsy, but the women's use of their own coping strategies was more helpful (O'Mahony 2001). Previous studies have also found that social support had little influence upon psychological distress in women receiving a cancer diagnosis and after being recalled following breast screening (Gerits & De Brabander 1999, Pineault 2007). Pineault (2007) found that among 631 women recalled after abnormal screening results 75% reported that the support of family and friends was comforting but did not diminish the participants' anxiety. However, it is also reported that social relationships have even been a source of distress and may lead to avoiding confronting the problems directly (Krishnasamy 1996, Shiozaki *et al.* 2011).

Among women with breast cancer social support is also important in adjusting to the diagnosis and treatment (Liu *et al.* 2006, Von Ah & Kang 2008). Several studies have concluded that social support, the size of the social network and the women's integration within it are relevant in adjustment during the breast cancer trajectory (Michael *et al.* 2002, Falagas *et al.* 2007, Gagliardi *et al.* 2009, Alqaissi & Dickerson 2010). Yet social support is not an unequivocal phenomenon (Drageset *et al.* 2010, Remmers *et al.* 2010). Women with breast cancer with inadequate social support from their network or a limited social network are at increased risk of experiencing psychosocial distress (Ganz 2008), anxiety and depression (Mehnert & Koch 2008, Gagliardi *et al.* 2009), and even increased cancer progression (Nausheen *et al.* 2009). Kroenke *et al.* (2006) found a higher risk of mortality from breast cancer among women who were socially isolated resulting from a lack of support from close relatives, friends and children prior to diagnosis. It has been found that pre-

diagnosis levels of social integration explain more of the variance in the quality of life of breast cancer survivors than treatment or tumour characteristics (Michael *et al.* 2002). Schroevers *et al.* (2010) found that a resource in the search for meaning in the cancer experience among cancer survivors was receiving support characterised by reassurance, comfort and help with problem-solving from family and friends in the period after diagnosis. The perceived availability of social support also improved the physiological and psychological functioning in women confronting a breast cancer diagnosis (Clarke *et al.* 2006, Ganz 2008), particularly in women with low optimism following breast cancer treatment (Shelby *et al.* 2008), and was even related to improved breast cancer prognoses (Falagas *et al.* 2007).

The effectiveness of the social support is influenced by several factors, such as whether it comes from family, friends, colleagues, healthcare professionals or other women with breast cancer (Taleghani *et al.* 2008, Alqaissi & Dickerson 2010, Koutsopoulou *et al.* 2010, Li *et al.* 2011). Among other things the type of relationship and the setting in which the support is given influence how the support is experienced (Gagliardi *et al.* 2009, Remmers *et al.* 2010). Burgess *et al.* (2005) found that women with newly diagnosed breast cancer who had no confidants or had relationship problems were more likely to develop anxiety and depression during the first five years after diagnosis. It is suggested that different types of social support are valuable to cancer patients at different stages in the disease and treatment (Liao *et al.* 2007, Budin *et al.* 2008, Demir *et al.* 2008). In the diagnostic period of breast cancer informational support seems more important than emotional support (Liao *et al.* 2007, Demir *et al.* 2008), whereas emotional support seems especially important during the period around surgery and recovery (Arora *et al.* 2007, Von Ah & Kang 2008, Remmers *et al.* 2010).

3.4 Background for research aims

In summary with regard to women with suspected breast cancer

Existing research concerning social support and coping in the diagnostic phase of breast cancer has focused upon overall social support in relation to coping. Little is known about how different components of social support relate to different coping and defence styles. Low levels of anxiety are supposed to be the result of good coping and support, yet how anxiety is

related to the interaction of different components of social support and different coping and defence styles remains insufficiently explored (Paper I).

Research into coping with a potential or actual breast cancer diagnosis has mainly focused on the association between social support and coping, and between demographic variables (particularly age and education) and anxiety and coping. Little is known about the association between demographic variables, social support, anxiety, coping and defence in the diagnostic phase (Paper II).

In summary with regard regard to women with breast cancer

Uncertainty, stress and anxiety are paramount during the diagnosis and treatment of breast cancer (Shaha *et al.* 2008, Vahdaninia *et al.* 2010) and even effect long-term adaptation (Montazeri 2008). To our knowledge, most qualitative studies on pre-surgery experiences of breast cancer have been conducted post-surgery and retrospectively. Quantitative studies, however, have focused on *selected* aspects of the experiences rather than on the *total* experience as subjectively expressed by the women as qualitative studies can do. Therefore in-depth understanding of these women's experiences is still needed, with data collected *during* this particularly stressful period when the stress level peaks (Ryburn 2003) (Paper III).

Research has indicated that preoperative experience and ways of coping with breast cancer have postoperative impacts (Stanton *et al.* 2002, Schou *et al.* 2005a, Jadouille *et al.* 2006). Previous studies of women's experiences of coping in the period between diagnosis and surgery do not provide in-depth understanding of their experiences. In addition, most studies of women's coping in the preoperative period are conducted retrospectively. Retrospective investigations imply disadvantages such as recall bias and repression of unpleasant memories as well as the fact that the outcome of the surgery may colour the memories. Therefore the study was conducted in the period between diagnosis and surgery, more specifically the day before surgery, to capture specific coping behaviours at a point where stress may be highest (Paper IV).

These studies have documented that social support is associated with a better adjustment to breast cancer and that inadequate social support increases psychological distress (Liu *et al.* 2006, Falagas *et al.* 2007, Ganz 2008, Gagliardi *et al.* 2009). However, the need for social support and other kinds of support during the breast cancer trajectory varies (Liao *et al.* 2007, Budin *et al.* 2008, Von Ah & Kang 2008). In order to facilitate the adjustment to breast

cancer, studies on women's support needs throughout the cancer experience are still required (Arora *et al.* 2007), particularly in the pre-treatment period (Dickerson *et al.* 2011). A qualitative approach seems best suited to gain in-depth information about women's individual experiences of and need for social support. To our knowledge, most qualitative studies on women's preoperative experiences of social support have been conducted postoperatively, implying disadvantages such as recall bias. This study therefore has been conducted preoperatively and aims to describe women's individual experiences of social support in the period between receiving their cancer diagnosis and awaiting primary surgery (Paper V).

4. Aims

The main aim of this thesis was to describe psychological distress, coping and social support among women in the diagnostic and preoperative phase of breast cancer using quantitative and qualitative approaches in sequence.

Using a quantitative method, a survey design (Papers I and II), the specific aims were:

To examine the relationships between social provisions, anxiety, coping and defence in relation to the mental health of women with suspected breast cancer. Social provisions were expected to be positively related to coping (instrumental- and emotional-focused coping) and negatively related to defence (cognitive defence and defensive hostility) and anxiety. Coping (instrumental- and emotion-focused coping) was expected to be negatively related to anxiety, whereas defence (cognitive defence and defensive hostility) was expected to be positively related to anxiety (Paper I).

To examine the relationships between demographic variables, social support, anxiety, coping and defence strategies among women with possible breast cancer, and to examine which social provisions are related to “instrumental-oriented coping” when demographic variables (age, educational level, employment, marital status and household status) are controlled (Paper II).

Using a qualitative method, a qualitative descriptive design (Papers III, IV and V), the specific aims were:

To describe women’s experiences after having received a breast cancer diagnosis and awaiting primary surgery (Paper III).

To describe coping strategies used by women between diagnosis of breast cancer and surgery (Paper IV).

To describe women’s individual experiences of social support in the period between receiving their breast cancer diagnosis and awaiting surgery (Paper V).

5. The study

5.1 Research design

The overall design of the work in this thesis is mixed methods which contain data collected, analysed and discussed both from a quantitative and a qualitative approach (Creswell & Plano Clark 2007, Creswell 2009). The rationale for using quantitative and qualitative approaches in sequence in this thesis was that this allows for a more complementary knowledge and better understanding of the overall research issue of “*Psychological distress, coping and social support in the diagnostic and preoperative phase of breast cancer*” than just one approach alone.

There are several types of mixed methods design; in this thesis a sequential emergent mixed method design was used. The purpose of this design was firstly to describe the relationships between demographic variables, social support, anxiety, coping and defence strategies among women with suspected breast cancer. The aim was to then use a qualitative approach, partly to gain insight into the relationships between demographic variables, social support, anxiety, coping and defence strategies among women with suspected breast cancer, and partly to gain an in-depth description of the women’s individual experiences after having received a breast cancer diagnosis, and of their coping strategies and experiences of social support awaiting primary surgery. The qualitative interview study followed from and was connected to the quantitative study by a semi-structured interview guide which was partly developed on the basis of the results from the quantitative study (see Appendix 1). Firstly, the quantitative data were collected and analysed, which was then followed by the collection and analysis of the qualitative data.

Figure 1

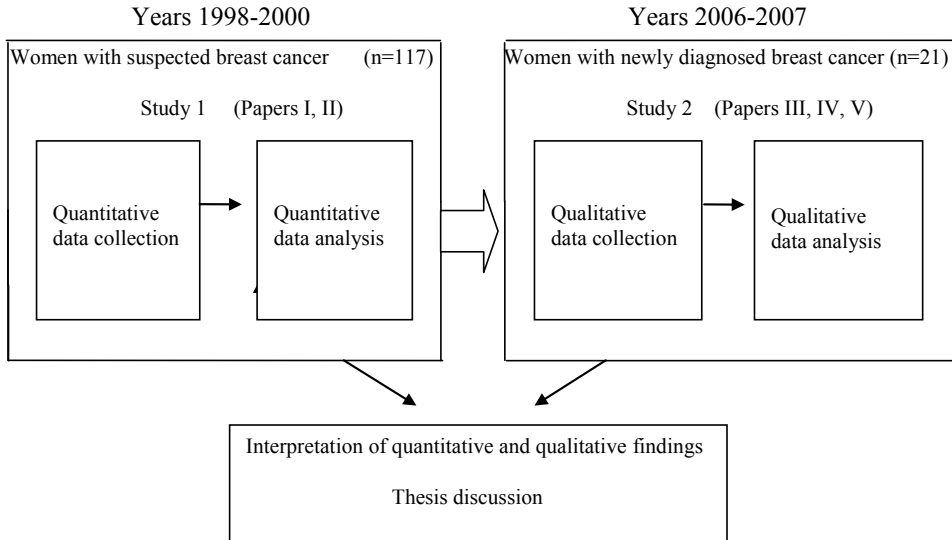
Sequential emergent mixed method design

Figure 1. Overall design in this thesis: QUAN: Quantitative. QUAL: Qualitative. The quantitative approach consisted of a survey study (cf. Papers I and II) and the qualitative approach consisted of an interview study (cf. Papers III, IV and V).

The findings from each of these studies were reported separately. In this thesis the findings from both studies are integrated in the final interpretation and discussion.

The appropriate paradigmatic foundation of this thesis is that of Creswell and Plano Clark (2007, 2011) stating that pragmatism can be an umbrella paradigm for mixed methods. For further discussion about the concept of pragmatism in this context, see Section 7.1.1.

5.2 Participants

5.2.1 Participants in the survey study (Papers I and II)

A convenience sample of 117 women with suspected breast cancer who had undergone breast biopsy under local anaesthesia at Haukeland University Hospital, Breast Clinic Department, Surgical Outpatient Clinic participated in this cross-sectional correlational survey. The patients were participants in a national mammography screening programme or were referred by their private physician. Women with an uncertain diagnosis after mammography screening were recalled for further diagnostic procedures: breast examination, mammogram and fine needle aspiration cytology (FNAC) after two weeks. When necessary, patients were in addition recalled for surgical breast biopsy after one to three weeks. Some were scheduled for immediate breast biopsy, depending on the seriousness of the findings. They had to wait one to three weeks for the results of the biopsy. The criteria for inclusion were being older than 18 years of age and being able to read and write Norwegian. Only 151 patients during this period fitted the inclusion criteria. All were invited to participate, of which 143 agreed and 117 completed the questionnaires, giving a response rate of 81.8%.

The women were aged between 25 and 76 years (mean: 53.6). Of the total sample, 73.5% were married or cohabiting, 8.5% were single, 7.7% were widowed and 10.3% were divorced. The majority (78%) lived with another person (spouse/partner/children). With regard to education, 39.7% had attended primary school only, 31% had attended grammar school, 18.1% high school and 11.2% had a university degree. Full-time or part-time employment was held by 70.9%, while 12% were unemployed/homemakers, 12.8% were retired and 4.3% were on sick leave. Eighty-five patients were participants in the national mammography screening programme and 32 were referred by their private physician.

5.2.2 Participants in the interview study (Papers III, IV and V)

Using convenience sampling, 21 women with newly diagnosed breast cancer were recruited from the day surgery unit at Haukeland University Hospital, Breast Clinic Department, Surgical Outpatient Clinic. The selection criteria were being scheduled for primary surgery,

i.e. lumpectomy or mastectomy, being over 18 years of age and being able to speak and write Norwegian. All were ethnic Norwegian, with similar culture, and came from the same geographical area. The sample size was determined by data saturation – the point at which no new information is obtained and redundancy is achieved (Polit & Beck 2008, p. 357). Since no new essential information was forthcoming after the twenty-first interview the data collection was discontinued at that point. Forty-eight patients were invited and 21 were interviewed. There were no essential demographic differences between participants and non-participants. The period between diagnosis and surgery varied from one to three weeks. The only reason given for not participating was the short notice before surgery. The participants received their cancer diagnosis following core needle biopsy. They had no information about the type of breast cancer, stage of disease or final treatment plans – this information was received about three weeks post surgery.

The women's mean age was 54 years, ranging from 41 to 73 years. Sixteen women were married or cohabiting, one was single, one was widowed and three were divorced. Sixteen had children, and 17 lived with somebody (spouse/partner/children). Nineteen were in full-time or part-time employment and two had retired. Five women had completed lower secondary school education and nine had attended upper secondary school, six had attended university colleges and one had a university degree.

5.3 Data collection

5.3.1 Survey study (Papers I and II)

Data were collected from September 1998 to February 2000. Women meeting the inclusion criteria were invited by a nurse to participate in the study following the breast biopsy procedure. Patients who agreed to participate received a description of the study, a consent form, the questionnaires and an envelope. The questionnaires could be filled out at home or at the hospital, but had to be returned to the researcher within a week and before the final diagnosis was given. All the women chose to fill out the questionnaires at home.

5.3.1.1 Instruments

Questionnaire regarding demographic information

The instrument used consisted of demographic characteristics such as age, level of education (primary school, grammar school, college and university), employment (full-time, part-time, unemployed, homemaker, on sick leave and retired), marital status (married/cohabiting, single, divorced and widowed) and household status (living alone and living with spouse/partner/children (See Appendix 2).

The instruments used consisted of four self-report questionnaires: the State-Anxiety Inventory (STAI-S), (Spielberger *et al.* 1970, 1983), the Social Provision Scale (SPS) (Cutrona & Russell 1987), and CODE (Eriksen *et al.* 1997) which consists of the Utrecht Coping List (UCL) (Schreurs *et al.* 1993) and parts of the Defense Mechanism Inventory (DMI) (Gleser & Ihilevich 1969).

5.3.1.2 The State-Trait Anxiety Inventory (STAI)

The State-Trait Anxiety Inventory (Spielberger *et al.* 1970, 1983) is a 40-item test designed to measure both state-anxiety and trait-anxiety. Only the State-Anxiety Inventory (STAI-S) was used in this study. This scale consists of 20 items measured on a four-point scale: not at all, somewhat, moderately so, very much so, with a total score range of 20 to 80 points. A higher score indicates more anxiety. The reliability and validity for both STAI-S and STAI-T are good (Spielberger *et al.* 1970, 1983). In the current study, the Cronbach's alpha for STAI-S was 0.94. A copy of STAI-S is presented in Appendix 3.

5.3.1.3 The Social Provision Scale (SPS)

The Social Provision Scale (SPS) (Cutrona & Russell 1987) was used to assess social support and social provisions. This scale consists of 24 items, four for each of the six social provisions in Weiss' (1974) theory: "reassurance of worth", "attachment", "opportunity for nurturance", "reliable alliance", "guidance" and "social integration". The responses are scored on a four-

point scale: strongly disagree, disagree, agree and strongly agree. Four items assess each provision: two describe the presence of provisions and two describe their absence. The negative items are reversed and added to the positive items to form a score for each social provision. High scores indicate high levels of the provision. Adding together the six individual provision scores gives a total social support score. The score for each of the subscales ranges from 4 to 16. The total social support score ranged from 24 (low social support) to 96 (high social support). The internal consistency for total score ranges from 0.85 to 0.92 and for the individual subscales from 0.64 to 0.76 across varying populations. Factor analysis has confirmed a six-factor structure corresponding to the six social provisions. Several studies support its construct validity (Cutrona 1986, Cutrona & Russell 1987). The reliability and validity of the Social Provisions Scale has been supported by several studies (Mancini & Blieszner 1992, Holland & Holahan 2003, Langeland & Wahl 2009). Cronbach's alpha in the present study was 0.82 for total SPS and for the subscales the values were: "reassurance of worth" 0.50, "attachment" 0.57; "opportunity for nurturance" 0.57, "reliable alliance" 0.71, "guidance" 0.77 and "social integration" 0.52. Principal components analysis with Kaiser Varimax rotation using a six-factor solution was carried out to confirm the components of the SPS. The scale was found to reflect a global factor and, to some degree, six separate factors. The six factors accounted for 59.4% of variance. A copy of the SPS is presented in Appendix 4.

5.3.1.4 CODE

The CODE instrument was developed by Eriksen *et al.* (1997) and is partly built on the coping concepts developed by Lazarus and Folkman (1984) by the use of the Utrecht Coping List (UCL) (Schreurs *et al.* 1993) and on parts of the Defense Mechanism Inventory (DMI) (Gleser & Ihilevich 1969). The UCL has 47 statements covering seven subscales measuring seven different coping strategies and is scored on a four-point scale ranging from 1 to 4 (1 = never or seldom, 2 = sometimes, 3 = often, 4 = very often). The seven subscales are: "active problem solving", "palliative responses", "avoidance and passive expectancy", "seeking social support", "depressive reaction patterns", "expressing emotions" and "comforting cognitions". The DMI has 60 statements covering five defence strategies: "turning against the object", "projection", "principalisation", "turning against self" and "reversal". The statement

is scored on a five-point scale (0 = absolutely not, 1 = probably not, 2 = maybe, 3 = probably and 4 = absolutely). CODE measures two coping factors, “instrumental mastery-oriented coping” and “emotion-focused coping”, and two defence factors, “cognitive defence” and “defensive hostility”. High scores indicate a high use of the strategy. Internal consistency reliability and construct validity of the UCL and DMI subscales have been evaluated, with satisfactory results. Construct validity using factor analysis has confirmed the four-factor structure of the CODE (Olf *et al.* 1993, Eriksen *et al.* 1997). For the present study the Cronbach’s alpha of total UCI was 0.83 and DMI 0.81. Principal components analysis with Kaiser Varimax rotation using an eigenvalue > 1.0 was conducted on UCL and DMI subscales. The analysis extracted four factors which accounted for 68.9% variance. A copy of the Norwegian version of the UCL and DMI are presented in Appendix 5.

5.3.2 Interview study (Papers III, IV and V)

Data were collected from February 2006 to February 2007. The participants meeting the inclusion criteria received the invitation to participate together with the information about the date of surgery. The interviews were conducted in the hospital one day before surgery and before preoperative individual information was given out. The interviews lasted between 50 to 120 minutes. The average length of the interviews was 97 minutes. The 21 interviews were recorded on MiniDisc (Creative Model No Dap-Flogis). I conducted all the interviews, took field notes, transcribed verbatim the interviews and prepared the transcripts for analysis. All the interviews were opened by reiterating the information in the letter of invitation and giving the participants an opportunity to ask questions about the investigation.

Demographic data were collected using an orally-administered questionnaire before the interview (Appendix 2).

A semi-structured interview guide was developed based on our previous research (Drageset & Lindstrøm 2003, 2005). The participants were asked specifically about the following themes: experiences regarding the diagnostic and preoperative phase, experiences of social support, experiences concerning coping efforts and defence strategies (actions, thoughts and feelings) and information needs (see Appendix 1). In Paper III the focus was on the women’s

experiences regarding receiving the diagnosis and the pre-surgery period, i.e. “How did you experience receiving the diagnosis?”, “How have you experienced this period before surgery?” In Paper IV the informants’ experience of and their coping efforts during the period between diagnosis and surgery were examined, i.e. “How have you experienced this period?”, “How have you coped with this situation?” In Paper V the informants’ experiences of social support were examined, i.e. “How have you experienced social support in this period?”, “What have you experienced as being the most important aspect of social support?” During the interviews themes mentioned by the women were probed. The interviewer’s impressions of the interview atmosphere and nonverbal communication were recorded immediately after each interview.

5.4 Analyses

5.4.1 Survey study (Papers I and II)

The SPSS PC statistical package, version 9.0, was used for data analysis (Norusis 1993). Cronbach’s alpha coefficient was used to determine the internal consistency reliability of STAI-S, UCL, DMI, SPS, and SPS-subcales. Principal components analysis, with Kaiser Varimax rotation was used to determine the construct validity for SPS, and subscales of UCL and DMI. Descriptive analysis was performed to assess the characteristics of the sample. Mean value, standard deviation and range were used to describe the distributions of state anxiety (STAI-S) (Papers I and II), the total SPS scale and subscales of SPS (Paper I), and subscales of CODE (Papers I and II). In Paper II the median value, SIQR (semi-interquartile range) and range for the total SPS scale were described. The following analyses were also employed: Pearson’s correlation (Paper I), Spearman’s correlation (Paper II), simple, multiple, and stepwise linear regression (Papers I and II). At each step, the independent variable not in the equation, which had the smallest significance probability in the F -test, was entered if that probability was less than 0.05. Variables already in the regression equation were removed if their F -test probability became larger than 0.10. The method terminates when no more variables are eligible for inclusion or removal. In paper II age was analyzed as year of birth. As employment, marital status and household status were at nominal levels, they

were grouped into two categories: employment (unemployed/homemaker/on sick leave/retired = 0; employed = 1), marital status (single/divorced/widowed = 0; married/cohabiting = 1); and household status (living alone = 0; living with spouse/partner/children = 1). Statistical significance was set at $P < 0.05$.

In Paper I Pearson's correlation analysis was used to investigate the relationships between state anxiety (STAI-S) and subscales of SPS and CODE. Simple, multiple and stepwise regressions analysis were used to investigate the relationships between anxiety (STAI-S) as dependent variable and the subscales of SPS and CODE as independent variables. As "instrumental-oriented coping" was an important variable in explaining state anxiety (STAI-S), a possible contribution of the subscales of SPS to this coping style was studied with simple, multiple and stepwise regressions, with "instrumental-oriented coping" as a dependent variable.

In Paper II due to lack of normality of SPS, Spearman's correlation analysis was used to investigate relationships between social provisions scale (SPS) and CODE subscales. Simple, multiple and stepwise regressions analysis were used to investigate the relationships between CODE subscales (dependent variable) and the demographic variables (independent variables). Simple, multiple and stepwise linear regression analysis were used to investigate the relationships between the social provisions scale (SPS) (dependent variable) and demographic variables (independent variables). Multiple regression analysis was carried out to investigate the association between state anxiety (STAI-S) as dependent variable and the demographic variables as independent variables. As SPS and education were important in explaining "instrumental-oriented coping" possible contributions from the subscales of SPS and demographic variables were studied in multiple and stepwise regression analyses with "instrumental-oriented coping" as the dependent variable.

5.4.2 Interview study (Papers III, IV and V)

There are various approaches to the qualitative analysis (Kvale & Brinkmann 2009). Some are strongly linked to scientific traditions and philosophical perspectives (Giorgi 2009).

Regardless of the method of analysis, there are several levels of interpretation (Kvale 2006, Malterud 2011). Following Kvale's (2006) guidelines meaning condensation analysis was

carried out at three levels: self-understanding, common-sense understanding and theoretical understanding. At the first level, the transcribed interviews were read to acquire a sense of the whole. The meaning units were identified and data condensed. Self-understanding emerged as the researchers condensed the women's personal statements according to the researchers' understanding of the expressed meanings. At the second level, transcriptions were read several times to achieve a common-sense understanding, providing a broader comprehension of the expressed meanings. The different themes were identified and transformed into meaningful units, then coded into major themes. In Paper IV some of the major themes were coded into sub-themes. At the third level, theoretical understanding meant discovering a deeper meaning where the mutual relationships between the whole and the parts became clearer. In all the Papers (III, IV and V) the themes were discussed in the light of earlier research. In addition, in Paper III the themes were discussed in the light of Mishel's nursing theory of "Uncertainty in illness" (Mishel 1988, 1990, Bailey & Stewart 2006). In Paper IV the themes were interpreted and discussed in the light of Lazarus' (1999) and Ursin's (1988) theories of coping and the Roy Adaptation Model (2009). In Paper V the themes were discussed in relation to relevant theoretical concepts.

The qualitative data analysis software QRS-NVivo 7 (www.qsrinternational.com/products_previous-products_nvivo7.aspx) was used for organising and processing the data. The demographic information was analysed using SPSS 16.0 (SPSS Inc., Chicago, IL).

5.5 Ethical aspects and approvals

The study complied with the principles embodied in the Declaration of Helsinki (www.etikkom.no/no/FBIB/Praktisk/Lover-og-retningslinjer/Helsinkideklarasjonen/).

The survey study (Papers I and II) was approved by the Regional Ethical Board (see Appendix 6), the hospital authorities and the Norwegian National Mammography Screening Programme. The patients were given oral and written project information and gave written informed consent before receiving the questionnaires. The returned questionnaires were

anonymous, meaning that no names or any other means of personal identification were associated with the questionnaires.

Ethical aspects may be involved in asking patients with a possible breast cancer diagnosis to fill in questionnaires while awaiting their diagnosis. Filling in questionnaires about, for example, anxiety may lead to more emotional distress. Therefore in order to deal with these potential problems all the patients were provided with the telephone number of the hospital breast cancer specialist nurse. No patients contacted the specialist nurse for support.

The qualitative study (Papers III, IV and V) was approved by the Regional Ethical Board (see Appendix 7) and the hospital authorities. The women were sent an invitation to participate in the study by the hospital outpatient breast cancer clinic together with the information regarding the date of surgery. They were asked to inform the outpatient clinic nurse whether they would be willing to participate before the preoperative information session and, if so, to sign the consent form and return it to the researcher prior to the interview. All participants were given oral and written project information and gave their written informed consent before the interview. Confidentiality was ensured through a coding system, with numbers replacing participants' names. The interviews were tape recorded and kept strictly confidential in accordance with the ethical guidelines. During the interviews the aim was to engender an atmosphere of trust so that participants would feel free to share their experiences, thoughts and feelings. The women's needs for emotional protection was respected by not dwelling too deeply on threatening issues, taking into consideration the fact that the day before surgery was particularly stressful. An arrangement with the outpatient clinic was made where the women were offered a special follow-up consultation with professionals after the interview if needed. None requested it. Most participants spontaneously reported that the interviews had been beneficial for them. Since the interviews took place on days when the women had to come to the hospital anyway they were not burdened by an extra visit.

6. Findings

The data for Papers I and II were obtained from the same survey study.

6.1 The mental health of women with suspected breast cancer: the relationship between social support, anxiety, coping and defence in maintaining mental health (Paper I)

Relationships between anxiety, social support, coping and defence in connection with mental health were studied among patients with suspected breast cancer awaiting diagnosis. A total of 117 women who had undergone a breast biopsy were included in the study. The results showed that patients reported elevated levels of anxiety and high levels of social support with the highest score on SPS subscales on “reliable alliance” followed by “guidance” and the lowest score on “opportunity for nurturance”. “Instrumental-oriented coping” showed the highest score and “defensive hostility” the lowest score on the CODE subscales (Table 1 in Paper I). Correlation analysis showed that anxiety was strongest and only related to “instrumental-oriented coping”. The strongest correlation between SPS subscales and “instrumental-oriented coping” were found between “attachment”, “reassurance of worth” and “guidance”. “Opportunity for nurturance” was unrelated. All social provisions were positively related to “emotion-focused coping” and unrelated to “cognitive defence”. “Attachment”, “reassurance of worth” and “reliable alliance” showed negative relationships with “defensive hostility”. The correlations between SPS subscales and CODE subscales were relatively low, with the strongest correlations to “instrumental-oriented coping” (Table 2 in Paper I). Stepwise regression analysis showed that anxiety was strongest and negatively related to “instrumental-oriented coping”, followed by “cognitive defence”. “Defensive hostility”, “emotion-focused coping” and social provisions were unrelated to anxiety (Table 3 in Paper I). Stepwise regression analysis showed that “attachment” (standardised beta coefficient 0.235, $P < 0.026$) and “reassurance of worth” (standardised beta coefficient 0.217, $P < 0.040$) were the most important and only significant contributors to “instrumental-oriented coping”.

6.2 Coping with a possible breast cancer diagnosis: demographic factors and social support (Paper II)

The aim was to examine the relationships between demographic characteristics, social support, anxiety, coping and defence among women with possible breast cancer. A total of 117 women who had undergone a breast biopsy were included. Correlation analysis showed that social support was positively related to “instrumental-oriented coping” and “emotion-focused coping” and unrelated to “cognitive defence” and “defensive hostility” (Table 1 in Paper II). Simple regression analysis showed that a higher education level and lower age were related to greater use of “instrumental-oriented coping” and, conversely, a lower education level, higher age and unemployment were related to more use of “cognitive defence”. A lower age and employment were related to a greater use of “emotion-focused coping” (Table 2 in Paper II). Stepwise regression analysis on the same variables showed that education level was positively related to “instrumental-oriented coping” ($B = 0.103$, $SE = 0.022$, $P < 0.001$). Employment ($B = -0.209$, $SE = 0.074$, $P < 0.006$), education level ($B = -0.091$, $SE = 0.033$, $P < 0.007$) and marital status ($B = -0.141$, $SE = 0.070$, $P < 0.045$) were negatively related to “cognitive defence”. Employment explained the largest portion of variance in cognitive defence, followed by education. Lower age was positively related to “emotion-focused coping” ($B = 0.082$, $SE = 0.003$, $P < 0.019$). The other demographic variables were unrelated to the CODE subscales. Stepwise regression analysis showed that educational level and household status were the most important contributors to social support, with education as the strongest predictor (Table 3 in Paper II). Stepwise regression analysis showed that education and “attachment” were the most important contributors to “instrumental-oriented coping”, with education as the strongest predictor (Table 4 in Paper II). There were no significant relationships between anxiety and demographic variables.

The data for the Papers III, IV and V were obtained from the same interview study

6.3 Being in suspense: women’s experiences awaiting breast cancer surgery (Paper III)

The aim was to describe 21 women’s experiences after having received a breast cancer diagnosis and awaiting primary surgery. The themes identified were: feeling healthy but

having to adapt to disease, waiting, uncertainty, having to tell others and existential awareness.

The diagnosis felt unreal for most of the women. They described feelings of crisis, paralysis and chaos, and that their world had changed quickly and dramatically. The women were feeling physically well, but had learned that they had a potentially serious disease. For most of them the diagnosis was frightening and difficult to understand and accept because the majority had not noticed any lumps or other symptoms.

The waiting period was experienced as frightening, hopeless, long and hard to endure – but also necessary. Some expressed apprehension because they could not do anything about their situation. Others emphasised that it was good to have some time between diagnosis and surgery to build themselves up to be prepared for what they were to go through and to spend time with their loved ones. The surgery date being set helped to alleviate their anxiety and the unbearable experience of waiting.

The findings revealed that uncertainty was related to three situations: the future, the surgery and losing a breast. How their breast cancer would influence their future was essential for almost all the women. Thoughts about both the anaesthesia and the surgery itself caused fear and a loss of control. The greatest fear was being informed of the presence of metastasis. Reactions to mastectomy were varied – for some it was acceptable, for others worrying and for some terrifying. However, getting rid of the cancer was the overarching goal for all.

Having to inform significant others about the diagnosis was a great burden. The women struggled with the question of what to say, and were afraid that the news of their cancer diagnosis would scare their friends and family. Most of the women had to offer support when informing others about the diagnosis. Social networks could both give and need support.

Furthermore, our findings revealed that most of the women expressed a new awareness of death. Some expressed death anxiety, although conversely some started to reflect on their priorities in life and pondered on possible “meanings” in getting cancer.

6.4 Coping with breast cancer: between diagnosis and surgery (Paper IV)

The aim was to describe the coping strategies used by 21 women between a diagnosis of breast cancer and surgery. Prominent themes about coping between diagnosis and surgery were: step by step, pushing away, business as usual, enjoying life, dealing with emotions, preparing for the worst and positive focus (Table 1 in Paper IV).

Step by step was the most common coping strategy. This coping behaviour was chosen so as to avoid being overwhelmed by threatening thoughts and emotions, and to reduce worrying. The women wanted only as much information as they considered relevant at each point in time, and only when they felt ready to receive it. Too much information at a time, whether from the hospital or the Internet, frightened them. Some felt they lost control because the information was overwhelming. In contrast, some women wanted all the information at once and used all available resources.

Some women tried to manage their anxiety and uncertainty by pushing away distressing thoughts and emotions, but with poor results. Clearly connected to “pushing away” was “focusing on something else”. Some managed to “push away” by finding something else to think about or by being physically active. Spending time with others was also a welcome distraction.

The fact that life continued as normal gave many a feeling of being in control. Work provided a distraction and people to talk to. Some women emphasised the importance of feeling included in the social environment at work. In general most of the women wanted to be treated as usual. Others’ pity and compassion triggered negative emotions and made some women feel vulnerable and scared. Enjoying life by focusing on meaningful values and activities helped some women in their coping process.

Some women prepared themselves mentally for the worst, anticipating that the cancer had spread and was totally incurable. Some were pessimistic and expected emotional loss reactions after surgery.

Emotions were differently experienced and expressed. Dealing with emotions by openness versus holding back was important. Some pointed out that expressing feelings did not help, as it reduced the feeling of strength and induced self-pity.

The women were highly aware of the threat of death but at the same time were hopeful and optimistic. This optimism seemed to be grounded on a general positive self-perception and on previous coping experiences. Good relationships with friends and family, a positive attitude, and supportive and realistic information about cancer from both medical sources and their private networks helped.

6.5 “The support I need”. Women’s experiences of social support after having received breast cancer diagnosis and awaiting surgery (Paper V)

The purpose was to describe 21 women’s individual experiences of social support after having received a breast cancer diagnosis and awaiting surgery. Methods of qualitative meaning condensation analysis revealed five themes: available support, information and advice, care, having confidants and balancing distance and closeness.

Knowing that family, friends, colleagues and healthcare professionals were available if needed, either in person or via the telephone, was important for all. It gave a sense of security. For most women their close family was considered to be the most important available support resource. Having support available following surgery was also important. Some women considered how to have support available during their sick leave. The situation was new and troubling for some. Support in terms of having somebody physically present when receiving the breast cancer diagnosis was emphasised by women of different family status.

Information and advice from healthcare professionals were also important. After being given the diagnosis by their physician, further information from healthcare professionals was still important for some participants, independent of age, marital status and education. Healthcare informational support was also valuable in helping to discriminate between fantasy and reality regarding cancer. However, some were afraid of disturbing the health personnel and uncertain of the expectations connected to their patient role.

Care that encompassed understanding, respect, comfort, being prayed for, empathy and love, and which could be received from family, friends and colleagues and from healthcare professionals, was important. Knowing that family and friends loved and respected them and were thinking of them gave many a sense of mental strength and security. Being contacted by

members of their social network and also by the hospital was an important feature in the women's experience of caring.

To have someone to talk personally with was an important component of social support. The women had varying degrees of closeness to their family members, friends and others. For some, only the closest family fulfilled the role of confidants. Others preferred to confide in someone outside their family, someone who was not too emotionally involved. Some wanted to talk personally with healthcare professionals, although for some women talking personally on the phone to healthcare professionals whom they perhaps had never met was difficult. Some women, both young and old, contacted their general practitioner to talk personally face to face.

Social support gave strength but too much could be experienced as difficult and frightening. The women needed to find a balance between being close to their social network and securing a certain distance from it, and between receiving enough but not too much social support and care.

7. Discussion

7.1 General methodological consideration

7.1.1 Mixed methods design

Tashakkori and Teddlie (2003) claimed that by using a mixed methods approach the researcher tends to embrace pragmatism as the world view or paradigm but that other world views exist. According to Creswell and Plano Clark (2007, 2011), multiple paradigms may be used in mixed methods research; researchers must simply be explicit in their use. Johnson and Onwuegbuzie (2004) argue that pragmatism in the sense of choosing the combination or mixture of methods and procedures that works best for answering the research questions can help to build bridges between conflicting philosophies. According to Creswell and Plano Clark (2011), pragmatism is typically associated with mixed methods research. The focus is on the consequences of the research, on the primary importance of the question asked rather than of the methods, and on the use of multiple methods of data collection to inform the issues being studied. In this thesis the quantitative and qualitative studies included both deductive/confirmatory and inductive/exploratory questions. Therefore a pragmatic approach which allows for both quantitative and qualitative approaches to be seen as complementary, using different paradigms and multiple methods of data collection and analysis (Morgan 2007, Creswell 2009, Creswell & Plano Clark 2011) was deemed appropriate.

The two studies were conducted separately with two different but for each study appropriate patient samples (see Section 5.1.1). Each of the studies was designed as a single method study. Combining the findings was done during the thesis's final interpretation and discussion process (Creswell & Plano Clark 2007, Creswell 2009).

Sequential emergent mixed methods designs, starting with quantitative standardised questionnaires followed by qualitative individual semi-structured interviews, were used in this thesis. The sequential mixed methods design using a quantitative approach followed by a qualitative approach is described as an explanatory design and is also called a qualitative follow-up approach (Morgan 1998, Creswell & Plano Clark 2011). The sequential emergent mixed methods design refers to the use of mixed methods (quantitative or qualitative) arising

from issues discovered in research processes where the second phase of the study can be designed based on what is learned in the initial phase. The researcher develops new questions based on, for example, quantitative results but which cannot be answered with quantitative data (Creswell & Plano Clark 2011). In this study a sequential emergent mixed methods design was deemed appropriate.

The quantitative study focused on selected aspects of the women's experiences rather than on the total experience as subjectively expressed by the women as qualitative studies can do. Mixed methods allow numeric data, i.e. amount and frequency as well as in-depth descriptions. For example, numeric data of coping strategies found in the quantitative study are not adequate to describe the multidimensional quality of coping processes and the actual strategies and behaviours used to deal with real-life situations. Coping has been one of the main focuses in this study. The major shortcoming of the ordinary understanding of coping with stress is the tendency to focus on the individual and to pay too little attention to the characteristics of the environmental contexts and the process of stress and uncertainty (Folkman & Moskowitz 2004). To understand the relational meanings underlying the coping process one must supplement questionnaires with interviews (Lazarus 1999).

In this thesis therefore the quantitative study focused on describing the measurable concepts of coping strategies, social support and anxiety, whereas the qualitative study described how the anxiety was experienced, how the social support was experienced and used, and what concrete behaviours were employed in order to cope. Data from the qualitative interview study helped to gain insight in the quantitative results by providing specific and detailed information. In this way a combination of methods contributed to enhance this research by "filling in the gaps" that a study adopting a singular approach would not be able to do (Creswell & Plano Clark 2007, Creswell 2009).

Since the intent of this design is to use qualitative data to provide more details about the quantitative results, the individuals best suited to do so are those who were included in the first study (Creswell & Plano Clark 2011). In this study they were participants recruited from two different samples, in different phases of the disease process – the first sample with suspected breast cancer and the second sample with a confirmed breast cancer diagnosis. Thus the participants differed in uncertainty regarding the type of medical information obtained by the pathology evaluation – with one group of patients who were preparing themselves

mentally for the possibility of having breast cancer, and a second group confronted with the reality of having breast cancer. However, both samples consisted of the same target group of women in the breast cancer trajectory admitted to Haukeland University Hospital, Breast Clinic Department, Surgical Outpatient Clinic for diagnostic evaluation and treatment. There was no intention of undertaking a second study while conducting the first study. Quantitative findings that were found to be important to elaborate upon in the qualitative interview study were determined once the quantitative study was completed. In addition, the quantitative study was anonymous. Permission had not been obtained from the Norwegian Social Science Data Services to obtain names or any other means of personal identification of the participants associated with the questionnaires (see Appendix 6). Thus it was impossible in the second study to return to the participants included in the first study for qualitative data collection. As mentioned earlier, the aim was to investigate the women's individual experiences of coping strategies and social support, in the diagnostic and preoperative phase, when they tried to deal with the threat of a potential and an identified cancer diagnosis at a point where stress may be at its highest. Therefore women with newly diagnosed breast cancer awaiting surgery were recruited. However, both studies were conducted in periods when the stress levels have been reported to be highest, i.e. waiting for the results of diagnostic testing, receiving the diagnosis and waiting for surgery (Green *et al.* 1998, Gurevich *et al.* 2002). Thus the participants in the two samples were in many ways in similar situations – in a stressful and anxiety-provoking situation related to breast cancer.

7.1.2 Sample and representativity

In the survey study (Papers I and II) all patients fulfilling the inclusion criteria were invited to participate – 151 were invited, 143 agreed and 117 completed the questionnaires, giving a response rate of 81.8%. Sending reminders to non-responders was not permitted by the Regional Ethical Board (see Appendix 6). The returned questionnaires were anonymous and the non-respondents could not be identified. Thus differences between the characteristics of participants and non-responders could not be documented.

The sample comprised 117 respondents. The sample size was somewhat low in relation to the study issue, methodological tools and expected variation. Although large samples do not

guarantee representativeness, larger samples are preferable to small ones to enhance statistical conclusion validity and representativeness (Polit & Beck 2012). Power analysis is recommended for estimating the sample size needed to diminish the risk of Type II errors (Polit & Beck 2012). Power analysis was not performed in the current study and the possibility of Type II errors is present.

When generalising the findings to other populations, it should be remembered that the study was based on a convenience sample from just one hospital in Norway, indicating that the probability of including all the characteristics of the population could not be estimated (Polit & Beck 2012). The majority of the participants were aged between 50 and 70, with a mean age of 54.3 years, which means that the younger age groups were somewhat underrepresented. However, the sample realistically represented the age groups of women who go through these diagnostic procedures (Norwegian Breast Cancer Group 2011). However, there is always a risk of selection bias with this selection method (Polit & Beck 2012).

In the interview study a convenience sample of 21 women with newly diagnosed breast cancer were recruited. The key in qualitative research is to discover and describe meaning and to extract the greatest possible information from the few cases in the sample, and a convenience sample may not provide the most information-rich sources. However, when recruiting participants from a particular clinical setting, as was the case in this study, a convenience sampling may work well (Polit & Beck 2012). Furthermore, if the participants are good informants who are able to reflect on their experiences, informational adequacy can be achieved through convenience sampling, although convenience sampling requires more cases to achieve saturation than purposive and theoretical sampling (Polit & Beck 2012). Although there was a possibility that the participants could be reluctant to fully share their thoughts due to the sensitive issues being studied, the data gave descriptions in rich detail of the women's experiences. A guiding principle in sampling is data saturation, i.e. sampling to the point at which no new information is obtained and redundancy is achieved, and adding one or two cases after achieving informational redundancy to ensure that no new information emerges (Polit & Beck 2008). In the current study saturation was achieved after the twentieth interview and one informant was added, resulting in 21 women being interviewed. Forty-eight patients were invited and 21 were interviewed. There were no essential demographic

differences between participants and non-participants. The short notice before surgery was the only reason given for not participating.

7.1.3 Reliability and validity

Reliability and validity of the survey study

An instrument's reliability is the consistency with which it measures the target attribute. The higher the coefficient, the more stable the measure. Reliability above .08 is usually considered good. Validity is the degree to which an instrument measures what it is supposed to measure. Reliability and validity are not independent qualities of an instrument. An instrument that is unreliable cannot be valid (Polit & Beck 2012).

State-Anxiety Inventory (STAI-S)

This instrument was used due to the quality of the instrument. It is well tested and widely used in clinical research (Spielberger *et al.* 1983, Alves *et al.* 2007). In the current study the Cronbach's alpha value indicated a good internal reliability (see Section 5.3.1.2). It is also said that the Cronbach's alpha must not be higher than 0.90 as this may indicate that too many variables in the instrument overlap (Streiner & Norman 2008). The instrument seemed to be easy to fill in, with few missing values. The Cronbach's alpha in this study is comparable with similar studies (Potter 2007, Liao *et al.* 2010, Dunn *et al.* 2012).

Factor analysis to support the instrument construct validity was not performed in this study due to the empirical support for the multidimensional concept of anxiety based on factor analysis across different groups in different cultures. The instrument has shown satisfactory validity in previous studies (Spielberger *et al.* 1970, 1983, Alves *et al.* 2007).

Social Provisions Scale (SPS)

The Chronbach's alpha value in this study for the total SPS indicated a good internal reliability, and for the subscales the most internal reliability values were acceptable (see Section 5.3.1.3). Compared to a previous study (Langeland & Wahl 2009), the Cronbach's

alpha value for the total SPS and the subscales was somewhat lower. This can be due to different sample characteristics (Polit & Beck 2012). The SPS was found to be applicable and there were few “missing” data.

Construct validity: Principal components analysis with Kaiser Varimax rotation using a six-factor solution was carried out to confirm the components of the SPS. The construct validity of the SPS in this study was perceived as satisfactory (see Section 5.3.1.3). It is suggested that the number of factors extracted should account for at least 60% of the total variance.

Generally, the factors obtained by factor analysis from a large sample are deemed to be more reliable than those obtained from a smaller sample (Polit & Beck 2008).

CODE (based upon the Utrecht Coping List [UCL] and parts of the Defense Mechanism Inventory[DMI])

The Cronbach’s alpha value in this study for the UCL and DMI indicated a good internal reliability (see Section 5.3.1.4). There were few missing data in the UCL, which can be interpreted to mean that the instrument was not too extensive or difficult to fill out. The DMI is a more comprehensive instrument and had more missing values in this study. Nine DMI instruments were returned without being filled in and consequently were excluded from the analysis.

Construct validity: Principal components analysis with Kaiser Varimax rotation using an eigenvalue > 1.0 was conducted on the UCL and DMI subscales. In accordance with previous studies (Olf *et al.* 1993, Eriksen *et al.* 1997) the four dimensions of the CODE were confirmed to a satisfactory degree (see Section 5.3.1.4). In conclusion the construct validity of CODE in this study was perceived as satisfactory.

Reliability and validity of the interview study

Trustworthiness in the qualitative research interview involves the extent to which the research has produced results that are credible, dependable, confirmable and transferable. These four criteria for trustworthiness represent parallels to the criteria of internal validity, reliability, objectivity and external validity in quantitative research. Credibility cannot be attained in the absence of dependability, just as validity in quantitative research cannot be achieved in the

absence of reliability (Kvale & Brinkmann 2009, Polit & Beck 2012). The trustworthiness of the data in this study was established by using the guidelines set by Malterud (2001) and Kvale (2006). The criteria for credibility and dependability were applied. Using adequate techniques for the handling and transcription of interview data will increase the dependability (Roberts & Priest 2006, Kvale & Brinkmann 2009). The interviews were recorded on high-quality MiniDiscs, and no parts of the interviews were missed due to difficulties in hearing what was said. All the interviews were conducted, recorded and transcribed verbatim by me. Memos were written during the analysis to ensure that impressions, ideas and reflections were not lost. Furthermore, member checking with participants was carried out continually as data were collected, i.e. through deliberate probing to ensure that I had understood what the participants meant in their statements. A potential difficulty in achieving credibility in qualitative research is researcher bias, which may arise from the selective collection and recording of data and from interpretations based on personal perspectives. The examples used should reflect the range and atmosphere of the responses given (Kvale & Brinkmann 2009, Malterud 2011, Polit & Beck 2012). Efforts were made to increase credibility. All the authors – two professors of psychology and a nurse with a doctoral degree (PhD), all with different professional perspectives – analysed the data independently, and the findings were discussed by all the authors throughout the analysis process to reach agreement. If doubts arose, we went back to the data and reassessed the meaning of the statements.

In qualitative studies the researcher is the data-collecting instrument (Malterud 2011). Therefore the researcher's qualifications, experience and reflexivity are relevant in establishing confidence in the findings. Qualitative studies document trustworthiness through reflexivity – which is the process of attending systematically and continually to the context of knowledge constructions – and in particular recognise the importance of the researcher's perspective in the research process and of the researcher's effect on the collection, analysis and interpretation of the data (Malterud 2001, Kvale & Brinkmann 2009, Stige *et al.* 2009). Throughout the study I took field notes to document my professional perspective, theoretical basis, experiences, thoughts and feelings in the research process. My experience as an anaesthetic nurse in meeting patients in the surgery department with suspected and confirmed breast cancer diagnoses, although in a limited phase of the patients' time, helped me to probe the participants' experiences and descriptions through the whole research process. However,

being familiar with the setting can also be problematic as it may make one overlook certain nuances and ambiguities in the data (Roberts & Priest 2006).

An important step in establishing credibility is a prolonged engagement to invest sufficient time in collecting data to gain an in-depth understanding, to build trust, to test for misinformation and distortions, and to achieve saturation of key categories (Polit & Beck 2008). Sufficient time for each interview was achieved by allowing approximately two hours per interview and data were collected to the point of saturation.

Transferability refers essentially to the data, i.e. the extent to which the findings from one study can be used as a guide as to what might occur in another situation (Malterud 2001, Kvale & Brinkmann 2009). The knowledge produced in this study may be transferable to other individuals or other settings, but not generalised to the breast cancer population as a whole as the findings could be unique to the relatively few women included in the study. On the other hand the responsibility of the researcher is to provide sufficiently rich descriptive data in the research report for readers to evaluate the applicability of the findings to other contexts (Polit & Beck 2010). This was sought through transparency of the descriptions of both the methods used for data collection and for analysis of the findings.

7.1.4 Limitations

Survey study (Papers I and II)

The survey study is limited by being a cross-sectional correlation survey and the directions of the relationships are unclear. Both coping and social support are at the same time modifying and outcome variables. It cannot be determined whether the women's coping resulted in having social support, or whether the women's social support promoted coping. Furthermore, the study was based on data collected at one point of time, and the inferences drawn are therefore limited by this.

Interview study (Papers III, IV and V)

Because of the cross-sectional design, the current study was not able to capture changes over time. Using personal interviews could further skew the sample toward participants who found it easy to talk about their situation with strangers, and perhaps it was the most articulate patients that agreed to participate. The participants came from the same geographical area and were of a similar ethnicity and culture. It is also possible that the most anxious patients may have declined to participate, and a more varied sample would probably have yielded different results.

7.2 Discussion of main findings

7.2.1 Psychological distress

Relationships between anxiety and demographic factors in the situation of having suspected breast cancer

Our findings revealed that the participants reported raised levels of anxiety (Papers I and II) exceeding normative values (Spielberger *et al.* 1983). Similar to findings from other studies (Deane & Degner 1998, O'Mahony 2001, Witek-Janusek *et al.* 2007, Montgomery & McCrone 2010, Blow *et al.* 2011, Iwatani *et al.* 2012) that demonstrate that undergoing diagnostic investigations such as a breast biopsy for suspected breast cancer is an emotional experience characterised by increased perceived stress, uncertainty, anxiety, fear and mood disturbance, we believe that this elevated level of anxiety was a result of the fact that these women were examined for a possible breast cancer diagnosis, a threatening and frightening situation. However, we found no particular relationship between age and anxiety as has been reported by others (Montazeri *et al.* 2000, Liao *et al.* 2008, Steffens *et al.* 2011), or between education level and anxiety as has been reported in previous studies (Andrykowski *et al.* 2002, Liao *et al.* 2008, Montgomery & McCrone 2010)(Paper II). The lack of relationships in this study may be caused by the fact that most participants were between 50 and 70 years old. In addition, the question of selection bias must be raised: perhaps women with high anxiety levels and more severe anxiety were over-represented among those who did not participate.

Women's emotional experiences in the situation of having breast cancer

The results of the survey study demonstrated that the women had elevated levels of anxiety while awaiting diagnosis. When women's individual experiences of the situation after having received a breast cancer diagnosis and awaiting surgery were explored, several themes illuminated the women's experiences.

Our findings revealed that most of the women had difficulties accepting the diagnosis while feeling healthy (Paper III). They felt their health status had changed overnight and that they had been affected by an uncontrollable and unpredictable disease, and experienced a sudden transition from a state of wellness to a state of illness and disease (Boehmke & Dickerson 2006). Their lack of symptom patterns and their ambiguous situation increased the uncertainty about their illness-wellness state. This is a situation which decreases the ability to determine the meaning of illness-related events, according to Mishel and Braden (1988). Our findings revealed that the diagnosis caused emotional reactions that can be characterised as a psychological crisis similar to that described by others (Landmark *et al.* 2001, Taleghani *et al.* 2008, Tobin & Begley 2008, Remmers *et al.* 2010, Blow *et al.* 2011). Our participants described feelings of stress, crisis, paralysis and chaos, and struggled to absorb and accept what had happened.

Furthermore, we found different emotional reactions such as anxiety, fear and suffering characterised by a feeling of intense uncertainty were present during the waiting time. Some of our participants appraised their diagnosis as a threat, implying unknown but anticipated negative consequences for their identity (Papers III and IV). Others trusted that the surgery would alleviate their suffering but found it difficult to endure the indeterminate waiting time. Suffering due to breast cancer is documented previously and involves physical, psychological, interactional and spiritual aspects (Arman & Rehnsfeldt 2003, Perreault & Bourbonnais 2005). Being informed as soon as possible of the date of surgery was essential. This information gave our participants a sense of control and of belonging to a healthcare system, and thus alleviated the unbearable experience of waiting. Loss of control is mentioned by many patients with breast cancer (Sharpley & Christie 2007, Barez *et al.* 2009, Henselmans *et al.* 2010). Lack of control may create helplessness and depression (Seligman 1975). Individuals who experience lack of control have more stress-related problems than those with a belief in their own ability to influence their situation (Olf 1991, Mishel 1997, Lazarus

1999). Despite the fact that the women expressed the wish to talk to somebody and were told that they could call the hospital nurse for counselling, many women were unfortunately reluctant to use this service. However, we also found some *positive* experiences related to waiting. For some women it was necessary to have a certain time to prepare themselves both physically and psychologically and to accept the diagnosis gradually. The importance of having some time before surgery to become emotionally prepared and to prevent strong negative reactions following surgery was also reported by others (Landmark *et al.* 2008).

Our participants' need for information and the unpredictability of their cancer and treatment increased their fear and uncertainty (Mishel 1988). Furthermore, uncertainty was primarily related to three situations: the future, surgery and losing a breast. Several studies have revealed that women with breast cancer have reported a strong need for cancer-related information from healthcare professionals to reduce uncertainty (Loiselle *et al.* 2006, Liao *et al.* 2007, Landmark *et al.* 2008, Lally 2009). In contrast, our findings revealed that *some* general information was welcome, but *too detailed* information was threatening (Papers III and IV). Most of the women wanted information on *their own* actual status in the disease process. Unfortunately, this information was impossible to obtain at this point of time.

Concerns about anesthesia and the surgery itself also caused fear, anxiety and loss of control for some of our participants. Preoperative routines and procedures seemed ominous because what they involved was unclear. But the greatest fear was connected to the post-surgery information: all feared receiving the message of metastasis. This finding confirms conclusions of similar studies (Montgomery *et al.* 2003, Schnur *et al.* 2008) that worry about the outcome was more stressful than aspects of the surgery itself. Furthermore, our participants were also concerned that the surgery and treatment would affect their total physical condition and the time needed to return to everyday life.

Breasts are considered as a symbol of femininity, womanhood, sexuality and self-concept (Yankaskas 2005, Demir *et al.* 2008, Helms *et al.* 2008, Cebeci *et al.* 2011). Nevertheless our participants had different attitudes to losing a breast. All regarded losing a breast as being of lesser importance if it reduced the risk of dying from breast cancer, as also reported previously (Landmark & Wahl 2002, Taleghani *et al.* 2008). However, anticipated changes in their appearance were the main concern for some participants. This has been a main concern primarily for younger women in earlier studies (Avis *et al.* 2004, 2005). It was therefore

surprising that this was also a major concern for some of the oldest women in our study. Furthermore, our findings revealed uncertainty regarding sexual attractiveness. Some connected their breast to their feminine identity and were afraid of feeling of less worth than women with two breasts. Their partner's reassurance was important. To know that they would still be valued and loved as a woman was essential.

Furthermore, anxiety about death was clearly apparent among our participants. Their existence, values and basic needs for meaning and purposefulness were threatened and they struggled to find meaning in their difficult situation. However, one important finding was that some started to reflect on their priorities in life. This is discussed in Section 7.2.2.

7.2.2 Coping related to breast cancer

Relationships between coping (instrumental-oriented/emotion-focused coping) and defence strategies (cognitive defence/defensive hostility) and anxiety in the situation of having suspected breast cancer

Our findings revealed that the women scored highest on “instrumental-oriented coping” followed by “emotion-focused coping” (Papers I and II). The findings are comparable with those reported in studies among Norwegian students and female back pain patients (Eriksen 1998, Eriksen & Ursin 1999). Furthermore, “emotion-focused coping” was not connected to low anxiety, whereas “instrumental-oriented coping” clearly was (Paper I). “Instrumental-oriented coping” is based on positive response outcome experiences, which tend to be generalised. This means that people who tend to use an “instrumental-oriented coping” style may have experienced enough successful coping to have established the expectancy of being able to handle any situation with a positive result. This coping style is associated with low anxiety and a reduced activation or stress response (Ursin 1988, Ursin & Eriksen 2004). Even in a situation such as this, where nothing could be done to influence the results of the biopsy, this attitude may in itself be anxiety reducing.

Furthermore, and somewhat surprisingly, cognitive defence was to some extent related to low anxiety (Paper I). Olff (1991) has reported similar results. Heckman *et al.* (2004) found that cognitive avoidance reduces anxiety in women recalled after an abnormal breast screening

mammogram. Whether reduced anxiety is a real consequence of defence or whether the anxiety is also denied and therefore under-reported, or whether it is both, is unclear. It should be noted that “cognitive defence” in CODE consists of various forms of defence mechanisms with varying adaptive qualities (Eriksen & Ursin 1999). Although very different from “instrumental-oriented coping”, this style may have positive effects such as modest anxiety-reducing effects (Eriksen *et al.* 1997, Drageset & Lindstrøm 2003). Yet there is reason to believe that generally the anxiety-reducing effect, if any, is mainly palliative and short-lived. When confronted with inescapable problems such as breast cancer, defensive strategies are not enough and may be detrimental to coping (Eriksen *et al.* 1997, Stanton *et al.* 2002, Elklit & Blum 2010). Furthermore, our findings revealed that “defensive hostility” was the least common coping style and was unrelated to anxiety, which may be a reason for its low frequency in this sample. Eriksen *et al.* (1997) have reported the same results. However, if frightening uncertainty and anxiety *itself* are the actual problems for someone with this coping style, it seems reasonable to assume that this person will show their anxiety through aggression and/or blaming of others (projection).

Women’s coping experiences in the situation of having breast cancer

The results from the survey study demonstrated that “instrumental-oriented coping” and “cognitive defence” reduced anxiety. “Emotion-focused coping” and “defensive hostility” were unrelated to anxiety. When women’s individual experiences of the situation of having received a breast cancer diagnosis and awaiting surgery were examined, several themes shed light on the details within their coping process.

Our findings revealed that some of the women wanted as much information as possible, a behaviour that is often documented as a positive coping strategy among women with breast cancer (Rees & Bath 2000, Long 2001, Loiselle *et al.* 2006). It was a paradox that most of them wanted information but felt that too much information was threatening. They did not want information about the possible consequences of breast cancer, only information relevant to their own case. Receiving information on a step-by-step basis was the most prominent coping strategy. This enabled the women to face the reality gradually, and facilitated the process of accepting and preparing for what might come. It also gave a sense of having

control over a situation they initially perceived as being beyond their control. Hestestad and Tjemsland (1996) have reported similar findings. The “step-by-step” strategy seems to allow a mixture of emotion-focused coping and avoidance that function simultaneously and facilitate each other, as suggested by Lazarus (1999). This strategy also reflects the cognator coping subsystem, using processes of selective attention and defence to avoid anxiety-provoking information, according to Roy (2009). By using this strategy the women avoided dwelling on problems that *might* arise and focus was maintained on actual facts in the present situation, which kept anxiety and uncertainty at a tolerable level (Papers III and IV). According to Folkman and Moskowitz (2004), “problem-focused coping” is associated with greater personal control than “emotion-focused coping”. However, these women were in a situation where solving the problem, “getting rid of the cancer”, was objectively beyond their control. Therefore this mode of “emotion-focused coping” seemed to be rational and adaptive, as also reported previously (Olf 1991, Lazarus 1999, Austenfeld & Stanton 2004). The women’s self-integrity was thus maintained and presented an adaptive self-concept mode response (Roy 2009).

We found that some women tried, with varying results, to manage anxiety and uncertainty by pushing away distressing thoughts and emotions (Paper IV). When talking about themselves many used “you” instead of “I”, indicating a defensive distancing from the situation as the cancer diagnosis threatened their self-concepts. For some “pushing away” functioned poorly and for others it functioned moderately. Poor results meant that no matter how hard they tried, disturbing thoughts returned. The most adaptive coping strategy for those who managed moderately was cognitive and emotional distancing by focusing on something positive. In situations where the opportunities for direct action are limited, coping by avoidance or distancing can be positive (Drageset & Lindstrøm 2005, Jadoulle *et al.* 2006) but the effect is short-lived (Stanton *et al.* 2002). An illness has to be faced, “accepted” and adapted to (Olf 1991, Stanton *et al.* 2002, Roussi *et al.* 2007). But there was nothing the women could do *themselves* to get rid of their cancer; they had to cope with having to wait. Furthermore, our findings revealed that active ways of coping such as focusing on activities requiring concentration and on physical activity generally helped. Physical activity appeared to be particularly effective – it produced positive emotions, reduced anxiety and provided physical and mental strength. The benefit of physical activity in women with breast cancer is also

reported by others (Kolden *et al.* 2002, Manuel *et al.* 2007, Duijts *et al.* 2011). However, our findings also revealed that spending time with others was helpful (Papers IV and V) – not only as an emotional support but also as a way of distracting disturbing thoughts through engaging in positive activities.

Furthermore, “business as usual”, signaling both to themselves and to others around them that “life was normal”, was an important element of these women’s ability to cope (Paper IV). Being engaged in work and getting positive responses from their colleagues for doing so, reduced anxiety, led to a sense of controlling something in life and thereby strengthened their self-confidence.

Struggling with uncertainty and existential threats may lead to increased attention to values in life and to a search for meaning (Logan *et al.* 2006, Skaggs & Barron 2006, Bertero & Chamberlain Wilmoth 2007, Giske & Gjengedal 2007). An important finding was that some of our participants started to reflect on their priorities in life, on what mattered most in life and on what gave them joy and positive emotions (Papers III and IV). They discovered that their cancer was a reminder and an opportunity to live in the moment and to appreciate life more. This enhanced sense of life purpose and appreciation of life is confirmed by others following breast cancer surgery (Cordova *et al.* 2001, Carver & Antoni 2004, Oxlad *et al.* 2008). If the uncertainty of illness is also appraised as an opportunity, it may become a positive element and may enable patients to perceive life’s possibilities more (Mishel 1990). Those of our participants who managed to find meaning by giving priority to valuable experiences found that this helped them to cope with uncertainty and death anxiety (Papers III and IV). Such a strategy is found to be adaptive in coping with stressful events (Folkman & Greer 2000, Folkman & Moskowitz 2004, Folkman 2008) and in women’s coping with breast cancer (Wallberg *et al.* 2003, Collie & Long 2005, Lally 2010). Some of the women even managed to reflect upon the positive aspects of having breast cancer and were convinced that it would increase their personal mental strength. According to Roy (2009), this way of coping may help patients to maintain a positive self-concept and psychological and spiritual integrity. This seems to have been the case for some of our participants.

Dealing with emotions, by either openness or holding back, was important in the women’s coping (Papers III and IV). Expressing emotions gave positive relief for some women (Paper IV). Crying, talking and writing could provide outlets for their emotions, helping the women

to keep calm and preventing feelings of depersonalisation. Disclosing their situation to trusted people was also central to our participants' coping processes (Papers IV and V). However, in this situation, the expression of emotions was a double-edged sword – it could lead to feelings of weakness and self-pity and thereby reduce the sense of coping (Paper IV).

Furthermore, an important finding was that some pessimism, negative thinking and doubt were always present no matter how hard the participants tried to think in an optimistic way (Paper IV). Some had a generally pessimistic orientation to life, as reported before among breast cancer patients (Schou *et al.* 2005b). Some prepared themselves mentally “for the worst”. According to Folkman and Moskowitz (2004), this can represent a future-oriented coping that reflects efforts to conserve strength to deal with events that might occur. Others tried to handle their emotional reactions by refusing to acknowledge the possibility of a fatal outcome, thereby avoiding rumination and self-pity which could lead to negative imaginings and anxiety. Self-pity threatened their integrity and reduced the confidence to cope.

Our participants were highly aware of the threat of death but at the same time were hopeful and optimistic; a double focus that has also been reported in similar studies (Rustoen & Wiklund 2000, Fu *et al.* 2008). The women's hope and optimism that led to generalised coping expectancies seemed to be related to a positive life attitude and a belief in their own resources. In addition, if they had previously dealt successfully with suffering and illness and had faith in their doctors' expertise and in the optimistic cancer survival statistics, this enhanced their feeling of coping and gave hope. Hope can be regarded as a coping strategy and helps people to endure uncertainty (Rustoen 1995, Stanton *et al.* 2002, Giske & Gjengedal 2007, Folkman 2010). Hope and fear are both intertwined and future-oriented (Lazarus 1999). In this situation metastasis and death were frightening possibilities; our participants were aware of the fact that coping would be hard and would take time, but most of them were strongly oriented towards the future and had positive expectancies that they would get rid of their cancer. Individuals are coping when they have established a positive response outcome expectancy (Ursin 1988). This strategy may be referred to as control (Ursin & Eriksen 2004) but also as a positive self-concept (Roy 2009). Most of the women were confident that they had the resources within themselves to do something to affect the outcome. Some even showed a fighting attitude, indicating that they viewed the situation not only as a threat but also as a challenge. Some had in previous difficult situations in life even

experienced having had unexpected strength and this made them expect to be able to also cope now. In addition, having good humour, being physically fit and employing positive self-talk were among factors that contributed to their positive thinking and coping. Having good friends and relationships and no other serious family problems to deal with were also contributory factors.

7.2.3 Social support related to breast cancer

Relationships between social provisions and anxiety in the situation of having suspected breast cancer

Our findings revealed that anxiety was surprisingly unrelated to social provisions (Paper I), while social provisions have been reported as being helpful in similar populations (Northouse *et al.* 1995, Fridfinnsdottir 1997, Liao *et al.* 2007, 2009, Blow *et al.* 2011). The levels of social support and social provisions were high in this sample (Papers I and II). This elevation may be partly because the sample consisted only of women, and generally women, compared to men, have larger social networks and more intimate friends (Cutrona & Russell 1987) and use social support more as a coping strategy (Monat & Lazarus 1991). Furthermore, our patients scored highest on “reliable alliance” followed by “guidance” (Paper I). Knowing that others are available to offer advice when needed is found to be an important social resource (Ganz 2008, Alqaissi & Dickerson 2010). Therefore we can conclude that these patients seemed to have solid networks which could support them in their difficult situation.

Nevertheless our findings indicate that this support did not reduce the women’s anxiety. Similarly, other studies have also shown that social support has not always emerged as an unequivocal adaptive resource (Helgeson 2003, Shiozaki *et al.* 2011). Needs served and benefits gained by talking about difficulties vary considerably, and are also dependent upon factors such as a willingness to listen (Kelly & McKillop 1996, Remmers *et al.* 2010). Talking too much about problems and expressing negative emotions such as anxiety may actually be aversive to the listeners and may lead to less social contact and support.

Interpersonal relationships may even strengthen existing stress or be inattentive to the emotional needs of the individual, and people may not always interpret the support they receive as positive (Sarason *et al.* 1990, Helgeson 2003, Shiozaki *et al.* 2011). In addition,

there may be a mismatch between the type of social support given and the needs of the individual, i.e. when a type of support is offered that the individual does not want (Reynolds & Perrin 2004).

The relationships between social support/social provisions, coping, defence and demographics in the situation of having suspected breast cancer

Our findings revealed that social support was most strongly connected to an “instrumental-oriented coping” style followed by an emotion-focused coping style, whereas the defensive styles (cognitive defence and defensive hostility) were unrelated to social support (Paper II). Moreover, our findings revealed that the social provisions were moderately differently connected to instrumental and emotional coping styles, with somewhat stronger relationships to “instrumental-oriented coping” (Paper I). This is surprising, particularly as “seeking social support” is a variable within the “emotion-focused coping” scale in CODE. For those relying most on “instrumental-oriented coping”, “attachment” and “reassurance of worth” were the most important social provisions. The most important kind of social support is suggested to be emotional (Cohen & Wills 1985), affirming the importance of “attachment”. “Reassurance of worth”, which communicates belief in the individual’s abilities, is generally regarded as the core of the social support concept and may help to promote effective coping (Cobb 1976). Our findings may therefore fit well with the view which regards social support as a resource that promotes coping. However, the relationship may also be the other way round: people who are good instrumental copers may also be good at attracting, building and maintaining a social network because of their coping abilities (Drageset & Lindstrøm 2003), and may be more engaged in social life (Henselmans *et al.* 2010). Also, those who rely on the more passive emotion-focused coping style may find it useful to have a qualitatively good social network. In both cases, the social networks may primarily be consequences of the coping styles rather than actual coping resources. Therefore, instead of primarily regarding social support as a resource for coping (Cobb 1976, Monat & Lazarus 1991) that has a one-way effect on coping, we believe that the social support system has a mutual interaction with coping and may indeed be a consequence of coping, particularly in connection with an “instrumental-oriented coping” style (Papers I and II).

When looking at the connections between demographic variables, social support and coping, some support for these ideas was found (Paper II). We found positive connections between education, “attachment” and “instrumental-oriented coping”, with education as the most important. Education may in itself enrich personal resources and self-efficacy and promote an active, instrumental coping style (Montgomery 2010, Rottmann *et al.* 2010a). According to Cohen and Wills (1985), “attachment” is suggested to be the most important kind of social support. Better education was particularly related to social support as also reported by others (Katapodi *et al.* 2002, Liao *et al.* 2007). However, without suggesting employment as a mediating variable it seems difficult to explain our finding. Receiving education may also lead to having social networks such as lasting friendships, colleagues and organisational connections at work. Therefore a social network may partly be a result of high education alone, or may lead to social contacts at work, which may be important resources for social support (Landmark *et al.* 2002, Johnsson *et al.* 2010, Mehnert 2011).

Household status was also positively related to social support; 78.8% of the women were living with their family or another person (Paper II). That family is an important primary contributor to social support is not very surprising and is also reported in similar studies (Fridfinnsdottir 1997, Veronesi *et al.* 1999, Montgomery 2010, Blow *et al.* 2011). In the relationship between education, social support and “instrumental-oriented coping” we found a pattern of “good copers”: women using “instrumental-oriented coping”, having a reasonably good education, living with others and with an available social network providing “attachment” and support if and when needed. Furthermore, “emotion-focused coping” was also connected to social support but in contrast “instrumental-oriented coping” was related to employment and not to education. This finding may reflect a pattern of important job-related social support in women with less education, who were using more of the “emotion-focused coping” style and thereby making friends at work.

“Opportunity for nurturance”, as also expected from other studies (Mancini & Blieszner 1992, Langeland & Wahl 2009), showed the lowest score of the social provisions (Table 1 in Paper I). In contrast to the other provisions it was unrelated to “instrumental-oriented coping” but slightly related to “emotion-focused coping” (Paper I). According to Cutrona and Russell (1987), it is questionable whether it acts as a provision at all because the individual is the

provider rather than the recipient of the support. To give nurturance may in many cases be a burden and not a chosen situation and may limit a person's opportunities to cope with problems in an active instrumental way (Bailey *et al.* 2010).

Social support was unrelated to "cognitive defence", a defensive style which was particularly connected to unemployment but also to low education, single/divorced/widowed status and higher age (Paper II). Younger age was related to "instrumental-oriented" and "emotion-focused" coping styles – styles which in turn were connected to social support. These differences may be a cohort effect. Younger cohorts of Norwegian women have more education and employment, and this may explain their greater use of "instrumental-oriented" and "emotion-focused" coping styles. That education and paid work increase women's self-confidence, belief in their coping abilities and general well-being are reported by others (Aber 1992, Kåresen & Langmark 1997, Li & Lambert 2007). Different cohorts are socialised under different sociocultural contexts, which may influence their coping. In this study older women tended to be unemployed, retired or homemakers. Therefore these cohorts had fewer opportunities for receiving education and being in employment and thus for the coping abilities and social networks that these may lead to. The life situations of older women may therefore favour a more passive cognitive defensive strategy than an "instrumental-oriented" or "emotion-focused" coping strategy (Vos & de Haes 2007). However, irrespective of age and cohort, this connection between low education, unemployment and a cognitive defensive style may also be characteristic of women in difficult life situations in general.

The "defensive hostility" style was unrelated to all demographic factors. However, as expected, it was negatively related to social support although not statistically (Paper II), and it was negatively related to the social provisions "attachment", "reassurance of worth" and "reliable alliance" (Paper I). The latter may have two explanations: people who are aggressive and hostile are unpleasant to be around and contact with them is avoided, or lonely people may, because of their loneliness, be aggressive and hostile towards others. We believe the first explanation to be the more reasonable but there may also be possible interactive effects between the two.

Women's experiences of social support in the situation of having breast cancer

The results from the survey study demonstrated that social provisions were unrelated to anxiety and somewhat related to “instrumental-oriented coping”, sparsely related to “emotion-focused coping”, unrelated to “cognitive defence” and partly negatively related to “defensive hostility”. When women’s individual experiences of social support after having received a breast cancer diagnosis and awaiting surgery were examined, several themes illuminate their experiences.

Our findings revealed that most women had good social supporters (Papers IV and V). Having support available and a continuity of support following surgery, either in person or via telephone, particularly from family members but also from friends and healthcare professionals, was important (Paper V). Support from both colleagues and superiors at work was highly valued and has been reported as a crucial component of well-being (Mahar *et al.* 2008, Drageset *et al.* 2010, Dickerson *et al.* 2011). Our participants felt reassured that their supporters were available if needed. Simply knowing that someone was available contributed to our participants’ feelings of mental strength. However, an important finding was that not only the perception of available support but also having close persons physically present all the time was important for some of them, particularly when receiving the diagnosis. Unfortunately, particularly for those living alone, the physical presence of supporters could be difficult to obtain.

Furthermore, an important component of social support was professional information and advice, which appeared to be motivated partly by a distrust of one’s memory and a fear of negative imaginings in the stressful situation and partly by a distrust of information from non-professional sources. Independent of age, marital status and education, most of our participants felt that they received less information than desired. Those who called the hospital nurses for information experienced that the nurses provided adequate information, helped to discriminate between fantasy and reality, and took sufficient time to listen. The threat perceived by patients following diagnosis strongly influenced their needs and experiences (Rottmann *et al.* 2010b, Drageset *et al.* 2011). However, despite being urged to call the hospital nurse for counselling and support and despite their need for professional support, many were reluctant to contact the clinic (Papers III and V). They were afraid to

disturb or to be a burden by using the professionals' time and resources as well as being uncertain as to what was expected of them as patients.

Emotional support refers to care and to having people available to listen, sympathise, provide reassurance and make one feel valued and loved (Helgeson 2003), as also expressed by our participants (Paper V). We found that the women wanted to be seen, understood, respected and valued as individuals. Knowing that others "were there for them" was central. Moreover, feelings of emotional closeness, of knowing that significant others valued, loved, prayed for and thought of them not only demonstrated care and gave feelings of security but also provided mental strength. Unfortunately, we found that some of our participants experienced that both family and friends tended to avoid them despite their need for care. This gave these participants the feeling of having a stigmatising and fatal disease, of being ignored, and of a withdrawal of care which imposed an extra burden on them. Moreover, nurses' and doctors' professional knowledge and clinical expertise in combination with relational qualities such as care and comfort were important sources of support for our participants. An important finding was that follow-up telephone contact at the initiative of healthcare professionals after the patients had received their diagnosis would have demonstrated individualised care and that the patients had not been forgotten.

Having confidants was central to our participants' social interactions (Papers IV and V), as also previously reported among women with newly diagnosed breast cancer (Burgess *et al.* 2005, Maunsell *et al.* 2009). In contrast to other studies that have shown that expressing concerns and sharing feelings are more beneficial with people within their inner circle (Finfgeld-Connett 2008, Alqaissi & Dickerson 2010), our findings revealed that talking personally face to face and expressing emotions to people outside the family and to friends who were not too emotionally close was also essential (Paper V). Talking to healthcare professionals was important in a similar way, but talking personally on the telephone to healthcare professionals whom the women had never met was difficult. Some therefore contacted their general practitioner to talk with them face to face. Such a consultation helped the women to express emotions and alleviated fears and concerns.

Balancing distance and closeness; social support and coping in the situation of having breast cancer

Social interaction may help by giving both information and emotional support (Mishel & Braden 1988, Gagliardi *et al.* 2009, Liao *et al.* 2010) as our findings confirmed (Papers III, IV and V). However, our findings also revealed that the presence of social networks may not always have positive effects – it may also be a source of distress and burden (Drageset & Lindstrøm 2003, Parrish & Adams 2003, Cordova *et al.* 2007). Having to tell significant others about their diagnosis was a major burden for most of our participants (Paper III). Some kept their diagnosis to themselves to prevent significant others' distress. Furthermore, the participants tried to lighten the burden on their family by choosing their words carefully and being strong, which meant depriving themselves of the ability to express their own reactions (Papers III and IV). Expressing emotions can be associated with decreased distress (Iwamitsu *et al.* 2005), but holding back and controlling emotions can also reduce distress (Bonanno *et al.* 1995, Drageset *et al.* 2010). Our participants gave priority to their family members' emotional needs. This may either have imposed a burden of self-control, or protected them from being overwhelmed. Paradoxically, instead of being comforted and supported themselves, the women took on the role of comforter towards their family. Most even increased their own distress by feeling guilty for imposing distress on others. Therefore their anticipated social supporters were not experienced unequivocally as resources.

Several studies have reported that women with newly diagnosed breast cancer have concerns about their children, primarily younger children (Billhult & Segesten 2003, Semple & McCance 2010). We found similar results although these children were all adolescents or adults (Paper III). Some of our participants chose to put the needs of the children in focus and to suppress their own concerns and needs when trying to maintain their role as a good mother within a normal family life. This composed attitude may possibly also have benefited the women (Taleghani *et al.* 2008).

Our findings revealed that not only was living as usual important but also being treated as usual was important (Papers IV and V). People who increased the women's vulnerability and anxiety by showing too much consideration and compassion were avoided. Receiving exaggerated compassion from others led to self-pity and made the women feel seriously ill as it signalled danger. Our findings thus revealed that consideration, sympathy and

encouragement from others could paradoxically be experienced as difficult and frightening. In contrast, some of our participants experienced that some people tended to encourage them too much, to be too optimistic and cheerful, when they wanted to express other feelings (Paper V). Instead of perceiving the support as well-intentioned encouragement, some of our participants perceived the support as trivialising and as ignoring their need to express emotions of fear and concern. Moreover, our findings revealed that some of our participants found that family members and friends provided too much information and advice. According to Reynolds and Perrin (2004), supporters who offered unwanted explanations and advice blocked the expression of thoughts and emotions. Our findings revealed that too much advice from other cancer patients was also unwanted and frightening. It could be burdensome and difficult, and also taxed our participants' resources (Drageset *et al.* 2011). Social support is linked not only to the structure of the network but also to the patients' capacity to contact and use these resources (Helgeson *et al.* 2004, Drageset & Lindstrøm 2005, Gagliardi *et al.* 2009, Lu *et al.* 2010). However, we also found that some of our participants did not need much social support but preferred to handle the situation in their own way. This attitude might also have been influenced by their perception of their own personal resources and coping abilities (Drageset *et al.* 2010). Our findings also revealed that some of the women wanted their social supporters to provide care only when they were really in need of care, while others had problems "opening up" to care. Some experienced the support offered as being "overprotective" and intrusive. Our participants' ambivalence could be misunderstood by their social network as being avoidance behaviour, resulting in confusion between the patients' needs and the supporters' assumptions about those needs (Arora *et al.* 2007).

7.2.4 Overall findings across methodological approaches

Psychological distress, coping and social support were studied by two different methods in this study. The first perspective described relationships among variables demographic characteristics, social support, anxiety, coping and defence among women with suspected breast cancer (Papers I and II). In the second study, using a qualitative approach, information was achieved through the women's own description of the processes they underwent after having received a breast cancer diagnosis (Papers III, IV and V). Some common features were

identified from this variation of data obtained from these two studies, from different samples at varied stages of the disease course and using two different methods of collecting data.

The findings from the survey study (Papers I and II) revealed elevated levels of anxiety among our participants while awaiting diagnosis. The findings from the interview study (Paper III) revealed that the women lived in a state of anxiety and ambivalence while waiting for surgery and treatment decisions. They described emotional reactions such as anxiety, fear and suffering, characterised by an intense uncertainty and a heightened awareness of life and death. These emotional reactions threatened their personal integrity. In these two studies a picture of perceived anxiety and uncertainty was prominent.

A general picture of the coping strategies (instrumental-oriented/emotion-focused coping) and defence strategies (cognitive defence and defensive hostility) were found in the survey study (Papers I and II). Furthermore, the findings demonstrated that “instrumental-oriented coping” and “cognitive defence” reduced anxiety. “Emotion-focused coping” and “defensive hostility” were unrelated to anxiety (Paper I). However, the dispositional measure of coping cannot characterise the array of actual coping strategies used in dealing with a complex stressful event. The functions of problem-focused/emotion-focused coping are seldom separate. Both are essential parts of the total coping effort and each may facilitate the other (Lazarus 1999). The findings in the interview study revealed that these two functions of coping covered themes such as “step-by-step”, “pushing away”, “dealing with emotions”, “positive focus” and “preparing for the worst”, and that several coping efforts were used concurrently. “Step-by-step” seemed to be a mixture of “emotion-focused coping” and “avoidance” functioning simultaneously, and helped our participants to keep anxiety and uncertainty at a tolerable level. “Pushing away” and “focusing on something else” to manage the anxiety and uncertainty were also used for this purpose. In this situation, cognitive and emotional distancing by focusing on something positive was experienced as the most adaptive coping strategy. “Step-by-step” and “pushing away” both reflected the cognitive defence concept in Ursin’s theory (1988) and emotional focused coping in Lazarus’ theory (1999).

It was found in the survey study that “instrumental-oriented coping” reflecting “positive response expectancy” as well as active “instrumental-oriented coping” was connected to low anxiety (Paper I). Moreover, this coping style was explored by the results in the interview study (Paper IV) as composing the theme “positive focus”, which gave hope and optimism.

Most of our participants had a positive expectancy that they would get rid of their cancer. Encouragement in the form of having good friends and positive self-talk were also contributing factors. According to Olff (1991), the distinction between coping and defence is a theoretical distinction. In reality it is not always easy to tell whether a certain thought or act is related to coping or defence. In this situation, maintaining a positive focus by constructive self-talk could be interpreted as emotional coping (Lazarus 1999), i.e. reappraising the situation. Reappraisal is suggested to be an effective way of coping with a stressful situation (Lazarus 1999, Manuel *et al.* 2007). However, comforting cognitions (Eriksen *et al.* 1997) involving defence by self-deceptive encouragement may also be too defensive (Olff 1991). Whether self-talk was “reappraisal” or “defence” for our participants was hard to determine. However, constructive self-talk reduced anxiety and generated positive emotional responses, at least during the period between the diagnosis and surgery.

The findings from the survey study (Paper I) revealed that “emotional-focused coping” was not connected to low anxiety. Moreover, the findings from the interview study (Paper IV) revealed that emotions were dealt with either by openness or by holding back. Expressing emotions was in fact a double-edged sword: it could either help the women to feel calm or could lead to feelings of weakness and self-pity. Moreover, the findings from the interview study revealed themes related to “emotional-focused coping”, such as “business as usual”, “enjoying life”, and “preparing for the worst”. This means that the “emotional-focused coping” was associated with both negative and positive emotions. This may thus be effective for one participant but not for another, depending upon the individual appraisal and previous experiences (Folkman & Moskowitz 2004).

In the survey study (Papers I and II) we found that the levels of social support and social provisions were high. The findings from the interview study (Papers IV and V) revealed that most of these women had good social support. Furthermore, the findings of the survey study (Paper I) revealed that our participants scored highest on “reliable alliance” followed by “guidance”, which seemed to reflect that social supporters were available to provide help and advice when needed. “Attachment” and “reassurance of worth” were the most important and only significant contributors to “instrumental-oriented coping”. According to Weiss’ (1974) theory, “reliable alliance” derives from relationships in which the person can count on assistance under any circumstances. “Guidance” is provided by relationships with trustworthy

individuals who can provide advice and expertise, “attachment” by relationships from which the person gains a sense of emotional closeness and security, and “reassurance of worth” by relationships in which the person’s skills and abilities are acknowledged. Moreover, the findings from the interview study (Paper V) revealed themes such as available support, information and advice, care and having confidants. These themes seemed to reflect the social support provisions found in the survey study. In addition, relational qualities in “care” such as understanding, respect, comfort, empathy and love gave our participants security and mental strength.

Furthermore, our findings from the survey study (Paper I) revealed that anxiety was surprisingly unrelated to social provisions. In the interview study (Papers III, IV and V) we found that social support could be a double-edged sword as the network’s offered support could sometimes be a burden. Pity and compassion could increase our participants’ feelings of fear and vulnerability. Moreover, the findings from the survey study (Papers I and II) revealed that social support might primarily be a consequence of the women’s coping styles, particularly in connection with an “instrumental-oriented coping” style. In the interview study (Paper V) we found that some of our participants did not need much social support but preferred to handle the situation in their own way. This attitude may have been influenced by our participants’ perception of their own personal resources and coping abilities.

This study revealed that the adaptive qualities of the coping processes need to be evaluated in the specific context in which they occur.

8. Conclusion

The use of quantitative and qualitative approaches in sequence, although used in two different samples at different stages of the disease course, has provided complementary knowledge and a better understanding of the psychological distress, coping and social support in the diagnostic and preoperative phase of breast cancer. Mixed methods provide more information than each separate approach can.

“Instrumental-oriented coping” and, to a lesser degree, “cognitive defence” were connected to low anxiety. “Emotion-focused coping” and social support did not in themselves repress anxiety. Social support is suggested to be the product of an “instrumental-oriented coping” style, not necessarily contributing to it.

Women who coped best while awaiting a possible breast cancer diagnosis had a reasonably good education and received support from relationships characterised by “attachment”. Unemployment, a low level of education and a single/divorced/widowed status were related to a greater use of “cognitive defence”. Those who used a defensive hostile coping style tended to receive poor social support.

While awaiting breast cancer surgery, as well as experiencing death anxiety the women directed most energy at handling uncertainty about the future and about the severity of their cancer. The women found the waiting time to be long and painful, but also necessary to prepare them physically and psychologically for surgery. Informing their family, friends and colleagues was experienced as a lonely burden of being obliged to both inform and console.

A major goal for the women was to avoid being overwhelmed by emotional reactions, in which keeping the diagnosis at some distance seemed helpful. Their coping strategies displayed similar patterns but diverged on some points. The women tended to use one of two opposite coping strategies in order to manage their situation: “information-seeking” versus “step-by-step”, “business as usual” versus “enjoying life”, and dealing with emotions by openness versus holding back feelings. In general they needed to manage their situation in their own way.

Social support was important for all of these women, but the support provided needed to be adjusted to each woman's individual needs. The social network offered support, but this could sometimes also represent a burden. Healthcare professionals were considered to be an important source of social support.

8.1 Implications for clinical practice

In general, healthcare professionals should offer support, care and advice on an individual basis to promote women's adjustment when facing the diagnosis of breast cancer. From a clinical nursing perspective, it is important to be aware of the patients' different coping styles and of the influence of demographic characteristics on social support, coping and defence. It is also important to identify poor copers, primarily those who tend to use defensive styles, as these are the patients who are most in need of professional support.

Healthcare professionals could acknowledge that setting the date of surgery helps to alleviate anxiety and is considerate of these women's individual needs regarding preparing themselves physically and psychologically for breast cancer surgery. Healthcare professionals could also take into account that the women have individual existential experiences, and could offer opportunities to talk about their emotions and thoughts while awaiting breast cancer surgery. By being attentive and supportive, healthcare professionals may help to prepare these women to inform their family and friends about their diagnosis.

Healthcare professionals should be aware of both the similarities and the variations in the coping strategies of women awaiting breast cancer surgery in order to be able to support the patients' individual coping. They could emphasise the value of maintaining a positive focus, but should also acknowledge and respect these women's fear and concerns. The women could benefit from being given information on a step-by-step basis and could be advised to live a normal life.

Healthcare professionals could make a telephone call to each patient during their waiting period, and also encourage the patients to make telephone contact if they felt the need to. Furthermore, if needed or preferred, they could offer confidential face-to-face consultations. This contact could function to support and inform patients in general, as well as helping those

in need of particular support and professional assistance, including those who may require a neutral confidant. Since having a significant person accompanying the women when receiving their diagnosis may help to alleviate anxiety, the clinic could suggest this. It is important to considering both the positive and the negative aspects of these women's experiences of social support while adjusting to their diagnosis. Healthcare professionals could encourage women to express what they actually want regarding support from their social network according to their individual needs. The results of this study may enhance healthcare professionals' awareness of the considerable individuality within these women's support needs.

8.2 Implications for further research

It would be interesting to make one or more follow-up studies of women during the diagnostic period and after the diagnosis is confirmed. Such an investigation, preferably a mixed method study, ought to have an emphasis on what the women actually did and thought, how they coped, and how they used their social resources when trying to deal with the threat of a potential and actual cancer diagnosis.

Future research should be directed at follow-up studies regarding the potential impact of pre-surgery experiences on later experiences of living with breast cancer, concerning physical, psychological, social and spiritual adaptation.

A longitudinal study could be made measuring the potential effects of nursing interventions in the form of longer follow-ups with breast cancer patients identified as having poor coping styles, low education and poor social support.

It could be studied whether a telephone call from the hospital a few days after the diagnosis could have beneficial effects on these women's coping and well-being, and whether receiving advice concerning emotion regulation could have a positive effect on coping in the period between diagnosis and surgery.

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