

**ICELANDIC WOMEN'S IDENTIFICATIONS OF STRESSORS AND SOCIAL
SUPPORT IN THE DIAGNOSTIC PHASE OF BREAST CANCER**

by

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Abstract

Breast cancer is the most common cancer among women. Approximately one in ten Icelandic women will develop breast cancer during her lifetime. Women cope with breast cancer in a wide variety of ways. Social support is an important coping resource and is seen as mediating the effects of stress on individual's well-being and adjustment.

The purpose of this descriptive exploratory research was to describe the nature of stressors Icelandic women identify in the diagnostic phase of breast cancer, what sources of social support they draw upon, and their satisfaction with the social support they receive. Lazarus and Folkman's (1984) theory of stress, appraisal, and coping was used as a theoretical framework for the study. Semi-structured interviews were conducted with twelve women in the diagnostic phase of breast cancer.

The diagnostic phase of breast cancer is a very stressful time in women's lives. Women experience the possibility of having cancer as an enormous threat, characterized by emotions like fear, anger, anxiety, restlessness, and sense of floating in the air. Women use emotion-focused coping throughout the diagnostic phase and, additionally, problem-focused coping after the diagnosis. Social support was a fundamental coping resource. Emotional support from husbands, family, and close friends was of utmost importance. Health professionals were not only the most important source of informational support but also a valuable source of emotional support. Acts people intended to be supportive, were in some cases perceived by the women as negative and a source of stress in themselves.

Research findings define the supportive roles Icelandic health professionals should play in the diagnostic phase of breast cancer. Findings also provide a framework for further research on social support and breast cancer.

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CHAPTER I

Background of the Problem

Breast cancer is the most common cancer among women (Funch & Mettlin, 1982). Approximately one in ten Icelandic women will develop breast cancer during her lifetime (The Cancer Society of Iceland, 1994). The diagnosis and treatment of a potentially fatal disease such as breast cancer creates a number of real and potential threats for the woman (Graydon, 1984; Lierman, 1984, 1988), and increases the demands on the woman's physical, psychological, and social resources (Porritt, 1979). The woman can draw upon several resources in coping with such a stressful encounter: positive beliefs, health and energy, problem-solving skills, social skills, and social support networks (Lazarus & Folkman, 1984). Indeed, women cope with breast cancer in a wide variety of ways (Lierman, 1988). Social support is seen to hold a prominent place among the variables that explain the differences in women's coping mechanisms (Porritt, 1979). The question then arises what is it that women view as social support and what resources do they draw upon for the kind of support they need? The purpose of this study is to answer these and related questions.

"The term social support has been used widely to refer to the mechanism by which interpersonal relationships presumably protect people from the deleterious effects of stress" (Wortman, 1984, p. 2339). In his theory of social support, House (1981) claims that social support reduces stress, improves health, and buffers the impact of stress on health. Social support has thus been seen as playing an important role in coping with different kinds of life events, including illnesses such as cancer (Lynam, 1990; Shumaker & Brownell, 1984).

Breast cancer patients experience an intense need for social support because of the uncertainty and fear that the diagnosis produces (Feather & Wainstock, 1989a; Wortman, 1984). The way in which the woman experiencing the threat of breast cancer

responds to the initial threat of diagnosis may influence the course of her illness (Lierman, 1988). A study conducted by Vachon (1986) revealed that women with breast cancer received less help than they wanted from health professionals at all times. Breast cancer patients with low expectations for good quality social support, especially from health care professionals, are said to be more vulnerable to poorer outcomes (Feather & Wainstock, 1989b). It is important, therefore, for health care professionals to have information about women's needs for social support, and their satisfaction with the support received when experiencing the threat of breast cancer, in order for the professionals to improve the health care delivered during this very stressful time in the women's lives. An understanding of the interactions that women perceive as supportive can clarify the professional's role in the provision of support (Lynam, 1990).

The majority of studies on social support in breast cancer have focused on women's needs and satisfaction with social support after mastectomy. Only a few studies have examined the diagnostic phase of breast cancer (Bredenberg, 1992; Jamison, Wellish, & Pasnau, 1978; Lierman, 1988; Morris, Greer, & White, 1977; Northouse, 1988). These studies indicate that the diagnostic phase is the most stressful time for many women with breast cancer. A sense of uncertainty, inadequate information, and the need to make difficult treatment decisions, are the main factors contributing to this diagnostic distress (Wainstock, 1991). As women contend with anxiety about pain, physical changes, treatment, isolation, and even death, their needs for support increase. Neuling and Winefield (1988) state that women who are satisfied with support from family members are significantly less anxious than others. Their study revealed that women seek empathic support from their families and friends, but desire informational support from health professionals.

There is, however, a gap in the literature regarding women's needs for and beliefs about social support in the diagnostic phase of breast cancer. Also, little is known about

the sources women draw upon for social support at the time of diagnosis. A phenomenological study conducted by this author revealed that Icelandic women who had mastectomy as a result of breast cancer experienced lack of social support throughout their illness experience (Fridfinnsdottir, 1993). These findings lead to questions like: What is the nature of stressors women experience in the diagnostic phase of breast cancer? What are women's needs for social support in the diagnostic phase of breast cancer? What meaning do women give to social support? What types of social support do women perceive as beneficial for them? To whom do they turn for social support? These and related questions need to be answered in order to promote women's overall well-being, and to enhance the care-givers' understanding of the sensitive care needed by women experiencing the difficulties related to the diagnostic phase of breast cancer.

Most of the literature and theories on social support are based on North American studies and North American values. The Icelandic society and the Icelandic health care system is different from the North American in many ways. The Icelandic society is homogeneous and almost socioeconomically flat. As a result of the small size of the country, family ties tend to be strong. The Icelandic health care system is different from the North American in that it is a social security system in which everyone is supposed to have the same access to the service. Women with breast lumps have access mainly to physicians but also to some extent to nurses. The aforementioned differences may lead to variance in Icelandic versus North American women's expectations of health services.

The social support process does not occur in a vacuum. It is shaped by characteristics of the persons involved and the social context where it takes place (Vaux, 1990). I am, therefore, very interested in studying Icelandic women's needs for and beliefs about social support in order to verify the aforementioned theories which are based on research in different ecological environments. Furthermore, I believe that by describing Icelandic

women's needs for and beliefs about social support the health care the women receive can be improved and tailored to meet their specific needs. Nurses can use the women's descriptions to define their roles in the diagnostic phase of breast cancer, what type of support they should provide for the women, and how they can plan their support interventions. I, therefore, believe that both Icelandic women and nursing can benefit from the description of the women's identifications of stressors, and their needs for and beliefs about social support.

Purpose of the Study

The purpose of this study was to describe the nature of stressors Icelandic women identify in the diagnostic phase of breast cancer, what sources of social support they draw upon, and their satisfaction with the social support they receive.

Theoretical Framework

As stated in the previous section, the diagnostic phase of breast cancer is a very stressful time period for women, a time period when women need to draw upon several resources in order to cope with the situation. Social support is one of these resources, available in women's social environment. In their research based theory of stress, appraisal, and coping, Lazarus and Folkman (1984) view social support as a transactional process that changes with demands of the stressful encounter. By emphasizing the notion of social support as a process Lazarus and Folkman (1984) highlight the ever changing environment and people's interactions with it. Within their view of social support, Lazarus and Folkman (1984) state that stress is neither in the individual nor in the environment but a product of their interplay.

Although 11 years have elapsed since the publication of Lazarus and Folkman's (1984) theory many authors still find their theory useful in various contexts. In light of my belief that the diagnostic phase of breast cancer is a very stressful time in the women's lives, and that they will draw upon social support in their coping with the

diagnosis, I decided to use Lazarus and Folkman's (1984) theory of stress, appraisal, and coping as a theoretical framework for this study. The theory is thoroughly reviewed in chapter two.

Research Questions

The research questions guiding this study were:

1. What is the nature of stressors identified by Icelandic women when they are in the diagnostic phase of breast cancer?
2. What sources of social support do Icelandic women draw upon in the diagnostic phase of breast cancer?
3. What types of social support do Icelandic women, in the diagnostic phase of breast cancer, perceive as beneficial?

Definitions of Terms

For the purpose of this research study the major concepts under investigation were defined as follows:

1. Diagnostic phase: The time from the woman's (or her physician's) discovery of a lump in her breast or from the time a suspicious mammography was taken, until treatment has started.
2. Stressful situation: A situation that is appraised by the woman as taxing or exceeding her resources and endangering her well-being (Lazarus & Folkman, 1984).
3. Social support: Interpersonal transaction which involves emotional concerns, information, and/or tangible aid, and which improves coping and/or moderates the impact of stressors.
4. Sources of social support: Persons women describe as able to meet their needs for social support (Lazarus & Folkman, 1984).

Assumptions

I assumed that the diagnostic phase of breast cancer would be a stressful situation in women's lives. I also assumed that Icelandic women in the diagnostic phase of breast cancer would be able to articulate their feelings, their needs for social support, and the sources of social support they draw upon in this stressful situation.

Significance of the Study

This study adds to the body of knowledge related to women's realizations of social support in stressful situations, particularly in the Icelandic community. An understanding of the stressors women experience in the diagnostic phase of breast cancer, their needs for and sources of social support, enables Icelandic health care professionals to plan the health care in a way to meet the women's specific needs. As very little is known about Icelandic women's realizations of social support when experiencing breast cancer this study furthers research in this area.

The history of nursing research in Iceland goes back only about 20 years. Although there has been significant growth during this period a research study like this, which focuses on the study of a known phenomenon in its Icelandic context, is a valuable contribution to health care in the country.

Summary

Breast cancer creates a number of real and potential threats for women and increases the demands on their physical, psychological, and social resources. Although women cope with breast cancer in a wide variety of ways, social support is seen to hold a prominent place as a coping resource. A number of studies have been conducted on women's needs for social support after mastectomy as a result of breast cancer, but there is a gap in the literature regarding the nature of stressors women experience and their beliefs about social support in the diagnostic phase of breast cancer. Furthermore, most of the literature and theories on social support are based on North American studies.

The purpose of this study was to describe the nature of stressors Icelandic women identify in the diagnostic phase of breast cancer, what sources of social support they draw upon, and their satisfaction with the social support they receive. Social support was defined by this author as interpersonal transaction which involves emotional concerns, information, and/or tangible aid, and which improves coping and/or moderates the impact of stressors. Lazarus and Folkman's (1984) theory of stress, appraisal, and coping was used as a theoretical framework for the study. Their theory is thoroughly reviewed in the next chapter.

CHAPTER II

LITERATURE REVIEW

Introduction

In this chapter Lazarus and Folkman's (1984) theory of stress, appraisal, and coping is presented. The literature on social support, sources of social support, and women's realizations of social support in relation to breast cancer is reviewed. Special emphasis is on studies that take into account the diagnostic phase of breast cancer. Other research findings relevant to this study are also presented, especially those which focus on breast cancer patients' beliefs about social support and the impact of social support on health and well-being.

Stress, Appraisal, and Coping

As stated in Chapter I, Lazarus and Folkman's (1984) theory of stress, appraisal, and coping is used as a theoretical framework in this study.

The Concept of Stress

Stress is a term widely used in the literature. Definitions vary from stress as a stimulus (Selye, 1976) to stress as an organizing concept for understanding a wide range of phenomena (Lazarus & Folkman, 1984). Stress, in the latter sense, is seen "as a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (p. 21). The person and the environment are in a dynamic relationship. This relationship is bi-directional, that is, the person and the environment are constantly acting on each other (Folkman, 1984). To understand any given encounter it is necessary to recognize the changes in the person-environment relationship, referred to here as a transaction, as the encounter proceeds (Lazarus, Kanner, & Folkman, 1980).

It is also necessary to give attention to individual differences and their sensitivity and vulnerability to a given encounter. Individuals interpret and interact differently to

certain types of events. Lazarus and Folkman (1984) emphasize the importance of what they call the psychological situation, which is a product of the interplay of personal and environmental factors. People's psychological situations affect the ways they cope with stress, which in turn affects their psychological, physical, and social well-being.

The Appraisal Process

Cognitive appraisal is an evaluative process focused on the meaning or the significance of an encounter for the individual's well-being (Lazarus & Folkman, 1984). This process reveals what is at stake for the individual in relation to a given encounter. Both personal and situational factors influence the cognitive appraisal process. An individual's beliefs and commitments are among the personal factors, and uncertainty, novelty, and timing among the situational factors. Lazarus and Folkman (1984) identify two basic appraisals, primary and secondary. One type of appraisal is not more important than the other nor does one precede the other in time. Primary and secondary appraisals converge to shape the meaning of every encounter (Folkman, 1984). Lazarus and Folkman (1984) also identify a third type of appraisal, reappraisal, which refers to a changed appraisal.

Primary appraisal is differentiated into three kinds: irrelevant, benign-positive, and stressful. An encounter with the environment is appraised irrelevant if it has no implications for the individual's well-being, if nothing is to be gained or lost in the transaction. Benign-positive appraisal occurs when the outcome of an encounter enhances the individual's well-being. Pleasurable emotions such as joy, happiness, love, and exhilaration are involved in benign-positive appraisals (Folkman & Lazarus, 1988). Stressful appraisals are of three kinds: harm/loss, threat, and challenge. Harm/loss refers to situations where the individual has already sustained damage, whereas threat concerns anticipated harms and losses (Lazarus & Folkman, 1984). Harm/loss and threat appraisals are characterized by negative emotions such as fear, anxiety, anger, and

resentment (Folkman, 1984; Folkman & Lazarus, 1988). The third type of stressful appraisal identified by Lazarus and Folkman (1984) is challenge, in which the individual recognizes the potential for gain or growth inherent in an encounter. Challenge is characterized by pleasurable emotions such as excitement and eagerness. Lazarus and Folkman (1984) emphasize that the relationship between stressful appraisals can shift as the encounter unfolds. They also emphasize that the three types of primary appraisals need not be mutually exclusive. Changes in the environment and/or the individual's cognitive coping efforts can, for example, change the appraisal of a situation from threat to challenge.

Secondary appraisal is the process used by individuals to evaluate what can or might be done with respect to the demands of the situation and what is at stake for the individual. This complex process takes into account what resources are available, the likelihood that a certain strategy or a set of strategies will be effective, and the possible consequences of using a particular strategy or a set of strategies (Lazarus & Folkman, 1984). Individual's coping resources are both personal and external to the individual. They include for example: physical, social, psychological, and material assets.

Reappraisal is a changed appraisal, perhaps a result of new information from the environment and/or the individual. Reappraisal always follows an earlier appraisal. Reappraisal changes the individual's emotions and his/her use of coping strategies (Lazarus & Folkman, 1984).

Lazarus and Folkman (1984) emphasize that primary and secondary appraisals interact in shaping the degree of the individual's stress experience and the strength of his/her emotional reaction. The way an individual appraises an encounter influences the individual's coping process and his/her emotional reactions. Cognitive appraisal rests on the individual's perception of a given transaction. Encounters that cause uncertainty

within the individual are, accordingly, often extremely stressful and can have immobilizing effects on coping processes.

The individual's appraisal of an event becomes more urgent and intense as an event is more imminent. The passage of time allows the individual to use cognitive coping to manage threat and can, thereby, reduce the stress reaction. An individual's appraisal is also affected by the timing of a stressful event over the life cycle. Events that are not expected are more threatening than life events that are predictable in the life course. Unexpected events deprive the individual of the opportunity to prepare or engage in anticipatory coping (Lazarus & Folkman, 1984), which increases the threat experienced.

Coping

Lazarus and Folkman (1984) define coping 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" (p. 141). Thus, coping refers to anything that the person does or thinks to manage demands regardless of how it works. Coping is independent of outcome. It is determined by the primary and secondary appraisals. Based on them, the individual either modifies the environment, or changes the meaning of a situation.

Coping is viewed as having two major functions: emotion-focused coping which refers to the regulation of emotions or distress, and problem-focused coping which refers to altering or managing the problem causing the distress (Folkman, 1984; Lazarus & Folkman, 1984). Both these forms of coping are used in most stressful encounters but the relative proportion of each may vary according to how the encounter is appraised.

A number of coping strategies have been distinguished in each form. Greer (1991) distinguishes emotion-focused coping into five coping strategies: denial (positive avoidance), fighting spirit, stoic acceptance (fatalism), helplessness/hopelessness, and anxious pre-occupation. After 15-year follow-up study of women with early breast

cancer, Greer (1991) concluded that the psychological stance which patients adopt towards their disease can affect the course of certain types of cancer. Passive and helpless/hopeless responses are, thus, related to poor outcomes, whereas denial is associated with longer duration of survival.

Coping resources are a major factor in determining the ways an individual copes. Lazarus and Folkman (1984) identify six coping resources: (1) health and energy, which facilitate coping efforts; (2) positive beliefs about oneself, which can serve as a basis for hope; (3) problem-solving skills, which include the ability to search for information, and select and implement appropriate coping strategies; (4) material resources, which refer to financial capacity and goods and services that money can buy; (5) social skills, which have a fundamental role in human adaptation and are crucial in peoples' ability to maintain supportive relationships; and (6) social support.

As stated earlier in this research report, the purpose of this study was to describe the nature of stressors Icelandic women identify in the diagnostic phase of breast cancer, what sources of social support they draw upon, and their satisfaction with the social support they receive. In the Icelandic health care system, the mean time that elapses from the discovery of a lump in women's breasts, or the finding of a suspicious mammogram, until treatment is started is 10 to 14 days. The first six to eight days are the prediagnostic phase, when the women are waiting for the diagnosis of the lump, or for a second mammography to be taken. The women have little or no organized access to health professionals in this time period. In the latter four to six days, after the lump or the suspicious area has been diagnosed, they usually have two meetings with their physician from the cancer screening agency and the physician organizing their treatment. As health professionals are one of the sources of social support women can draw upon in the diagnostic phase of breast cancer, their accessibility can affect the women's satisfaction with the support they receive. For the purpose of this study it was necessary

to examine social support in depth and the next unit is, therefore, devoted to the conceptualization of the different dimensions of social support.

Social Support

Research has shown that social support mediates the effects of stress on individuals' health and well-being. It also alleviates distress and facilitates adjustment for stressed individuals (Dunkel-Schetter, Folkman, & Lazarus, 1987; Shumaker & Brownell, 1984; Wortman, 1984). Characteristics of the recipients of social support, providers of social support, stressors, and environments are among the factors that possibly influence the recipients' realization of its presence. Among the characteristics of the individual that might influence this realization are gender, age, race, self-esteem, autonomy needs, sociability, and interpersonal skills. The characteristics of providers that might influence the recipients' realization of social support are perceptiveness of the recipients' needs, motivation, and his/her ability to be supportive. Intensity, duration, and ambiguity characterize stressors in addition to the appraisal of the degree of threat for the individual. Characteristics of environments include the structures of environments and social networks (Shumaker & Brownell, 1984; Wortman, 1984). Wortman (1984) also identifies the recipient's coping style as an important factor in determining his/her realization of social support.

Schaefer, Coyne, and Lazarus (1981) distinguish three types of functions of social support. These three types are: emotional support, informational support, and tangible support. These distinctions are important elements of the framework used for this study and form a base for the development of the interview guide that was used to collect data (see Appendix A, p. 74, for *Streita og Studningur Vidtalsdreg - Stress and Social Support Interview Guide - Translation*). The following review will examine how social support has been defined and characterized in the current literature. For the purpose of

this study, and with respect of the Icelandic context, the author developed a definition of social support from the available literature.

a) Emotional support contributes to the feeling that one is cared for and loved (Cobb, 1976; House, 1981; Lazarus & Folkman, 1984; Schaefer et al., 1981; Wortman, 1984). Emotional support has been seen as the most important type of social support. The impact of emotional support on stress and health has been clearly documented, and studies have revealed that when individuals think of people being supportive toward them they think mainly of emotional support (House, 1981). Feelings derived from emotional support are: attachment, empathy, love, care, esteem, trust, and reassurance (Cobb, 1976; House, 1981; Lazarus & Folkman, 1984; Schaefer et al., 1981; Wortman, 1984).

Cobb (1976) identifies emotional support as one of three types of information constituting social support. An individual receives emotional support from relationships with significant others. Esteem support is perceived by the individual from co-workers or social situations and health professionals. It leads the individual to believe he/she is esteemed and valued. Network support leads the individual to believe he/she belongs to a network of communication and mutual obligation. Emotional support as outlined by Schaefer and colleagues (1981) includes all these three types.

Wortman (1984) emphasizes the acknowledgement of the individual's beliefs, interpretations, and feelings in his/her conceptualization of social support. He also states that encouraging the individual to express these beliefs and feelings is one type of social support. According to Schaefer, Coyne, and Lazarus (1981) such acknowledgement and encouragement is a part of emotional support.

b) Informational support means providing the individual with information or advice that he/she can use in coping with personal and environmental problems. It also includes giving feedback about how she/he is doing (House, 1981; Lazarus & Folkman,

1984; Schaefer et al., 1981; Wortman, 1984). Cobb (1976) claims that informational support facilitates independent behaviour by enabling the individual to make decisions about responses to stressful situations.

c) Tangible support, sometimes referred to as instrumental support, involves direct aid such as loans or gifts, help such as doing one's job or taking care of someone who is ill (Lazarus & Folkman, 1984; Schaefer et al., 1981; Wortman, 1984). Tangible support often overlaps emotional support by signalling that the provider cares about the recipient and that the latter is valued.

In their definition of social support, Shumaker and Brownell (1984) introduced the concept of reciprocity in relation to social support. They define social support as "an exchange of resources between two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient" (p. 11). Thus social support involves at least two individuals and there are potential costs and benefits associated with the exchange for both individuals. Shumaker and Brownell (1984) claimed that reciprocity is a norm within western culture and that people usually return the benefits received from others. If the recipients feel they will not be able to return the benefit, they are less likely to seek assistance or accept it when offered. Such lack of reciprocity in social support can, therefore, become a barrier to the individual's use of support (Harrison, Neufeld, & Kushner, 1995). In close relationships, the exchange of support occurs over time and immediate reciprocity is not valid. Even the closest relationships will, however, eventually be threatened if reciprocity cannot be fulfilled. Misconceptions between the provider and the recipient regarding the support offered are likely to lead the recipient to feel his/her needs for support are unfulfilled. The recipient may also be unable to express his/her needs for social support, in which case the provider may be hesitant to help because his/her effort might do more harm than good (Shumaker & Brownell, 1984). The notion of reciprocity may be meaningful in relation

to social support needed and received by Icelandic women in the diagnostic phase of breast cancer. It can affect which sources they draw upon for social support and the type of support they seek from each source.

Many of the early studies on social support were primarily concerned with the relationship between support and various outcome variables. These studies provided little information regarding the process through which social support may influence health outcomes. However, such information is critical in the development of effective interventions to promote social support.

Two models that attempt to explain the aforementioned process are presented here. The main effect model suggests that social support can directly enhance health and well-being by meeting important human needs such as for affection, belonging, approval, security, and social contact (House & Kahn, 1985; Lazarus & Folkman, 1984; Shumaker & Brownell, 1984). The buffering model emphasizes the potential of social support to buffer the impact of stress on health. It can decrease stress by making harmful or threatening experiences seem less consequential. Social support can also be a valuable coping resource when stress does occur (House & Kahn, 1985; Lazarus & Folkman, 1984; Shumaker & Brownell, 1984).

Recent studies provide evidence for both direct and buffering effects of social support on health and well-being. The effects may, however, be linked with different conceptions of social support (Cohen & Syme, 1985). To explore these different effects in more depth, researchers have emphasized the necessity of studying social support in various field settings (Shumaker & Brownell, 1984).

Sources of Social Support

Social network refers to a specific set of persons upon whom individuals can draw to meet their needs for social support (Lazarus & Folkman, 1984). House (1981) has listed nine possible sources of social support: one's spouse or partner; other relatives; friends;

neighbours; one's work supervisor; co-workers; service or caregivers; self-help groups; and health professionals. Wortman (1984) and Neuling and Winefield (1988) state that there is considerable evidence that particular types of social support are regarded as more beneficial when received from some providers than from others. Informational support, for example, is seen by breast cancer patients as beneficial when received from physicians, but not valuable when received from family members or friends (Lierman, 1984). By referring to other researchers Wortman (1984) argues that social support provided by spouse and immediate family, physicians and other health care professionals, and self-help groups are of the greatest importance to breast cancer patients.

The individual differences in meanings of a given event may influence not only the individual's needs for social support, but also the availability of social support (Lynam, 1990). It has been argued that the larger the social network, the more social support will be available. Although the size of the social network may be important, the quality of the social support received has been shown to be far more important (Lazarus & Folkman, 1984; Neuling & Winefield, 1988; Porritt, 1979).

As outlined earlier in this report, the findings of an Icelandic study of women's lived experiences of undergoing mastectomy as a result of breast cancer revealed that social support might be lacking in the diagnostic phase of breast cancer (Fridfinnsdottir, 1993). These results lead to the belief that it is valuable to study the stressors Icelandic women with breast lumps identify, their sources of social support, and also what they perceive as high quality social support.

Social Support and Women with Breast Cancer

The multiple uncertainties and fears related to the diagnosis of breast cancer produce intense needs for social support. The woman who has this experience needs clarification of what is happening (e.g., informational support), and reassurance that others will

continue to love and appreciate her (e.g., emotional support) (Wortman & Conway, 1985).

In recent years many researchers have studied the impact of social support on women's (and their husbands') adjustment to and recovery from breast cancer. These studies indicate that social support is a significant component in women's adjustment to breast cancer. For example, it reduces their stress, increases their self-esteem, and increases women's perceptions of control over the situation (Bloom, 1982; Cawley, Kostic, & Cappello, 1990; Feather & Wainstock, 1989a; Feather & Wainstock, 1989b; Funch & Mettlin, 1982; Jamison, Wellish, & Pasnau, 1978; Lierman, 1984, 1988; Morris, Greer, & White, 1977; Northouse, 1988; Peters-Golden, 1982; Zemore & Shepel, 1989).

Feather and Wainstock (1989a) studied how age, marital status, and education were related to breast cancer patients' perceptions of social support. Breast cancer patients (N=613) who had a mastectomy within the previous 24 months responded to the Norbeck Social Support Questionnaire, which has reported good validity and reliability (Norbeck, Lindsey, & Carrieri, 1981). To enrich and explain the quantitative data, interviews were subsequently conducted with 27 women, randomly selected from their original sample. The authors concluded that social support received increased with age, but the size of the women's social network decreased with age. Being married had a significantly positive relationship with emotional support. From the interview data, Feather and Wainstock (1989a) hypothesized that different sources of support provide unique types and different amounts of support for breast cancer patients.

Peters-Golden (1982) examined, in a qualitative study, perceived social support of 100 breast cancer patients, contrasted with anticipated social support among 100 disease-free individuals. A semi-structured interview guide was used to collect data. Her study revealed that the majority of the disease-free individuals expressed confidence that they

would receive the support they needed if they contracted cancer. The patients, however, found that the network of support they expected did not materialize for them. Only half of the patients reported that the support they received was totally adequate. Peters-Golden (1982) concluded that the disease-free individual's misconceptions "lead to a lack of fit between interactive and support needs as identified by the patients, and the quality of interaction and support provided by the healthy individuals" (p. 487).

The Peters-Golden (1982) sub-samples differ internally in two important ways. The mean age in the disease-free sample was significantly lower (35 years) than in the patient sample (57 years) and, as Feather's and Wainstock's (1989a) results reveal, age is a significant predictor when social support is evaluated. The sub-samples in the Peters-Golden (1982) study also differed in relation to gender. In the disease-free sample there were both males and females, compared with females only in the patients sample. This introduces a significant bias, considering the findings of a study conducted by Folkman and Lazarus (1980) which reveal that there is a gender difference in relation to ways of coping. Women use emotion-focused coping more than do men within similar contexts of living. Callaghan and Morrissey (1993) also emphasize that men experience social support differently than do women. Gender differences in the Peters-Golden (1982) sample may account for some of the differences between groups. Another factor that may in part explain these differences, is that there is a stigma to cancer which affects how people respond to cancer patients.

Bloom (1982) studied the relationship between social support and adjustment in a sample of 130 women in the early stages of breast cancer. The mean age of her sample was 51 years. Emotional support was measured by four items adapted from the 1974 Family Environmental Scale. Self-concept was measured by items adapted from the 1958 Janis-Field Scale. Adjustment was measured by the Social Readjustment Rating Scale, by Holmes and Rahe (1967). Bloom's (1982) results indicated that women who

had more social support had a higher self-concept, used fewer modes of stress reduction, exhibited less psychological distress, and perceived themselves to be more in control than did women with less social support.

Neuling and Winefield (1988) conducted a quantitative study where they interviewed 58 women after surgery for breast cancer. The women's ages ranged from 34 to 82 years. Thirty-five of the women had a mastectomy and 23 minor surgery. Neuling and Winefield (1988) measured source, type, and frequency of support received using the Multi-Dimensional Support Scale by Bloom and Spiegel (1984). This scale includes the recipients' rating of adequacy of each behaviour from each person. Their results show that satisfaction with support varied with the type of support given and the source from which it was received. Emotional support was desired from all sources, but informational support was preferred from surgeons rather than from family or friends. The women reported, however, inadequate support from surgeons, generating the greatest amount of dissatisfaction with social support received. Women's satisfaction with support from surgeons was highly important during the time when they received biopsy results. The women's self-esteem was positively related to their satisfaction with support from surgeons in the month prior to surgery. Perceived support from surgeons gives the woman a sense of control over the situation and, thereby, has positive effects on her self-esteem (Royak-Schaler, 1991). These results show the importance for surgeons and other health professionals to acknowledge and act on women's needs for social support in this stressful situation.

Northouse (1988) collected quantitative data from 50 mastectomy patients and their husbands at three days and 30 days post surgery. The purpose of the study was to determine the nature of the relationship between social support and adjustment of mastectomy patients and their husbands over time. The results show that women whose husbands offered support reported better adjustment to their situation. Northouse's

(1988) results support the findings of earlier studies, that the family's reaction to the breast cancer patient is a critical factor in their adjustment (Lindsey, Norbeck, Carrieri, & Perry, 1981; Wortman, 1984).

In a quantitative retrospective study, Funch and Mettlin (1982) examined the relationship between social support and short-term recovery from breast surgery. One hundred and fifty-one female breast cancer patients who were three to twelve months postoperative participated in the study. Their ages ranged from 29 to 92 years with a mean age of 59.5 years. Sixty percent of the women were married and 28 percent were widowed. The results of this study revealed that women seemed to adjust more successfully to their situation when they perceived informational support from health professionals.

Vachon (1986) studied distress and adaptation of women in relation to two major life events, breast cancer (N=168) and the loss of a husband (N=162). The ages of the breast cancer patients ranged from 28 to 65 years. Seventy-three percent were married, ten percent widowed, 9 percent separated or divorced, and 8 percent single. The results revealed that 40 percent of the women with breast cancer experienced high distress. Emotional support from husbands facilitated the women's adjustments. The breast cancer patients reported lack of social support which was reflected in their needs to keep up a front instead of being able to express their feelings openly. They also received less help than they wanted from health professionals. Vachon (1986) emphasized the crucial part social support plays in women's adaptation to stressful life events and states that social support may even be related to whether people with cancer live or die.

These reviewed studies reveal that women receiving their desired types of social support from appropriate sources exhibit less psychological distress and perceive themselves in more control over the situation than do women receiving inadequate support. The studies also reveal that the support network women expect does not always

materialize for them and, furthermore, that women are dissatisfied with the support received from surgeons after mastectomy. All the aforementioned studies focus on social support after mastectomy. A few studies that take into account the diagnostic phase of breast cancer will be presented in the following section.

Social Support in the Diagnostic Phase of Breast Cancer

As stated earlier in this proposal, only a few studies on social support in relation to breast cancer take into account the diagnostic phase. Jamison, Wellish and Pasnau (1978) used an extensive questionnaire to study pre- and post-mastectomy adjustment, the influence of age on adjustment, and the effects of mastectomy on sexual relationship. Forty-one women responded to the questionnaire. The mean age of the sample was 52.7 years. Eighty percent of the women were married, ten percent widowed, and ten percent single. Eighty-five percent of the women had first discovered the lump or abnormality in their breasts themselves. The median number of days between discovery of the lump and examination by a physician was six days. The results revealed that the younger women (under the age of 45 years) rated their adjustment as significantly poorer than did the older women. Seventy-one percent of the women rated their husbands' reactions to the mastectomy as extremely or very understanding. A positive relationship was seen between the husbands' reactions and the women's coping. Forty-two percent of the women judged the pre-mastectomy period as the most difficult time for them emotionally of all the illness experience. Jamison and his colleagues (1978) suggest that women should have counselling at this period of maximum stress. Although these results give some indications of women's adjustment to breast cancer, it should be noted that the sample in Jamison, Wellish, and Pasnau's (1978) study is too small from which to generalize.

A phenomenological study conducted by Fridfinnsdottir (1993), on Icelandic women's lived experiences of undergoing mastectomy as a result of breast cancer,

showed that five of seven participants perceived the diagnostic phase as the most difficult time to cope with in their illness trajectory. The ages of the women ranged from 40 to 66 years and all were married. The time of the interviews after mastectomy ranged from five months to seven years. The women experienced emotions such as shock, fear, and apathy while waiting for the diagnosis. They emphasized the importance of making this stressful experience as short in time as possible and stated that they experienced lack of social support at this time, especially from health care professionals. The women expressed a sense of relief once they had the diagnosis because of the uncertainty during the waiting time. Among positive aspects of their experience were: sense of interest from health professionals; support from their husbands; support from other mastectomy patients; and more open communication with their family members. Among negative aspects of the women's experiences were: lack of time available from health professionals; stranger's disgust; isolation; feelings of emptiness; worries about home and family; uncertainty about the future; and lack of social support from health professionals.

In a retrospective descriptive study, Lierman (1988) examined women's responses to the discovery of breast symptoms using Lazarus and Folkman's theory of coping as a framework. Using a semi-structured interview guide, Lierman (1988) interviewed 20 women up to three months after mastectomy. The women's ages ranged from 50 to 73 years with a mean age of 63.6 years. Eleven of the 20 women were married, four widowed, four divorced, and one single. Lierman (1988) categorized the women's behavioural responses to the discovery into four categories: (1) early help-seeking, which was indicative of problem-focused coping; (2) ignoring symptoms, which indicated emotion-focused coping with the use of minimization of the significance of the symptom, avoidance, and selective inattention; (3) wait and see, indicated both emotion-focused and problem-focused coping with the use of minimization and avoidance also;

and (4) preparation for death, which the author identifies as a form of problem-focused coping. For the women in the last category, breast cancer meant suffering and death. Lierman (1988) emphasizes the importance of targeting nursing interventions at helping women change their appraisal of the discovery of a breast lump and to develop new coping skills.

In her doctoral dissertation Bredenberg (1992) examined how women, severely stressed by breast cancer, defined and mobilized social support, the types of support they found effective at specific intervals, and the forms of support women believed enhanced or impaired their ability to cope with threats they faced. Bredenberg (1992) interviewed 121 women newly diagnosed with breast cancer. She also conducted intensive interviews with 20 women and a person deemed a significant supporter, three and twelve months following diagnosis. Among the many specifically interesting research findings were that women sought different types of support from different members of their large social network at particular points. Most frequently other women were the ones providing the most valued assistance. Women were supportive in the ways they themselves had experienced in the past or in the way the breast cancer patient asked for. This was the most effective support. Men, on the other hand, gave support they felt they themselves would appreciate in somewhat similar situation. The participants demonstrated resourcefulness and skills in finding out the kind of informational support they needed. Negative support was experienced as painful and depressed the women especially if experienced from an intimate. Bredenberg (1992) concluded that the multiple myths and stigmas associated with cancer impeded women's mobilization of support and support attempts by social network members.

Thus, published literature supports the notion that the diagnostic phase is the most difficult time emotionally for many women during their breast cancer experience. It also

supports the idea that women should have access to some counselling at this period of maximum stress.

Summary

In Lazarus and Folkman's (1984) theory of stress, appraisal, and coping, stress is seen as a relationship between the individual and the environment which exceeds the individual's resources and endangers his/her well-being. Lazarus and Folkman (1984) emphasize the individual's appraisal of any stressful situation, such as breast cancer, and the meaning of the encounter for the individual's well-being. The individual copes with the problem causing the distress by regulating his/her emotions and by altering the problem. Lazarus and Folkman (1984) identify social support as one of six coping resources. Social support is seen as mediating the effects of stress on individuals' well-being and adjustment. Three types of functions of social support have been distinguished: emotional support, informational support, and tangible support. Each type of social support is regarded as more beneficial when received from some sources than from others. Informational support, for example, is seen by breast cancer patients as beneficial when received from physicians, but not valuable when received from family members or friends.

A review of published research on social support in relation to breast cancer patients reveals several factors that influence women's identifications of stressors, the sources of social support they draw upon, and their satisfaction with social support received. The results of the research reveals that: received social support increases with the age of the woman; women report higher self-esteem and less psychological distress when satisfied with the social support they receive; being married has a significantly positive relationship to emotional support and the women's adjustment; support received from women is, in most cases, valued as more effective than support received from men; and negative support is experienced as painful and depressing. Also informational support

from health professionals and emotional support from husbands and families is of utmost importance for women in the diagnostic phase of breast cancer.

Furthermore, the studies reviewed for this research study reveal women's dissatisfaction with social support from health professionals. Therefore, further studies are needed to explore, in depth, women's needs for and satisfaction with, social support when experiencing breast cancer. It is important to note that all except one of the reviewed studies use American women in the samples and most of them focus on the time after mastectomy. Thus, in order to understand Icelandic women's responses to breast cancer better, and to plan better care, it is important to describe their identifications of stressors, and their sources of and satisfaction with social support in the diagnostic phase of breast cancer.

CHAPTER III

METHODOLOGY

Introduction

As outlined earlier in this report, the purpose of this research study was to describe the stressors Icelandic women identify in the diagnostic phase of breast cancer, what sources of social support they draw upon, and their satisfaction with the social support they receive. This chapter describes the research design, research setting, participants and how they were selected, data collection procedure, data analysis, and procedures to protect human rights.

Research Design

Because so little is known about the topic of this research study, a descriptive exploratory design was chosen. Descriptive methods aim predominantly at describing and documenting aspects of a situation as it naturally occurs, rather than explaining it (Polit & Hungler, 1991). They are considered useful when the research topic is at an early stage and the findings will, therefore, be preliminary to the development of focused enquire (Bredenberg, 1992). Three types of data collection procedures are outlined for descriptive studies: questionnaires, interviews, and observations (Parse, Coyne, & Smith, 1985). The choice of a procedure or a combination of procedures depends on the research question. Semi-structured interviews were chosen to collect data for this research study.

An interview guide was developed from the theoretical framework outlined in chapters one and two. The main concepts derived from the framework were: stressful encounters; primary and secondary appraisals; and coping strategies. As the purpose of this study was to describe, not only stress and coping, but also sources of and women's satisfaction with social support received, the last was also included as a major concept in

the interview guide (see Appendix A, p. 74, for *Streita og Studningur - Vidtalsdreg - Stress and Social Support Interview Guide - Translation*).

The aforementioned concepts provided preliminary categories used in the data analysis. In addition, the use of semi-structured interview guide allowed new pertinent categories to be included in the findings.

It should be noted that the concepts in the literature guiding this study are derived largely from North American context. The development of a new interview guide allowed me as a researcher to establish areas of congruence and to introduce new pertinent categories in the area under investigation. It also allowed the exploration of dimensions of a specific event which had not been studied before.

Research Setting

This study was conducted in Reykjavik, the capital city of Iceland. The Icelandic Cancer Society Screening Center in Reykjavik offers a regular (most often every second year) gynaecological examination for all Icelandic women over the age of 20 years. A mammography is recommended every second year for all women age 40 years and over. Women can also make an appointment at the Screening Center if they suspect that something is wrong, such as a growth in their breasts. Because the population in Reykjavik and its vicinities is about 60 percent of the total Icelandic population, the majority of Icelandic women have fairly good access to cancer screening services.

Semi-structured interviews were used to collect data. The participants in the study were asked to choose an interview site in which they would feel comfortable and where they could be undisturbed during the interview. Eight of the twelve participants in the study chose their homes for the interviews. Two of them chose the place of their work and one asked the researcher to choose an interview site as she did not live in Reykjavik. One participant asked to be interviewed over the phone.

Participant Selection and Criteria

A purposive sampling approach was used to select the sample for this study. Thus, individuals sharing the same experience were the only ones who could be selected to participate in the study (Morse, 1986). The sample size in descriptive studies is commonly 25-30 individuals (Burns & Grove, 1993; Carter, 1993). As this was a student's project and the time for the study was limited, a sample size of 12-14 women was considered sufficient for the purpose of this study. Sandelowski's (1995) idea that an adequate sample size should be determined, among other things, by the particular research method and the uses to which it will be put, affirms the sufficiency of the sample size in this study.

Participants were required to meet the following criteria:

1. In the diagnostic phase of breast cancer.
2. One of the following indications of malignancy:
 - a) sister(s), mother, or grandmother previously diagnosed with breast cancer.
 - b) growth poorly limited.
 - c) growth painless.
 - d) nipple retraction.
 - e) nipple secretion.
 - f) skin changes over the lump.
 - g) suspicious mammography.
3. Live within one hour's drive from Reykjavik.
4. Able to communicate verbally in Icelandic.
5. Consenting.

Exclusion to participation was the following:

1. Women not meeting the above criteria, or who were unlikely to be able to respond to the interview questions, or who were unable to consent.

The sample was recruited with the help of Mrs. Valgerdur Sigurdardottir, Head Physician at The Cancer Screening Center in Reykjavik. After a meeting with Mrs. Sigurdardottir, where the study was explained, she was sent a letter with detailed explanations (see Appendix B, p. 78, for *Bref til laekna* - Letter to Physicians - Translation). On the women's first visit, Mrs. Sigurdardottir handed out an introductory letter about the research (see Appendix C, p. 82, for *Kynningarbref I* - Introductory Letter I - Translation) to women meeting the criteria. Women willing to participate were asked to contact the researcher directly on the phone. Mrs. Sigurdardottir began to hand out the introductory letter on November 4th 1994. On December 6th 1994, 17 women had received the letter but none had contacted the researcher. After a discussion with Mrs. Sigurdardottir, the thesis committee members were contacted and asked for advice. Their suggestion was to ask for permission to add the following sentence to the Introductory Letter: "If I have not heard from you in one week I will give you a follow up telephone call" (see Appendix D, p. 84, for *Kynningarbref II* - Introductory Letter II - Translation). After Mrs. Sigurdardottir had discussed the proposed changes with her colleagues at The Cancer Screening Center, the changes were permitted. Mrs. Sigurdardottir started to send out the new introductory letter on January 24th 1995. On February 27th 1995 she had sent out 20 letters, all to women who were asked to come for a second mammography because something seen in recently taken mammography needed more examination. In these 35 days no woman meeting the criteria, came to the Cancer Screening Center because of a breast lump identified by herself or her physician. Only one of the 20 women made the initial contact with the researcher. When asked what made her contact the researcher she described a specific interaction with a health professional she needed to tell someone within the health care profession about. After a follow up telephone call from the researcher eleven other women were willing to

participate in the study. The other eight either felt they had nothing to tell or they thought they were not ready yet to talk about their experience.

Data Collection

Data were collected through one semi-structured interview with each participant. Semi-structured interviews were chosen in order to ensure that the participants would all describe the same fundamental issues. The researcher had developed an interview guide based on the reviewed literature and conceptualization of social support (see Appendix A, p. 74, for *Streita og Studningur - Vidtalsdreg - Stress and Social Support Interview Guide - Translation*). The interviews were, however, not confined to the questions in the guide. To allow for more detailed exploration of the subject matter, the researcher encouraged the women to describe their experiences in their own words. In addition to information on stressors and social support, demographic data such as the woman's age, marital status, work employment status, and family history of cancer were collected. The length of the interviews ranged from 35 minutes to two hours. They were all audio-taped and transcribed by the researcher. The interviews were conducted and analyzed in Icelandic but appropriate summaries and quotations translated into English for the thesis.

All the participants expressed their uncertainty about if they really had anything valuable to share with me. Nonetheless, they valued the participation as an indirect way of helping future women in similar situation. Two of the participants also asked specific questions about the possible outcomes of the biopsy, possible treatment, recovery after mastectomy, and breast reconstruction. I was well aware that as a researcher I was supposed to maintain neutrality and objectivity in order to obtain valid and reliable data. Because the participants asked these questions near the end of the interviews I felt the answers would not affect the data already gathered. Therefore, I answered the questions to the best of my ability and also encouraged the women to ask their physician these and other questions they might have.

Data Analysis

The interviews transcriptions were thoroughly read by the researcher and then coded according to predetermined categories as noted on the interview guide. The categories were: primary appraisal, secondary appraisal, coping, emotional support, informational support, and tangible support (see Appendix E, p. 86, for Coding Sheet). After this primary coding the transcripts were read through again to find sub-categories. By reading the transcripts for the third time the researcher was able to identify important descriptions not fitting the predetermined categories and previously found sub-categories. These additional descriptions were analyzed by the use of thematic analysis (Strauss & Corbin, 1990). Selective coding was used, followed by identification of sub-themes and themes. As the participants did not use a word that could be translated to "appraisal" but rather something similar to "response", "Initial response" was identified as a theme instead of the categories "Primary appraisal" and "Secondary appraisal". Another theme that emerged from the narrative data was "Nature of stressors" consisting of three sub-themes. The predetermined categories and identified sub-categories, themes, and sub-themes were then joined together to form a description of Icelandic women's identifications of stressors and social support in the diagnostic phase of breast cancer.

Trustworthiness Criteria

The trustworthiness of research findings can be evaluated through reliability and validity measures. Reliability refers to the accuracy of the measurements of the phenomenon under investigation. Validity refers to the degree to which an instrument used in a specific study, measures what it is supposed to be measuring (Polit & Hungler, 1993). Reliability and validity are not totally independent qualities. An instrument can, for example, not be valid unless it is reliable (Polit & Hungler, 1993). Enerstvedt (cited in Halldorsdottir, 1995) argues that one word, either validity or reliability, should be

used when evaluating the trustworthiness of research methodology and findings. He claims that only one general concept is necessary, the concept of validity.

Kvale (1989) states that validation of an interview consists of continually questioning the interpretations. He suggest that researchers should ask themselves if the interview questions lead to a production of meaning, a structure of language, logic, and narratives. Kvale (1983) outlines three important factors in validating the quality of research interviews: the interview subject's experience, a common-sense understanding, and theoretical knowledge of the researcher.

In this study the semi-structured interview guide was designed by the researcher and based on the theoretical framework of the study. Designing the interview guide, therefore, demanded a thorough reviewing of the pertinent literature. The theoretical knowledge of the researcher was thus substantial. The participation criteria for the study triggered that only women experiencing the diagnostic phase of breast cancer were considered eligible to participate. The evaluation of a common-sense understanding is, however, more difficult and subjective. Nonetheless, it should be noted that the researcher has ten years of practical experience in the various fields of nursing.

It is the researcher's conviction that the interview guide used in this research study truly lead to a production of meaning. The researcher's knowledge of the theoretical framework and the participants' experiences, as well as the continuous questioning of the interpretations of the data, should insure the trustworthiness of the research findings.

Procedures for the Protection of Human Rights

Approval for this research study was obtained from The University of British Columbia Behavioural Sciences Screening Committee for Research and Other Studies Involving Human Subjects (see Appendix F, p. 87, for Certificate of Approval). Approval was also obtained from The Icelandic Cancer Society (see Appendix G, p. 88, for Approval from The Science Committee of The Cancer Society of Iceland) and The

Icelandic Data Protection Commission, Ministry of Justice (see Appendix H, p. 89, for Fyrsta heimild - First Approval from Data Protection Commission - Translation; and Appendix I, p. 93, for Onnur heimild - Second Approval from Data Protection Commission - Translation).

To protect the ethical and human rights of the participants in this study, a detailed description of their rights was included in the introductory letter (see Appendix D, p. 84, for Kynningarbref II - Introductory Letter II - Translation). As the researcher contacted the participants directly on the phone, the physicians at the Cancer Screening Center could not know what 12 women out of the 20 receiving the introductory letter participated in the study. Prior to the interview a written consent (see Appendix J, p. 95, for Samþykkt - Consent Form - Translation) was obtained from each participant (except for the participant interviewed over the phone who gave her verbal consent after the researcher had read for her what was stated on the Consent Form). On this first contact with the participants the researcher emphasized confidentiality and that participation in the research would not jeopardize nursing and/or medical care needed by the participants or their families. Furthermore, the researcher made clear that the participants could withdraw from the research at any time without consequences to care or treatment.

All data was kept in a locked cabinet accessible only to the researcher. Only the researcher listened to the audio-tapes. The transcribed interviews were only accessible to the researcher, and some translated portions to the thesis advisors. All tapes were destroyed after completion of the study. To insure confidentiality, all names and identifying information were deleted from the transcripts and no revealing or identifying stories will appear in publications.

Description of the Participants

The participants in this study were all, except one, born in Iceland. All communicated well in Icelandic. Ten participants lived in Reykjavik, one in a village

nearby, and one in the country site. Their ages ranged from 39 years to 58 years with the mean age of 48.33 years. Nine were married, one divorced, and two had never been married. All except two of the married participants had children. The divorced woman had two daughters and the unmarried women had no children. Only one participant did not work outside the home. All except four knew of someone in their families previously diagnosed with cancer. None of the participants had found anything wrong with their breasts themselves. All of them had gone for a routine mammography where a suspicious area was detected. At the time of the interview ten participants had already gone for a second mammography. A biopsy had been taken in all cases. Four of these ten women were still waiting for the results of the biopsies but six of the participants had already been diagnosed at the time of the interviews. Three women had been diagnosed with benign breast changes and three with malignant breast cancer. The latter three had not begun any treatment and where, therefore, considered still in the diagnostic phase of breast cancer (see Definitions of Terms, p. 5).

Summary

As little is known about the research problem, a descriptive exploratory design was chosen for this research study. The study was conducted in Reykjavik, the capital city of Iceland. The sample was recruited with the help of the Head Physician at The Cancer Screening Center in Reykjavik. A purposive sampling approach was used to select the sample. Women had to meet specific criteria to be eligible for participation. Twelve women aged 39 to 58 years (mean age 48.33 years) participated in the study. Data were collected through one semi-structured interview with each participant. The interviews were all audio-taped and transcribed by the researcher. Data were coded according to predetermined categories as noted on the interview guide and the narrative data by thematic analysis. To protect the ethical and human rights of the participants in this research study approval for the research was obtained from the ethical committees of

The University of British Columbia and The Icelandic Cancer Society, and also from The Icelandic Data Protection Commission. A detailed description of the participants rights was included in the introductory letter sent to women eligible to participate. A written consent was obtained from participants prior to the interview.

CHAPTER IV

FINDINGS AND DISCUSSION

Introduction

The purpose of this research study was to describe the nature of stressors Icelandic women identify in the diagnostic phase of breast cancer, what sources of social support they draw upon, and their satisfaction with the social support they receive. In this chapter the research findings will be presented and discussed. The organization will be congruent with the semi-structured interview guide developed by the researcher and based on the theoretical framework, Lazarus and Folkman's (1984) theory of stress, appraisal, and coping. The themes identified from the narrative data will be intertwined with the predetermined categories. At the end of each section, the findings will be discussed and related to previous research findings in the area under investigation. It is this authors belief that by relating the discussion directly to the findings, the text will become more complete and repetition is less likely to occur. For the purpose of this research report the participants will be given Icelandic pseudonyms and the age of the participants will be declared in relation to the quotations.

As outlined earlier in this research report none of the twelve participants in the study had found a lump in their breasts themselves. All had gone for a routine mammography where a suspicious areas in their breasts were identified. At the time of the interviews ten participants had already gone for a second mammography where a biopsy had also been taken. Four of these ten women were still waiting for the results of the biopsies but the other six had already been diagnosed, three with benign breast changes and three with malignant breast cancer.

Nature of Stressors

The purpose of this section is to illustrate the nature of stressors Icelandic women identify in the diagnostic phase of breast cancer. Three major stressors were analyzed

from the interview data: receiving the letter; waiting for the results (duration of the event); and uncertainty about the future.

Receiving the Letter

As outlined earlier all the participants got a letter from the Cancer Screening Center asking them to come for a repetition of a mammography, because something seen in the routine mammography previously taken needed more examination. Receiving such a letter was a major stressor for the women.

I found it extremely unpleasant to receive a letter from The Cancer Society. I have regularly had a check—and everything has been OK. You always expect it will be like that—and I found it very unpleasant to get that—that letter.

Kristin, age 51.

No matter whether or not the women had ever thought of getting cancer or if anyone in their families had previously been diagnosed with cancer, the letter came as "a big shock" to them. In part because of the negative attitude towards cancer and the stigma related to it, but also because of its common relation to pain, suffering, and death. This is congruent with the results of other studies (Bloom, 1982; Carlsson & Hamrin, 1994; Lierman, 1988; Neuling & Winefield, 1988; Wainstock, 1991). These authors all emphasize the significance of this event in women's lives because of the immediate linkage of cancer to death.

I think this is the most difficult thing I have ever gone through. I think so—even if you think this isn't—anything—this is very difficult. You have already buried yourself hundred times and—and then come back to life—and will you live next Christmas?—and all that.

Barbara, age 58.

Only four of the participants did not know of anyone in their families previously diagnosed with cancer. Two of them had never even thought of the possibility of having cancer at any time in their lives. The other two were nurses who both had cared for women with breast cancer. The knowledge of cancer in the family, therefore, seemed to alert women that they themselves might have to face the possibility of having cancer. It

affects the expectancy of the event which can in turn affect the woman's use of cognitive coping to manage this threat of cancer and can, thereby, reduce her stress (Lazarus & Folkman, 1984). Instead of asking "why me?" the women rather asked "why not me?".

The participants all commented on the practice of sending out a letter to inform women about a suspicious mammography, an area that needed more examination. They found this very impersonal and found it deprived them of the opportunity to ask questions and get some immediate answers. Although the letter indicated that they could call a physician at the Screening Center, four of them found it difficult to have to be the initiator of such relation. Eight participants used that opportunity and found it very helpful. To make this initial contact more personal the women suggested a phone-call when they would be asked to come for a second mammography, preferably immediately. This is related to the importance of the time elapsing from the reception of the letter until the second mammography was possible.

Duration of the Event

The time from the reception of the letter to the second mammography and simultaneous biopsy was from three to eight days, depending on the waiting list at the Screening Center. Three of the participants got their results when in the second mammography, the others had to wait from three to seven days for the results. One woman had to go for a third visit because the biopsy was too small to be analyzed. The women found it understandable that they would have to wait for the biopsy results but to have to wait up to eight days for the second mammography was very hard for them.

Yes I thought—I think it is normal to have to wait for the results of the biopsy but I think the time from calling—. You have received the letter and of course you call them right away and then you have to wait for a week. I think that is too long—and—I was sort of floating in the air after I called them. I thought that—I wanted to go the next day.

Elin, age 47.

I think the waiting period shouldn't be so long. They didn't have to contact me until the day I was supposed to come for the second mammography you see. This waiting time is—it can just finish some women off I'm sure.

Karen, age 58.

The duration of the event (waiting time) was thus of utmost importance for the women. As outlined by Lazarus and Folkman (1984), and Selye (1976) enduring stressors have negative effects on people both physically and psychologically. Although, the physical effect was not obvious in this research study, some of the participants described difficulties sleeping despite their belief that they needed more rest than usual. They also expressed their need for everything to be "normal", that is nothing out of their day to day routine. The psychological effect was, however, quite clear. The women tended to withdraw from social settings and found themselves somehow numbed.

I thought this week was terribly long. I went to our summer house but I just actually sat there you see. You become somehow numb—that's what it is, you become numb.

Elin, age 47.

Theorists have viewed the waiting for the results of a suspicious mammography, whether it is a cancer or not, as a chronic intermittent event (Lazarus & Folkman, 1984). However, as with other chronic intermittent patterns the women had some time off to the extent that they were sometimes able to put the waiting out of mind.

I admit that I think a lot about this but I'm not depressed—but sometimes maybe I feel a little more tedious than other times—but then all of a sudden I'm not thinking about this because I'm doing something else—but then I suddenly remember, and then, Oh God.

Kristin, age 51.

However, the psychological effect of waiting for a second mammography and consequent results was profound on the participants in this research study. As Liernan (1988) has outlined, the psychological effect of a given encounter on an individual and his/her response may influence the course of his/her illness:

Uncertainty about the Future

The identified theme "uncertainty" in this research study, can be identified both as a consequence of the two aforementioned stressors but also as a stressor in itself. The women still waiting for the diagnosis felt uncertain both regarding the time they would have to wait for the final diagnosis and the diagnosis itself.

When you have dealt with something you always think that the difficult part is still ahead of you—and it—you know if for example—. I don't know how I would react if I would be diagnosed with—you know if this turns out to be cancer. That is what scares me. You know I'm still just in the stairway, I don't know where to go.

Maria, age 51.

All the participants expressed considerable uncertainty about the future, how others would respond, what would happen and how long they would live.

You think of everything from A to Z. I think of maybe loosing my breast and how short life is.

Karen, age 58.

I have been thinking—that—when I had my hysterectomy it was a big shock for me. If I need to have a mastectomy it will be a big shock for my husband.

Edda, age 43.

Not being able to foretell the future is, thus, the main part of the uncertainty experienced. Even though a breast lump or a suspicious area in a mammography turned out to be benign the women were still not certain about the future.

I'm a little scared you know. I mean—I mean this time it was just a cyst but—it is there. Maybe I will not be so lucky in two years.

Sigrun, age 39.

Women may, however, desire to maintain a state of uncertainty as it can also be a facilitator of hope (Lazarus & Folkman, 1984).

I decided not to call the physician at the Screening Center and I'm glad I didn't. I think it would have made me even more scared.

Karen, age 58.

Budner has defined uncertainty as "a cognitive state created when a person is unable to assign definite values to objects and events and/or is unable to accurately predict

outcomes" (cited in Hilton, 1990, p. 87). The uncertainty of cancer is enduring, the cancer patient cannot be sure for many years whether or not a cure has been effected (Bredenberg, 1992; Fridfinnsdottir, 1993; Hilton, 1990).

Waiting for the diagnosis refers to what Lazarus and Folkman (1984) identify as "event uncertainty" which in turn introduces the notion of probability. What is the probability for each of these women to be diagnosed with cancer? Is it "my turn now?" (Marta, age 41). One hypothesis of event uncertainty is that there is a curvilinear relationship between certainty and arousal, with the peak occurring with maximum uncertainty (Lazarus & Folkman, 1984). Arousal is seen here as a sign of fear and/or threat. The uncertainty experienced by women waiting for probable cancer diagnosis is, therefore, an indicator of the threat appraised. It limits the women's control over their lives and increases their sense of helplessness.

Women's Responses

Questions related to women's appraisals of the stressful situation they were experiencing, were a fundamental part of the interview guide. None of the women did, however, use a word that could be translated to the word "appraisal". The Icelandic word they used has the same meaning as the word "response" in English. This category is, therefore, called "Women's responses" rather than "The appraisal process" as was intended. However, what the women outline as their responses can be viewed as corresponding Lazarus and Folkman's (1984) ideas of appraisal process.

Nine of twelve participants in this research study emphasized how they thought personal factors would affect the way women would respond to the possibility of having cancer. Factors identified by the women as having positive effects were: being married; good financial status; and higher age. Poor financial status and having young children were the main factors identified as having negative effects on women's responses to possible cancer diagnosis.

I expect that you would experience a loss if you would loose your health—but the breast itself—I don't think so. I'm at that age, I'm not married and I'm not looking for a husband.

Sunna, age 55.

For women experiencig financial difficulties—I think that things like that—I think this must be terribly hard for them.

Maria, age 51.

This is congruent with Holland and Jakob's ideas that the woman's social situation at the time of diagnosis is one of three important factors affecting how she copes with breast cancer (cited in Baider & Kaplan De-Nour, 1988).

In addition to these personal factors the aforementioned stressors, which can be considered as situational factors, all affected the women's responses. Clear commonalties could be identified in their responses.

Initial Response

Women's initial responses to the possibility of having cancer are seen as synonymous with primary appraisals (Lazarus & Folkman, 1984). Primary appraisal shapes the meaning of every encounter people face in their lives (Folkman, 1984). Of the three types of primary appraisals outlined by Lazarus and Folkman (1984) that is irrelevant, benign-positive, and stressful appraisals, only the last one was identifiable in these interviews. Stressful appraisals are of three kinds: harm/loss, threat, and challenge. As the diagnosis of breast cancer is extremely relevant for women's well-being, their health and even lives are at stake, they experience the possibility of cancer diagnosis first and foremost as an enormous threat.

This is a shock—an enormous shock—just knowing that—that there might be cancer in your body.

Inga, age 56.

You have this body you know. You care about this body and even more if you are loosing something—or think you are. Regardless of your age—you always have this house—that you care for and if one door falls off and everything becomes fragile you think of yourself as some trash. Yes it's like that, you want to keep this as long as

possible. I know of course that I'm going to die one day, but you are just not ready yet.

Karen, age 58.

The emotions women related to this threat were: fear, anger, worry, anxiety, restlessness, heaviness, irritation, numbness, and sense of floating in the air. Women facing the possibility of having cancer fear the unknown; the possible pain, hospitalization, suffering, and negative influences on their families and marriages; but most of all they fear untimely death.

I have this terrible fear that this is something very serious.

Linda, age 41.

You care about life and if something threatens life you'll get scared.

Barbara, age 58.

In addition to deep fear, the women described, emotions like heaviness, numbness, and a sense of floating in the air. Some of the participants felt their concentration was worse than usual. They described that they found themselves shifting from one task to another without finishing anything. At the same time they felt they had to finish as much as possible of their usual tasks because they feared they didn't have the time to do it. They did not know how long they still had to live.

At the moment I'm a little bit—well what I did was to try to finish off everything I had to do. Even things I hadn't finished on time before—and—I need to tie all loose ends.

Sunna, age 55.

Yet another frequently identified emotion related to women's initial response to possible cancer diagnosis was anger.

Of course I was angry—extremely angry—hurt—maybe with life and the whole of creation. Maybe with myself, you don't quite know. I was just angry, I don't know with whom or what.

Inga, age 56.

Like Inga, none of the other women were able to express what their anger was directed towards. Some even emphasized that their anger was not really directed to themselves,

not to God, not to their husbands, but still they felt angry. Lazarus and Folkman (1984) relate anger to individual's perception of the intention of another to hurt or to give him/her less than his/her due. The women's experiences of anger when facing the possibility of having cancer might, therefore, be related to their perceptions of unfulfilled expectations of long and healthy lives.

Realization

As outlined in chapter three, six of the participants in the study were in the prediagnostic phase of breast cancer at the time of the interview. The other participants (also six) knew the diagnosis at that time. The women's responses changed considerably when the diagnosis was clear, independent of the outcome. Knowing the diagnosis was a great relief for the women with benign breast changes.

It was a cyst that just needed to be emptied—and what a relief.

Karen, age 58.

The diagnosis of a malignant growth in the women's breasts was also, to some extent, a relief for them. Knowing what it was they had to deal with decreased their uncertainty and fear, and made it easier for them to decide on what there was to be done. It also may have fostered their hope.

Now I feel I'm somehow in some system, some treatment—that I will someday, somehow come through.

Kristin, age 51.

This feeling of being in the health care system enabled the women to use the coping resources built into the system, in addition to resources in their social network.

Despite the relief following the knowledge of what the women were dealing with they still felt anxious about the future. The treatment became the cause of their anxiety.

At this moment I'm anxious about the operation. I expect that later on I will have to think of something else—it depends on how the operation goes.

Sunna, age 55.

Knowing the diagnosis, thus seemed to change the women's predominant emotions from fear to anxiety.

Some studies in the 1980s reported that women under the age of 50 have greater difficulties with anxiety than have women over the age of 50 (Royak-Schaler, 1991). In this study six participants were under the age of 50 and six over the age of 50. No perceptible difference in the participant's difficulties with anxiety was found in this study. It should, however, be noted that because of the small sample such difference cannot be ruled out.

Coping

As outlined by Lazarus and Folkman (1984), most stressful situations are ambiguous in one way or another, either information is missing or what is known is unclear. In the situation of the participants of this research study, the fundamental information is missing: whether the suspicious area in the breast, seen on mammogram, is cancer or not. The women felt helpless because at this point in time there was not much they could do to change the outcome.

I think that talking about this—it doesn't change anything. I just have to wait and see what answer I'll get on Friday and then—think things over. I'm not—I don't want to think too much about it—because really it won't change anything just to think about this. I just have to take it.

Anna, age 40.

Despite this feeling of helplessness, the women all evaluated their coping resources and activated the ones they thought would help them through this waiting. They appraised what was at stake as of utmost importance. Their lives could be at stake. Their inability to affect the diagnosis and the importance of it, increased the stress experienced. This is very important in light of many study results which indicate that a woman's psychological state before breast cancer and her coping with the diagnosis can affect the course of the disease and the woman's adjustment (Lierman, 1988; Royak-Schaler, 1991; Taylor, Lichtman, & Wood, 1984).

Coping has been defined as cognitive and behavioural efforts independent of outcomes (Lazarus & Folkman, 1984). Coping is divided into two categories: problem-focused coping that is directed at managing or altering the problem causing the distress; and emotion-focused coping that is directed at regulating the emotions arising in relation to the problem. An individual's primary and secondary appraisal determines his/her coping efforts.

Problem-focused Coping

The participants in this study described a sense of helplessness facing the problem of possibly having cancer. While they were waiting for the diagnosis the actual nature of the problem was still not clear. They felt that at this point there was nothing they could do to affect the outcome of the second mammography and the biopsy; that is, they could not alter the problem causing their distress. Problem-focused coping was, therefore, not an alternative for the women in the prediagnostic phase of breast cancer.

The three women that, at the time of the interview, had been diagnosed with malignant breast cancer used problem-focused coping to some extent. It is, however, difficult to evaluate the modes of problem-focused coping used by these women because only one to three days had elapsed from the day of diagnosis until the day of the interview. The woman diagnosed three days before the interview expressed her need to organize everything before she would start the treatment, both matters related to her work and her private life. It would give her freedom to concentrate on herself and the treatment.

I don't want to have anything on my back while I'm going through this. I just want to concentrate on myself and—and care about myself.

Sunna, age 55.

This behaviour is what Kahn has pointed out to be a problem-oriented strategy directed to one self (cited in Lazarus & Folkman, 1984). It is also congruent with Royak-Schaler's (1991) notion of confrontational coping identified in women with breast

cancer who believe in their ability to control their own health. Such a belief increases the likelihood that the woman will take an active role in her treatment and recovery, which in turn appears to affect her psychological well-being and, thereby, can be evaluated as prognostic indicator (Greer, 1991; Lierman, 1988; Royak-Schaler, 1991).

The three women diagnosed with benign breast changes also used problem-focused coping.

I think that—there has been a change in my thinking. I thought this was a little—I saw this as a kind of warning. I have these few extra pounds and I'm now going to try to lose some weight. I saw this as a kind of warning, that I needed to do something specifically for my self.

Linda, age 41.

This citation reflects a change in the woman's attitude towards her control over her own health. Since confrontational coping with malignant breast cancer is seen to have positive effect on women's psychological well-being and even be a prognostic indicator (see above) it would be interesting in future research to study if there is a relationship between confrontational coping with benign breast changes and later diagnosis of malignant breast cancer.

It should be mentioned here that one of the women already diagnosed with malignant breast cancer emphasized the effect she thought age would have on her ability to cope with the problem:

I think there is something else that really matters. I couldn't have dealt with this when I was thirty because I feel I have so much more—I think I have so much more inside myself to deal with this now—more skills. We can just say I'm more matured and—I have more variety of ways inside myself—just because of experience—and maybe we can just say more common sense.

Inga, age 56.

This demonstrates one woman's relating age not only to increased social support as in Feather and Wainstock's (1989a) research, but also to having a greater variety of coping strategies.

Emotion-focused Coping

Lazarus and Folkman (1984) outline various forms of emotion-focused coping in their theory of stress, appraisal, and coping. They list cognitive forms like avoidance, minimization, distancing, selective attention, and wresting positive value from negative events. Some of these cognitive forms change the way an encounter is construed without changing the objective situation. Such strategies are equivalent to reappraisals. Although some forms of emotion-focused coping are reappraisals, others are not, and still others sometimes are and sometimes are not. The meaning of the encounter can thus remain the same even if, for example selective attention or avoidance have been exercised.

The participants in this study used several modes of emotion-focused coping both in the prediagnostic phase and after diagnosis. Denial was apparent before diagnosis.

This is the second time I received a letter like that. I received a letter like that after my regular mammography two years ago—and then I went for another mammography and a biopsy. There was something in both my breasts but both were benign. I didn't need to worry about it—so when I got this letter my first reaction was, well they haven't looked at the old x-rays—it was there last time too. I didn't want to call them right away.

Edda, age 43.

Edda received her letter about a second mammography five days prior to the interview. By denying the existence of any new changes in her breast she diminishes the threat of possible breast cancer. Another form of denial is trying not to think about the possibility of having cancer, putting it behind and getting on with one's life:

I see this as a temporary situation. When I have got the answer tomorrow then this is just a closed case. I'm not seeing anything else. On Friday this is just over.

Elin, age 47.

Greer (1991) has equated denial with positive avoidance. His follow-up study results indicated that women using denial to cope with cancer were less likely to show evidence of recurrence five and 15 years after diagnosis, than women not using denial as a coping

strategy. Denial may thus be a predictor of a positive disease outcome. This is notable as it contradicts, for example, the widely accepted theories of Kübler-Ross (1969) who emphasizes the negative effects of denial, and Lazarus and Folkman's (1984) theory of the ineffectiveness of denial because the individual then fails to engage in appropriate problem-focused coping.

Another identified emotion-focused coping strategy used by two participants in this study was selective attention. The women tried not to think too much about the mammography and diagnosis, and tried to divert their attention to their work or their homes.

I have been very busy—I have my work and this and that—and this is what I think helps me most, that is, to be active in something but not—. But then you start thinking and the fear comes back.

Karen, age 58.

Bloom, Houston, Holmes, and Burish (1977) reported that encouraging individuals who are experiencing threat to think of something else reduces their stress levels. It might, therefore, be concluded that women's occupational status can be a significant factor influencing the effectiveness of women's coping strategies as it enables them to use selective attention. As only one of the participants in this study was not working outside her home (because of rheumatic arthritis) all comparison in relation to women's occupational status was impossible. That would, however, be an interesting research matter.

The third emotion-focused coping strategy identifiable in this study was what Greer (1991) calls stoic acceptance. From my experience fatalism is very common among Icelanders. People believe that their fate is determined at their birth and there is nothing much they can do to change it. Such views were apparent in some of the interviews.

You just have to wait and see what will happen because I don't want to do this again and again. You know, why think about things you might not have to—. I'm not forgetting this—I just think you should take what you have to face in life.

Anna, age 40.

In Greer's (1991) follow-up study, women showing stoic acceptance had higher recurrence rate of breast cancer than did women using for example positive avoidance as a coping strategy. Other studies have linked such fatalism and helplessness to poor prognosis (Carlsson & Hamrin, 1994; Watson, et al. 1991). In light of these results, the commonality of fatalism in Icelanders is very important. It raises questions like whether recurrence of breast cancer is more common in Icelandic women than in others, which in turn would be valuable information in organizing interventions aiming at directing women's coping strategies towards those predicting positive disease outcomes.

Social Support

As the purpose of this study was to describe the social support perceived by Icelandic women in the diagnostic phase of breast cancer, social support was the main focus of the interviews. All the participants thoroughly described the social support needed and perceived. Social support was seen as a fundamental coping resource. The women's descriptions will be outlined here according to Schaefer, Coyne, and Lazarus' (1981) distinction of three types of functions of social support: emotional support; informational support; and tangible support. As studies have shown that women's satisfaction with social support is strongly related to the source from which it is received (Neuling & Winefield, 1988) my report of the sources of social support Icelandic women draw upon in the diagnostic phase of breast cancer will be intertwined with the description of the types of social support they perceive as beneficial for them.

Emotional Support

The women's strong needs for emotional support was apparent both prior to and after diagnosis of the suspicious areas in their breasts. They needed others to share their concerns and fears, to care for them, to reassure them, and to show them love.

I want people to ask about this. I want people to show something—interest and that they are willing to talk to me. I just want them to show their concerns and worries.

Marta, age 41.

I want people to respond like I do—to deny this—to support me and act like I do.

Barbara, age 58.

Bredenberg (1992) has pointed out the importance of the woman's action of making known to another the suspicion of something abnormal in her breast. Telling someone can be seen as a necessary catalyst to activate social support. In light of Northouse's (1988) conclusions, one might assume that the woman's husband would be the first one told. That was the case in this study. All the nine married participants told their husbands first about the suspicious area in their breast appearing in the mammography. In Bredenberg's (1992) study that was the case only in 38 out of 98 cases. The explanation of the difference between these two studies is not obvious. The Icelandic women emphasized that they expected their husbands to be their most important source of support. In most cases the husbands fulfilled these expectations. However, two of the participants felt that the support they anticipated from their husbands did not materialize for them.

It's just like he is not willing to discuss this except saying that this is going to be OK—and I was very disappointed this morning when I came home from the second mammography and—. I mean that wasn't the first thing he asked about how it went—and it hurts because I felt this should be number one, two, and three in his mind.

Sigrun, age 39.

Such a failure of the husband to respond as the woman expects can increase the sense of threat the woman is experiencing to intolerable levels (Bredenberg, 1992).

The three unmarried participants first told the ones they thought of as their closest family members or friends. In these cases, all the individuals showed concern and understanding of the woman's feelings.

The women showed quite a difference in their needs to talk about their situation. Some needed to tell all members of their family and closest friend.

I tried to inform people of what was happening. It was rather strange, I would have thought that I wouldn't react like that, but I did. I called my friend and—and my

aunt—and of course my children. I told everyone that this might be something bad, but then it might not be—that it would turn out to be OK.

Barbara, age 58.

Others did not want too many to know about their situation because they felt they could not foretell their reactions and feared possible overreaction.

When I told my boss I asked her not to talk too much about this for the time being. It's OK I'm not denying it, but I don't want to have too many days risking that people will look at me and think, "Oh the poor thing, she is dying" or something like that—because we all know what cancer—what people think about cancer.

Sunna, age 55.

Women clearly had different expectations regarding emotional support of individuals in their social network. They needed to talk about their situation with persons whose reactions they knew and protected themselves from overreacting people by not talking to them about the suspicious area in their breasts. The quality of the emotional support perceived from few key sources like husbands, immediate family, and closest friends was more important than the number of supportive people in their social network.

Northouse (1988) has pointed out that breast cancer patients' husbands experience as much distress as the patients themselves throughout the cancer experience. She also introduces the notion of reciprocity by stating that spouses' and family support is as important to the husband as it is to the woman with breast cancer. This might explain why the expected emotional support from husbands and even closest family members did not always materialize for the participants in my study. Some of the participants recognized their husband's distress and may have lessened their demand of emotional support from them in response.

My husband he does not talk—he is rather reticent. Yet I know that even though he does not say much, I feel he observes and knows what's going on and is, you know maybe worried too—just like me.

Kristin, age 51.

In the case of relatives and/or good friends the women didn't acknowledge the notion of reciprocity. They felt that they shouldn't have to support others and that relatives and friends should respect their needs.

I can't turn to my mother. When I told her about this she just—you know I get no support from her. It's me who has to support her—and I feel I shouldn't have to do that.

Anna, age 40.

My mother—I know she is very worried although she does not say anything. She has been—she is always visiting me and I think she feels she is helping me a lot—and she is trying to prevent that I won't be alone—. But I like being alone—she does not understand that. You know I really like being alone with myself and my thoughts.

Maria, age 51.

Most of the participants described their need of someone to be close to them in particular situations, such as in the second mammography and when they were told the diagnosis. Just knowing of their husband in the waiting room was helpful. Having someone nearby when told the diagnosis was supportive; the closeness in itself was supportive but so was knowing that they would not have to remember everything they were told. One woman commented on the necessity for the husband to go through the interviews with the woman as it would enable him to support her in the way she needed. The husband's presence in the interviews can also facilitate the husbands' perceptions of support from health professionals, which studies have shown to be lacking (Northouse, 1988).

Although studies have shown that women seek emotional support mainly from their husbands, families, and close friends and less from health professionals (Lierman, 1984; Neuling & Winefield, 1988; Wortman, 1984), the participants in this study articulated their needs for and experience of emotional support from health professionals:

The people there [at the Screening Center] were wonderful. They somehow went through my discomfort with me. They acted like this was the only case this year—I had all their time while I was there.

And the same woman continues:

He acted so kindly—almost as if it influenced him personally—like I could be his daughter or his sister or something like that. It was nothing inconvenient or like he was pretending—I felt it was so sincere.

Kristin, age 51.

Not all the participants felt the health professionals acted in the way they wanted them to act:

I just wanted more kindness and—it's nothing much that really needs to be done—maybe just talk a little bit more with you.

Marta, age 41.

Marta is one of the youngest participants in the study and her description raises the question if health professionals have more difficulty with breast cancer in one so young?

Just as the women described their needs and experiences of emotional support from health professionals, eight of them also clearly articulated how they wanted the latter to act as the source of emotional support they should be. At the first meeting their handshake should be firm and their introduction clear. Both were seen as supportive as they increased the woman's trust on the physician/nurse. The health professionals should not pretend but act sincerely and in a way that the woman will feel she is the center of everything, that she is not merely one more case. Being humorous was also seen by many women as supportive.

Those women who did not find anyone among their family members or friends who they felt really comfortable talking to expressed their interest of meeting someone at the Screening Center who they could talk to, who would listen and answer their questions. These participants thought that for some women it might even be easier to talk to someone outside the family about their emotions and experience.

I think that there should be someone like you—or—or someone at the Screening Center who would talk to all these women. This is such a difficult time—to wait—because you can't talk—not everybody can—I mean I can't talk not even with my mom—about everything we have been talking about. It's sometimes easier to talk to

someone outside the family, just feel free to talk—and even for the ones who need to—just to cry.

Sigrun, age 39.

Some participants felt it was easier to talk if the health professional was a woman. A woman would be more understanding as she would have more insight into such women's issues. Others stressed that the gender of the health professionals is not what matters; what matters is the individual's character as described above.

Informational Support

The research participant's needs for informational support in the diagnostic phase of breast cancer was apparent in all the interviews. The women all said they sought informational support first and foremost from health professionals. They needed information and explanations of "why this could happen" not because they blamed themselves but rather because they needed some logic in the situation. They wanted detailed information about what had been seen in the first mammography. They wanted honest information which relates to emotional support through the notion of trust. Last but not least they wanted clear information about when they would have "the final answer". All of them were satisfied with the information received from health professionals.

The women already diagnosed with benign breast changes needed information about the likelihood of these changes turning into malignant cancer later on. They also needed information regarding how their future checks and observations would be planned.

The women already diagnosed with malignant breast cancer needed to know "what was next", what their options were. One of the three expressed her satisfaction with the way her physician explained the treatment options and allowed her to have something to say about which treatment would be chosen.

The physician explained the options I had and said that it wasn't obvious which I should choose. She said she knew this was difficult for me to have to decide this but also that she wanted me to think of all the options.

Sunna, age 55.

The physician's recognition that the decision making was in it self stressful for the woman was also perceived by the woman as emotionally supportive.

Informational support like in the above citation enables the woman to make decisions about the treatment options, that is the stressful situation. It thus facilitates independent behaviour and allows the woman to take some responsibility for her own health. As outlined in the discussion of problem-focused coping earlier in this chapter, woman's responsibility for her own health affects her psychological well-being and is a prognostic indicator (Greer, 1991; Lierman, 1988; Royak-Schaler, 1991). Informational support as described in Sunna's statement above is, therefore, of utmost importance in the health care services available to women in the diagnostic phase of breast cancer.

The women in this study also sought informational support from women close to them who they knew had similar experiences. It seemed especially important if the other woman had recovered well from the breast cancer. In addition to the information and advice, they were reassured that breast cancer need not to be fatal.

Tangible Support

Tangible support was not a finding in this study's interviews. When asked, the women denied needing more help than usual with their daily tasks and stated that they kept on working as before. The three women diagnosed with malignant breast cancer were, however, an exception. They appreciated a concession regarding their jobs.

I was supposed to work this weekend. I had been told that—of course I should not do it. I came here and called everyone and told them I would be away for the next couple of weeks—at least—and—it was good to do that and I—of course I talked to my colleagues here—and then I went home.

Barbara, age 58.

This study indicates that tangible support need not to be activated in the diagnostic phase of breast cancer. Its importance after mastectomy has, however, been demonstrated (Bredenberg, 1992; Feather & Wainstock, 1989a; Fridfinnsdottir, 1993; Funch & Mettlin, 1982).

Negative Support

Relatively little has been written about negative social support. In their definition of social support, Shumaker and Brownell (1984) articulate the necessity of two individuals being involved when social support takes place, and that either the provider or the recipient need to perceive the act as enhancing the well-being of the recipient. Peters-Golden's (1982) study revealed a discrepancy between the intended supportive behaviour of healthy individuals and perceived support by breast cancer patients. Bredenberg's (1992) study affirms this discrepancy. Negative support can be of two kinds, either the act of the provider is harmful in itself or the act is perceived by the recipient as negative (Stewart, 1993).

Negative support was apparent in many of this study participants' descriptions. In all cases the act of the provider was well intended but perceived by the woman as negative and in some cases even harmful.

Some of my friends have just said "Oh, everything is going to be OK"—in fact I think they are trying to comfort me but it's not that—yes of course you need others to be comforting—but—then you can't continue to talk.

Maria, age 51.

A remark like Maria mentions is intended to be supportive, to reassure the woman. It does, however, imply that there is nothing more to talk about. It deprives the woman the opportunity to talk which, as outlined earlier, is seen as an activator of social support (Bredenberg, 1992). It also affects the sources women draw upon for social support. Most importantly, just as social support reduces stress, negative social support can itself be a significant source of stress. The acknowledgement of negative social support is, therefore, crucial in the diagnostic phase of breast cancer.

Summary of the Findings

The diagnostic phase of breast cancer is a very stressful time in Icelandic women's lives. The major stressors are: receiving a letter from The Screening Center, and waiting for the diagnosis (duration of the event). Sending a letter saying that the woman needs

another mammography was seen as very impersonal and depriving the woman the opportunity to ask questions and get some information. The waiting time for the diagnosis was in all cases seen as too long and having immobilizing effects on the women. Uncertainty can be seen both as a consequence of these two stressors and also as a stressor in itself. The uncertainty arises because the woman is unable to predict the outcome of the second mammography and/or the biopsy. Uncertainty limits the woman's control over her life and increases her sense of helplessness.

The participants in this study appraised their situation as stressful. Of the three kinds of stressful appraisals outlined by Lazarus and Folkman (1984), threat appraisal was by far the most important in this study. The situation threatened the women's health and even lives. Identified emotions were: fear of the unknown, possible pain and suffering, and untimely death; anxiety regarding the treatment; and anger with life and the whole of creation. Interestingly, whereas fear was the prominent emotion experienced in the prediagnostic phase of breast cancer, anxiety was the most frequently mentioned emotion after diagnosis.

As with most other stressful situations, the one under study here is ambiguous in the sense that the crucial information is missing — whether the suspicious area is cancer or not. Such ambiguity results in the feeling of helplessness. Still the women evaluated their coping resources and activated the ones they thought would help them through this waiting.

The women's appraisals changed considerably when the diagnosis was clear, independent of the outcome. Knowing the diagnosis was a relief not only for the women with benign breast changes, but also to some extent to women with malignant breast cancer. Knowing what it was they had to deal with decreased their fear and made it easier for them to decide what there was to be done. Before the diagnosis of the suspicious areas in the women's breasts, they did not know what the problem was and,

therefore, problem-focused coping was not an alternative for them. As soon as the diagnosis was clear, problem-focused coping was initiated. The women with benign breast changes saw this experience as a warning that they should take more responsibility for their own health. The ones with malignant breast cancer tried to free themselves from duties in work and in their private lives, to enable them to concentrate on themselves and the treatment. One participant emphasized the linkage of older age to the ability to utilize problem-focused coping.

The forms of emotion-focused coping used by the participants in this study were: denial, which was striking before diagnosis; selective attention; and stoic acceptance (fatalism). According to Greer's (1991) theory, denial and selective attention are linked to positive disease outcomes whereas stoic acceptance is considered to have negative effects on disease outcomes. In light of the commonality of fatalism by Icelanders the acknowledgement of these effects is important in planning nursing interventions for women in the diagnostic phase of breast cancer.

Social support was seen as a fundamental coping resource by all the participants. The women's strong needs for emotional support were apparent both prior to and after diagnosis of the suspicious areas in their breasts. They needed others to share their concerns and fears, to care for them, to reassure them, and to show them love. Telling someone was an activator of emotional support. All the married participants first told their husbands about the suspicious results. They felt that their husbands should be their main source of emotional support and in most cases they turned out to be. In a few cases, however, the husbands were not as supportive as the women needed them to be, possibly due to their own distress in the situation. The unmarried participants first told the ones they thought of as their closest family members or friends.

The women also sought emotional support from health professionals and described how they wanted the latter to act to be the source of emotional support they should be.

Health professionals were the participants' main source of informational support in the diagnostic phase of breast cancer. They wanted honest information about "why this could happen", what had been seen in the first mammography, when they could have the final diagnosis, and what their treatment options were if diagnosed with malignant breast cancer. Some of the women also sought informational support from women close to them who they knew had similar experience.

Tangible support was not apparent in this study's interviews. The women denied needing more help than usual with their daily tasks and duties.

Negative support was identifiable in many descriptions. In all cases the act of the provider was well intended but perceived by the woman as negative and in some cases even harmful. The acknowledgement of negative support in the diagnostic phase of breast cancer is, therefore, very important.

The findings of this research study reveal that the diagnostic phase of breast cancer is a very stressful time in women's lives. The findings also reveal that women need both informational and emotional support from health professionals during this time. In the next chapter the conclusions drawn from these findings are presented, as well as the implications for nursing practice, education, and research.

CHAPTER V

CONCLUSIONS AND IMPLICATIONS

Introduction

This study was designed to describe the nature of stressors Icelandic women identify in the diagnostic phase of breast cancer, what sources of social support they draw upon, and their satisfaction with the social support they receive. Approximately one in ten Icelandic women will develop breast cancer during her lifetime. Little is known about women's needs and situations while waiting for diagnosis of a breast lump or a suspicious mammography.

Lazarus and Folkman's (1984) theory of stress, appraisal, and coping was used as a theoretical framework for this study. Stress is seen by them as a relationship between the individual and the environment which exceeds the individual's resources and endangers well-being. An individual's appraisal of any situation and the meaning of every encounter for the individual's well-being is a fundamental part of the theory. Social support is identified as one of six coping resources and is seen as mediating the effects of stress on individual's well-being and adjustment.

A review of the pertinent literature revealed that most of the studies on women with breast cancer focus on the time after diagnosis and even more commonly after mastectomy. These studies indicate, however, that the diagnostic phase of breast cancer is identified by many women as the most difficult time to cope with of all their illness experience. The way in which the woman experiencing the threat of breast cancer responds to the initial threat of diagnosis may influence the course of her illness.

A descriptive exploratory research design was chosen for this study as little is known about the topic under investigation. The sample consisted of 12 women: six waiting for the results of a second mammography; three newly diagnosed with malignant breast cancer; and three diagnosed with benign breast changes. Semi-structured interviews were

conducted to gather the data. Data were coded according to predetermined categories as noted on the interview guide, then narrative data were analyzed by using thematic analysis.

From the findings of this study the diagnostic phase of breast cancer appears to be a very stressful time in women's lives. Stressors like: receiving a letter from The Cancer Society; waiting for the second mammography and consequent diagnosis; and the uncertainty related to unpredictable future, were identified. Women experience the possibility of having cancer as an enormous threat, characterized by emotions like fear, anger, anxiety, restlessness, and sense of floating in the air. Their appraisals change considerably when the diagnosis is clear, even with a diagnosis of a malignancy. Women use emotion-focused coping throughout the diagnostic phase and, additionally, problem-focused coping after the diagnosis.

Social support is seen as a fundamental coping resource. Emotional support from husbands, family, and close friends is of utmost importance. Women seek informational support mainly from health professionals, but also, to some extent from other women known to have had breast cancer. Health professionals are not only the most important source of informational support but also a valuable source of emotional support. Tangible support is not sought by women in the diagnostic phase of breast cancer. Acts intended to be supportive, are in some cases perceived by the women as negative and a source of stress in themselves.

Conclusions

There are six main conclusions to this study.

1. The diagnostic phase of breast cancer is in some cases the most difficult experience Icelandic women have to deal with in their lives.

2. The reduction of the waiting time for diagnosis of a breast lump or a suspicious mammography is an effective way to minimize the stressors acting on Icelandic women in the diagnostic phase of breast cancer.
3. Icelandic women seek different kinds of social support from different sources. Emotional support from husbands, family, and close friends is of most value to them.
4. Icelandic health professionals can not only be the main source of informational support but also a valuable source of emotional support.
5. Icelandic women experience some negative support from all sources, when in the diagnostic phase of breast cancer.
6. Lazarus and Folkman's (1984) theory of stress, appraisal , and coping is transferable to the Icelandic context.

From these findings and conclusions implications for practice, education, and research are articulated.

Implications for Nursing Practice

Women waiting for the diagnosis of a breast lump or a suspicious mammography experience a deep threat to their health and even lives. They are uncertain about their future and what life will be for them and their families. They don't feel they are in the health care system until the diagnosis is clear. Their access to nurses is limited to the scene of mammography. There is, however, an important role for nurses to play during the entire diagnostic phase.

Women describe, not only their needs for informational support, but also their needs for emotional support from Icelandic health professionals. Nurses trained in therapeutic communication should be available for women who need to tell their stories. The opportunity for women to tell someone, even a stranger (preferred by some women), about how they feel, what they fear, others reactions, and so on, is an extremely important coping resource. Such interviews can be therapeutic in themselves. Nurses

need to increase their availability and service to women in the diagnostic phase of breast cancer and, thus, be the foundation of informational and emotional support from health professionals.

Another important role Icelandic nurses can play is to identify the coping strategies women use in the diagnostic phase of breast cancer. In light of the suggestions that some coping strategies appear to be more linked to positive disease outcomes than others, it might be of great value to intervene methods to facilitate women's adoptions of the positively linked coping strategies.

Although not solely related to nursing practice it should be emphasized here that the reduction of the waiting time for diagnosis seems to be the single most important way to improve the health care service available to Icelandic women in the diagnostic phase of breast cancer. The necessity to revise the method used to inform the women about a suspicious area seen in the mammography should also be stressed.

Implications for Nursing Education

Although nurses have not been playing a primary role in the health care of Icelandic women waiting for the diagnosis of a breast lump or a suspicious mammography, the implications for education are many. First and foremost it is important to recognize the need for nursing service in this time period and, consequently, encourage nursing students to make themselves available to women experiencing the threat of possible breast cancer diagnosis.

Nursing students must understand theories of stress, coping, and social support to be cognisant of women's situations and feelings, and to be the source of social support women need to draw upon. Therefore, they not only need to be introduced to these theories in their nursing programs, but they also need to be able to incorporate these theories into their practical training.

An important implication for nursing education in Iceland is the communication and interviewing skills nurses need to have. The possible therapeutic effects of interviews taking place in the diagnostic phase of breast cancer is a verification of the necessity to actively train nursing students in conducting interviews.

Implications for Nursing Research

The diagnostic phase of breast cancer is a time period in women's lives which has not been studied in any depth. Numerous implications for nursing research can, therefore, be drawn from this research study findings. The diagnostic phase of breast cancer is a very stressful time for Icelandic women and they experience intense need for social support not only from husbands, family, and friends, but also from health professionals. As the sample in this study was rather small and limited to Icelandic women, it would be valuable to replicate the study in some other context and with a larger sample.

Icelandic women's appraisals change considerably when the diagnosis of a breast lump or a suspicious mammography is clear. A longitudinal study focusing on the appraisal process throughout women's illness experience is crucial in the attempt to understand their specific needs for health service each step of the way.

The linkage of the use of different coping strategies to disease outcomes needs to be explored in depth. As fatalism is very common in Iceland it would be of great interest to compare the recurrence rate of breast cancer in Icelandic women, to the recurrence rate in a society where fatalism is not as common.

Limitations of the Study

This study is limited by the characteristics of the sample. Participants were limited to those who were at special risk of breast cancer because of family history or clinical symptoms. Participants were also limited to those who were able to communicate verbally in Icelandic and who lived within one hour's drive from Reykjavik, where the

Cancer Screening Center is located. Women living elsewhere in Iceland have different accessibility to health care services and cancer screening.

As this was a graduate level thesis the sample size at the outset of the study was restricted to 12 to 14 participants. The small sample size is, therefore, another limitation to the study.

It is acknowledged that these limitations to the study produce a sample from a selected group of women which limits the generalizability of the research findings.

Closing Statement

This research study has shed a little light on a difficult experience many women have to deal with at some time in their lives. It is also an addition to the short tradition of nursing research in Iceland. Most importantly, the findings of this study can be used as an indication for health professionals in Iceland, in their endeavour to improve the health care available to women experiencing the diagnostic phase of breast cancer.

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APPENDICES

Appendix A

Streita og Studningur - Vidtalsdrog (Stress and Social Support Interview Guide)

Vegna thess sem konur i svipadri adstöðu og thu hafa sagt mer, veit eg ad thetta er erfidur timi i lifi thinu. Eg hef ahuga a ad fa vitneskju um reynslu thina med thad ad markmídi ad baeta tha heilbrigdisthjonustu sem konum stendur til boda a thessu timabili i lifi theirra. Thaer spurningar sem eg mun spyrja thig ad eru unnar upp ur rannsoknum thar sem thatttakendurnir hafa verid konur i svipadri adstöðu og thu.

Viltu vinsamlegast lata mig vita ef thu tharft ad taka ther hle fra vidtalinu. Viltu einnig lata mig vita ef thu vilt ekki svara einhverri spurningu og tha fer eg yfir i naestu spurningu.

1. Getur thu lyst fyrir mer hvad gerdist thegar thu tokst eftir thvi ad eitthvad var athugavert vid brjostid? (merking/mikilvaegi atburdar).
2. Hvada tilfinningar fylgdu uppgötvun hnutsins? (upphafsmat)
3. Ertu reid, hraedd, eda kvidin? (skadi/missir og ognun).
4. Finnst ther ad ther se ognad eda ögrad, eda jafnvel ad thu hafir misst eitthvad? (streita).
5. Hversu streituvaldandi er thessi reynsla i samanburdi vid adrar streituvaldandi adstaedur sem thu hefur reynt?
6. Finnst ther önnur ord lysa tilfinningum thinum betur?
7. Hafa thessar tilfinningar breyst sidan thu uppgötvadir hnutinn? (breyting á mati).
8. Hvernig er su tilfinning ad thurfa ad bida eftir frekari upplýsingum? (varanleiki atburdar).
9. Hefur thu einhvern tima haldid ad thu aettir eftir ad standa frammi fyrir thvi ad thu vaerir hugsanlega med krabbamein? (vaenting atburdar).
10. Hvað gerir thu og hugsar til ad rada vid thessar adstaedur? (stjornun).
11. Tilfinningalegur studningur:
 - Getur thu talad vid einhvern um lidan thina?
 - Virdist hann/hun skilja lidan thina og adstöðu?
 - Finnst ther ad thu sert elskud og um thig se hugsad?
 - Fra hverjum faerdu thaer tilfinningar?
 - Syna adrir ther skilning?

Finnst ther einhver önnur ord lysa því betur hvernig adurnefnt folk laetur ther lida?

Hvernig lidur ther i samskiptum vid heilbrigdisstarfsfolk?

12. Upplýsingastudningur:

Konur sem hafa verid i svipadri adstöðu og thu hafa lyst thörfum sinum fyrir ad fa upplýsingar um adstaedur og hvad muni líklega gerast. Hefur thu thörf fyrir thetta?

Til hvers/hverra leitar thu eftir upplýsingum?

Laetur hann/hun ther í te thaer upplýsingar sem thu þarfnast?

Bregst folk a einhvern hatt vid því sem thu gerir til ad takast a vid thessar adstaedur?

Hvernig bregst það vid?

Viltu bæta einhverju vid vardandi thörf thina fyrir upplýsingar?

13. Athreifanlegur studningur:

Konur í svipadri adstöðu og thu hafa latid i ljós ad thaer þurfi meiri hjalp en venjulega vid dagleg störf sin. Þarft thu a aukinni hjalp ad halda?

Hvert leitarðu eftir hjalp?

Hvers konar hjalpar þarfnast thu?

Færdu þa hjalp sem thu þarfnast?

Hvernig lidur ther þegar/ef folk bidur ther hjalp?

14. Samantekt:

Hvern litur thu a sem thinn helsta studningsadila?

Hvad er það sem hann/hun gerir eða segir til ad ther finnist hann/hun stydjandi?

Hvernig laetur hann/hun ther lida?

15. Viltu bæta einhverju vid það sem thu hefur thegar sagt mer i samtali okkar?

Hef eg sleppt einhverju sem thu vilt segja mer um thessa reynslu thina eða sem myndi hjalpa mer ad skilja thessar adstaedur betur?

Adur en vid haettum, langar mig til ad spyrja þig fjögurra spurninga um sjalfa þig (ef það hefur ekki thegar komid fram i samtalinu).

16. Hvað ertu gömul?

17. Hver er hjúskaparstada þin?

18. Hver er atvinnustada þin?

19. Hefur einhver i þinni fjölskyldu greinst med krabbamein?

Stress and Social Support Interview Guide - Translation

I know from other women I've talked to in your situation that this is a difficult time in your life. I am interested in learning about your experience in order to improve the health services women are offered at this time in their lives. The questions that I will ask you arose from previous studies of other women who were in situations similar to yours.

Please let me know if you need a break from the interview. Also, if there are any questions which you do not wish to answer let me know and I will move to the next question.

1. Can you describe for me what happened when you first noticed that something was wrong with your breast? (Meaning/significance of the encounter).
2. What emotions followed the discovery of the lump? (Primary appraisal).
3. Do you feel angry, scared, or anxious? (Harm/loss and threat appraisals).
4. Do you feel threatened or challenged, or even that you have lost something? (Stressful appraisal).
5. How stressful is this experience compared to other stressful situations you have experienced?
6. Are there any other words that describe your feelings better?
7. Have these feelings changed since the time you discovered the lump? (Change of appraisal).
8. How do you feel about having to wait for further information? (Duration of the event).
9. Did you ever think that you would have to face the fact of possibly having cancer? (Expectancy of the event).
10. What do you do and think to manage this situation? (Coping).
11. Emotional support:
 - Are you able to talk to someone about how you feel?
 - Does he/she seem to understand your feelings and situation?
 - Do you feel that you are loved and cared for?
 - From whom do you get those feelings?
 - Are others empathetic towards you?
 - Are there any other words that you would use to describe how the

aforementioned people make you feel?
How do you feel when interacting with health professionals?

12. Informational support:

Women in similar situation to yourselves have expressed their needs to get information about the situation and what is likely to happen. Do you have similar needs?

Who can you turn to for information?

Does he/she give you the information you need?

Do people respond to what you do to manage the situation?

How do they respond?

Is there anything that you would like to add regarding your need for information?

13. Tangible support:

Women in similar situation to yourselves have revealed that they need more help than usually in doing their every-day work. Do you need some additional help?

Who do you turn to for help?

What kind of help do you need?

Do you get the help you need?

How do you feel when/if people offer you some help?

14. Summary:

Who do you think of as the most supportive person now?

What does he/she do or say to make you feel he/she is so supportive?

How does he/she make you feel?

15. Would you like to add anything to what you have already told me during our conversation?

Have I missed out anything that you would like to tell me about your experience or that would help me understand this situation better?

Before we end, I would like to ask you four questions about your self (if not already brought up in the conversation).

16. How old are you?

17. What is your marital status?

18. What is your employment status?

19. Has anyone in your family been diagnosed with cancer?

Appendix B

Bref til laekna (Letter to Physicians)

Kaeri

Eins og við raeddum thegar við hittumst á stofunni þinni er ég að undirbúa rannsókn á mati íslenskra kvenna á streituvöldum og studningi á greiningartíma brjóstakrabbameins. Þessi rannsókn er hluti þess sem krafist er í meistaranámi mínu við háskolann í Bresku Kolumbíu í Vancouver, Kanada. Ég lit svo á, bæði í ljósi reynslu minnar sem hjúkrunarfræðings og þess sem ég hef lesið mér til um efnid, að greiningartími brjóstakrabbameins sé mjög streituvaldandi tími í lífi kvenna. Ég tel að meiri thekking og skilningur á serstaðum þörfum þessa hóp skjölstaedinga, muni auðvelda hjúkrunarfræðingum og öðru heilbrigðisstarfsfólki að gera áætlanir um bætt heilbrigðistjónustu sem serstaklega miða að því að mæta serstaðum þörfum þessara kvenna.

Leyfi fyrir þessari rannsókn hefur fengist hjá Visindaradi Krabbameinsfelags Íslands og Tölvunefnd Íslands. Leyfi hefur einnig fengist hjá rannsókn- og síðanefnd háskolans í Bresku Kolumbíu.

Greiningartíma brjóstakrabbameins skilgreini ég í þessari rannsókn sem tímann frá því konan (eða laeknirinn) finnur hnút í brjóstinu þar til meðferð er hafin. Skilyrði urtaks í þessari rannsókn eru eftirfarandi:

1. A greiningartíma hnúts í brjósti.
2. Einn eftirfarandi þatta, sem auka líkur á að um illkynja vöxt sé að ræða, verða að vera til stadar:
 - a) systir(ur), modir eða amma hafa áður verið greindar með brjóstakrabbamein.
 - b) hnúturinn í brjóstinu er illa afmarkaður.
 - c) hnúturinn er sarsaukalaus.
 - d) geirvarta er inndregin.
 - e) utferð er úr geirvörtu.
 - f) hudbreytingar eru til stadar yfir hnútnum.
 - g) grunsamleg nidurstada brjóstamyndatöku.
3. Búa innan klukkustundar aksturs frá Reykjavík.
4. Tala íslensku.
5. Gefa skriflegt samþykki sitt.

Frabending um thatttöku er eftirfarandi:

1. Þaer konur sem uppfylla ekki ádurtalin skilyrði, eru ekki líklegar til að geta svarað spurningum þeim sem felast í viddalínu, eða eru ekki færar um að veita samþykki sitt.

Letter to Physicians - Translation

Dear

As we discussed when we met at your clinic I'm planning to study Icelandic women's identifications of stressors and social support in the diagnostic phase of breast cancer. This study is a part of the requirements in the Masters program I'm enrolled in at The University of British Columbia School of Nursing, in Vancouver, Canada. I assume, both from my experience as a practising nurse and by reviewing the literature, that the diagnostic phase of breast cancer is a very stressful time in women's lives. I believe that better knowledge and understanding of the special needs this group of clients has, will facilitate nurses' and other health professionals' planning of better health services to meet the women's specific needs.

Approval for this study has been obtained from The Science Committee of The Icelandic Cancer Society and The Icelandic Data Protection Committee. Approval has also been obtained from The University of British Columbia Behavioural Sciences Screening Committee for Research and other Studies Involving Human Subjects.

For the purpose of this study I have defined the diagnostic phase of breast cancer as the time from the woman's (or physician's) discovery of a lump in her breast until treatment has been started. The sample selection criteria for this research study is as follows:

1. In the diagnostic phase of breast cancer.
2. One of the following indications of malignancy:
 - a) sister(s), mother, or grandmother previously diagnosed with breast cancer.
 - b) growth poorly limited.
 - c) growth painless.
 - d) nipple retraction.
 - e) nipple secretion.
 - f) skin changes over the lump.
 - g) suspicious mammography.
3. Live within one hour's drive from Reykjavik.
4. Able to communicate verbally in Icelandic.
5. Consenting.

Exclusion to participation is the following:

1. Women not meeting the above criteria, or who are unlikely to be able to respond to the interview questions, or who are unable to consent.

Appendix E

Coding Sheet

CODING SHEET

COPING RESOURCES

EMOTIONS

[illegible]