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Pilvikki Absetz

DETERMINANTS AND PSYCHOLOGICAL IMPLICATIONS OF BREAST CANCER RISK PERCEPTIONS IN THE COURSE OF MAMMOGRAPHY SCREENING

ACADEMIC DISSERTATION

To be publicly discussed, by due permission of the Faculty of Arts at the University of Helsinki in auditorium XII, on the 11th of October, 2002 at 12 o'clock.

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TABLES AND FIGURES

Tiivistelmä

Rintasyövän riskiä koskevia käsityksiä määrittävät tekijät ja käsitysten psyykkiset vaikutukset mammografiaseulontaprosessissa.

Tässä prospektiivisessa pitkittäistutkimuksessa tarkasteltiin rintasyövän riskiä koskevia käsityksiä, niitä ennustavia tekijöitä sekä niistä seuraavia käyttäytymiseen ja psyykkiseen hyvinvointiin liittyviä tekijöitä mammografiaseulonnan kuluessa.

Lähtömittauksen aineisto kerättiin postikyselyllä mammografiaseulontaan ensimmäistä kertaa kutsuttavilta naisilta (50-v., N = 16 886) kuukautta ennen seulontakutsua. Kysely lähetettiin samanaikaisesti myös seulonnan ulkopuolella olevien naisten keskuudesta satunnaisesti valitulle vertailuryhmälle (48-v., N = 1 781). *Seulontaan kutsuttavien kohderyhmästä* valittiin 1680 naisen *satunnaisotos* edustamaan seurantamittauksissa seulonnasta normaalivastauksen saaneita naisia. Seurantakyselyt tehtiin kaksi kuukautta ja yksi vuosi viimeisen seulontaan liittyneen tutkimuskäynnin jälkeen lähtömittaukseen vastanneille, mikäli he a) kuuluivat satunnaisotokseen ja olivat saaneet seulonnasta normaalivastauksen (n = 883); b) olivat joutuneet seulonnasta jatkotutkimuksiin (koko kohderyhmästä sisältäen satunnaisotoksen), mutta varmistustutkimusten (n=319) tai kirurgisen biopsian (n = 39) jälkeen heidät oli todettu rintojen osalta terveiksi tai heidän rinnoissaan havaitut muutokset oli todettu hyvänlaatuisiksi; tai c) kuuluivat vertailuryhmään (n = 929). Naisille, jotka kutsusta huolimatta jäivät pois seulonnasta, lähetettiin yksi seurantakysely kaksi kuukautta annetun seulonta-ajan jälkeen (n = 629). Lähtömittauksessa kyselyyn vastasi 61 % ja seurantamittauksissa 82,7 % sekä 76,0 % tutkittavista.

Lomakkeiden kysymykset koskettelivat riskikäsityksiä, rintasyöpäkokemusta, syövän varhaistoteamiskäytäntöjä, mielialaa, terveyshuolestuneisuutta ja rintasyöpähuolestuneisuutta. Analyysimenetelminä käytettiin varianssianalyysiä, lineaarista ja logistista regressioanalyysiä sekä non-parametrisiä testejä.

Tutkimukseen osallistuneilla naisilla oli optimistinen käsitys omasta rintasyöpäriskistään verrattuna ikäistensä naisten riskiin, varsinkin mikäli heidän lähipiirissään ei ollut ollut rintasyöpää. Kohtalaiseksi koettu riski ennusti osallistumista rintasyöpäseulontaan, mutta korkea riski ei. Aiempi käsitys omasta alttiudesta sairastua rintasyöpään oli yhteydessä psyykkiseen kuormittuneisuuteen sekä terveyttä ja rintasyöpää koskevaan huolestuneisuuteen paitsi ennen seulontakutsun saamista, myös seulonnan jälkeen, seulontalöydöksestä riippumatta.

Vaikka terveyshuolestuneisuus lieventyi seulonnan myötä kaikkien tutkittavien joukkoa tarkasteltaessa, kielteisiä vaikutuksia esiintyi kahdessa erityisessä alaryhmässä: Naiset, joilla oli etukäteen kokemusta rintasyövästä lähipiirissään, raportoivat enemmän masennusoireita sekä terveys- ja rintasyöpähuolestuneisuutta seulonnan jälkeen. Mammografiakuvauksen perusteella varmistustutkimuksiin kutsutuilla naisilla havaittiin enemmän rintasyöpähuolestuneisuutta, ja heidän käsityksensä omasta rintasyöpäriskistään kohosi pysyvästi seulonnan jälkeen.

Seulontaa tulisi kehittää siten, että sen kuluessa pystyttäisiin tunnistamaan ne naiset, jotka ovat huolissaan rintasyöpäriskistään ja jotka hyötyisivät yksilöllisesti sovitetusta neuvonnasta tai seulonta-aikataulusta. Jatkotutkimuksiin kutsutut naiset tarvitsisivat todennäköisesti myös lisäselvitystä rintasyöpäriskistään. Nämä toimenpiteet auttaisivat välttämään huolestuneisuutta, joka ei raukea seulonnassa vaan jää nykyisessä järjestelmässä tunnistamatta ja hoitamatta.

Abstract

This prospective, longitudinal study examined breast cancer risk perceptions, their determinants, and their behavioural and psychological implications in the course of mammography screening.

Baseline data (T1) were collected by questionnaires, which were mailed to women in their first screening round (age 50, N = 16,886) one month before they received an invitation for screening. Questionnaires were also sent to a group of referents outside screening (age 48, N = 1,781). Follow-ups conducted two months (T2) and one year (T3) after the last screening appointment included a random sample of women with a normal screening finding (n = 883); all women whose findings were normal or benign after further examination (n = 319) or surgical biopsy (n = 39); and the referents (n = 929). Non-participants in screening were followed up only at T2 (n = 629). The response rates were 61% at baseline and 82.7% and 76.0% at follow-ups.

The measures included risk perceptions, breast cancer experience, cancer detection behaviours, general distress, health-related concerns, and breast cancer-specific concerns. General linear models, linear and logistic regression analyses, and non-parametric tests were used for data analysis.

The women in the study had optimistic perceptions of their personal risk of breast cancer in comparison with peers' risk, especially when lacking vicarious experience of the disease. Moderate rather than high perceived risk predicted participation in screening. Increased risk perception was related to higher levels of general distress, health-related concerns, and breast cancer-specific concerns even before the screening invitation, an association that persisted throughout the process, regardless of the screening findings.

While health-related concerns were alleviated in the screened population as a whole, adverse effects emerged in two distinct subgroups: Women with pre-existing experience of breast cancer reported more depressive symptoms and health-related and breast cancer-specific concerns after screening. Women recalled to further examinations reported more breast cancer-specific concerns than the other screened groups, and their risk perception increased permanently due to screening.

The screening system should be developed to identify women who are concerned about their breast cancer risk and are likely to benefit from individualised risk counselling or screening schedule. Women recalled for further examinations probably also need more thorough risk counselling. This would help to avoid the post-screening concern that remains unidentified and unresolved in the present screening system.

List of Original Publications

I Absetz, P., Aro, A.R., Rehnberg, G., Sutton, S.R. (2000). Comparative optimism in breast cancer risk perception: effects of experience and risk factor knowledge. *Psychology, Health & Medicine*, 5, 371-380.

II * Aro, A.R., de Koning, H.J., Absetz, P., Schreck, M. (1999). Psychosocial predictors of first attendance for organised mammography screening. *Journal of Medical Screening*, 6, 82-88.

III Aro, A.R., Absetz-Ylostalo, P., Eerola, T., Pamilo, M., Lönnqvist, J. (1996). Pain and discomfort during mammography. *European Journal of Cancer*, 32, 1674-1679.

IV Absetz, P., Aro, A.R., Sutton, S.R. (2002). Factors associated with breast cancer risk perception and psychological distress in a representative sample of middle-aged Finnish women. *Anxiety, Stress, and Coping*, 15, 61-73.

V Aro, A.R., Absetz, P., van Elderen, T.M., van der Ploeg, E., van der Kamp, L.J.T. (2000). False-positive findings in mammography screening induce short-term distress - breast cancer-specific concern prevails longer. *European Journal of Cancer*, 36, 1089-1097.

VI Absetz, P., Aro, A.R., Sutton, S.R. (2002). Experience with breast cancer, pre-screening perceived susceptibility, and the psychological impact of screening. *Psycho-Oncology*, 10, 1-14.

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1. Introduction

In our daily living, we are constantly faced with threats to our health and our well-being. Information flow about various risks and factors that either increase or decrease these risks is seemingly endless, and old and new threats co-exist and compete for our attention. This affects us not only emotionally but also behaviourally; in order to manage the threats, we need to do something about them. We need to make use of protective behaviours that will lower our risk of being victimised by these threats, thereby giving us a sense of security and furthering our emotional well-being.

Various dimensions of risk influence how threatening and severe it is perceived to be. These include *voluntariness*; *immediacy of effect*; *knowledge by those exposed to known risk factors*; *knowledge by science*; *control*; *newness*; *chronic-catastrophic character*; *common-dread character*; and *severity of consequences* (Slovic, Fischhof, & Lichtenstein, 1985). In these terms, the risk of getting breast cancer and the risk factors for breast cancer could be described as involuntary, remote, not known to the exposed, not fully known to science, uncontrollable, chronic, dreaded, and potentially with very severe consequences. The threat of breast cancer is probably old and familiar but new and novel risk factors may emerge. On most dimensions, breast cancer seems to fall on the high-risk end. Furthermore, it is a threat that basically all women have to live with. Thus the psychological burden on the population may be considerable even if it does not reach clinically significant levels in individuals. The purpose of this study is to look at women's perceptions of their breast cancer risk and to examine the correlates of these perceptions. I examine this question from the point of view of a health psychologist, but also consider the public health context in which this disease largely emerges and, in particular, is controlled for.

1.1. Breast cancer as the most common cancer type among women

1.1.1. Breast cancer incidence and prevalence in Finland

Breast cancer is the most common female cancer in the Western countries with constantly increasing incidence rates. In the last thirty-five years, the number of new breast cancer cases (i.e., the incident number) in Finland has grown more than twofold and the age-adjusted incidence rate (i.e., the incident number divided by the person-time) per 100,000 person-years has also increased from 33 to 79. In 1966-1970 the mean number of new cases per year was 1009, while in 1998 the number of new cases was 3426. The increase in the number of cases is due to an increase in the number of elderly women in the population, the strengthening effect of risk factors on the female population, and improvements in diagnostic methods (Hakulinen, Kenward, Luostarinen, Oksanen, Pukkala, Söderman, & Teppo, 1989). Since screening starts at the age of 50, most breast cancers are found among women in the age group of 50 to 54 years. (Finnish Cancer Registry, 2001). The cumulative incidence by the age of 85 years is 10%, i.e., 1 in 10 women in Finland get breast cancer in their lifetime (Pukkala, Sankila, & Vertio, 1997).

Because of increasing incidence rates as well as improving survival rates, the prevalence (i.e., the proportion of a population that has a disease at a specific point in time) of breast cancer is also increasing. Twenty years ago, the number of prevalent breast cancer cases was 15,000 (Hakulinen et al., 1989); by 1998 it had gone up to 32,000 (Finnish Cancer Registry, 2000). This means that the number of healthy women who have contact with breast cancer via some significant other with the disease, and who are psychologically influenced by the experience, is also growing.

The prognosis of breast cancer is relatively good – the 5-year survival rate for all breast cancers in Europe is over 70%, in Finland almost 80% (Quinn, Martinez-Garcia, & Berrino, 1998). For stage I breast cancers, the 5-year survival rate exceeds 90% (Dickman, Hakulinen, Luostarinen, Pukkala, Sankila, Söderman, &

Teppo, 1999). Still, pessimistic views concerning this as well as other cancer types prevail among the lay population (Aro, Nyberg, Siikaranta, & Ullberg, 1999). Breast cancer is still a disease that raises a lot of concern, and largely this depends on the fact that it is not within the individual's control. The lack of control is mostly due to the nature of the known risk factors: many of them cannot be changed by individual volition.

1.1.2. Breast cancer risk factors

Age is the most important risk factor for breast cancer (McPherson, Steel, & Dixon, 2000). Apart from age, known breast cancer risk factors are mainly hormonal, related to prolonged or increased exposure to estrogen. Early age at menarche, nulliparity, late first full-term pregnancy, late natural menopause, and prolonged postmenopausal estrogen use have been found to increase breast cancer risk (Martin & Weber, 2000; McPherson et al., 2000). A previous benign breast disease, atypical hyperplasia, is also a risk-increasing factor (McPherson et al., 2000). Of dietary and other life-style factors, alcohol consumption has been most consistently linked with increased breast cancer risk (Martin & Weber, 2000; McPherson et al., 2000). Evidence concerning the risk-increasing nature of high dietary fat is still controversial (Martin & Weber, 2000).

A further risk factor that has gained a lot of attention in recent years is family history of the disease, suggesting genetic susceptibility. Two mutations which have been linked with breast cancer susceptibility have been located in the BRCA1 (Miki et al., 1994) and BRCA2 genes (Wooster et al., 1994), but according to present knowledge, the inherited forms of breast cancer account only for some 5-10% of the cases. (Willet, 1995). In a recent Finnish study, 30% of breast cancer patients were found to have some family history of breast cancer and 7-9% were identified as true hereditary cases (Eerola, Blomqvist, Pukkala, Pyrhönen, & Nevanlinna, 2000). In a population-based study among an unselected sample of Finnish breast cancer

patients, mutations in BRCA1 and BRCA2 accounted for 0.4% and 1.4%, respectively, of the breast cancer cases (Syrjäkoski et al., 2000).

Gail and colleagues (1989) created a model to estimate the chance that a woman with given age and risk factors will develop breast cancer over a specified time interval. The risk factors used were early age at menarche, late age at first live birth, a high number of previous biopsies, and a high number of first-degree relatives with breast cancer. Distinct proportional hazards' models of relative risks for various combinations of these factors were developed for women under age 50 and for women of age 50 or over. The Gail et al. model has been widely used for the purposes of counselling and research (Lipkus, Kuchibhatla, McBride, Bosworth, Pollak, Siegler, & Rimer, 2000; Skinner, Kreuter, Kobrin, & Strecher, 1998).

1.1.3. Breast cancer prevention: primary and secondary

Discovery of mutations in the BRCA1 and BRCA2 genes has provided the option of genetic testing for breast cancer susceptibility, but since only a small fraction of the disease is of genetic origin, testing is not feasible for most women. The other known risk factors do not provide basis for practical means of prevention: the associations between lifestyle or behavioural factors and increased risk are relatively weak and the more influential hormonal factors cannot easily be acted upon.

As primary prevention is usually not a real option, prevention of the disease relies mainly on early detection (secondary prevention). The goal is to discover cases in a pre-clinical phase to secure efficient treatment and cure, and thereby to reduce both morbidity and mortality. The main methods for detection are mammography (i.e., breast x-rays), clinical breast examinations for example by the woman's gynaecologist, and regular breast self-examinations (BSE) by the woman herself. As age is a major risk factor, mass screening programs by mammography have been

set up to examine entire age cohorts of a-symptomatic women. The majority of breast cancers found in mammography screening are stage I breast cancers (Dean & Pamilo, 1999) with a favourable prognosis and, as mentioned, a high 5-year survival rate (Dickman et al., 1999).

Most countries with organised screening provide either a free or a low cost service for women age 50 and older. In Finland, mammography screening was started as a public health policy by statute in 1987, with women age 50-59 invited to free screening every two years. In 1998, 97% of the municipalities carried out screening as stated in the statute (Marjamäki, Kolimaa, & Söder, 1999). Most municipalities continue screening even after women turn 60.

In mammography screening, the majority of women get *a normal screening finding.* In a substantial proportion of those recalled for further examinations (usually consisting of an additional mammogram, an ultra-sound scan, and/or a fine needle aspiration), the finding turns out to be *false positive.* The rest are further referred to surgical biopsy, where the final diagnosis is set. About 35% of the women at this phase are found to have a *benign* condition while 65% are diagnosed with breast cancer (Dean & Pamilo, 1999).

In the screenings organised in Finland in 1987-1997, 3.3% of the women were recalled for further examinations (including the 0.7% who were further recalled for surgery), and 0.4% were found to have breast cancer, resulting in a 2.9% false positive rate (Dean & Pamilo, 1999). The false positive rate in Finland was slightly lower than the rate reported in the United Kingdom: 1.1 million women aged 50-64 years attended mammography screening as part of the UK NHS Breast Screening Programme in 1994-1995. Of them, 4.9% were recalled, and 0.6% were found to have breast cancer (Brett, Austoker, & Ong, 1998). In the United States, approximately 11% of the screened women are recalled because of abnormal mammograms, probably due to service providers being more concerned about *false negative* findings (i.e., cancer cases that remain undiagnosed), but this is at the

expense of up to 10% of the screened women getting a false positive finding (Brown, Houn, Sickles, & Kessler, 1995).

Organised screening concerns a large number of women. Consequently, even with a low false positive rate, the number of those recalled and found to have false positive findings becomes large, too. During the first eleven years of screening in Finland, 43,425 women were found to be false positive after recall (Dean & Pamilo, 1999). As women undergo repeated mammography over time, an individual woman's chances of a false positive result also become high. One study estimated that nearly 50% of U.S. women experience at least one false positive recall after 10 rounds of screening (Elmore, Barton, Moceri, Polk, Arena, & Fletcher, 1998).

1.1.4. Risk from an epidemiological viewpoint

Risk as an epidemiological concept is defined "as the probability of disease developing in an individual in a specified time interval" (Rothman & Greenland, 1998, p. 37). This concept of risk applies only to individuals, while "average risk", a synonym for incidence proportion, applies to populations (Rothman & Greenland, 1998). As the causal components of breast cancer etiology are not known, individual risks cannot be measured. Instead, risks are estimated by the components that are known, and equal risks are assigned to individuals with identical causal status of the known components. For example, all individuals within the specific category of "women having a family history of breast cancer with an affected mother and a sister" are assigned the average value of that category. As knowledge of other risk factors expands, the risk estimates will depart from the average depending on the absence or presence of these factors (Rothman & Greenland, 1998).

To interpret the values of average risk and an individual's risk, specification of the time period to which it applies is needed. Without this specification, the values of

risk become meaningless (Rothman & Greenland, 1998). In health education, risks are often presented in the form of "1 in 10 lifetime risk", but they make more sense to an individual if they are put into absolute figures and specific timeframes. In these terms, the average woman's lifetime risk up to age 80 in the United States is 11% (1 in 9, which is slightly higher than in Finland). However, up to age 50, it has been calculated to be only 2%. If she has not got the disease by the time she is 50, her chance of getting it between 50 and 70 is 6%, and if she still has not got it, the chance between 70 and 80 is 3%. (Kelly, 2000).

1.2. Formation of an individual's risk perception

1.2.1. Perceived risk, perceived susceptibility, and perceived vulnerability.

There is considerable evidence that risk perceptions reflect a broader set of cognitive and affective beliefs than just estimations of the likelihood of an event (Rothman & Kiviniemi, 1999). An individual's perception of herself/himself and the world builds up gradually in a process where new information is assimilated into the individual's existing conceptual systems, also called schemata (e.g., Stahlberg, Petersen, & Dauenheimer, 1999). Information that is consistent with self-schemata is preferred, and has stronger cognitive associations with other self-relevant cognitions and higher resistance to change (Petersen, Stahlberg, & Dauenheimer, 2000), while incongruent information is often totally ignored or neglected. Perceptions concerning vulnerability or susceptibility to a particular health problem or disease are also formed in this manner. In the process of integrating information into their conceptual systems or schemata, people may have come to think that they belong to "a cancer family" or to "a heart disease family", and are thus susceptible to that disease but not to others. Aiken and colleagues (1995) showed this in their study where women described heredity as either a risk-increasing or a risk-decreasing factor for breast cancer. For example, women who saw heredity as a risk-decreasing factor expressed this by saying that they had "lucky ancestors" or that the "family had other diseases".

These kinds of views underlying risk perceptions may have developed over many generations and may be very hard to change. In fact, often some major event is needed that challenges the whole conceptual system, starting a process of re-evaluation and restructuring of one's views that allows profound changes to take place. After experiencing an accident, a disease or some other traumatising event, the stability and the coherence of one's conceptual system is severely threatened, and basic assumptions concerning the world and oneself are re-evaluated (Janoff-Bulmann, 1989). At this stage people have been found to view the traumatising events as more common, and to be more inclined to believe that they themselves would become future victims (Taylor, 1995; Weinstein 1987, 1989). A time period like this when people think about their risk more often and with greater clarity has been called a "window of vulnerability" (Taylor, 1995).

The concepts of risk perception, perceived susceptibility, and perceived vulnerability are used interchangeably in the literature. They may cover very general perceptions and beliefs about a health problem's salience to oneself, and some researchers have developed specific measures to tap these general beliefs (see Slenker and Grant, 1989, and Stillman, 1977). However, often risk perceptions are examined and instrumentalised as more or less precise likelihood estimations. Two different perspectives on risk perceptions as likelihood estimations are commonly used, one assessing personal absolute risk ("How likely are you to get breast cancer in your lifetime?" e.g., Lipkus et al., 2000), the other comparative risk. Comparative risks are measured either directly ("Compared to other women your age, how likely are you to get breast cancer in your lifetime?" in Lipkus et al., 2000, other examples of direct measures can be found e.g. in Eiser, Eiser, & Powels, 1993, and Weinstein, 1982) or indirectly (by subtracting absolute peers' risk from absolute personal risk, e.g., in Fontaine & Smith, 1995; Hoorens & Buunk, 1993; and Perloff & Fetzer, 1986). Measuring scales used for personal absolute risks are either numerical (e.g., "10%") or verbal (e.g., "moderate risk"), direct comparative risks are measured with verbal scales.

In general, lay people have been shown to have difficulties understanding risk figures, and it has been suggested (Weinstein & Diefenbach, 1997) that verbal estimates should be used if there is no particular reason (e.g., comparison to medical risk information) favouring the use of percentage estimates. For example, in the study by Lipkus and colleagues (2000) focusing on breast cancer risk perceptions, women between the ages of 45-54 years were found to report comparable figure estimates for both their lifetime risk (34.4%) and their 10-year risk (30.2%). Both estimates were grossly overestimated compared to mean Gail scores for actual risk (8.1% and 2.9%, respectively). On verbal scales, however, both risks were perceived as "below average" (Lipkus et al., 2000).

1.2.2. Determinants of perceived risk: aspects of family history as a risk-increasing factor; behaviour as a risk-decreasing factor

What are the factors that determine whether people perceive themselves at high or at low risk? Studies on the associations between medical risk factors and risk perception (Lipkus, Rimer, & Strigo, 1996; Vernon, Vogel, Halabi, & Bondy, 1993) suggest that having a first-degree relative with breast cancer is by far the most important risk factor influencing risk perception. In fact, in the study by Lipkus and colleagues (1996), it was the only significant predictor of subjective risk among all the components defined by the Gail model (Gail et al., 1989).

Does knowledge of having the risk factor account for the correlation between perceived susceptibility and heredity? These associations were studied in depth by Drossaert and her colleagues (1996), who attempted to distinguish experience with breast cancer through a close person from knowledge of this being a risk because of common genetic inheritance. The results suggested that perceived risk is partially affected by experience and partially by knowledge of hereditary risk, indicating that even among first-degree relatives of breast cancer patients, having an objectively elevated risk is only one of the factors influencing risk perception.

Aiken and colleagues (1995) asked women to report both risk-increasing and risk-decreasing factors. Heredity was most often mentioned as a risk-increasing factor, but also physiological factors were mentioned. Both were especially frequently mentioned among women with higher than average perceived risk. Heredity was often also mentioned as a risk-decreasing factor, the majority of women with lower than average perceived risk mentioning it. While many women, especially those with lower than average perceived risk, mentioned personal actions (e.g., regular mammograms and performing BSE) as decreasing their risk, personal actions that would have increased the risk were very rarely mentioned. This is interesting, as a lot of health education is targeted at changing individuals' risk behaviours.

Even when engaging in a behaviour that is undeniably risky, people manage to make self-favouring interpretations for example by creating "risk stereotypes" that depend on their own risk behaviour in a self-protective way (Hahn & Renner, 1997). Hahn and Renner (1997) found that individuals who smoke avoid labelling their own behaviour as high risk by consistently setting the limit for "high risk cigarette consumption" over their own level of consumption. Thus the more a person smokes the higher s/he judges the level of high risk consumption to be. Hoorens and Buunk (1993) discovered that the healthier the behavioural pattern reported by subjects, the lower their own estimated risks, and also the larger the difference between their personal risk estimations and their risk estimations for other people. Thus risk perceptions are dependent on people's own actions which are viewed against some personally set norm and which are also socially compared. E.g., "I do not eat these risk-increasing foods; in fact I have a healthier diet than most others and therefore my risk for this particular disease is lower, so I am not at high risk".

1.2.3. Accuracy and self-favourable comparisons in risk perception: why would women be comparatively optimistic about breast cancer?

Tversky and Kahneman (1974) used the concept of "availability bias" to describe how people's judgements are biased by heuristic processing, i.e., the use of cues to arrive more easily at a judgement in order to save cognitive work. While heuristic processing relies on the ease of recall, another processing strategy, i.e., systematic processing, involves scrutiny and comparison of the information content, and typically, heuristic processing is associated with judgement of less risk while systematic processing is associated with greater motivation (Grayson & Schwarz, 1999; Trumbo, 1999). Recent research among men with and without a family history of heart disease suggests that the personal relevance of a judgement task may influence an individual's judgement strategy (Rothman & Schwarz, 1998).

The accuracy of judgements can be evaluated using different criteria: correspondence with a criterion for reality; consensus with other people's judgements; and pragmatic utility, i.e., the adaptive or functional value of the judgement (Kruglanski, 1989). In making judgements about breast cancer risk, correspondence with "objective" criteria such as Gail's model for determining medically increased risk (Gail et al., 1989) has been used to approximate the accuracy of risk perception (Lipkus et al., 2000; Skinner et al., 1998). These studies have shown that perceptions of breast cancer risk are related, but imperfectly, to objective risk status.

However, most often accuracy has been examined with the second criterion (Kruglanski, 1989) that deals with consensus, even though implicitly. Research has demonstrated that when people estimate comparative risks, most tend to see their own risks as lower than the risks of their peers. Thus there is no consensus between people's risk estimates. It is impossible for all people or even for most people to have lower risks than their peers. This phenomenon, called "unrealistic optimism" or more recently, "comparative optimism" has been found for a diversity of

negative events such as accidents, criminal victimisation, and diseases (e.g., Eiser, Eiser, & Powels, 1993; Fontaine & Smith, 1995; Hahn & Renner, 1997; Perloff & Fetzer, 1986; Rutter, Quine, & Albery, 1998; Van der Velde, Hooijkaas, & Van der Pligt, 1991; Weinstein, 1980, 1982, 1984, 1987; Wilcox & Stefanick, 1999).

Weinstein (1987) claimed that the degree of comparative optimism is associated with the following four factors: a belief that if the disease has not yet appeared, it will not in the future; a perception that personal action can prevent the disease; a perception that the disease is infrequent; and finally, a lack of personal experience with the disease. A further possible explanation is a lack of predisposing signs and symptoms. (Taylor, 1995). Could these factors also operate in making judgements about breast cancer risk? Non-specified form of cancer has not yielded comparative optimism in most of the earlier research (McCoy, Gibbons, Reis, Gerrard, Luus, & Von Wald Sufka, 1992; Weinstein, 1980, 1982, 1983, 1984, 1987). However, risk estimations concerning specific forms of cancer like stomach cancer (Eiser et al., 1993) or lung cancer (Hahn & Renner, 1997; Van der Velde et al., 1991; Weinstein, 1980, 1982, 1987) have usually been found to be comparatively optimistic, and some recent studies have also supported comparative optimism in breast cancer risk perception (Aiken et al., 1995; Lipkus et al., 2000; Skinner et al., 1998).

The belief that breast cancer will not develop in the future if it has not yet developed is unlikely at least to a certain age, since the risk of breast cancer increases with age. Mass screening to detect the disease only starts when women turn 50. Still, Aiken and colleagues (1995) found that the older women in their sample (where the mean age was 52 and the maximum age was 77 years) held this belief – it might be that especially those women who have already experienced normal mammograms are falsely reassured. The same study also found evidence for the second belief in that personal action was the second most frequently mentioned risk-decreasing factor. However, the specific behaviours mentioned were mammography and breast self-examination, both behaviours that do not affect actual risk of getting the disease even if they may lower the risk of dying from it. In

general, estimations of one's own health behaviours vs. other people's health behaviours have a tendency to be self-favouring (e.g., the belief that others smoke more and exercise less than oneself).

The third belief, i.e., that breast cancer is infrequent, is quite unlikely since e.g., media coverage on breast cancer is extensive (Pietilä & Aro, 1995). Lack of experience, however, is a highly likely source of optimism. Lack of signs and symptoms is a further likely contributor to comparative optimism especially among women who have not sought screening themselves (as is the case in invitation-based screening). Thus comparative optimism is also likely for breast cancer, at least in some sub-populations of women, implying that the second criterion for accuracy in breast cancer risk perception, consensus, is not met.

Pragmatic utility, which is the third criterion, is important, provided that accurate risk perception leads to proper actions (Robins & John, 1997). The next section examines risk perception as a motivational factor for health behaviours.

1.3. Implications of risk perception

1.3.1. Risk perception as a motivational factor

Risk perception is one of the major components in many health psychology theories based on social cognitive theories. The health belief model (Becker, 1974), protection motivation theory (Rogers, 1983), subjective utility theory (Ronis, 1992), and the theory of reasoned action (Ajzen & Fishbein, 1980) are probably the most frequently used theories for explaining an individual's behaviour including the risk component. The Health Action Process Approach (Schwarzer, 1992) integrates some of the main components of these theories into a two-stage model with separate processes for pre- and post-intentional phases. In the pre-intentional phase, risk perception is a key component. Many of these models have been used for

explaining both breast self-examination and screening attendance (e.g., Norman, 1991; Rutter, 2000).

The motivational hypothesis – i.e., that perceptions of risk are related to motivation to act and to action - is one of the underlying assumptions behind all of these models. At first glance, it also seems valid when studying factors related to breast cancer detection behaviours. As these behaviours are not preventive, i.e., they do not lower an individual's actual risk as primary prevention does, risk perceptions should not change as a result of engagement in these behaviours. In other words, it would be reasonable to expect that risk perceptions would motivate a behaviour rather than be influenced by it (at least as long as no abnormality is detected). However, this might not be the case. As stated earlier, Aiken and colleagues (1995) found that women reported mammography and breast self-examination as risk-decreasing factors, an unpublished finding of our own study, too. Furthermore, taking mammograms results in a *finding* that may influence risk perception: women may falsely interpret a normal screening finding as a sign of low future risk and a false positive finding as a sign of high future risk. Thus the theories may provide a limited view on the association between breast cancer risk perceptions and detection behaviours.

The majority of empirical studies examining the associations between perceptions of personal risk and mammography behaviour have found positive correlations between increased perception of risk and behaviour (see a meta-analysis on the relationship between breast cancer risk and mammography by McCaul, Branstetter, Schroeder, & Glasgow, 1996). Findings for other detection behaviours, mostly breast self-examination, have been inconsistent (Calnan & Rutter, 1986; Champion, 1988, 1992; Nemcek, 1990; Vernon et al., 1993; Wyper, 1990).

A problem with many studies examining the association between risk perceptions and behaviour is that they use correlational data, so inferences about causality cannot be made. When prospective designs have been used, the association between

risk perception and previous behaviour has been controlled infrequently. Aro (1996) investigated participation in invitation-based screening among the women in the present study. In a discriminative function analysis, neither perceived absolute risk nor perceived susceptibility was found to correlate significantly with the discriminative function calculated to classify participants and non-participants. Instead, among the factors (earlier, clinical mammograms, pap-screening, smoking, and marital status) found to correlate significantly with the discriminative function, earlier mammograms, i.e., previous behaviour, showed the highest correlation (Aro, 1996). Furthermore, a strong positive association between earlier mammograms and an increased perception of absolute risk was found among the screening non-participants but not among the participants.

A further problem with earlier research is that the association between risk perception and behaviour may change considerably over time – even if high risk were an important predictor of behaviour at one point, it may cease to be such as time passes by (Weinstein, Rothman, & Nicolich, 1998). It seems that when new precautions depending on self-initiated behaviour are introduced, people with high perceived risk are the first ones to adopt the behaviour. This phenomenon probably accounts for the findings of an early study by Rutledge and colleagues (Rutledge, Hartmann, Kinman & Winfield, 1988) showing that susceptibility was highest among women with a recent mammogram and lowest among women who declined an invitation to screening. Later on, when the amount of precautionary behaviour has become relatively stable or when adoption is no longer dependent on self-initiation (like e.g. in an invitation-based screening program), other factors become more influential predictors.

1.3.2. Psychological distress related to perceived susceptibility

Research suggests that medically-defined risk or having known risk factors are not sufficient to cause psychological distress – instead, the individual's perception of

risk is the effective factor (Watson, Lloyd, Davidson, Meyer, Eeles, Ebbs, & Murday, 1999). Earlier research shows that first-degree relatives of breast cancer patients tend to be concerned about their risk (Anderson, Steel, Smyth, & Cull, 1994; Vernon et al., 1993; Vogel , Schreiber, Vernon, Lord, Winn, & Peters, 1990). Some of them exhibit high distress, and some are even in need of counselling (Kash, Holland, Halper, & Miller, 1992; Lerman et al., 1993). A substantial proportion of women coming to risk counselling with high perceived breast cancer risk have been found to suffer from psychological problems ranging from intrusive thoughts about breast cancer to impairments in daily functioning due to breast cancer worries, and to sleep disturbance (Lerman et al., 1993).

However, most studies on the psychological implications of risk perception have been conducted among high risk populations (Anderson et al., 1994; Kash et al., 1992) — some of them self-selected to detection programs for high risk women (Kash et al., 1992) or to risk counselling clinics, some notified of increased risk. A review (Vernon, 1999) on studies of risk perception concluded that overall, very few studies have examined psychological or psychosocial measures in relation to perceived risk. Only one of the studies in the review was carried out among a normal risk population. This was a small-scale cross-sectional study (Bowen, Hickman, & Powers, 1997) among African-American women. Risk over-estimators were found to score higher on anxiety and depression. Another recent study not included in the review tested an intervention on genetic testing intentions (Cameron & Diefenbach, 2001). It was conducted in a student sample and was thus not representative of the normal population, but it found a significant correlation between breast cancer worry and perception of personal risk. In one study (Lipkus et al., 2000) both absolute and comparative risk perceptions for breast cancer were examined in a normal population sample (N = 581 women between the ages of 45-54, mean age 49.5 years). On average, the women believed their risk was lower than the risk of other women their age and race; thus they were comparatively optimistic. Worries were associated with both absolute and comparative risk perceptions.

One possible implication of increased risk perception and risk-related psychological distress is heightened anxiety and nervousness during mammography. These may lead to increased sensitivity to physical pain. It seems that many women undergoing mammography experience pain during the procedure. The reported prevalence of pain ranges from around 50% up to 75% (Bruyninckx, Mortelmans, van Goethem, & van Hove, 1999; Drossaert, Boer, & Seydel, 2001; Dullum, Lewis, & Mayer, 2000; Fallowfield, Rodway, & Baum, 1990; Hafslund, 2000; Keemers-Gels, Groenendijk, van den Heuvel, Boetes, Peer, & Wobbes, 2000; Nielsen, Miaskowski, Dibble, Beber, Altman, & McCoy, 1991; Scaf-Klomp, van Sonderen, van den Heuval, 1997). In explaining pain, most studies have examined factors related to the woman's demographic background and medical history or to the screening procedure and personnel. Distress indicators such as anxiety and screening-related nervousness have been studied more rarely. It seems that screening-related nervousness is related to pain (Boer, 1993; Bruyninckx et al., 1999; Nielsen et al., 1991), but the findings on anxiety are ambiguous (Hafslund, 2000; Keemers-Gels et al., 2000; Rutter, Calnan, Vaile, Field, & Wake, 1992). Of the studies on mammography pain, only one (Drossaert et al., 2001) examined the role of risk perception in pain, finding that these factors were unrelated.

1.3.3. Individual differences in responses to health threats: the effect of coping styles

Individuals vary a great deal in how they respond to a health threat. The two probably most widely used models of what factors are involved when an individual encounters a health threat are Leventhals' self-regulatory model of illness representations (Leventhal, Diefenbach, & Leventhal, 1992; Leventhal, Leventhal, & Contrada, 1998) and the Transactional Theory of Stress and Coping by Folkman and colleagues (Folkman, 1984; Folkman & Lazarus, 1988). In the self-regulatory model, outside stimuli provoke not only a representation of the health threat but also

a representation of the emotion involved. These then lead to coping procedures and appraisals of the outcomes. In the Transactional Theory of Stress and Coping, an encounter with a stressful event produces primary appraisal whereby the person evaluates whether she has anything at stake in the encounter. Risk perception can be seen as a product of this process. Secondary appraisal involves evaluating what, if anything, can be done. Finally, coping is defined as constantly changing cognitive and behavioural efforts to manage demands that exceed the person's resources (Folkman & Lazarus, 1988). Appraisals in the transactional theory are very similar to threat representations in the self-regulatory model. Another interesting feature both models have in common is the inclusion of coping.

Coping has been viewed as *situation-specific coping strategies* (e.g., Folkman & Lazarus, 1988), *attentional styles* in information seeking (Miller, 1987), and *dispositional coping styles* (e.g., Carver, Scheier, & Weintraub, 1989; Endler & Parker, 1994). The latter two are personality trait-like constructs. Despite differences in how coping is conceptualised, most researchers (e.g., Carver et al., 1989; Endler & Parker, 1990; Folkman & Lazarus, 1988) share the idea that one basic dimension of coping is directed at reducing the threat itself (monitoring; problem-focused coping, approach coping). Another dimension aims at reducing the emotional reaction caused by the threat (blunting; emotion-focused coping). Some have found it useful to separate avoidance from emotion-focused coping as a third distinct dimension (Endler & Parker, 1994).

The adaptiveness of any coping strategy is likely to depend on the circumstances (see, e.g., Zeidner & Saklofske, 1996). Problem-focused coping is associated with less depression and is usually seen as more adaptive in the long-term (Vitaliano, Dewolfe, Maiuro, Russo, & Katon, 1990). Emotion-focused coping and avoidance, on the other hand, may have short-term advances especially if the person is unable to deal directly with the threat. However, because they are associated with greater psychological distress (Holmes & Stevenson, 1990; Suls & Fletcher, 1985) and

depression (Endler & Parker, 1990; Vitaliano et al., 1990), they are probably maladaptive in the long run.

Optimism as a stable personality characteristic (distinct from comparative optimism) is a construct that has been shown to have important implications for how people manage their lives (Scheier & Carver, 1985). It has been associated with successful coping (Scheier, Weintraub, & Carver, 1986), and some researchers consider it as an independent coping dimension (Julkunen, 1996). Increasingly, there is evidence that optimism predicts both psychological well-being (Scheier & Carver, 1992; Triemstra, Van der Ploeg, Smit, Briët, Adèr, & Rosendaal, 1998), and somatic well-being (Helgeson & Fritz, 1999; Raikkonen, Matthews, Flory, Owens, & Gump, 1999; Scheier, Matthews, Owens, Schulz, Bridges, Magovern, & Carver, 1999).

Recently, some studies examining the association between cancer risk perceptions and psychological distress have also looked at how the association is influenced by individual differences in coping styles (Schwartz, Lerman, Miller, Daly, & Masny, 1995; Wardle, 1995). These studies examined the role of monitoring coping strategy and perceived cancer risk in predicting psychological distress among women at increased risk for ovarian cancer; however, the findings were contradictory (Schwartz et al., 1995; Wardle, 1995). Wardle (1995) found that monitoring coping strategy and risk perception were independent predictors of cancer worry. Optimism was related to both lower cancer worry and lower risk perception. In the second study (Schwartz et al., 1995), monitoring coping strategy and risk perception were found to be related, but had no direct association with psychological distress. Instead, the association was indirect, through intrusive thoughts. However, this study was limited to women with first-degree relatives with ovarian cancer, and the risk perception scale focused on the family history effect on perceived risk, making comparisons difficult.

1.4. Impact of screening: population level and individual perspectives

When women in the normal population are approached for screening, they are made to face a health threat. Important questions for service providers are not only the population level benefit/harm ratio of the service in terms of morbidity and mortality, but also the psychological impact of the service on the whole group (Wilson & Jungner, 1968). However, there may be great individual differences — e.g. in the level of awareness — that influence how people respond to the threat. While the literature on risk perceptions and their associations with behaviour is based on social-cognitive models, literature on implications of the screening process and findings has a nearly non-existent theoretical framework. The cognitive-behavioural models of illness anxiety arising from the tradition of psychosomatic studies have mostly been used to guide research questions and the development of methods (Aro, 2001).

1.4.1. How does screening influence the psychological well-being of the screened population?

Attending screening is different from most health behaviours in that the initiative for the behaviour comes from outside the individual (Aro, 2001). It does not necessarily require the same motivational processes as more complicated behaviours such as regular breast self-examination that demand longer-term personal engagement. Furthermore, women who are invited and come to screening are probably less aware of the procedure itself as well as the possible consequences, and thus also less likely to be psychologically prepared for them, compared to women coming in for testing (Aro, 2001).

In terms of psychological well-being, there are some specific phases of the screening process that are critical (Aro, 2001): Getting an invitation to screening may raise worry concerning both the procedure and the disease. Attending the

screening test may be inconvenient and painful. Getting a normal finding is probably a relief, but may also influence health behaviour in one direction or the other. If the mammogram has been abnormal, the diagnostic work-up that follows can be mutilating and raise anxiety. Getting a false positive finding is a relief, but worry and high risk perceptions may remain. Getting a true positive finding, i.e., cancer, usually results in an improved prognosis, but it can also compromise the quality of life, especially if the cancer cannot be cured. Getting a false negative finding results in false reassurance and a delayed diagnosis. Of these phases, most research has focused on the impact of false positive findings; however, the vast majority of these studies have been carried out in contexts other than organised screening programmes.

Two prospective studies that were carried out in the United Kingdom to examine the stressfulness of routine mammography screening (Sutton, Saidi, Bickler, & Hunter, 1995; Walker et al., 1994) found that anxiety was lower at the clinic than at pre-invitation baseline. Reassuringly, women who were borderline or clinically depressed or anxious were more likely to become normal than vice versa (Walker et al., 1994). Most women (80-95% depending on the Health Questionnaire item) reported normal behaviour and feelings during the week prior to screening. However, of the remaining 5-20%, most reported changes towards “worse than normal”. Sleep disturbance and an inability to stop worrying, to relax, or to concentrate were the most often reported changes for the worse. Women most anxious or depressed at baseline reported the most stress-related behaviour changes in the week prior to screening (Walker et al., 1994).

The study by Sutton and colleagues (1995) included not only women with normal screening findings but also women with false positive findings. A further strength of the study was a long-term measurement nine months after baseline. Women with a false positive finding reported retrospectively being extremely anxious after the recall letter, but also recollected more anxiety at earlier stages in screening and more pain and discomfort during the x-ray. The authors suggested that a repeated

measurement effect accounted for the decrease in anxiety from baseline to clinic — this seems quite likely especially since no differences were found in the clinic measurements between those assessed before and those assessed after the screen test.

Two longitudinal studies investigated the consequences of further investigation after mammography screening (Brett et al., 1998; Lampic, Thurfjell, Bergh, & Sjödén, 2001). When a generic measure was used, i.e., the Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983), a high prevalence of anxiety prior to recall and significant differences in short term distress depending on the types of examination and information received at the recall visit were found. However, there was no evidence of prolonged distress in recalled women with false-positive mammograms twelve months after the recall. (Lampic et al., 2001).

When the impact of screening was evaluated using a breast cancer-specific measure (PCQ, Perceived Consequences Questionnaire by Cockburn, De Luise, Hurley, & Clover, 1992), adverse effects were found to remain also in the long term (Brett et al., 1998). Women who went on for further investigation during routine breast screening reported significantly higher adverse effects even five months after their last screening visit compared with women who received a clear result after mammography. The nature and extent of the further investigation that women were exposed to during breast screening determined the intensity of the PCs. Notably, women with benign biopsies reported the most PCs both at one month and five months after their last appointment.

Eerola (1995) used both qualitative and quantitative data to describe short-term reactions to invitation to further examinations and to analyse the effect of coping on these reactions among the women in the present study. Her study showed that over 30% of the women became very worried at the invitation, and almost 60% became somewhat or slightly worried. When using the qualitative data to look more specifically at the cognitive and emotional reactions behind “worry”, Eerola (1995)

found that many women had been shocked by the invitation. During the waiting period, many reported having been pre-occupied with thoughts and fears of cancer, of losing their breasts, and even of dying. Associated problems with daily functioning and sleep, similar to those reported by Walker et al. (1994), were also found (Eerola, 1995).

None of these studies investigated screening impact on risk perception. Pisano and colleagues (Pisano, Earp, Schell, Vokaty, & Denham, 1998) surveyed 43 women who had undergone excisional breast biopsies after false-positive mammograms and found that still after three years they had higher perceived susceptibility to breast cancer than women with normal mammograms. However, as the study was retrospective, they were unable to control for pre-screening risk perceptions.

Comprehensive epidemiological research incorporating the strengths of these earlier studies is clearly called for. These include a prospective design with pre-invitation baseline and long-term follow-up, different screening findings including normal finding, false positive finding and benign biopsy, a referent group outside screening, and outcome measures ranging from generic to breast cancer-specific measures and to risk perception.

1.4.2. Do family history and increased risk perception influence responses to screening?

The epidemiological, population level analysis comparing groups with different screening findings is, however, insufficient because it neglects the importance of individual differences. Women come to screening with different backgrounds and different levels of awareness and these may influence how they respond to screening. Gilbert and colleagues (Gilbert, Cordiner, Affleck, Hood, Mathieson, & Walker, 1998) pointed out the lack of studies on these issues, calling for research on the psychological effect of screening in women who have a family history of breast

cancer. They predicted that these women would be particularly adversely affected by a false-positive recall (Gilbert et al., 1998). Women may also have high perceptions of risk for various other reasons, and suffer from related distress. The effect of screening on these women has also been neglected to an even greater extent.

Besides the work by Gilbert and his colleagues (1998), we know of only one other study that investigated the impact of mammography screening on women with a family history of breast cancer. This was a small-scale study with 26 self-selected women with first-degree relatives with breast cancer and normal mammograms and 27 control women with no family history of breast cancer and not undergoing mammography (Valdimarsdottir, Bovbjerg, Kash, Holland, Osborne, & Miller, 1995). Perceived lifetime risk measured before screening was higher among cases than among controls, but grossly overestimated in both groups (59.2 vs. 28.1 on a percentage scale). In both groups, the level of intrusive thoughts decreased from baseline (before screening in the family history group) to one month, but women with family history had higher levels of intrusive thoughts on both assessment days. They also had higher levels of non-specific distress than the control group even a month after notification of normal mammography results. Acute distress among the family history group was significantly higher at screening, prior to mammogram than immediately after receiving the results on the same day or one-month later. However, a decrease in non-specific distress, intrusive thoughts and avoidance was also found among the control group. One possible explanation for decrease in stress is the one raised by the epidemiological studies, i.e., repeated measurement effect (Sutton et al., 1995). The self-selected women with family history of breast cancer were probably also more concerned about the possibility of having breast cancer than are women in organised screening programmes based on invitation.

The study by Gilbert and colleagues (1998) was a large-scale prospective study with pre-invitation baseline and last follow-up at 4 months after screening. Problematically, only women who were recalled were assessed after screening, and

reasons for recall varied from having either a significant family history, or a mammographic abnormality, or both. This study showed a significant increase in anxiety at the recall visit. Stress-related behaviour changes were assessed by asking the subjects to compare their reactions during the weeks prior to recall and prior to screening. Women with a family history seemed to be better prepared for screening. They were more likely to score in the normal range of depression at screening, and they reported fewer stress-induced behaviour changes in the week prior to screening. The authors concluded that screening appears to be reassuring for women with a family history of breast cancer. All in all, studies on individual differences in screening are sparse and the same criticism that was raised when evaluating the epidemiological studies also applies here: a comprehensive approach is clearly called for.

1.5. Summary of current research needs in breast cancer risk perception and the aim of this study

While there is extensive literature on people's perceptions of different health risks, and a substantial amount of the research is specific to breast cancer, several limitations needing to be addressed were identified. Risk perceptions have been studied using different types of measures, from absolute to comparative risk estimates and to more general feelings of susceptibility. While studies with both absolute and comparative measures (Lipkus et al., 2000) have shown that these are incongruent, studies examining absolute and comparative risks as well as perceptions of susceptibility are non-existent. Only one study (Drossaert et al., 1996) has examined the roles of both experience with breast cancer and knowledge of hereditary risk in the formation of risk perception.

The main problems with existing studies on the association between risk perception and behaviour are correlational designs and the inability to control for the effect of

previous behaviour on risk perception (McCaul et al., 1996). Little research exists on the associations between psychological well-being or worry and risk perceptions (Vernon, 1999). With the existing studies, representative samples are rare, and psychological measures tend to be limited. Studies on factors that could be mediating the effect of risk perception on psychological well-being, such as coping, are limited in number and focus on coping as an information processing style (Schwartz et al., 1995; Wardle, 1995).

Worldwide, millions of women are invited to mammography screening each year and a substantial number are recalled for further examinations. Still, prospective, longitudinal studies examining the psychological impact of screening with representative samples of women with different screening findings are sparse (Sutton et al., 1995), and risk perception has not been included in these studies. The effects of screening and different screening findings on women's risk perceptions are among the most neglected possible implications of screening, and without longitudinal studies, the stability of risk perceptions as well as the effects of previously existing risk perceptions on responses to screening remain largely unknown.

The aim of the present study was to get more information about factors that influence the formation of risk perceptions; to examine the stability of risk perceptions; to identify behavioural and psychological implications of risk perceptions; to clarify the role of risk perception in women's responses to screening; and to show how screening and different screening findings influence women's risk perceptions as well as their psychological well-being in the screening process and afterwards. In order to overcome some of the problems in earlier research, the present study had a prospective, longitudinal design with representative samples of women with different screening findings in a national screening program. Measurement covered different aspects of risk perceptions from absolute to comparative risk and perceived susceptibility (see table 1.1.), and a wide

range of mainly standardised measures were used for assessing psychological factors.

Table 1.1. Description of the different risk perception concepts in the study

Risk perception concept	Description
Personal lifetime risk or Perceived absolute personal risk or Personal risk likelihood estimate	Estimate of one's own chances of getting breast cancer during one's lifetime. Specific, verbal categories ranging from non-existent risk to very high risk.
Peers' lifetime risk or Perceived absolute peers' risk or Peers' risk likelihood estimate	Estimate of the chances of an average, same age woman getting breast cancer during her lifetime. Specific, verbal categories ranging from non-existent risk to very high risk.
Comparative optimism	Belief that one's own chances of getting breast cancer are lower than the average woman's. A difference-score calculated from personal and peers' lifetime risk.
Perceived susceptibility (PS)	A general feeling of vulnerability to breast cancer, raised into consciousness by triggers in specific situations (e.g., hearing about others with the disease). A multi-item scale.

1.6. The Research Questions Addressed in this Dissertation

1.6.1. Are women comparatively optimistic in their perception of their breast cancer risk? Are comparative optimism and perceived susceptibility to breast cancer determined by breast cancer experience via a significant other? (See conceptual map in figure 3.1.; Articles I and IV).

1.6.2. Does increased perception of risk predict engagement in behaviours targeting breast cancer detection, i.e., participation in mammography screening and practice of breast self-examination (BSE)? (See conceptual map in figure 3.2.; Article II and an additional analysis predicting BSE not included in the original articles).

1.6.3. Is increased perception of breast cancer susceptibility related to psychological distress? (See conceptual map in figure 3.3.; Articles IV and VI).

1.6.4. What are the roles of breast cancer experience and coping style in risk perception? Do some coping styles indicate better adjustment in terms of lower levels of psychological distress? (See conceptual map in figure 3.3.; Article IV).

1.6.5. Do increased perception of risk and screening-related experiences predict pain and discomfort experienced during screening mammography? (See conceptual map in figure 3.4.; Article III).

1.6.6. How do mammography screening and its various findings influence women's risk perception, psychological distress and breast cancer-specific health behaviour? (See conceptual map in figure 3.5.; Articles V and VI, and

an additional analysis on whether screening finding predicts comparative optimism, not included in the original articles).

1.6.7. Do pre-existing experiences of breast cancer via a significant other and an increased perception of susceptibility predict women's psychological and behavioural responses to screening and screening finding? (See conceptual map in figure 3.6.; Article VI).

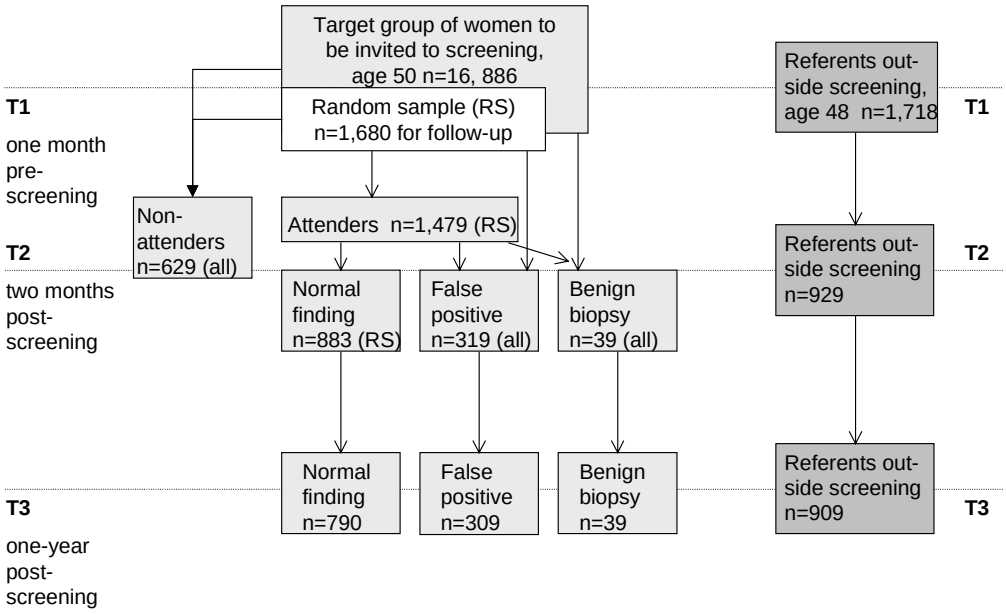
2. Methods

2.1. Participants

Participants were women (age 48-50 years) who took part in a nation-wide study evaluating the psychological impact of the Finnish public health programme for mammography screening (see figure 2.1.). Both women invited to screening as well as referents outside screening were included in the study. The study was a prospective survey, comprising three measurements: T1 one month before the screening invitation, T2 two months and T3 one-year post-screening. At T1, the survey questionnaire was sent to a target group of 16,886 women who were to be invited to screening (age 50) and 1,718 community referents (age 48). Because of the impending screening, targeted reminders to the non-respondents could not be sent. The response rate at T1 was 61.1% among screening participants and community referents, but only 38% (n = 641/1695) among screening non-participants.

At T2, tailored questionnaires were sent to five different groups of T1 respondents: 1) Women with a normal screening finding (from a random 1/10 sample of the target population, n = 883). 2) Women with a false positive screening finding (all women in the target group including the random sample who were recalled but found normal, n = 319). 3) Women with benign biopsy (all women in the target group including the random sample, who had undergone benign surgical breast biopsy, n = 39). 4) Screening non-participants (n = 629). 5) Community referents as group controls (n = 929). At T3, tailored questionnaires were again sent to all these T1 respondents, excluding the group of screening non-participants. Response rates at T2 and T3 were 82.7% and 76.0%, respectively.

Figure 2.1. Study groups and measurements.



The screening flow with different groups and different measurement points are presented in figure 2.1. Study designs and the specific groups in analysis for answering each research question are shown in figures A1-A7 in the Appendix. For research question I, a cross-sectional study design with data from T3 was used (figure A1); for question II, a prospective design with data from T1 and T2 (figure A2); for question III, a cross-sectional design with data from T3 and a longitudinal design with data from all measurement points (figure A3); for question IV, a cross-sectional design with data from T1 (figure A4); for question V, a prospective design with data from T1 and T2 (figure A5); and for questions VI and VII, prospective designs with data from all measurement points (figures A6 and A7).

2.2. Measures

A detailed description of the measures (examples, response format, reliabilities, etc.) can be found in Articles I-VI in the appendix. Risk perceptions were used as dependent variables in answering research questions I, IV, and VI, and as

independent variables in answering research questions II, III, V, and VII. They were measured as:

1. Personal[T1,T3] and peers' lifetime risks [T3]of developing breast cancer (also called "absolute perceived risks" or "risk likelihood estimates"), assessed with two single items. Response categories in both questions were 1 = "non-existent risk", 2 = "low", 3 = "moderate", 4 = "quite high", 5 = "very high risk", and an additional option "cannot tell". The item concerning personal risk preceded the item on peers' risk on the questionnaire.

2. Comparative optimism, a difference-score calculated from personal and peers' lifetime risk, excluding the option "cannot tell".

3. Perceived susceptibility[T1], a subscale from the Breast Cancer Susceptibility Scale, BCS (Slenker & Grant, 1989; Stillman, 1977), α = 0.69. Perceived susceptibility was used as a continuous variable (dependent variable) and as an ordinal variable (independent variable) with the following three categories: *low susceptibility* ($\leq$ mean - 1 SD); *moderate susceptibility* (mean $\pm$ 1 SD); and *high susceptibility* ($\geq$ mean + 1 SD).

Other main independent variables of the study were the following:

1. Experience of breast cancer at close range[T1]. In Article III, the following categories were used: 1) a first-degree relative with breast cancer (FDR); 2) other blood relative with breast cancer (OBR); 3) a friend with breast cancer (FRIEND); 4) knew someone else with breast cancer (ELSE); and 5) knew nobody with breast cancer (NO). In answering the first research question (Article I), categories 3 and 4 were collapsed. In answering research question VII (Article VI), categories 2, 3, and 4 were collapsed, leaving three categories: *familial experience* (had a first-degree relative with breast cancer); *other experience*; and *no experience*).

2. Knowledge that heredity is a risk factor[T1]. All those selecting heredity among the three most important risk factors for breast cancer were classified as having this knowledge.

3. Screening finding for the study participants was received from the screening centres. Women were categorised into three groups: *a normal finding* (i.e., a negative result of the screening mammogram); *a false positive finding* (i.e., a positive result from the screening mammogram but a negative result from further examinations); and *a benign biopsy* finding (i.e., a positive result from both screening mammogram and further examinations but a benign finding from breast surgery).

4. Coping strategies[T1] were measured with the COLOSS (Coping with Losses) Scale. Based on his earlier work with cardiac patients (Julkunen & Saarinen, 1994), Julkunen modified the scale for this study. Respondents were asked to recall a situation during the past two years where they or a person close to them were confronted by a serious disease, and to describe their own reactions in that situation. Even though the instruction was situation-specific, it was assumed that the same coping styles would be applied across other disease-related situations, too, i.e., the coping strategies were assumed to be dispositional. The scale comprises 21 statements. The answer format is a 4-point Likert-type scale ranging from "completely disagree" to "completely agree". Two hundred and nineteen subjects stated that they had not experienced such a situation during the requested time and left the scale unanswered. Four factors extracted in a factor analysis on the random sample and the referents were used: 1) depressive resignation to represent emotion-focused coping (general reliability = 0.78); 2) repression to represent avoidance (general reliability = 0.83); 3) re-orientation to represent problem-focused coping (general reliability = 0.75); and 4) optimism (general reliability = 0.79). Based on the factor structure, averaged sumscores were calculated (i.e., totals were divided by the number of items contributing to the score). Means were used as the cut-off

points to separate those who had used a given coping strategy from those who had not.

A variety of psychological responses were measured and used mainly as dependent variables (except for research questions II and V in which screening participation and experience of mammography pain were predicted from some of these variables). They indicated general distress, health-related concerns, breast cancer-specific beliefs, breast cancer-specific concerns, and screening-related experiences.

1) Indicators of general distress: State anxiety$^{T1, T2, T3}$ as measured with the state portion of Spielbergers State-Trait Anxiety Inventory (Spielberger, Gorsuch, & Lushene, 1970), scale range 20-80, $\alpha = 0.95$. Depression $^{T1, T2, T3}$ as measured with the Beck Depression Inventory (Beck, Ward, & Mendelson, 1961), scale range 0-63, $\alpha = 0.88$.

2) Health-related concerns: The Illness Attitude Scales $^{T1, T2, T3}$ (IAS, Kellner, 1987, item scale range 0 = "never" to 4 = "most of the time"): concern about pain and bodily preoccupation (CP), $\alpha = 0.70$; negative effects of bodily symptoms (EfS), $\alpha = 0.90$; fear of death (FD), $\alpha = 0.71$; worry about illness (WI), $\alpha = 0.60$; and fear of illness (FI), $\alpha = 0.73$.

3) Breast cancer-specific beliefs: Severity of breast cancer$^{T1, T3}$, a BCS subscale (Slenker & Grant, 1989; Stillman, 1977), $\alpha = 0.60$. Single items were used for measuring breast cancer prevention efficacy$^{T1, T3}$ (1 = "no"; 2 = "low"; 3 = "moderate/high"); self-efficacy in breast self-examination$^{T1, T2, T3}$ (BSE) (1 = "no"; 2 = "low"; 3 = "moderate/high"); importance of BSE$^{T1, T2, T3}$ (1 = "unimportant"; 2 = "quite important"; 3 = "very important"); confidence in mammography^{T1} (1 = "100%"; 2 = "95%"; 3 = "≤ 70%"); and beliefs concerning the quality of most breast lumps^{T1} (1 = "benign"; 2 = "cancer"; 3 = "don't know").

4) Breast cancer-specific concerns: Single items were used for measuring frequency of intrusive thinking[T2, T3] (1 = "never"; 2 = "sometimes"; 3 = "often/most of the time"); and current worry about breast cancer [T2, T3] (1 = "no"; 2 = "a little"; 3 = "quite/a lot").

5) Screening-related experiences: Single items were used for measuring anticipation (T1) and actual experience (T2) of pain[T1, T2] and discomfort [T1, T2] (1 = "not at all"; 2 = "moderately"; 3 = "severely"; 4 = "cannot tell"). At T2, feelings evoked by either the invitation or the screening situation were measured with the following single items: Worry about breast cancer evoked by the invitation; nervousness experienced before screening; feelings of tenseness and fear, being relaxed, and embarrassment evoked by the screening situation (all ranging from 1 = "not at all" to 4 = "very"). Perceptions of the staff were measured at T2, with 5-point graphic scales from "friendly" to "unfriendly"; "helpful" to "unhelpful"; "reassuring" to "worrying"; and "interested" to "indifferent"). Based on a factor analysis (see Article III for a detailed description of the analysis) these items were reduced to two factor scores, one for screening-related nervousness ($\alpha = 0.83$) and the other for positive perceptions of the staff ($\alpha = 0.88$).

Health behaviours measured in this study were a variety of cancer detection behaviours and other health-promoting behaviours. Participation (participants/ non-participants) in the mammography screening was received from the screening centres, and single items were used for measuring past mammograms[T1] [1 = "during past 6 months"; 2 = "> 6 months ago"; 3 = "never". In answering research question V (Article III), the first two categories were collapsed]; frequency of BSE[T1, T2, T3] (1 = "rarely/never"; 2 = "occasionally"; 3 = "monthly"; 4 = "weekly"); pap-smear screening [T1] (1 = "during past 5 years"; 2 = "> 5 years ago"; 3 = "never"); and gynaecological examinations[T1] (1 = "once a year"; 2 = "occasionally"; 3 = "if/when symptoms"; 4 = "never"). Health habits[T1, T2, T3] (HH, $\alpha = 0.64$) and treatment experiences[T1, T2, T3] (TE, $\alpha = 0.86$) were measured using subscales from the IAS

(Kellner, 1987, item scale range from 0 = “never” to 4 = “most of the time”), and smoking^{T1} as a single item (yes/no).

In addition, the following health history and socioeconomic factors were measured: recent cancer diagnosis; history of serious illness; marital status; education; working status; income; and area of residence. These were all measured at T1. The categories can be found in Article II, Table 1.

2.3. Statistical analysis

As most of the study questions concerned differences between groups, the main analytic strategy used was analysis of variance (ANOVA), but univariate and multivariate logistic regression analyses with odds ratios and 95% confidence limits as well as linear regression analyses were also used. Effect sizes for all the effects in analyses of variance were based on Eta-squared. Of the outcome measures, BDI and STAI were used as sumscores. All other multi-item scales were factor analysed using maximum likelihood solution and varimax-rotation, and eigenvalues >1 to determine the number of factors. Averaged sumscores were calculated based on the factor solutions. SPSS 10.0 for Windows was used for all other analyses except the factor analyses and the logistic regression analyses, which were performed using Survo 84C software.

To answer the first study question and to determine the extent of comparative optimism, the likelihood ratings of developing breast cancer with reference to oneself and a peer were examined by an ANOVA. A multivariate solution was used, with target (i.e., the person rated) as a within-subject factor. To analyse the effect of experience (with the categories “FDR”, “OBR”, “ELSE”, and “NO”) and knowledge of hereditary risk (“yes”, “no”) on comparative optimism, these were included as the between-subjects factors in the analysis. To examine the influence

of the same factors on perceived susceptibility, an analysis of covariance (ANCOVA) with an adjustment for education was also conducted.

Two analytic strategies were used for examining whether increased risk perception predicts breast cancer detection behaviours. Prediction of screening participation was studied with univariate and multivariate logistic regression analyses, and prediction of BSE frequency with multiple linear regression analysis. In both analyses, past behaviour was also included in the multivariate models.

To answer the question whether increased risk perception is associated with psychological distress, two sets of analyses were conducted. First, the associations between perceived susceptibility and distress variables were analysed with multiple hierarchical regression analyses in a cross-sectional design. Second, the effect of perceived susceptibility (categories “low”, “moderate”, and “high”) on levels of distress over time was analysed with repeated-measures MANOVAs, with separate analyses for general distress, health-related concerns, breast cancer-specific beliefs, breast cancer-specific concerns, and behavioural indicators of distress.

The roles of breast cancer experience and coping style in risk perception and psychological distress were studied with separate analyses of variance for each coping style with experience, knowledge of hereditary risk, and one of the coping styles as the between-subjects factors and education as a covariate in each analysis. A fifth category to the experience variable, i.e., a “FRIEND” was separated from the category “ELSE”. For risk perception, a univariate approach was used (ANCOVA). For psychological distress, a multivariate approach was used, with risk perception as a covariate (MANCOVA).

The influence of risk perception on pain and discomfort experienced during mammography screening was analysed with two-way contingency tables and chi-square tests. Furthermore, separate linear regression analyses to predict pain and

discomfort were conducted among women with and without previous mammograms.

The population level influence of screening on psychological distress and breast cancer-specific health behaviours adjusted for background factors, personality measures and pre-screening distress was analysed with a MANCOVA, with screening groups (“normal finding”, “false positive finding”, and “community referents”) as a between-subject factor. An additional ANOVA was conducted to examine the effect of screening finding (“normal finding”, “false positive finding”, and “benign biopsy”) on comparative optimism. Patterns of psychological distress over time related to screening finding were analysed with repeated-measures MANOVAs with time as the within-subject factor. Separate analyses were carried out for general distress, health-related concerns, breast cancer-specific beliefs, breast cancer-specific concerns, and behavioural indicators of distress.

To analyse how previous experience of breast cancer (“familial”, “other”, and “no”) and pre-screening risk perception (“low”, “moderate”, and “high”) influence women’s responses to screening finding (“normal finding” and “false positive finding”) repeated-measures MANOVAs were used. Again, separate analyses were carried out for general distress, health-related concerns, breast cancer-specific beliefs, breast cancer-specific concerns, and behavioural indicators of distress.

For more detailed information on factor analyses, alpha- and general reliabilities, replacement of missing values, and other issues concerning data management, see the individual articles in the appendices.

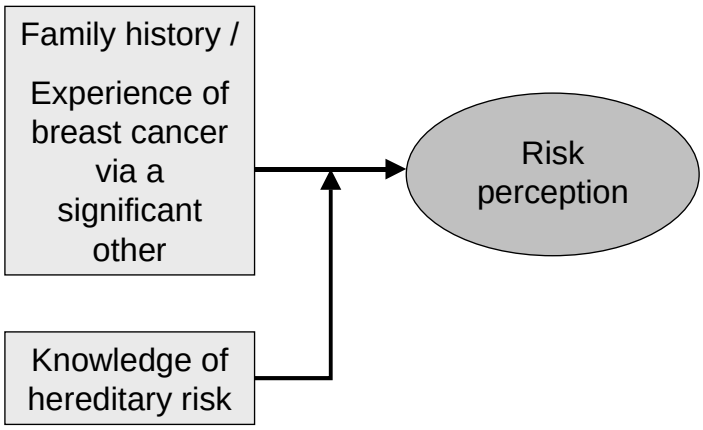
3. Results

3.1. Are women comparatively optimistic in their perception of their breast cancer risk? Are comparative optimism and perceived susceptibility to breast cancer determined by breast cancer experience via a significant other (Articles I and IV)?

To answer the first research questions, the level of comparative optimism and the extent to which breast cancer experience influences risk perception were examined (see figure 3.1. for a conceptual map and table 3.1. for frequency distributions and means of risk perception variables). When analysing women's perceptions of personal and peers' breast cancer risk, a strong comparative optimism was found among the study participants as a group: personal risk was perceived to be lower than peers' risk. Only a minority of women felt especially vulnerable to breast cancer, less than 4% perceiving their own risk as higher than their peers' risk. Thirty-seven percent believed they themselves had the same risk as their peers, and 31% believed their personal risk was lower. A substantial number of women (28%) were unable or unwilling to estimate the risks.

When the effect of experience of breast cancer on comparative optimism was examined, it was found that in all other groups except women having first-degree relatives with breast cancer, i.e., FDRs, the personal risk of developing breast cancer was perceived to be lower than their peers' risk. The FDRs' perception of personal risk was higher when compared with the other groups, reaching the level of their perception of peers' risk (Article I, Table 2). Knowledge of hereditary risk did not have a statistically significant effect on the perceptions of personal or peers' risk. Thus even though women with a family history of breast cancer perceived their personal risk to be higher than the other groups, this was independent of whether they knew that heredity is a risk factor.

Figure 3.1. Conceptual map. Determinants of perceived risk: aspects of family history as a risk-increasing factor.



The association between experience of breast cancer and risk perception was studied in terms of perceived susceptibility, with similar findings. As expected, the closer the experience, the higher the perceived susceptibility. The highest perceived susceptibility was found among women having a first-degree relative with breast cancer and knowing that heredity is a risk factor (Article IV, Table I). Thus, knowledge of hereditary risk had an effect on perceived susceptibility but not on perceptions of personal or peers' risk.

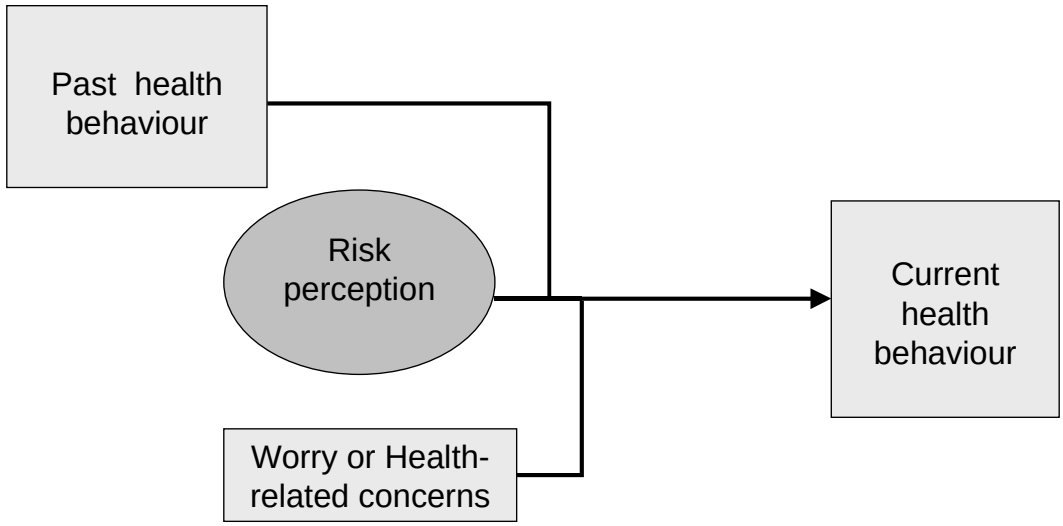
Table 3.1. Frequency distributions [%, (n)] and means (SD) of risk perception variables by experience of breast cancer in a significant other.

	Experience of breast cancer in a significant other				
	FDR	OBR	ELSE	NO	Total
Personal risk					
- non-existent	-	-	1.8 (7)	3.2 (19)	2.2 (26)
- low	8 (7)	26 (23)	29.7 (113)	30.0 (180)	27.9 (323)
- moderate	52 (44)	46 (41)	37.8 (144)	34.1 (205)	37.5 (434)
- quite high	18 (15)	6 (5)	4.5 (17)	3.5 (21)	5.0 (58)
- very high	8 (7)	1 (1)	0.8 (3)	0.3 (2)	1.1 (13)
- don't know	14 (12)	22 (20)	25.5 (97)	29.0 (174)	26.2 (303)
Total	100 (85)	101 (90)	100 (381)	51.9 (601)	100 (1157)
Peers' risk					
- non-existent	-	-	0.3 (1)	0.2 (1)	0.2 (2)
- low	9 (8)	10 (9)	11.5 (44)	14.8 (89)	13.0 (150)
- moderate	58 (49)	49 (44)	57.7 (220)	60.2 (362)	58.3 (675)
- quite high	29 (25)	34 (31)	26.2 (100)	15.5 (93)	21.5 (249)
- very high	4 (3)	-	0.8 (3)	0.8 (5)	1.0 (11)
- don't know	-	7 (6)	3.4 (13)	8.5 (51)	6.1 (70)
Total	100 (85)	100 (90)	100 (381)	100 (601)	100 (1157)
Comparative risk					
Mean	0.0	0.47	0.53	0.46	0.44
(SD)	(0.71)	(0.74)	(0.73)	(0.74)	(0.74)
n	n = 73	n = 68	n = 282	n = 413	n = 836
Perceived susceptibility					
Mean	2.81	2.65	2.61	2.53	2.58
(SD)	(0.58)	(0.51)	(0.57)	(0.58)	(0.58)
n	n = 105	n = 130	n = 501	n = 808	n = 1593

3.2. Does increased perception of risk predict breast cancer detection behaviours (Article II)?

The influence of risk perception on participation in a first round mammography screening was analysed with univariate and multivariate logistic regression analyses using a prospective design (see conceptual map in figure 3.2.). The influence of both personal risk and perceived susceptibility was examined in a random sample of the women invited to screening. In addition, all the screening non-participants from the target group were included in the analysis.

Figure 3.2. Conceptual map.
Risk perception in predicting detection behaviour.



In the univariate logistic regression analysis, both personal risk and perceived susceptibility had statistically significant effects on screening participation (Article II, Table 2). In comparison to women who believed their risk was low, women with moderate perceived risk were twice as likely (OR = 2.00, 95% Cl 1.54 – 2.61) and women who were unable or unwilling to estimate their risk were 70% more likely to

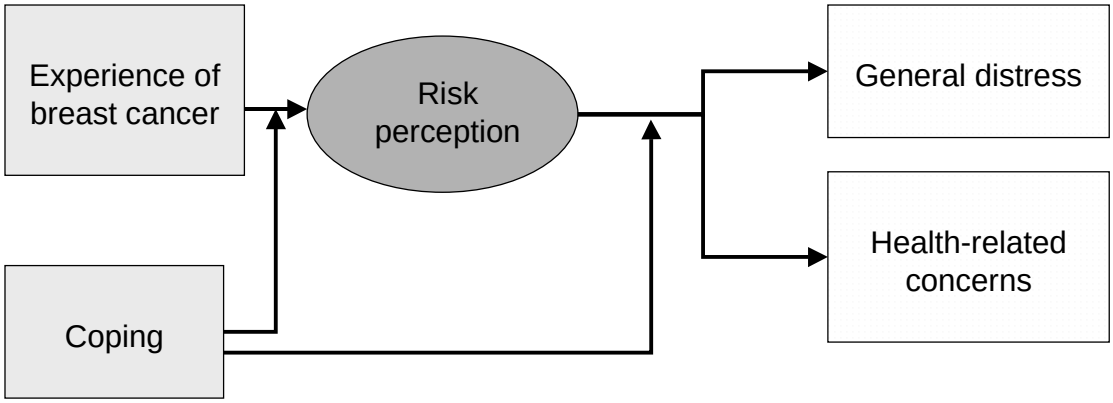
participate (OR = 1.70, 95% Cl 1.27 – 2.27). A similar effect was found for perceived susceptibility: probability of participation increased 26% for each one scale point increase in perceived susceptibility (OR = 1.26, 95% Cl 1.08 – 1.45). Also, worry about illness predicted screening participation in the univariate analysis (OR = 1.21, 95% Cl 1.06 – 1.39). In the multivariate model where the effect of previous mammograms was controlled, both risk perception variables remained statistically significant, but worry about illness ceased to yield significance (Article II, Table 3). Women with previous mammograms were less likely to attend screening, especially if they had had mammograms during the past six months.

As the study included prospective data on perceived personal risk and BSE practice, an additional linear regression analysis was conducted among women with a normal screening finding, controlling for the effect of past BSE practice on current BSE practice. Using a stepwise method with T3 BSE practice as the regressant and T1 risk perception and BSE practice, and T2 breast cancer worry as the regressors, past practice was found to explain over one third of the variance in current practice ($t = 17.89$, $p < 0.001$, $R^2 = 37.2\%$). Inclusion of worry produced a small but statistically significant change in the R square [$F(539, 1) = 7.959$, $p = 0.005$, $R^2 = 0.9\%$]. Risk perception did not enter the models.

3.3. Is increased perception of breast cancer susceptibility related to psychological distress (Articles IV and VI)?

A map of the concepts underlying the third research question is presented in figure 3.3. Perceived susceptibility was found to have a strong association with health-related concerns as well as with the more general forms of distress, i.e., anxiety and depression (Article IV, Table II). The effect size for this effect in the regression analysis reached 13%.

Figure 3.3. Conceptual map. Risk perception, psychological distress, and the effect of coping styles.



Moreover, when data from all measurement points was analysed, women with high perceived susceptibility before screening were found to have higher levels of distress on all measurement points, from pre-screening to one-year after screening (Article VI, Table 3). The differences could be seen on breast cancer-specific concerns and beliefs as well as on health-related concerns and general distress. At T1, anxiety scores were 37.2 (SD 12.2) and 31.5 (SD 9.0) among women with high and women with low perceived susceptibility; at T3, the scores were 35.9 (SD 10.2) and 31.3 (SD 10.1). The depression scores were 9.2 (SD 8.0) and 5.7 (SD 6.3) at T1 and 9.3 (SD 8.3) and 5.9 (SD 7.7) at T3. The level of depression was close to being clinically significant.[1]

[1] Beck et al. (1988) gave the following cut-off scores for severity of depression: 0-9 none or minimal; 10-18 mild to moderate; 19-29 moderate to severe; and 30-63 for severe depression.

3.4. What are the roles of breast cancer experience and coping style in risk perception? Do some coping styles indicate better adjustment in terms of lower levels of psychological distress (Article IV)?

To extend the analysis to individual differences in responses to health threats, coping styles were incorporated into the analysis on perceived susceptibility (see conceptual map in figure 3.3.). The roles of problem-focused coping, emotion-focused coping, avoidance, and optimism were analysed each in a separate ANCOVA. Optimism was found to have a significant interaction effect with experience of breast cancer on perceived susceptibility. Women with no experience of breast cancer and an optimistic coping strategy had a markedly low perceived susceptibility score (Article IV, Table I). Analyses with the other coping strategies revealed a significant main effect for emotion-focused coping: women scoring higher on emotion-focused coping also scored higher on perceived susceptibility. Problem-focused coping and avoidance had no effect on perceived susceptibility.

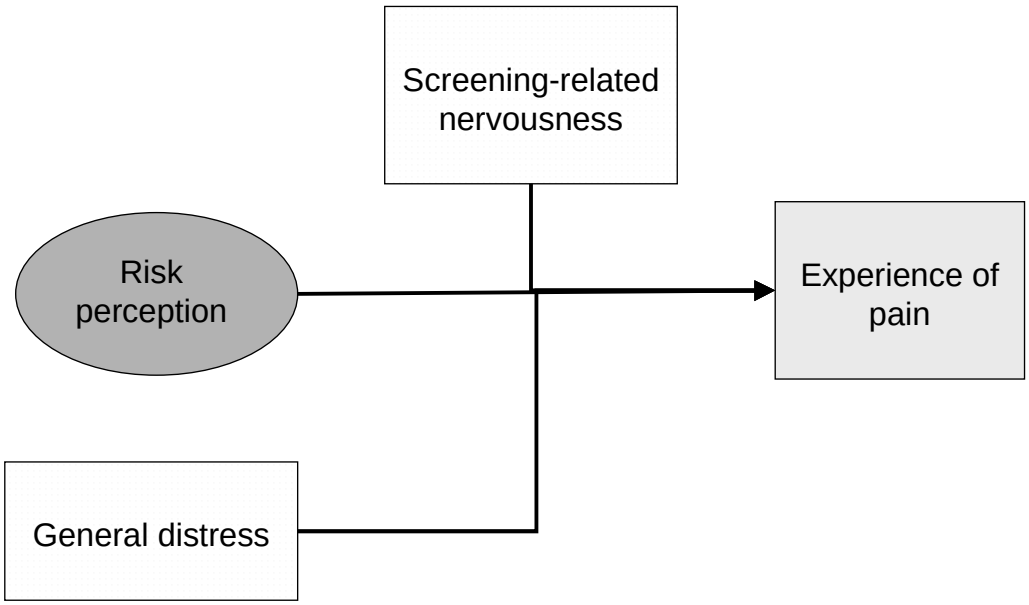
In order to study whether some coping styles indicate better adjustment, separate MANCOVAs were conducted for each coping style on psychological distress. All the coping styles were found to have significant main effects on distress. Optimism and problem-focused coping indicated better adjustment by being related to lower distress scores while avoidance and emotion-focused coping were related to higher distress scores and thus indicated worse adjustment (Article IV, Table IV). Emotion-focused coping had the strongest effect on distress, being related to both health-related concerns and to more general distress (Article IV, Table III).

3.5. Do increased perception of risk and screening-related experiences predict pain and discomfort experienced during screening mammography (Article III)?

Experience of pain and discomfort during mammography was studied among the women with a normal screening finding in a random sample of all the women

invited to screening (see conceptual map in figure 3.4.). Over half of the women reported having experienced at least some pain (61%) or discomfort (59%) during the mammography (Article III, Table 1). In the analyses of pain predictors, a composite score of pain and discomfort was used. Pre-existing perception of personal risk was not associated with pain and discomfort. Pain and discomfort were found to have different sets of predictors, depending on whether women had had any earlier mammograms or not (Article III, Table 4). Among women who had earlier experience with mammography, anticipation of pain and discomfort, screening-related nervousness, and higher education were associated with the actual experience of pain and discomfort during mammography. Among women who attended mammography for the first time in their lives, screening-related nervousness and negative perceptions of the staff were associated with the pain and discomfort they experienced. Pre-screening anxiety and depression were not significant predictors in either group.

Figure 3.4. Conceptual map. Risk perception, psychological distress, and the experience of pain in mammography.



3.6. How do mammography screening and its various findings influence women's risk perception, psychological distress and breast cancer-specific health behaviour (Articles V and VI)?

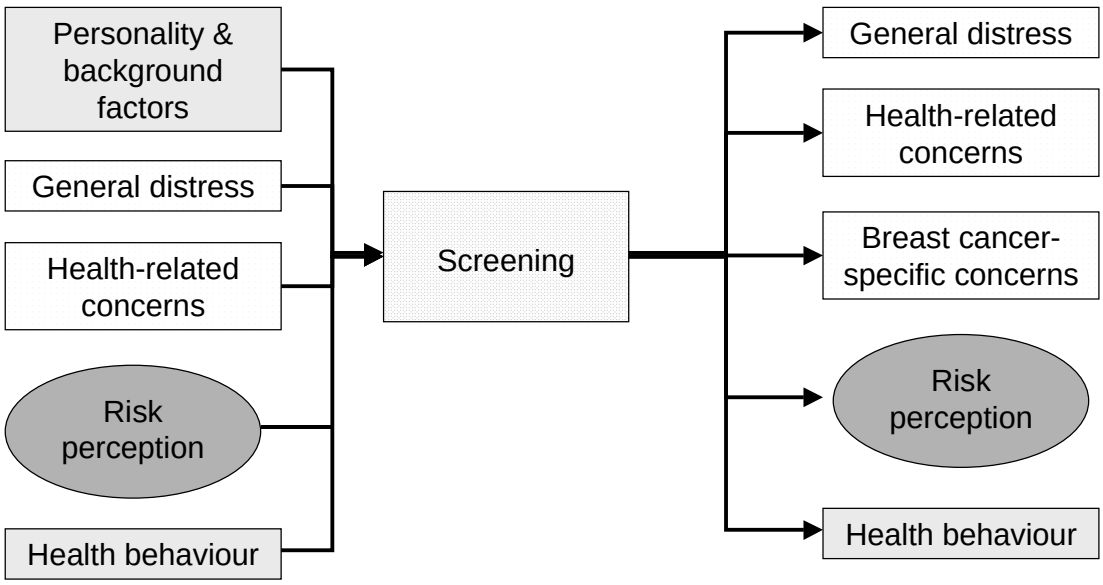
An analysis of the population level psychological impact of the screening programme was carried out using psychological distress and health behaviour as the outcome variables in a prospective design with a pre-invitation baseline and two and twelve month follow-ups (see the conceptual map in figure 3.5.). Women with normal and false positive screening findings as well as community referents were included in the analyses of variance, and between-groups differences were examined at each of the measurement points. In order to get the net effect of screening, personality and background factors as well as pre-screening distress were controlled for.

In a univariate condition (ANCOVA), in comparison to the normal finding group and the community referents, the false positive group reported more breast cancer-specific concerns and increased perceived susceptibility both two and twelve months post-screening (Article V, Table 2). They also reported more breast symptoms and more frequent breast self-examination (Article V, Table 3). In a multivariate condition (MANCOVA), the effect yielded significance at two months but not at twelve months.

To examine whether screening finding influences the degree of comparative optimism, an additional analysis (ANOVA) was conducted. It showed that a year after screening, all screened groups were comparatively optimistic in their risk perceptions. The risk difference score (personal – peers' risk) ranged from -.80 in the normal finding group [$F(559,1) = 332.71$, $p < 0.001$, effect size 37.3%] to -.58 in the benign biopsy group [$F(21,1) = 5.40$, $p < 0.001$, effect size 21%] and to -.54 in the false positive finding group [$F(228,1) = 73.81$, $p < 0.001$, effect size 25%].

Thus the effect was much stronger for women with normal screening finding than for women who had been recalled.

Figure 3.5. Conceptual map.
Impact of screening on population level psychological well-being.



The patterns of psychological distress and risk perception over time in the screened groups were examined using repeated-measures MANOVAs with the groups of normal finding, false positive finding, and benign biopsy in the analysis (Article VI, Table 1A). The total sample exhibited a decrease in health-related concerns (worry about illness and negative effects of symptoms) from pre-screening to two and twelve months post-screening. Perceived personal risk decreased in the normal finding group as well as in the benign biopsy group from pre-screening to post-screening, but increased in the false positive finding group. Both the groups that had been recalled for further examinations experienced a decrease in their self-efficacy in performing BSE. However, despite the decrease in self-efficacy, BSE frequency increased in the false positive group. To summarise the results, screening with a false positive finding

had adverse effects in terms of breast cancer-specific concerns and beliefs, effects that a normal finding or even surgical biopsy — a more radical but also a more conclusive procedure — did not have.

3.7. Do pre-existing experiences of breast cancer via a significant other and an increased perception of risk predict women's responses to screening and screening finding (Article VI)?

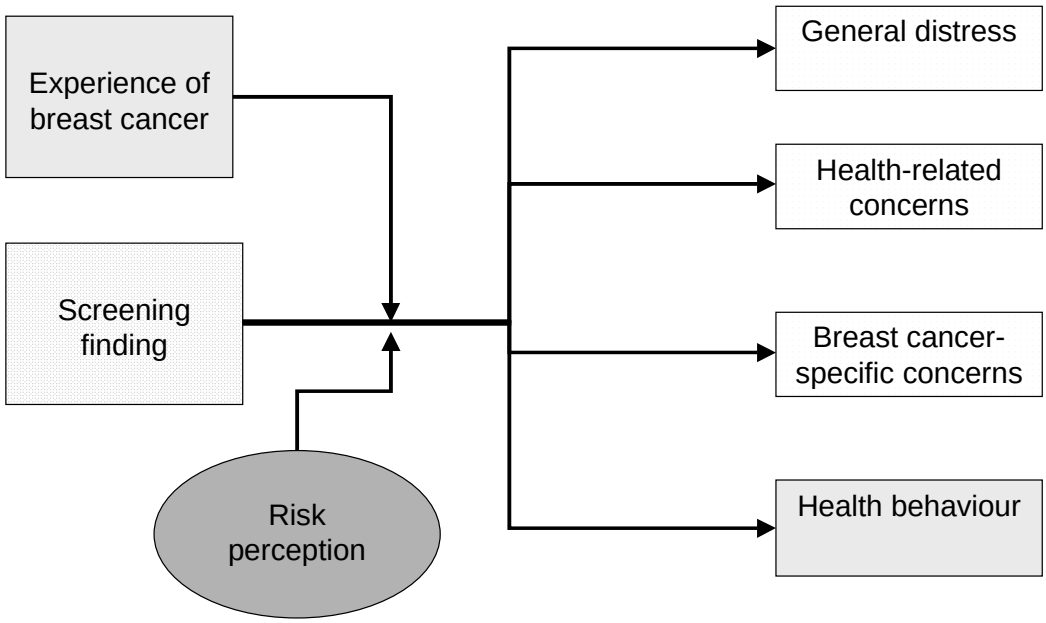
Individual differences in responses to screening were studied in terms of interaction effects of pre-existing breast cancer experience and pre-screening perceived susceptibility with screening finding on distress levels and patterns of distress change over time (see conceptual map in figure 3.6.). Repeated-measures MANOVAs were conducted with the groups of normal finding and false positive finding in the analysis. The within-subjects analyses on patterns of distress over time did not reveal any interaction effects between experience, perceived susceptibility, and screening *finding*, meaning that the impact of screening finding could not be shown to depend on the women's background.

However, perceived susceptibility was found to influence the reaction to *screening* in terms of general distress: Among women with low susceptibility, the level of depression remained low throughout the screening process (Article VI, Table 3). Among women with high susceptibility, depression decreased slightly from pre-screening to two months post-screening but increased back to the initial level at one-year post-screening.

The higher level of anxiety and the more frequent health-related and breast cancer-specific concerns found among women with high perceived susceptibility in comparison to women with low perceived susceptibility (see section 3.3. and Article VI, Table 3) were unaffected by the screening process, persisting still one year after

screening. Women with high perceived susceptibility were more distressed despite getting normal results from mammography.

Figure 3.6. Conceptual map.
Individual differences in responses to screening.



Breast cancer-specific concerns and health-related concerns such as worry about illness, concern about pain and fear of death were also more frequent among women *with* rather than *without* any experience of breast cancer (Article VI, Table 5.). However, these effects were found only at the two and the twelve month post-screening measurements. Among women with familial experience of breast cancer as well as among women with high perceived susceptibility, perception of personal breast cancer risk remained at a higher level even after a normal mammogram. Interestingly, the post-screening levels of breast cancer-specific concerns among women with familial experience of breast cancer and women with high pre-screening perceived susceptibility were very similar to those of women with a false positive finding in screening.

Thus instead of affecting the patterns of distress from pre-screening to one year post-screening, pre-existing experience of breast cancer and perceived susceptibility were found to influence the level of distress, which persisted despite getting a normal result in mammography screening. Of the two personal background factors, perceived susceptibility was found to have a stronger influence on distress.

4. Discussion

In this study, risk perceptions and their associations with pre-existing experience with breast cancer as well as with health behaviours and with psychological distress were examined before the screening process, during it, and one year afterwards. Risk perceptions were examined in four different ways (table 1.1.): as a generalised perception of being susceptible to breast cancer; as an estimate of absolute personal lifetime risk of getting breast cancer; as an estimate of the absolute lifetime risk of a peer, i.e., an average woman of their same age; and as comparative optimism, a self-favouring difference between the two absolute risk estimations. Overall, the 50-year-old Finnish women in our study did not perceive their risk of getting breast cancer as very high. As a group, these women were comparatively optimistic in risk perception, thinking that their personal risk was lower than the risk of an average woman their age. However, the closer an experience women had with breast cancer, the higher their lifetime risk estimations and their perceptions of susceptibility. The highest perceived susceptibility was found among women who had a first-degree relative with breast cancer and who also knew that heredity is a risk factor. Interestingly, knowledge of hereditary risk did not have any effect on the more specific estimations of personal or peers' absolute lifetime risk.

Both perception of personal risk and perceived susceptibility were found to influence first round screening participation, the effect remaining also when past mammograms were included in the analysis. However, risk perception had no effect on breast self-examination, past BSE practice and breast cancer worry being the main predictors of current BSE practice.

Even though having a family history of breast cancer was a predictor of psychological distress, the association was relatively weak. A much more important factor for distress was women's perceived susceptibility to breast cancer: it not only

had a strong association with breast cancer-specific concerns, but was also related to other health-related concerns, and to more general distress.

Mammography screening, which makes the threat of a disease salient in a very concrete way, was found to have negligible long-term adverse effects on the population level when background factors, women's personality characteristics, and pre-existing distress were controlled for. Women with a false-positive screening finding reported more breast cancer-specific concerns (especially intrusive breast cancer thoughts) and an increased perception of susceptibility both at two and twelve months after screening.

When the influence of individual differences on responses to screening and screening findings was analysed, women who had high perceptions of susceptibility before entering screening were found to be more distressed. This distress was observed throughout the screening process across a wide range of measures, from breast cancer-specific concerns to other health-related concerns and to general distress, and it prevailed despite getting normal findings from mammography. Furthermore, women with breast cancer experience were found to be more distressed at the post-screening measurements, also regardless of the screening finding. Thus, mammography failed to relieve concerns experienced by both groups of women.

4.1. Comparative optimism about breast cancer

Even though comparative optimism was also found to prevail for breast cancer, the percentage of comparative optimists in our study seem to be lower than the percentages of comparative optimists for other threats reported as typical by Taylor and Brown (1994). In the other studies on comparative breast cancer risk, Aiken et al. (1995), and Lipkus et al. (2000), reported somewhat higher percentages of both comparative optimists (49% and 43%, respectively) and comparative pessimists

(16% and 12%, respectively) than we did, and Skinner et al. (1998) found more comparative pessimists (12%). None of these studies, however, provided the subjects with a "cannot tell" option.

Skinner and colleagues (1998) claimed that "in a relatively healthy sample, it is possible for a majority to rate their risk below average without being biased." In the studies by Skinner et al. (1998) and Aiken et al. (1995), 12% and 16% of the women, respectively, estimated that their chances of getting breast cancer are higher than average. Thus these women could see themselves as future breast cancer patients. As 11% of the female population get breast cancer during their lifetime, these figures seem actually quite comparable. It is plausible that when women answer the comparative risk questions, they have in their minds a stereotype of a woman getting breast cancer rather than "an average woman their own age". When Aiken et al. (1995) inquired about factors influencing risk, only 19% of all women but 50% of those with average risk talked about chance, some showing that they understood what average risk means (e.g., "My chances are the same as any woman"). For others, chance reflected a sense of fortune ("It is pot luck") or fatalism ("If you're going to get it, you're going to get it").

Of factors likely to be associated with the degree of comparative optimism, our study focused on personal experience. As expected, women with a family history of breast cancer were less likely to be comparatively optimistic but instead estimated that their risk was the same as their peers' risk. However, as their true risk is higher than average, they were probably either optimistic or ignorant. Also Skinner et al. (1998) found a large group of women with a family history who viewed themselves as being at average risk (47%) or even below average risk (16%), compared with other women their same age. They concluded that a substantial number of women with family history probably do not understand that their personal breast cancer risk may be affected by the presence of breast cancer in a close family member. In our study knowledge of hereditary risk was found to influence the more general beliefs

reflected in perception of susceptibility, but the more specific risk likelihood estimates were not influenced by it.

People come to understand their risk on the basis of their ability to mentally simulate or imagine themselves experiencing the problem (Armor & Taylor, 1998). Being invited to screening is a factor that may produce mental images of oneself as a potential breast cancer patient, and being recalled for further examinations most probably intensifies the mental simulation. Being recalled may weaken the belief that if a disease has not yet appeared, it will not in the future. Even though comparative optimism in risk perception was found in all screened groups one year after screening, the degree of optimism was greater among women with normal screening finding than among women who had been recalled.

Weinstein and Klein (1995) suggest that reminding people of risk factors does not have much impact on personal risk perception and does not reduce people's tendency to claim that they are less at risk than their peers. On the contrary, they have evidence showing that focusing attention on risk-increasing factors can actually exaggerate optimism. This is congruent with the view that people tend to ignore information that does not fit their perceptual system. When faced with unfitting information, they strengthen their defence of the existing belief system.

4.2. Risk perceptions in predicting breast cancer detection behaviours

Recently, considerable criticism has been targeted at studies examining the association between risk perception and behaviour (e.g., Gerrard, Gibbons, & Reis-Bergan, 1999; Leventhal, Kelly, & Leventhal, 1999; McCaul and Tulloch, 1999; Weinstein et al., 1998). The main criticism concerns the use of inadequate study designs (Gerrard et al., 1999; Weinstein et al., 1998), but also some factors making the study of risk perceptions difficult have been pointed at. Associations of risk perception with behaviour may change considerably over time (Weinstein et al.,

1998), and especially associations with cancer prevention and detection behaviours have been weak (Leventhal et al., 1999; McCaul and Tulloch, 1999). Furthermore, as stated earlier, it has proven difficult to bring perceived risk in line with estimates of actual risk (Leventhal et al., 1999; McCaul and Tulloch, 1999).

The criticism on inadequate study designs concerns mainly the use of correlational data, that does not allow making causal inferences (Gerrard et al., 1999; Weinstein et al., 1998). Also, the prospective studies that have sought evidence for the "motivational hypothesis" — i.e., that risk motivates behaviour — have often overlooked the fact that the association between T1 risk perception and T1 behaviour accounts for the relationship between T1 risk perception and T2 behaviour (Gerrard et al., 1999; Van der Pligt, 1994; Weinstein et al., 1998).

According to a meta-analysis on the relationship between risk and mammography behaviour (McCaul et al., 1996), increased perception of personal risk correlates positively with behaviour, but with a modest effect size. Furthermore, the effect was found to be weaker in studies using prospective rather than cross-sectional design. Leventhal et al., (1999) stated two reasons why modest effect sizes between risk perception and screening behaviour should be expected. First, screening behaviour is not solely controlled by individual volition and, therefore, would not necessarily reflect individual risk perceptions. Second, as independent variables, risk perceptions are variable. Judgements of risk change depending on the response format and the frame in which they are presented (risk tied to a timeframe vs. cumulative risks).

The present study offered a possibility to analyse the association between perceived personal risk and behaviour prospectively both in the case of screening participation and breast self-examination, controlling for past behaviour. In the present study, both perception of personal absolute lifetime risk and the more general perception of susceptibility were found to predict screening participation. Interestingly, perception of personal absolute lifetime risk was one of the most influential among

a set of 14 significant predictors, due to women with moderate risk perception being twice as likely as either low or high risk women to participate. Furthermore, in comparison to women with low risk perception, women with high risk perception were no more likely to participate. These effects were not accounted for by past mammography behaviour. The non-linearity of the effect probably accounted for the fact that risk perception predicted screening participation in the logistic regression analysis used here, while in a previous discriminant function analysis (Aro, 1996), risk perception did not discriminate screening participants from screening non-participants.

However, it has to be noted that as the women in our study were in their first round of screening, the past mammograms they had were probably due to slightly different decisional processes. Moderate risk as a predictor for attendance may be a characteristic of *organised screening*, though it may have different predictors from self-initiated mammography. In a study investigating reasons for non-participation in the present sample, women who had declined the screening invitation because of a recent self-initiated mammogram were found to have high perceived susceptibility, not moderate (Aro, de Koning, Absetz, & Schreck, 2001). Also earlier, high susceptibility has been found among women with a recent mammogram and low susceptibility among women who have declined the screening invitation (Rutledge et al., 1988). Furthermore, Aiken et al. (1995) observed a diminishing relation of perceived susceptibility to mammography compliance over time: Women compliant in initial mammography had higher perceived susceptibility; later, women with lower susceptibility became compliant in mammography, probably seeing this as a further risk-decreasing factor.

Findings for other detection behaviours, mostly breast self-examination, have been inconsistent (Calnan & Rutter, 1986; Champion, 1988, 1992; Nemcek, 1990; Vernon et al., 1993; Wyper, 1990). In the present study, risk perceptions did not predict frequency of breast self-examination. Instead, past breast self-examination practice was found to be the main predictor of current practice. In addition, breast

cancer worry was found to be another significant predictor of current behaviour, even though the association was relatively weak.

4.3. High perceived susceptibility as one dimension of a cluster of concern

Existing studies examining the associations between distress and risk perception have mostly been conducted in high-risk populations and/or with correlational designs. McCaul and Tulloch (1999) reviewed studies on the association between distress and risk perceptions for different cancer types, finding modest positive correlations. The highest correlation reported was .36 between intrusive thoughts and breast cancer risk (McCaul & O'Donnel, 1998). In a recent study, Cameron and Diefenbach (2001) found a relatively high correlation (.53) between breast cancer worry and the perception of personal risk for the disease. Lipkus et al. (2000) also found correlations of similar magnitude between breast cancer worry and both personal absolute risk and comparative risk (.46 and .43 respectively). However, both correlations decreased substantially (to .25 and .19 respectively) when they were partialled.[2]

It is probably impossible to establish causality between worry and risk perception for any generally known disease. However, the underlying assumption has been that increased risk perception produces worry – e.g., Weinstein (1982) interpreted the association between risk and worry in terms of people being "afraid because they see themselves as being relatively high in risk" (p. 452). More recently, it has been suggested that risk communication that increases perceived susceptibility without simultaneously enhancing worry may be ineffective in raising behavioural intentions (Cameron & Diefenbach, 2001) - implying that worry and risk perception are independent phenomena. This suggestion arises from studies showing that there is a positive association between worry and behaviour, independently of risk perception. The association has been found both with behavioural intentions

(Cameron & Diefenbach, 2001; Weinstein, 1982), and with actual behaviour, i.e., mammography use (Diefenbach, Miller, & Daly, 1999) and, in the present study, breast self-examination.

The data reviewed by McCaul and Tulloch (1999) also suggested that instead of screening avoidance, worries lead to efforts to take the screening opportunities. Therefore, based on the view that worry has positive effects as a motivator for active problem solving, McCaul and Tulloch (1999) called it "constructive worry", a concept that also reflects the involvement of cognition. Congruent with this view, McCaul and Tulloch (1999) specifically made a distinction between worry and anxiety, pointing out that anxiety has not been associated with high screening levels. On the contrary, anxiety may be a barrier to screening. For example, Aro and others (2001) found that among women who had declined an invitation to organised screening mammography, anxiety was significantly higher among those who lacked self-initiated mammograms, in comparison to those who had them. Thus, anxiety seems to lack the positive outcomes that worry may have (McCaul & Tulloch, 1999).

In the present study, increased risk perception was found among approximately 20% of women, and was associated with a range of psychological distress indicators, from anxiety and depression to health-related and disease-specific concerns. Contrary to our expectation, it did not predict heightened sensitivity to pain and discomfort in mammography. This latter finding is supported by the study by Drossaert and her associates (2001), in which risk perception was also found unrelated to mammography pain. In the present study as well as in the previous ones (Boer, 1993; Bruyninckx et al., 1999; Nielsen et al., 1991; Rutter et al., 1992), the physical experience of pain could not be predicted with either anxiety or depression, but screening-related nervousness was associated with it. Furthermore, when long-term influences of risk perception on psychological distress were

[2] Absolute risk partialled for comparative risk and comparative risk partialled for absolute risk.

examined in the present study, the distress among women with high perceived susceptibility was found persistent.

When all these findings are put together, a multidimensional cluster of concern composed of a variety of disease- and health-related concerns can be found among a substantial proportion of the women. A health concern is not equivalent to "health awareness" because there is an affective component involved. In fact, the level of depression among these women almost reached clinically significant levels (exceeding 9, when 10 has been given as a cut-off score for mild to moderate depression by Beck and others, 1988). Also the level of anxiety was high, exceeding anxiety found in a recent Finnish study (Aktan-Collan, Haukkala, Mecklin, Uutela, & Kääriäinen, 2001) that was conducted in the context of genetic counselling and predictive testing for hereditary non-polyposis colorectal cancer. In the test-disclosure session, STAI anxiety among mutation-positive clients, i.e., people who have and who are also aware of having a medically increased risk for cancer, was only 35.4 (SD 9.1), and at one month after the testing, it had decreased back to the pre-test level, which was 31.6 (SD 8.0). Furthermore, the more general forms and the persistent character of distress found in the present study imply that there may be a dispositional element behind the distress and that rather than a factor causing distress, risk perception is probably one dimension of distress along with the other dimensions. The underlying disposition may be similar or related to one of those characteristic to anxious patients: a general cognitive style characterised by excessive perception of threat (Beck & Emery, 1985; Blackburn & Davidson, 1994; Uhlenhuth et al., 2002).

Further support for this view comes from our findings on the differences in the individual styles of coping with threat. Women with an optimistic coping style perceived the least breast cancer threat – they scored markedly low on perceived susceptibility, especially if they had no experience of breast cancer, and they were also less distressed. Women with emotion-focused coping had higher perceived susceptibility and also showed worse adjustment in terms of psychological distress.

However, we should point out that even though depression and anxiety scores were clearly elevated among women with high perceived susceptibility, they did not reach levels where therapeutic interventions would be warranted as in the study among women with increased risk by Kash and colleagues (1992). Furthermore, we do not have any evidence that the health concern found would undermine engagement in cancer detection behaviours. Hence, even though there seems to be a multidimensional cluster of concern, the concern is likely to remain non-pathological.

4.4. The population level psychological impact of screening

Findings of the two earlier prospective epidemiological studies (Sutton et al., 1995; Walker et al., 1994) assessing the psychological impact of a routine mammography screening similar to the Finnish screening program were reassuring; no increase in distress was found among women who had normal mammograms. On the contrary, both studies found a decrease in distress, even though this effect was probably due to repeated measurement rather than the screening itself. Our study confirmed these findings by showing that for most women screening is not a distressing experience. However, those women who underwent further examinations but were found false positive experienced adverse effects of screening at least in the short term. They had more breast cancer-specific distress than women with a normal screening finding, including a higher perception of personal lifetime risk of breast cancer. A previous, qualitative description of the cognitive and emotional responses among these women (Eerola, 1995) revealed considerable acute stress due to recall.

Differential effects among women exposed to different kinds of further examinations before surgical biopsy were not investigated in the present study. Brett and colleagues (1998) found breast cancer-specific adverse effects among women who were recalled for further examinations, but the nature and the extent of the further investigations determined the intensity of these effects. Women with benign biopsies reported

most adverse effects still five months after the surgery. However, while adverse effects were related to doubts concerning the test results both among women who were waiting for an early recall and among women with “clear after fine needle aspiration”, among women with benign biopsies they were unrelated. Thus the surgical operation had clarified definitively that the women did not have breast cancer. (Brett et al., 1998).

Also, in the present study although perceived personal risk increased among women with a false positive screening finding, it tended to decrease among women with benign biopsies. Furthermore, all the screened groups were comparatively optimistic in their risk perception at one year after screening, but the effect was strongest among women with a normal screening finding. Skinner and colleagues (1998) found that women who had had benign breast biopsies were more likely than women with normal mammograms to be comparatively optimistic in risk perceptions. The authors were concerned about the possibility that some women may interpret a normal mammogram or a benign breast surgery as a clean bill of health or as evidence of low breast cancer risk for the future. They suggested that if the interpretation leads the women to be less vigilant in complying with screening recommendations in the future, educational strategies or messages provided to women during mammography should be reconsidered.

Women going through surgical biopsy may experience severe acute stress during the time of further examinations and surgery (e.g., Benedict, Williams, & Baron, 1994), but acute reactions were not measured in the present study. Brett and others (1998) found adverse effects even five months after screening among women who were recalled from mammography but were found to be normal or to have benign conditions in the process. The intensity of the effects was determined by the nature of the further examinations, and women with benign biopsies reported most of them.

Contrary to these previous studies, the present one found no indications of severe stress in the biopsy group in the post-screening measurements, i.e., after the women

had been informed of the benign finding. Partly this might be due to the small sample size of the biopsy group and to the differences in measures used (Brett et al., 1998, used the Perceived Consequences Questionnaire by Cockburn et al., 1992), but partly also to differences in the respective health care systems. A study on satisfaction with information at breast biopsy conducted among these women (Rehnberg, Absetz, & Aro, 2001) suggested that the Finnish health care system provides information that has the potential to reduce the distress associated with the biopsy, unlike some other settings (Northouse, Jeffs, Cracchiolo-Caraway, Lampman, & Norris, 1995).

On general distress, i.e., depression and anxiety, no evidence of either a short-term or long-term negative influence was found among any of the screened groups. Lampic and colleagues (2001) recently reported a similar finding. Even if depression and anxiety do not increase because of an abnormal mammography finding, women who suffer from them initially may also be more prone to experience breast cancer-specific distress in the course of screening. At least this is what the findings by Walker and colleagues (1994) suggested.[3]

4.5. Influence of family history and increased risk perception on responses to screening

Thus far it has become clear that people differ in the extent to which they feel vulnerable to health threats. Some people are more prone than others to believe that any negative events that do occur will not happen to them. An unfortunate side effect of positive beliefs is to make negative events all the more threatening to one's conceptual system (Janoff-Bulman, 1989). On the other hand, people who lack the positive beliefs may be better prepared for negative events such as being recalled to further examinations in mammography screening.

[3] When examining individual differences in responses to screening in this study, the influence of pre-existing anxiety or depression was not tackled, because it would not have led to service development anyway. Instead, it might have led to labelling women who experience breast cancer-specific distress as having mental problems.

In the present study, pre-existing experience of breast cancer and high perceived susceptibility were examined as factors underlying the preparedness. Both factors were found to be associated with a higher level of distress, which persisted despite getting a normal result in mammography screening, but neither factor affected the pattern of change in distress over time in the different screened groups. Thus reactions to the different screening findings did not depend on these factors.

As stated earlier, both previous studies (Gilbert et al., 1998; Valdimarsdottir et al., 1995) examining responses to screening among women with a family history of breast cancer had limited generalisability because of the nature of the study populations and some features characterising the recall process. However, the present study, which was able to overcome these limitations, confirmed the earlier findings. Furthermore, the analysis was extended from women with a family history of breast cancer also to other women with high perceived susceptibility of breast cancer. In the study by Valdimarsdottir and colleagues (1995), women with a family history of breast cancer going through mammography with normal findings had higher levels of breast cancer-specific concerns (intrusive thoughts) both before screening and one month after it. They also had higher levels of non-specific distress even a month after notification of the normal results. We found higher levels of general, health-related and breast cancer-specific distress not only among women with a family history of breast cancer but also and even to a greater extent among women with high perceived susceptibility before screening. Interestingly, the distress remained despite a normal screening finding.

Gilbert and colleagues (1998) reported that women with a family history seemed to be better prepared for screening. They were more likely to score in the normal range of depression at screening, a finding similar to our finding on depression patterns among women with high perceived susceptibility. The authors concluded that screening appears to be reassuring for women with a family history of breast cancer. Even if this is accurate, the reassurance does not seem to be very long lasting. Our results showed that even though depression decreased among women with high

perceived susceptibility in the short-term (and it was the only distress indicator to clearly decrease), it had increased back to the initial level by one year after screening.

4.6. Limitations of the study

Our target population of approximately 18,000 women between the ages of 48 and 50 represented fairly well the Finnish female population of that age. At the study baseline, our timetable with an impending screening did not allow us to send targeted reminders to the non-respondents. This was probably the main reason for the lower-than-expected response rate (61%) at baseline. The reported response rates of studies from other screening programmes have typically been around 70% (Brett et al., 1998; Drossaert et a., 2001; Lampic et al., 2001; Sutton et al., 1995). However, no differences were found between the respondents and the non-respondents in their geographical area of residence, the only available background information we had on the non-respondents. On later measurements, attrition was not a problem. Even though we only had a very limited age range, it is an age when breast cancer risk is probably most salient. The findings of this study are probably fairly well generalisable to middle-aged Finnish women, and associations found between risk perception, breast cancer experience, behaviour, and indicators of distress are probably also similar to same-aged women in other western cultures. However, the findings concerning screening impact may not be directly applicable outside the context of organised screening.

Risk perceptions were measured as perceived susceptibility and as personal and peers' lifetime risks. These measures may have been somewhat inadequate for predicting behaviour, a limitation of most other studies, too. Gerrard and colleagues (1999) claim that appropriate risk questions are different for people who are already engaging in the behaviour under study (e.g., BSE) than for those who are not ("Even if I develop breast cancer, I won't die from it because I intend to be vigilant

about early detection"). This was not taken into account in this study. A further limitation concerns the way family history of breast cancer and other risk factors were measured – the data collection was not designed for estimation of medical risks. Assessment of knowledge of hereditary risk identified women who could mention heredity as one risk factor, but mentioning is not equivalent to understanding what hereditary risk really means. Information of factors that these women viewed as increasing or decreasing their own risk of getting breast cancer (as in the study by Aiken et al., 1995) would have been valuable, but it was not included in the study. A wide range of distress measures was used, including standardised scales for measuring depression, anxiety, and health-related concerns. The measure for dispositional coping had not been previously used, but the factors that emerged supported the prevailing view that the main dimensions of coping include problem- and emotion-focused coping, as well as avoidance and optimism.

Breast cancer-specific concerns (worry and intrusive thinking) after screening were assessed among women with surgical biopsies only at one-year post-screening. This was because the study design did not allow us to make a distinction between women with malignant and benign biopsies at the time when the questionnaire was sent (this was approximately 10 weeks after the biopsy but before the screening centres had been informed of the biopsy findings by the hospitals). The breast cancer-specific questions would have been inappropriate for women with a malignancy. Thus it cannot be known with certainty whether some adverse effects that could have only been tapped with these measures remained undiscovered.

4.7. Theoretical implications

Some important theoretical implications can be drawn from the existing research on risk perceptions, including the present study. First, there are some implications for how risk perceptions are inquired and measured. As people's beliefs are rather ambiguous, and as contradictory views may emerge depending on whether one

thinks about risk-increasing or risk-decreasing factors, structured survey questions may not give the best picture of risk perceptions. The fact that people are unwilling to give risk likelihood estimates and may also generally have difficulties in understanding them (Weinstein & Diefenbach, 1997) should be considered. The study by Aiken and associates (1995) also gives some valuable insight into the complexity of risk perceptions. Cognitive theories of information processing (e.g., Petersen et al., 2000; Stahlberg et al., 1999; Trumbo, 1999) could further the understanding of risk perceptions and their formation, but are only rarely used in an explicit way in health risk research (see Grayson & Schwarz, 1999, and Rothman & Schwarz, 1998). For example, consideration of potential differences in strategies used for risk information processing among women who do and who do not have experience with breast cancer would be a valuable asset for the design of interventions targeted at risk perceptions or screening participation.

Second, inclusion of affective factors in the theoretical models for explaining behavioural intentions or predicting behaviour seems to be of utmost importance. In this study, affective factors were shown to have strong associations with risk perception. This is congruent with the clinical research findings suggesting that perception of threat is one characteristic of a general cognitive style found among anxious patients (Blackburn & Davidson, 1994). However, differing from anxiety, worry may have some beneficial influences, and in fact, some earlier studies have shown that it is an important predictor for behavioural intentions or behaviour (Cameron & Diefenbach, 2001; Weinstein, 1982; see also the review by McCaul & Tulloch, 1999). This was also evident in this study. In Leventhal's (1970) parallel response model, affect is present in the "fear control" process of the model, but it has received less emphasis than the cognitive-behavioural "danger-control" process.

Finally, the role of personality psychology in the examination of health concerns would be of interest. The findings on the associations between health concerns and coping styles suggest that a dispositional component might be involved. Dispositional optimism is one personality construct that has been shown to be

related to increased and adaptive health information processing (Aspinwall & Brunhart, 2000), and the associations it has with risk perception have been recently studied (Radcliffe & Klein, 2002). There is some new interest on studying the associations of risk perceptions and preventive behaviours with the Big Five personality dimensions (e.g., Ingledew & Brunning, 1999). Also, concepts such as health hardiness (Kobasa & Puccetti, 1983), health locus of control (Wallston, Wallston, & DeVellis, 1978), perceived or personal competence (Wallston, 1992), and generalised perceived self-efficacy (Schwarzer, 1992) would be worth studying from this perspective.

4.8. Practical conclusions and suggestions

Some practical suggestions arise from the findings of this study and from how they relate to previous research. These concern mainly risk communication as a part of health education, and the development of screening practices.

Inclusion of risk information in health education is motivated by the fact that the perception of being at risk is a prerequisite for health-protecting behaviour. However, while it is a necessary condition for behaviour, it is not a sufficient condition (e.g., van der Pligt, 1994). There are other important factors like worry that should also be kept in mind.

When giving risk information, some aspects related to individual risk processing should be regarded. Many people have difficulties in understanding numerical information (Weinstein & Diefenbach, 1997), and sometimes it would be useful to consider other forms of information. If risk is given in numerical form, absolute instead of relative figures should be used, and they should be put into a timeframe (Kelly, 2000). As far as the goal of health education is to increase accuracy in risk perception, people's tendency to use self-favouring comparisons by means of risk stereotypes, over-emphasis of personal risk-protecting factors and de-emphasis of

personal risk-increasing factors should be acknowledged. Rothman and Kiviniemi (1999) suggest that a contextualised approach should be used in risk communication, providing people with an informational context in which to understand and interpret their risk. However, an important point that needs to be strongly emphasised is that accuracy should not self-evidently be set as the primary goal in risk communication. Instead, the goal should be to get risk perception at a level sufficiently high to motivate health behaviour without inducing pathological levels of concern (Lipkus et al., 2000; McCaul & Tulloch, 1999).

How should the screening practice be developed? For the majority of women, screening seems to be reassuring. It does not induce excess distress among women with normal screening findings, and even women going through surgical biopsy seem to be reassured by the experience at least if judged by their risk perceptions after screening. However, more attention should be paid to women with false positive findings as well as some other specific groups of women.

The findings by Gilbert et al. (1998) suggested that screening is reassuring for women with a family history, but also that routine recall to assessment clinics after a normal mammogram because of a significant family history induces considerable stress. Based on these findings, the routine recall practice in the screening programme that they studied was terminated. Instead, screening results as well as an offer for genetic counselling were mailed to the women as part of the normal screening program. According to the authors, 50% of the women take up the opportunity to attend a genetics clinic (Gilbert et al., 1998). The authors did not comment on the concern that may be induced by the mailed information, but given the substantial proportion of women deciding to come to the genetics clinic, it is highly likely that many experience such concern.

Based on the findings of the present study, it seems that there are some specific groups of women who, even if probably not in need of *genetic counselling*, would benefit from getting some risk information. This study points out a need to take into

account concerns not only among women with medical risk factors such as a family history of breast cancer but also among women who hold high perceptions of risk for some other reason. In the Finnish screening system, some medical background information is obtained from the women at the screening appointment, but systematic information on risk factors or women's risk perceptions is not collected from the women nor discussed with them. If women explicitly ask, they are informed about the possibility of genetic counselling. (Rautalahti, personal communication). Thus it is not surprising that in this study, high perceptions of risk and psychological distress were found to prevail despite normal screening finding among women with pre-existing high perception of susceptibility.

It seems that the screening appointment would be an appropriate instance to identify women who are concerned about their breast cancer risk. However, at present this is not feasible, but would require profound changes to take place in the Finnish screening practice. Among those who are found to be concerned, a brief assessment of both medical risk factors as well as risk perceptions should be conducted during the appointment. The latter should include assessment of perceived susceptibility, an evaluation of the match between women's perceived and women's objective risk-increasing and risk-decreasing factors, as well as assessment of breast cancer worry. Based on these assessments, women needing more thorough risk counselling or an individualised screening schedule could be identified. Women who are recalled for further examination would probably benefit from more thorough risk counselling that would include discussion of how the recall relates to their future breast cancer risk if they are found to be false positive. This would help to avoid the post-screening concern that at present remains unidentified and unresolved in the screening system.

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