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# **Factors affecting attendance at population-based mammography screening**

by

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*To Henrik*

## SUMMARY

The aim of the studies described in this thesis was to explore factors affecting attendance at outreach mammography screening, and to assess possible associations between socioeconomic factors and breast cancer survival.

The relation of non-attendance at mammography screening to sociodemographic factors, indicators of general health behavior, self-rated health, experience of cancer in others, and own cancer or breast problems was studied in a case-control study with 434 non-attenders and 515 attenders identified in a population-based mammography register in the county of Uppsala (Paper I). Exposure information was obtained through telephone interviews. Being single and being non-employed were the only important sociodemographic predictors of non-attendance. Non-attendance was more likely among women who smoked regularly, had not visited a doctor in 5 years, had never had cervical smear tests, had never used oral contraceptives or hormone replacement therapy, never drank alcohol, and who reported no breast cancer in the family or among friends or history of own breast problems.

In the same case-control study the effects of attitudes, beliefs and knowledge were evaluated (Paper II). Multivariate analysis showed that non-attendance was almost five times higher among women with the highest scores of perceived emotional barriers compared to women with the lowest scores. Both absence of worry about breast cancer and low scores of perceived benefits were associated with non-attendance. Other factors associated with non-attendance were less knowledge about mammography and breast cancer, lack of advice from a health professional to participate, and very poor trust in health care.

To obtain descriptive insights into women's rationales for attending or not attending mammography screening, eight focus group discussions were conducted (Paper III). Through inductive analysis, six main issues were identified: negative experiences, perceived risk factors, knowledge of one's own body, perceived problems with mammography, political, ideological and moral reasoning, and involuntary non-attendance.

The association between sociodemographic factors and non-attendance at mammography screening was further investigated in a record-linkage study with data from the mammography register in Uppsala, the Census of 1990 and the Fertility Register (Paper IV). Multivariate analyses among 4,198 non-attenders and 38,972 attenders confirmed that non-attendance was more common among women living without a partner, and among those who were not employed. Non-attendance was also more frequent among both childless and high-parity women, among those renting an apartment (rather than owning their apartment or house), and among immigrants from non-Nordic countries.

The association between socioeconomic factors and survival among 4,645 women with a first diagnosis of breast cancer in 1993 was assessed in a register study (Paper V). Sociodemographic data were obtained from the Census of 1990 and the Fertility Register. Stage of disease at diagnosis was obtained from Regional Cancer Registers. Follow-up through 1998 in the Swedish Cause of Death Register revealed that 772 of the 4,645 women had died of breast cancer. Five-year survival was 59% higher among women of higher socioeconomic status, after adjustment for stage of disease and age.

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## LIST OF PUBLICATIONS

This thesis is based on the following papers, which will be referred to by their Roman numerals:

- I. Lagerlund M, Sparén P, Thurffjell E, Ekbom A, Lambe M. Predictors of non-attendance in a population-based mammography screening programme; socio-demographic factors and aspects of health behaviour.  
*Eur J of Cancer Prev* 2000; 9:25-33.
- II. Lagerlund M, Hedin A, Sparén P, Thurffjell E, Lambe M. Attitudes, beliefs, and knowledge as predictors of nonattendance in a Swedish population-based mammography screening program.  
*Prev Med* 2000; 31:417-28.
- III. Lagerlund M, Widmark C, Lambe M, Tishelman C. Rationales for attending or not attending mammography screening – a focus group study among women in Sweden.  
*Eur J of Cancer Prev* 2001; 10:429-442.
- IV. Lagerlund M, Maxwell AE, Bastani R, Thurffjell E, Ekbom A, Lambe M. Sociodemographic predictors of non-attendance in invitational mammography screening – a population-based register study (Sweden).  
*Cancer Causes Control* 2002; 13 In press.
- V. Lagerlund M, Bellocco R, Karlsson P, Tejler G, Lambe M. Socioeconomic factors and breast cancer survival – a population-based cohort study in Sweden.  
Manuscript.

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## **LIST OF ABBREVIATIONS**

BSE	Breast Self-Examination
CI	Confidence Interval
FGD	Focus Group Discussion
HBM	Health Belief Model
HRT	Hormone Replacement Therapy
ICD, ICD-7	International Classification of Diseases
NRN	National Registration Number
OC	Oral Contraceptives
OR	Odds Ratio
SEI	Socioeconomic Index



# 1 INTRODUCTION

Breast cancer is the most common form of cancer among women in the western world, and is a major public health issue. In the absence of efficient methods for primary prevention, secondary prevention by mammography screening plays an important role in efforts to reduce breast cancer mortality. It has been estimated that the detection of early disease by mammography decreases mortality by about 31% in women 50 years of age or older (Larsson *et al.* 1996; Morrison 1993). A positive public health impact of population-based screening programs depends to a large extent on optimizing participation rates. Despite large-scale investments in mammography screening programs since the late 1980s, little is yet known about what affects participation in Sweden. To gain a better understanding of the factors ultimately influencing attendance and non-attendance at outreach mammography screening programs is of importance for further improvement of the organization and effectiveness.

Epidemiologic findings indicate that breast cancer survival is related to socioeconomic factors. Women of lower socioeconomic status tend to have poorer survival compared to socioeconomically more favored women (Kogevinas and Porta 1997). It would seem of importance to explore and monitor social differences in breast cancer survival at different periods of time as the findings may indirectly reflect the degree of equality regarding detection of the disease and treatment received, and help to identify prognostic factors amenable to intervention.

The aim of the present studies was to investigate factors affecting attendance at outreach mammography screening, and to assess the effect of socioeconomic factors on breast cancer survival following the establishment of such screening in Sweden.

## 2 BACKGROUND

### 2.1 BREAST CANCER

In 1999 more than 6,000 new breast cancer cases were diagnosed in Sweden, accounting for 30% of all female cancers in this country (National Board of Health and Welfare 2001a). Each year about 1,500 women die of the disease (National Board of Health and Welfare 2001b). The average annual increase in breast cancer incidence between 1980 and 1999 has been 1.7% (National Board of Health and Welfare 2001a), while breast cancer mortality decreased by on average 0.8% per year between 1987 and 1999 (National Board of Health and Welfare 2001b). In the European Union breast cancer represents 28% of all new cancers and 19% of female cancer deaths (Black *et al.* 1997). Estimates from 1985-1989 indicate that during that period breast cancer survival in Sweden was above the European average. Between the periods 1978-1980 and 1987-1989, the 5-year age-standardized survival rate in Northern Europe (Sweden, Finland and Iceland) improved by 5.1 percentage points (Quinn *et al.* 1998). In Sweden the relative 5-year survival of breast cancer increased steadily from 63.2% in 1960-62 to 84.2% in 1993-95 (Talback 2001).

Risk factors for breast cancer are increasing age, nulliparity, early menarche, late menopause, obesity in postmenopausal women, current and increasing duration of use of hormonal replacement therapy (HRT), high concentrations of endogenous estradiol, alcohol consumption, and heredity. Prolonged current or recent use of oral contraceptives (OC) has also been implicated as a cause of a small increase in the risk of breast cancer. Childbearing is an established protective event, with greater protection in association with a young age at first birth and a larger number of full-term pregnancies. Breast feeding and physical activity probably also have a protective effect (Key *et al.* 2001).

Converging epidemiologic findings indicate that both the incidence of breast cancer and breast cancer survival are related to socioeconomic factors. Women of lower socioeconomic status are at lower risk of developing breast cancer (Faggiano *et al.* 1997; van Loon *et al.* 1995). The social gradient in incidence has been attributed to differences in reproductive behaviors; in general, women of higher socioeconomic status have a lower parity, higher age at first birth, greater prevalence of childlessness, shorter duration of breast-feeding and later age at the menopause – all factors which are known to increase the risk of breast cancer (Kelsey and Horn-Ross 1993). Less is known about the etiology of social differences in breast cancer survival. Suggested factors of importance include timing of diagnosis, type and quality of treatments, biological characteristics of the neoplasm, and host factors such as co-morbidity and psychosocial factors (Vågerö and Persson 1987).

Most studies that have dealt with the effect of the socioeconomic status on breast cancer survival have shown a higher survival among women in higher socioeconomic groups (Auvinen *et al.* 1995; Bassett and Krieger 1986; Bonett *et al.* 1984; Boyd *et al.* 1999; Coleman *et al.* 2001; Delgado *et al.* 1995; Franzini *et al.* 1997; Gordon *et al.* 1992; Greenwald *et al.* 1996; Karjalainen and Pukkala 1990; Kravdal 1999; Mackillop *et al.* 1997; Nandakumar *et al.* 1995; Pollock and Vickers 1997; Schrijvers *et al.* 1995b; Stavrayk *et al.* 1996; Thomson *et al.* 2001; Waxler-Morrison *et al.* 1991; Vågerö and Persson 1987), while other studies have revealed no significant association (Boffetta *et al.* 1993; Ell *et al.* 1992; Haybittle *et al.* 1997; Keirn and Metter 1985; Rosso *et al.* 1997; Schrijvers *et al.* 1995a; Taylor 1997) or a reversed association (Kogevinas *et al.* 1991; Reeves *et al.* 2000). These studies varied greatly in the number of patients, whether ecological or individual measures of exposure were used, the availability of data on prognostic factors, the length and period of follow-up, and whether the cause of death was known or not.

## **2.2 MAMMOGRAPHY SCREENING**

Mammography screening programs in Sweden operate in a national health care system with a guiding principle of equal access to care, primarily funded through taxation.

### **2.2.1 History**

During the sixties, seventies and eighties, randomized trials of breast cancer screening by mammography were initiated in several countries. The Swedish trials of mammography showed a 29-30% mortality reduction in the age group 50-69 years (Nyström *et al.* 1993). Consequent to these findings and to similar results obtained in trials in other regions, and in compliance with the European Union recommendation that all women of ages 50–70

years should undergo mammography every second year (European Commission 1996), screening was initiated in many countries during the 1980s and 1990s. Population-based programs are now operating in Australia, Finland, Iceland, the Netherlands, Sweden, and the United Kingdom (Shapiro *et al.* 1998). In Sweden, breast cancer screening programs were introduced in the late 1980s and the subsequent participation rates have ranged from 63% to 89%, varying over time, by age and by region (Olsson *et al.* 1995). By 1997 screening programs had been established in all parts of the country (Jonsson *et al.* 2000). Recently, and since the data collection in the studies described in this thesis, the quality of the randomized trials that formed the basis for introducing population-based mammography screening programs has been questioned (Gotzsche and Olsen 2000; Olsen and Gotzsche 2001). The basis for these allegations has, in turn, been criticized (Cates and Senn 2000; Duffy 2001; Hayes *et al.* 2000; Law *et al.* 2000; Moss *et al.* 2000; Nyström 2000). Also, new findings based on observations in a clinical setting indicate that organized screening can reduce breast cancer mortality by as much as 50% (Cady 2001; Tabar *et al.* 2001). It is not known whether and how this debate will affect screening attendance in the future.

High attendance rates are one of the criteria listed by WHO for considering screening examinations meaningful and ethically acceptable (Wilson and Jungner 1968):

- The condition being screened for should be a common disease that causes problems in the population
- The natural history of the condition should be well known
- Effective treatment should be available for all individuals that are diagnosed with the disease
- *The rates of attendance at the screening should be high*
- Diagnosis and treatment of the condition being screened for should lead to a higher quality of life
- The examination should not involve unacceptable risks or inconveniences

Despite the relative success of the Swedish mammography screening programs in recruiting women for screening, non-attendance still occurs. In 1992, the screening participation rate (proportion of women who attended among those invited) in the big Swedish cities (Stockholm, Göteborg and Malmö) ranged between 66% and 70%, and the national mean participation rate among invited women was around 81%. This rate exceeded the goal set by the European Guidelines for Quality Assurance in Mammography Screening, i.e., a “desirable” level of at least 75% (de Wolf and Perry 1996). It also exceeded the goal of at least 65% attendance in the largest urban areas of Sweden and at least 75% in other regions, set by an expert group assigned by the National Board of Health and Welfare (National Board of Health and Welfare 1998).

### **2.2.2 Organization**

The regional mammography program of the county of Uppsala in central Sweden started in 1988. There are four screening clinics within the region, operating in the daytime on weekdays, to which women between the ages of 40 and 54 are invited every 18 months and women between 55 and 74 are invited every second year. All women of eligible ages receive a letter giving a specific date and time for a mammography examination. The out-of-pocket cost has varied over time and was 120 SEK (approximately 13 EUR and

12 USD) in 1997. The staff conducting the mammography examination is predominantly female and consists of radiology nurses/technicians with special training in mammography. The participation rate was 86% in the first two years after the introduction of screening, but dropped slightly thereafter. Overall, the yearly uptake was fairly stable over the 10-year period 1988–1997, ranging from 76% to 87%, with an average of 80% (Table 1). The fact that a reminder was sent only in the first screening round could have affected the change in attendance rate. However, it appears unlikely that this can explain the whole decrease in attendance between the first and second screening round. Other screening programs have also shown a decrease in attendance over time (Otten *et al.* 1996; Roberts *et al.* 1990).

**Table 1.** Participation rates (percent) across the first to the sixth invitation from 1988 to 1997, based on all subjects invited (n=69,804) and a total of 250,269 invitations.

Year	Invitations						Total
	1 <sup>st</sup>	2 <sup>nd</sup>	3 <sup>rd</sup>	4 <sup>th</sup>	5 <sup>th</sup>	6 <sup>th</sup>	
1988	84						84
1989	87						87
1990	85	78					81
1991	77	77	69				77
1992	73	77	76				76
1993	76	78	79	79			79
1994	76	75	77	77			77
1995	78	80	81	82	80		81
1996	83	77	79	81	82	80	81
1997	76	77	79	81	81	81	79
<b>Total</b>	83	77	78	80	81	80	80

## 2.3 FACTORS AFFECTING ATTENDANCE/NON-ATTENDANCE

Reasons for non-attendance at mammography have almost exclusively been studied in countries without an established public and organized screening system, particularly in the United States. Among countries with national screening programs similar to that in Sweden, non-participation has been investigated most thoroughly in the UK (Calnan 1984; Fallowfield *et al.* 1990; French *et al.* 1982; Hobbs *et al.* 1980; Kee *et al.* 1992; Maclean *et al.* 1984; McEwen *et al.* 1989; Orton *et al.* 1991; Sutton *et al.* 1994), in Finland (Aro *et al.* 1999), the Netherlands (Scaf-Klomp *et al.* 1995), and also in some countries with regional or pilot programs (Ciatto *et al.* 1992; Donato *et al.* 1991; Gram and Slenker 1992; Hagoel *et al.* 1999; Hunt *et al.* 1988; Luengo *et al.* 1999; McNoe *et al.* 1996; Meystre-Agustoni *et al.* 1998; Ore *et al.* 1997; Schofield *et al.* 1994; Seow *et al.* 1997). Most of these studies, however, have been based on data collected in the early stage of these programs.

### 2.3.1 Sociodemographic factors

Comparisons with findings in earlier studies are best made with those conducted in countries or areas with outreach screening programs similar to that in Sweden.

Higher age has been found to predict non-attendance in some studies (Hobbs *et al.* 1980; Kee *et al.* 1992; Scaf-Klomp *et al.* 1995; Schofield *et al.* 1994), but in many other studies no significant association with age has been detected (Calnan 1984; French *et al.* 1982; Hagoel *et al.* 1999; Luengo *et al.* 1999; Maclean *et al.* 1984; McNoe *et al.* 1996; Ore *et al.* 1997; Orton *et al.* 1991; Seow *et al.* 1997; Sutton *et al.* 1994).

With few exceptions (French *et al.* 1982; Luengo *et al.* 1999; Ore *et al.* 1997), married women have been found to be significantly more likely to attend than other women (Aro *et al.* 1999; Calnan 1984; Donato *et al.* 1991; Scaf-Klomp *et al.* 1995; Seow *et al.* 1997; Sutton *et al.* 1994). Except for one study (Seow *et al.* 1997), parity has generally not been shown to affect mammography screening attendance (Donato *et al.* 1991; Ore *et al.* 1997; Sutton *et al.* 1994). The role of social support in general is unclear. A positive association between social support and attendance was found in one study (Calnan 1984), but in another study no significant association was found (Schofield *et al.* 1994). The results from a third study even indicated that social isolation was more common among attenders (Hunt *et al.* 1988).

Different indices of socioeconomic status have been used. The educational level has generally not been found to be an important predictor of participation (Calnan 1984; Hagoel *et al.* 1999; McNoe *et al.* 1996; Ore *et al.* 1997; Schofield *et al.* 1994; Seow *et al.* 1997; Sutton *et al.* 1994), except in two studies in which women with higher education were found to be less likely to attend (Aro *et al.* 1999; Donato *et al.* 1991), and in a Spanish study in which the reverse association was found (Luengo *et al.* 1999).

With a few exceptions (French *et al.* 1982; Hagoel *et al.* 1999), socioeconomic status or social class has not been proven to predict attendance (Calnan 1984; Donato *et al.* 1991; Hobbs *et al.* 1980; McNoe *et al.* 1996; Ore *et al.* 1997; Sutton *et al.* 1994). Higher income was found to predict attendance in one study (Aro *et al.* 1999), but not in another (McNoe *et al.* 1996). Home-ownership or size of dwelling significantly predicted attendance in some studies (Seow *et al.* 1997; Sutton *et al.* 1994), but not in all (Schofield *et al.* 1994).

In some studies women with part- or full-time employment have been found to be more likely to attend than non-employed women (Aro *et al.* 1999; French *et al.* 1982; Gram and Slenker 1992; Kee *et al.* 1992; Schofield *et al.* 1994; Seow *et al.* 1997), while others have failed to detect an effect of employment status (Calnan 1984; Hobbs *et al.* 1980; Luengo *et al.* 1999; McNoe *et al.* 1996; Ore *et al.* 1997).

### **2.3.2 Health behavior**

Positive health-related behaviors such as having had cervical smear tests and visits to doctors have been found to correlate with mammography attendance in countries with mammography screening programs similar to that in Sweden (Aro *et al.* 1996; Calnan 1984; French *et al.* 1982; Hobbs *et al.* 1980; Kee *et al.* 1992; Maclean *et al.* 1984; Ore *et al.* 1997; Schofield *et al.* 1994; Seow *et al.* 1997; Sutton *et al.* 1994). The findings regarding dental check-ups are less consistent. In some studies it was found that attenders were more likely to go regularly to the dentist for check-ups (Calnan 1984; French *et al.*

1982; Maclean *et al.* 1984; Sutton *et al.* 1994), while in others no association was detected (Hagoel *et al.* 1999; Hobbs *et al.* 1980; Ore *et al.* 1997).

Reports concerning breast self-examination (BSE) in earlier studies have varied. One study showed a positive association with frequency of BSE (Calnan 1984), while in another study non-attenders were found to be more likely to practice BSE compared to a population sample (Gram and Slenker 1992). In some studies, on the other hand, no significant relation between performance or frequency of BSE and compliance was found (Ore *et al.* 1997; Schofield *et al.* 1994; Seow *et al.* 1997; Sutton *et al.* 1994). From a Finnish study it was reported that women who performed BSE weekly were less likely to attend screening than those performing BSE monthly (Aro *et al.* 1996). A positive association between clinical breast examinations and mammography screening attendance has been detected in some studies (Hagoel *et al.* 1999; Ore *et al.* 1997; Seow *et al.* 1997).

With one exception, a study in which smokers were found to be less likely to attend mammography screening (Aro *et al.* 1996), smoking habits have generally not been shown to be associated with attendance (Hagoel *et al.* 1999; Maclean *et al.* 1984; Ore *et al.* 1997; Sutton *et al.* 1994). In at least one study it was found that non-drinkers (teetotalers) were less likely to participate in mammography screening programs (Sutton *et al.* 1994). The same study showed that women who reported drinking every day had an attendance rate similar to that of teetotalers.

Self-rated health was found to affect the screening attendance in one investigation, where women with good health were more likely to attend mammography screening (Calnan 1984), but others have not shown this relationship (Hagoel *et al.* 1999; Ore *et al.* 1997). Emotional distress and sleep problems have been found to be more common among non-attenders (Hunt *et al.* 1988).

Physical activity and diet have generally not been found to predict screening behavior (Aro *et al.* 1999; Hagoel *et al.* 1999; Maclean *et al.* 1984; Ore *et al.* 1997; Sutton *et al.* 1994). However, an association with mammography has been reported for seat belt use (Maclean *et al.* 1984), and for an index of personal health behavior including smoking, diet, exercise and seat belt use (Calnan 1984).

### **2.3.3 Experiences of breast disease**

Somewhat surprisingly, a family history of breast cancer has not appeared to influence mammography attendance (Hobbs *et al.* 1980; Luengo *et al.* 1999; Schofield *et al.* 1994; Sutton *et al.* 1994), except in an Italian study (Donato *et al.* 1991). Similarly, having a family member or friend who had had breast cancer was not found to be associated with attendance (Luengo *et al.* 1999; McNoe *et al.* 1996). Knowing someone who had had breast cancer or having had some previous contact with breast cancer was associated with attendance in several studies (French *et al.* 1982; Ore *et al.* 1997; Schofield *et al.* 1994; Sutton *et al.* 1994), but not all (Calnan 1984; Hagoel *et al.* 1999). Own experience of cancer has not been found to predict attendance (Aro *et al.* 1996). Findings have suggested that a personal history of breast disease or symptoms increase mammography attendance (Luengo *et al.* 1999; Schofield *et al.* 1994), but this has not been found consistently in all studies (Calnan 1984; Hobbs *et al.* 1980; Sutton *et al.* 1994).

### 2.3.4 Knowledge and attitudes

A positive association between different items or scales of knowledge and attendance has been reported from many studies (Aiken *et al.* 1994; Bastani *et al.* 1991; Champion 1992; Fajardo *et al.* 1992; Glanz *et al.* 1992; Marshall 1994; Rimer *et al.* 1991; Rutledge *et al.* 1988; Schofield *et al.* 1994; Taylor *et al.* 1995), with some exceptions (Burton *et al.* 1998; French *et al.* 1982; Luengo *et al.* 1999; Miller and Champion 1993). The questions chosen to reflect women's knowledge about breast cancer and mammography have varied substantially between studies, and encompass knowledge about breast cancer treatment and detection, what age group is most at risk of having breast cancer, lifetime prevalence of breast cancer, risk factors for breast cancer, knowledge of screening guidelines, and breast cancer mortality.

#### 2.3.4.1 The Health Belief Model

To explain health behavior, several theoretical models have been developed, for example the Health Locus of Control, the Transtheoretical Model of Behavior Change, the Theory of Planned Behavior, and the Health Belief Model (Ogden 1996).

The Health Belief Model (HBM) is one of the most widely used psychosocial approaches in attempts to explain health-related behavior (Glanz *et al.* 1990). The HBM, or its components, have previously been used to organize the theoretical predictors of mammography screening behavior in the UK (Calnan 1984; Fallowfield *et al.* 1990), in Israel (Shiloh *et al.* 1997), in Canada (Beaulieu *et al.* 1996), and extensively in the US (Aiken *et al.* 1994; Bastani *et al.* 1991; Champion 1992; Fulton *et al.* 1991; Glanz *et al.* 1992; Rimer *et al.* 1989; Rutledge *et al.* 1988; Stein *et al.* 1992; Taylor *et al.* 1995; Thomas *et al.* 1996). However, this model has never before been applied to Swedish data on mammography utilization.

The HBM postulates that the likelihood that an individual will engage in a given health behavior is a function of subjective perceptions of: (a) *perceived barriers*, i.e., potentially negative aspects of a particular health action that may act as obstacles to undertaking the recommended behavior; (b) *perceived benefits* of taking health action, (c) *perceived severity*, i.e., subjective perception of the seriousness of contracting an illness, (d) *perceived susceptibility*, i.e., subjective perception of the risk of contracting a health disorder; and (e) *cues to action* that may sometimes trigger the health behavior. The original model, presented by Rosenstock (1974), was later expanded to include *self-efficacy*, i.e., the belief in one's ability to carry out the recommended action (Rosenstock *et al.* 1988). Empirical evidence supports the predictive value of three of the four main components of the model, namely susceptibility, benefits and barriers, in relation to different health behaviors (Harrison *et al.* 1992; Janz and Becker 1984), including participation in mammography programs (Aiken *et al.* 1994; Rutledge *et al.* 1988; Shiloh *et al.* 1997; Stein *et al.* 1992). Points of criticism that have been raised against the HBM include uncertainty regarding the causal relation between beliefs and behaviors, the model's focus on individual rather than environmental factors, its lack of quantification, and a concern that focusing on individual determinants of health behaviors might lead to victim-blaming (Rosenstock 1990).

In general, different aspects of practical and emotional barriers have been shown to constitute major predictors of non-attendance (Bastani *et al.* 1991; Beaulieu *et al.* 1996; Champion 1994; Friedman *et al.* 1995; Orton *et al.* 1991; Rimer *et al.* 1989; Shiloh *et al.* 1997; Stein *et al.* 1992; Sutton *et al.* 1994), but not in all studies (Glanz *et al.* 1992; Schofield *et al.* 1994; Thomas *et al.* 1996).

Most earlier studies concerning mammography screening have shown a positive association between perceived benefits, particularly perceived efficacy of the screening, and the likelihood of attendance (Bastani *et al.* 1991; Calnan 1984; Champion 1992; Champion 1994; Ore *et al.* 1997; Orton *et al.* 1991; Rutledge *et al.* 1988; Shiloh *et al.* 1997; Sutton *et al.* 1994; Thomas *et al.* 1996), but some studies have shown no such association (Glanz *et al.* 1992; Schofield *et al.* 1994; Stein *et al.* 1992).

Women who perceive their susceptibility to breast cancer as high have frequently been shown to be more likely to attend mammography screening (Calnan 1984; Champion 1992; Lerman *et al.* 1990; McNoe *et al.* 1996; Rutledge *et al.* 1988; Seow *et al.* 1997; Stein *et al.* 1992; Sutton *et al.* 1994; Taylor *et al.* 1995). In one study, however, a reverse association was found (Schofield *et al.* 1994), and some studies have shown no significant association (Champion 1994; McCaul *et al.* 1996; Rimer *et al.* 1989).

Measures of perceived severity of cancer have not often produced significant results in earlier studies, possibly for the reason that cancer is generally thought of as a serious disease (Janz and Becker 1984). However, a positive association between severity and attendance has been found in a few studies (Champion 1992; Champion 1994; McCaul *et al.* 1996; Rimer *et al.* 1989). Some previous studies have also shown that non-attenders believe to a greater extent than attenders that cancer can never be cured (Glanz *et al.* 1992; Hobbs *et al.* 1980) and that the prognosis is poor if they develop the disease (Burton *et al.* 1998). Women who did not intend to participate in an Italian screening program were also found to be more pessimistic about the possibility of preventing and curing cancer compared to those who intended to participate (Gordon *et al.* 1991).

According to experiences in the US, advice given by the medical profession to have a mammogram is a leading determinant of attendance. Advice, recommendation or encouragement from health professionals has been found to increase the likelihood of attendance in most previous studies (Aiken *et al.* 1994; Friedman *et al.* 1995; Fulton *et al.* 1991; Lerman *et al.* 1990; Miller and Champion 1993; Mootz *et al.* 1991; Rimer *et al.* 1991; Seow *et al.* 1997; Stein *et al.* 1992; Zapka *et al.* 1991). However, one Australian study (Schofield *et al.* 1994) failed to ascertain such an association.

Self-efficacy has been found to correlate with other health behaviors, such as breast self-examination, cessation of smoking, use of condoms, being on a diet, etc., but it is less certain that it is a useful predictor of mammography attendance, which depends less on personal skills such as technique and perseverance. Some studies have shown an association with past behavior (Lechner *et al.* 1997) and future intention (Allen *et al.* 1998; Lechner *et al.* 1997). To some extent attenders have been shown to report a greater sense of control over their health (Champion 1992; Champion 1994; Fajardo *et al.* 1992).



In addition to the main HBM components, there are other factors of general interest in relation to motivation for screening, namely worry, trust in the ability of the health care system to prevent and treat cancer, and fatalism. The findings regarding worry and anxiety are inconsistent. While some previous studies have shown a positive association between worry and attendance (Calnan 1984; Gram and Slenker 1992; Mootz *et al.* 1991; Schofield *et al.* 1994), others have shown a negative (French *et al.* 1982; Lerman *et al.* 1990) or no association (Burton *et al.* 1998; Siegler and Costa 1994). In one study a U-shaped association was found, where attendance was highest in the group of women who said that they were "a bit worried" about developing breast cancer; women at the two extremes (very worried or not worried at all) were significantly less likely to go for screening (Sutton *et al.* 1994).

Faith in medicine has not been shown to differ between attenders and non-attenders (Calnan 1984). However, non-attenders have been found to be significantly more likely to feel that "one should not go looking for trouble/health problems" (French *et al.* 1982; Maclean *et al.* 1984).

### **2.3.5 Immigrants**

Most studies on factors affecting utilization of mammography screening among immigrants have been conducted in the US. Only a few studies have addressed this issue in countries with a similar health care system or similar mammography screening programs to that in Sweden. White, Black and Hispanic women have been included and compared in several US studies (Calle *et al.* 1993; Fox and Stein 1991; Martin *et al.* 1996; Stein *et al.* 1991; Thomas *et al.* 1996), and also Asian women in some (Hyman *et al.* 1994). Subgroups of Hispanic (Peragallo *et al.* 1998; Zambrana *et al.* 1999), Filipino and Korean immigrants (Maxwell *et al.* 2000) have been specifically targeted in some studies. The ethnic composition of immigrants varies between the US and Europe, which makes generalizations and comparisons difficult. In one study in Israel, with universal access to preventive care, no significant differences in utilization of outreach mammography were noted between ethnic groups (Hagoel *et al.* 1999), but in another study Russian immigrant women in Israel were found to be less likely to attend if they were over age 60, less educated, unemployed, or blue-collar workers (Remennick 1999).

## **2.4 FOCUS GROUPS**

In addition to the use of questionnaires and personal interviews, focus groups have been employed to examine women's attitudes toward both mammography and cervical cancer screening (Dignan *et al.*, 1990; Schechter *et al.*, 1990; Tessaro *et al.*, 1994; Danigelis *et al.*, 1995; Straughan and Seow, 1995; Kelly *et al.*, 1996; Jennings, 1997; Thompson *et al.*, 1997; Williams *et al.*, 1997; Bobo *et al.*, 1999). To date, most of these studies have been conducted in the US and none in a setting with population-based outreach mammography screening.

Focus groups are carefully planned groups, that are set up to obtain information on perceptions and norms and to identify issues important to a target group on a specified topic, with data generated from discussions and social interactions within a small group (Basch 1987; Kreuger 1994; Morgan 1997). There is general acceptance of focus groups as an appropriate tool for exploratory research, for example, and the method has been

widely used in the planning and evaluation of health services (Barbour 1995; Kitzinger and Barbour 1999).

In a focus group study in the US it was found that among multiethnic groups of low-income women, factors that could counteract annual attendance at mammography included perceived problems with mammography (radiation and failure to detect some cancers), experiences during a prior mammogram, and procrastination (Bobo *et al.* 1999). Results from focus groups with Black and White women in two North American states highlighted perceived lack of personal risk, procrastination, and absence of physician's influence as important barriers to screening (Schechter *et al.* 1990). Important barriers to mammography among Chinese women in Singapore were fatalism and mystification of cancer, misinformation regarding mammography, perceived costs, lack of belief in the benefits of early detection, and perceived norm (Straughan and Seow 1995). In a study among US African-American women, it was found that perceived breast cancer risk, reliance on breast self-examination, fear of finding cancer, and a tradition of seeing a physician only when they had a specific problem were important in explaining screening behavior (Tessaro *et al.* 1994). Although many concerns may be the same, independent of setting, some are also likely to be culture-specific and dependent on a specific health care system.

### **3 AIMS**

The overall objective of these studies was to increase the understanding of factors affecting mammography uptake in a country with population-based screening programs, and to determine whether there was a socioeconomic gradient in breast cancer survival after the introduction of these programs. The specific aims were:

- to identify predictors of non-attendance at invitational mammography screening, focusing on sociodemographic factors (Papers I and IV), general health behavior, experiences of cancer and breast problems, and self-perceived health (Paper I), and attitudes, beliefs and knowledge (Paper II);
- to obtain descriptive insight into the meanings that women in Sweden attach to mammography and their rationales for attending or not attending mammography screening (Paper III);
- to assess the role played by socioeconomic factors in survival among women with breast cancer since the introduction of low-cost outreach mammography screening (Paper V).

## 4 MATERIAL AND METHODS

Two types of epidemiologic study designs were used in these studies, namely the case-control design (Papers I, II and IV), and the cohort design (Paper V). In addition, focus groups, a qualitative research method, were used (Paper III). All studies were conducted in Sweden, where population-based registers and the possibility of linking these registers through the national registration number (NRN) provide an excellent setting for epidemiologic studies. The NRN is an individually unique identifier assigned to each resident in Sweden at the time of birth or residency.

### 4.1 REGISTERS

In the included studies we used one or more of the following of Sweden's population-based registers:

**The National Population Register**, which is the basic register of the population, is kept by Statistics Sweden and provides continuously updated information on current residents of Sweden. The most important information in the National Population Register is the name, NRN, and residential address.

**The Mammography Register** in the county of Uppsala, administered by the Section of Radiology at the University Hospital in Uppsala, was established in 1988 when the screening program was initiated. This register records information on the woman's name, NRN, current address, and invitations and participation in the screening program. It also keeps record of women who have explicitly asked not to be invited to the screening program (refuser list). The Mammography Register forms the basis for issuing the invitations to mammography screening. Since 1992 the register has distinguished between a diagnostic\* and a screening mammogram.

**The Swedish Census of the Population and Housing of 1990** is the most recent Population Census and is based on a mandatory questionnaire that had to be completed and returned by each household in Sweden. The register provides information on socio-demographic characteristics such as household size, housing, marital status, employment, occupation, income and education for each household member in 1990. Data on the country of origin and citizenship were retrieved from the National Population Register, and data on immigrations and emigrations were retrieved from the Emigration Register and added to the Census files through record linkages (Papers IV and V).

**The Fertility Register** was founded in 1971 and includes information about women born in 1925 onward. This register was originally based on women born between 1925 and 1960 who were permanent residents in Sweden in 1960. For these women, reproductive data (nulliparity and the number and dates of live births occurring during the period 1943–1960) were collected retrospectively at the 1960 Census. Later birth cohorts of Swedish women have been added continuously, and the women's childbirths have been recorded

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\* Diagnostic mammography (or clinical mammography) is defined here as a mammography examination initiated because of signs or symptoms that may indicate breast cancer, and that takes place outside the scheduled screening interval for that particular woman.

annually via vital statistics records. Based on a nationwide reporting system of all births in women residing in Sweden, the data concerning number and dates of birth are generally of high quality (Johansson and Finnäs 1983).

**The Swedish Cancer Register** was established in 1958. Since the initiation of this nationwide register, cancers have been coded according to the seventh edition of the International Classification of Diseases (ICD-7). In six regional cancer registers covering the whole country, all new cancer cases are continuously registered. Notification of newly diagnosed cancers is mandatory. The Cancer Register includes information on the name, NRN, sex, and domicile of the individual at the time of diagnosis, date of diagnosis, and the clinical and morphologic diagnosis. The register is updated yearly. Nearly 100% of all diagnosed cancers are recorded and 97% of these are histologically verified. The proportion of registered cytologically or histologically verified breast cancers was 100% in 1998 (National Board of Health and Welfare 2000).

**The Cause of Death Register** is kept by the National Board of Health and Welfare and records information on all deceased persons registered as residents in the country at the time of death, irrespective of whether death occurs in Sweden or abroad. The register was initiated in 1952 and provides information on underlying and contributing causes of death, date of death, and age at death. The cause of death is generally determined from the medical death certificates, which are designed in accordance with internationally established conventions. The attending physician or the coroner is responsible for completing and filing the medical certificate. All causes of death are coded in accordance with the International Classification of Diseases, Injuries, and Causes of Death (ICD). The number of missing cases is small (0.5% of all deaths among women in 1997). According to an evaluation of the quality of the register, 3% of the deaths had been recorded with an incorrect underlying cause of death at the four-digit ICD code level (National Board of Health and Welfare 2000).

#### **4.2 DEFINITIONS OF ATTENDERS AND NON-ATTENDERS (PAPERS I-IV)**

In the present studies a non-attender (case) was defined as someone who had failed to attend in response to the two most recent invitations to the mammography screening program in the county of Uppsala, and had not been known to have attended clinical mammography (for any reason) in 1993 or later. A single failure to participate was not considered as a definite sign of a woman's decision not to participate, since non-attendance can be due to temporary circumstances. An attender (control) was defined as someone who had been invited at least twice and had participated on at least one of the last two occasions, but not necessarily both.

In some of the analyses a distinction was made between present non-attenders and absolute non-attenders (never-attenders). A present non-attender was defined as someone who had attended at least once but not in response to the two most recent invitations, and an absolute non-attender was defined as someone who had never attended, but had been invited at least twice. A distinction was also made between present attenders, who had sometimes failed to attend earlier but had attended in response to at least one of the two most recent invitations, and absolute attenders, who were defined as those who had never failed to attend.

### 4.3 PAPERS I AND II

We conducted a case-control study among women in the county of Uppsala in an attempt to identify predictors of non-attendance in a population-based mammography screening program.

#### 4.3.1 Study population

Women invited for mammography screening in the county of Uppsala between January 1, 1988 and June 30, 1997 were identified in the Mammography Register. To be eligible as a candidate for our interview study, a woman had (a) to be alive on June 30, 1997, (b) to have been a resident in the the county of Uppsala since at least 1993, (c) to have been invited for screening at least twice, (d) to have been born in 1923 or later, (e) to have been born in Sweden, and (f) not to have had a breast cancer diagnosis.

From 60,571 women in the Mammography Register, we excluded women who did not fit the inclusion criteria and randomly selected 650 attenders and 800 non-attenders (with the aim of obtaining 500 interviews within each group and based on response rates in the pilot study). These women were sent a letter in which they were asked if they would participate in a telephone interview. The criteria for being a non-attender or attender were used up until the point in time when the women included in the study were interviewed or, in the case of those not reached, up until the day on which the study letter was mailed.

**Table 2.** Numbers and percentages of women initially invited, contacted by telephone, interviewed, and included in the analysis, by attendance status, with reasons for dropouts at the different steps.

	Attenders		Non-attenders	
	n	(%)	n	(%)
Initial sample invited by letter	650	(100%)	800	(100%)
Missing phone number	10	(1.5)	19	(2.4)
Ex-directory phone number	14	(2.2)	61	(7.6)
No answer to phone call	31	(4.8)	26	(3.3)
Moved out of region or deceased	0		10	(1.3)
Change of attendance status	1	(0.2)	2	(0.3)
Reached by telephone	594	(91.4)	682	(85.3)
Recent change of attendance status	2	(0.3)	31	(3.9)
Mammography elsewhere	7	(1.1)	25	(3.1)
Not resident in region	4	(0.6)	8	(1.0)
Reached and eligible	581	(100%)	618	(100%)
Participation prevented*	6	(1.0)	28	(4.5)
Refused participation	58	(10.0)	152	(24.6)
Discontinued interview	2	(0.3)	4	(0.6)
<b>Interviewed and included in analysis</b>	<b>515</b>	<b>(88.6)</b>	<b>434</b>	<b>(70.2)</b>

\* Because of temporary disease, institutionalization, or physical or mental obstacle

Table 2 illustrates the different steps in determining the study population. The final analysis was based on completed computer-assisted telephone interviews with 515 attenders and 434 non-attenders, representing 88.6% and 70.2%, respectively, of those eligible and reached by telephone.

### **4.3.2 Data collection**

The telephone interviews were conducted by 19 professional female interviewers at Statistics Sweden between November 1997 and March 1998, and lasted on average 29.6 minutes.

The study questionnaire was developed on the basis of a two-step procedure: (a) unstructured personal face-to-face interviews were conducted with ten non-attenders in order to identify some of the reasons that women may have for not participating, and (b) a pilot questionnaire was tested in another sample of 40 women. The final version of the questionnaire included questions in the following nine areas: (1) sociodemographic factors (age, childbirth, educational level, marital status, occupation), (2) experience of breast disease, cancer, and mammography, (3) health behavior and self-perceived health, (4) knowledge, attitudes, and beliefs concerning breast cancer, treatment and mammography, (5) trust in the health care system, (6) social influence, (7) self-efficacy, (8) attitudes toward dissemination of health-related information, and (9) self-reported reasons for non-attendance. The importance of factors assessed in areas 1, 2 and 3 in relation to mammography attendance was addressed in Paper I, while Paper II focused on areas 4 to 7.

In Paper II The Health Belief Model was used as a reference in the construction and analysis of some of the interview questions. Social support was assessed by three questions adapted from a social support instrument measuring extent of social integration and attachment (Orth-Gomer *et al.* 1993).

### **4.3.3 Statistical methods**

#### *4.3.3.1 Paper I*

A univariate logistic regression analysis of the effects of the independent variables on the odds of being a non-attender was performed, with adjustment for age. In a second step, only those variables that were significant in the univariate analysis were tested in a multivariate model. To find the best-fitting model, the likelihood ratio test was used to include and exclude variables. Except for employment status ( $p=0.06$ ), all variables in the final model were significant ( $p<0.05$ ). The best-fitting model predicting non-compliance was estimated with pseudo  $R^2$  (Walsh 1990).

#### *4.3.3.2 Paper II*

Most of the items measuring attitudes and beliefs were formulated as statements where answers were given on a 6-point Likert scale (Kerlinger 1986), which was verbally anchored at each end, and ranged from 1 (completely disagree) to 6 (completely agree).

Thirty-six different items were retained in 17 final single- or multi-item subscales. A priori reasoning about the questions, and results of the univariate analysis, factor analysis, and correlation analysis (Cronbach's  $\alpha$ ) contributed to the different constructs. The

internal consistency of each subscale including more than one item was measured with Cronbach's  $\alpha$  (Cronbach 1951), ranging from 0 to 1, where 0.6 or more was considered to be a sufficient value of internal consistency. The five multi-item subscales were: emotional barriers (Cronbach's  $\alpha=0.58$ ), benefits (0.62), susceptibility (0.69), worry (0.79), and social support (0.91). Subscale scores were formed for each subject by summing the scores for the included items. As a rule, missing values for a maximum of one-third of the items were allowed per subscale; data from those subjects who failed to respond to more than this proportion were treated as missing. Individuals with missing values within this allowed proportion were assigned the average score for the items to which they did respond.

Because of their specific knowledge content, seven multiple-choice questions out of a total of 21 questions about breast cancer and mammography were chosen for inclusion in a knowledge subscale. The answers to these seven questions reflect what today can be considered a reasonable level of knowledge in Swedish women concerning mammography, breast cancer, and its risk factors. When the respondent was unable to give any answer, the answer was treated as incorrect. Data from three women who refused to respond to six or all seven of the items were treated as missing.

We computed odds ratios (OR) and 95% confidence intervals (CI) as measures of relative risk. To examine the effects of the independent variables on the odds of being a non-attender, we conducted a univariate logistic regression analysis. All items were treated as categorical variables in the analysis. In a second step, only the subscales significant in the univariate analyses were tested in a multivariate model that also included age and other background variables that have been found to predict mammography screening attendance in Paper I. To find the best-fitting model, the likelihood ratio test was used. All variables included in the final model contributed significantly to the model ( $p<0.05$ ). Interaction effects among these variables were also examined by adding the interaction (cross-product) term to the model. The statistical significance of these interactions was assessed using the likelihood ratio test.

#### **4.4 PAPER III**

We conducted focus group discussions among women in the county of Uppsala in order to obtain descriptive insight into the meanings that women in Sweden attach to mammography and their rationales for attending or not attending mammography screening. This qualitative approach was chosen to further the understanding of women's concerns and to probe more deeply into attitudinal factors related to mammography screening.

##### **4.4.1 Recruitment of study participants**

While many focus group studies have used convenience samples, we based this study on an existing population-based register in order to maximize the heterogeneity of the sample. Computer lists of randomized samples for the focus groups were generated from the Mammography Register in the county of Uppsala. Only women with an identified telephone number (sought manually) were contacted. In order to minimize complications caused by language barriers in the group discussions, women with foreign names were not contacted in this study.



To achieve intra-group homogeneity and inter-group heterogeneity, the population was divided by age (three age groups) and previous attendance at mammography screening (attenders, present non-attenders and never-attenders). A total of nine groups were planned; one group per combination of age and screening history.

To get sufficient numbers of participants in each group, a total of 321 letters describing the study and asking the women to participate at a specific date were sent out, whereupon a recruitment assistant tried to reach all of the women by telephone to ask them to participate. A few days before the focus group sessions, each woman who had agreed to attend (n=56) was sent a reminder. We were able to recruit only one older present non-attender (in the age group 65–74), although 40 letters were sent out followed by telephone recruitment, and the group was therefore cancelled. Never-attenders in this age group were also difficult to recruit, but after 54 delivered letters we recruited two participants to this group. A total of 31 women ultimately participated in the eight focus groups, which ranged in size from two to five women (Table 3).

**Table 3.** Focus group composition (n=31).

Attendance status	Age groups		
	44–54	55–64	65–74
Attenders	n = 5	n = 4	n = 4
Present non-attenders	n = 3	n = 5	
Never-attenders	n = 4	n = 4	n = 2

#### 4.4.2 Procedures

In order to ensure that the focus group discussions (FGDs) would not be interrupted, and that the selected site would not convey messages about health care or affiliation with screening, the FGDs were carried out in small rooms of a centrally located conference center. The sessions were held during weekday evenings. Two persons led the FGDs; one of whom was a more experienced moderator. The second moderator provided practical assistance, observed, and audiotape-recorded the sessions. The same major issues were raised with each group: (1) signs of women’s good health and ways for women to remain healthy, (2) common health problems among women over 40 and why some women are more prone to such problems than others, and (3) attitudes, beliefs and experiences of mammography and cervical cancer screening. We allowed the participants’ comments and interests partially to direct the discussions rather than using a standardized set of questions. Each session lasted between 1.5 and 2 hours. The discussions were conducted from March to October 1999.

#### 4.4.3 Data analysis

The audiotape-recorded discussions were transcribed and copies were given to each person in the research team. Two researchers (the first and second authors) individually read and coded the transcripts. During a 6-day intensive analysis session the coding systems were discussed and revised. The transcripts were further analyzed for trends and themes that emerged within the FGDs. Related comments were grouped together.

Illustrative verbatim quotes from the sessions were selected to highlight the themes. Another researcher, who read the transcripts and attended some of the FGDs, had a validating function throughout the process of analysis. ATLAS.ti, a software program for analyzing qualitative data (Scientific Software Development 1999), was used as a structural aid in the analysis.

## **4.5 PAPER IV**

### **4.5.1 Study population**

We conducted a register-based case-control study of women in the county of Uppsala to assess the impact of sociodemographic factors on mammography screening attendance. All women (n=60,571) who had been invited at least twice to the screening program in the county of Uppsala between February 1, 1988, and June 30, 1997 were identified in the Mammography Register.

The Mammography Register in the county of Uppsala was linked to the Census of 1990, the Fertility Register, the Swedish Cancer Register, and the Swedish Cause of Death Register. After linkage of the databases, we excluded women who were deceased (2,044), non-residents in the county of Uppsala (3,331), older than 74 years (6,386), listed on the refuser list (502), or non-attenders known to have received a diagnostic mammogram in 1993 or later (593). In addition, we excluded 549 women for whom no information was available in the Census, and 106 women who had immigrated or emigrated during the years 1993 to 1997. Women with a history of breast cancer (1,042) were excluded for the reason that they were more likely to have attended screening. After these restrictions, the final study population consisted of 46,041 women who could be defined as either attenders (41,298) or non-attenders (4,743).

### **4.5.2 Data collection**

Information on sociodemographic characteristics was obtained from the Swedish Census of the Population and Housing in 1990. Information used in the present study included cohabitation, country of origin, date of immigration, and different socio-economic indicators such as occupation, employment status, educational level, and income. Information on parity was obtained from the Fertility Register. Parity was primarily used as an indicator of the woman's social situation (social support, family situation and work load).

Educational level (highest attained) was categorized according to classifications used in the Swedish school system: (1) low (mandatory school,  $\leq 9$  years), (2) medium (high school, 10-12 years), (3) high (college and university,  $>12$  years), and (4) extra-high (PhD degree). The socioeconomic classification (SEI) was based primarily on occupation, different occupations being allocated to socioeconomic groups according to the required level of education. The following eight categories were used: (1) skilled and (2) unskilled blue-collar workers, (3) low- (4) medium- and (5) high-level white-collar workers, (6) self-employed and farmers, (7) not gainfully employed, and (8) unclassifiable and missing.

The Census data did not include information on the educational level of women aged 65 years or older in 1990, and these women were therefore included in the category of

'education missing'. Similarly, retirement pensioners (women aged 65 years or older in 1990) were all counted as not gainfully employed. Since date of immigration was first recorded in the National Population Register in 1968, women registered as born abroad and for whom information on date of immigration was missing were treated as having immigrated in 1967.

In the multivariate model, broader categorizations were used and women with missing observations for one or more of the variables cohabitation, employment status and home ownership were excluded (n=2,871).

#### **4.5.3 Statistical methods**

A univariate logistic regression analysis of the effects of the independent variables on the odds of being a non-attender was conducted. All independent variables were categorized by creating dummy variables. Significant variables ( $p < 0.01$ ) were tested in a full multivariate model. When variables were correlated, such as education, employment status, total income, and home ownership, only one of them was considered in the model. Correlations between categorical variables were estimated by using polychoric correlation. Goodness-of-fit in the multivariate models was obtained by using the Hosmer-Lemeshow test. Interaction effects among the selected variables were also examined by adding the interaction (cross-product) term to the model. The statistical significance of these interactions was assessed with the likelihood ratio test. Interactions with a p-value below 0.05 were considered significant.

### **4.6 PAPER V**

We examined the association between socioeconomic factors and survival among women with a first diagnosis of invasive breast cancer in a population-based register study. A cohort of women diagnosed with breast cancer in 1993 was established retrospectively and followed up through 1998 for death from breast cancer. The study was based on linkage between ten Swedish population-based registers: the Cancer Register, five regional cancer registers, the 1990 Census, the Fertility Register, the Emigration Register, and the Cause of Death Register.

#### **4.6.1 Cohort and follow-up**

All breast cancer cases diagnosed from January 1 to December 31, 1993 were identified from the Swedish Cancer Register. A total of 5,853 breast cancers (in 5,649 women) were diagnosed in 1993, of which all first diagnoses of invasive breast cancer were chosen for inclusion in the analysis. We excluded women with: (1) any diagnoses of invasive breast cancer before 1993, (2) other invasive cancers diagnosed before 1993, and (3) other histopathological types of breast cancer than adenocarcinoma. Additional diagnoses established more than one month after the first diagnosis in 1993 were considered as new tumors (n=171, of which 85 were breast cancers). Cases first diagnosed at autopsy (n=10) were included in the analysis with zero survival, as it cannot be excluded that social class might affect the probability that the cancers remained undetected until death. The final study population consisted of 4,645 women.

Study subjects were followed up for emigration through the Emigration Register and for death through the Cause of Death Register up to December 31, 1998, which was the most recent available year with complete information on cause of death. Women who emigrated permanently (n=17) were censored at the date of emigration, while those who returned to Sweden did not contribute to person-time during the period for which they stayed abroad (n=3).

#### 4.6.2 Statistical Methods

Age at diagnosis was studied in five categories (stratified into <50, 50–59, 60–69, 70–79, ≥80), three categories (<50, 50–79, ≥80), and in continuous form. Information on tumor characteristics at diagnosis was obtained from five of Sweden's six regional cancer registers (covering 80.4% of the Swedish female population (National Board of Health and Welfare 1996)). Variables that were included in all five registers included tumor size and nodal involvement according to UICC (Union Internationale Contre le Cancer/International Union Against Cancer) (Hermanek and Sobin 1987), and estrogen receptor status.

Four different categorical variables were used as indicators of socioeconomic status:

- The socioeconomic index, SEI (derived from occupation), for the woman and for the household, was stratified into: (1) low (including blue-collar workers and low level white-collar workers), and (2) high (including all other classifiable groups).
- Education (the highest formal education attained) was classified into three categories: (1) low (mandatory school, ≤9 years), (2) medium (high school, 10–12 years), and (3) high (university, >12 years).
- Individual income was stratified into quartiles (in hundred SEK): (1) 0–558, (2) 559–961, (3) 962–1420, and (4) 1421–50000.
- Home ownership was stratified into two groups: (1) renting and (2) owning.

Other factors that were considered in the analyses were: marital status (married/unmarried (including divorcees or widows)); parity, categorized into either three groups (nulliparous/1 child/2 children or more) or two groups (nulliparous/parous); total number of people living in the household (including the woman), categorized into two groups (1/>1); country of origin, stratified into three groups (Sweden/Nordic country/non-Nordic country); region of diagnosis, according to the six regional cancer registers (Göteborg, Linköping, Lund, Norrland, Uppsala, and Stockholm); and access to a mammography screening program within the county of residence or not.

The Kaplan-Meier technique and log-rank test were used to estimate the crude cause-specific survival distribution of time from diagnosis of breast cancer to death, and to assess the effect of socioeconomic status. The Cox proportional hazards regression model (Cox 1972) was implemented to test the null hypothesis of no effect of socioeconomic status (both women and household), while taking into account the simultaneous and independent effect of the demographic and clinical variables. Parameter estimates and 95% CI were obtained by maximizing the partial log-likelihood. Model fitting and residual analysis were based on graphical and statistical tests, using Schoenfeld and cumulative martingales residuals based on L.-J. Wei results (Lin *et al.* 1990). STATA7 (StataCorp 2001) and Splus 2000 (Splus 2000) were used for statistical analyses.

## 5 RESULTS

### 5.1 SOCIODEMOGRAPHIC FACTORS (PAPERS I AND IV)

We assessed the association between sociodemographic factors and non-attendance at population-based mammography screening in an interview-based case-control study with 494 non-attenders and 515 attenders. On average, the non-attenders were slightly older than the attenders. Women over the age of 70 years were found to be significantly more likely not to participate compared to women 40–49 years old. Other factors that were found to affect non-attendance significantly after adjustment for age were marital status, parity, socioeconomic status and employment status. A higher likelihood of non-attendance was observed among women who were single, nulliparous, blue-collar workers, and currently non-employed. However, marital status was the only socio-demographic factor significantly associated with the outcome in all steps of the multivariate analysis (Table 4). Women employed full- or part-time were significantly more likely to attend than those who were not employed, but not significantly more than retirement pensioners, when adjustment was made for other factors.

The association between sociodemographic factors and non-attendance at mammography screening was also evaluated in a register-based case-control study comprising 41,298 attenders and 4,743 non-attenders. Both in the univariate analysis and after adjustment for other factors in the multivariate model (Table 5), older age (70–74 years) showed a discernible negative effect on screening attendance. A U-shaped association was found between parity and non-attendance; women who were childless or had given birth to five or more children were most likely to be non-attenders. Not living with a spouse or partner was associated with a 79% higher likelihood of being a non-attender, compared to living with a partner. Univariate analysis also showed that mammography participation was somewhat lower among women with the lowest and highest level of education compared to women with an intermediate level of education.

Among gainfully employed women, univariate estimates revealed little difference in attendance between different socioeconomic levels; unskilled blue-collar workers and high-level white-collar workers being somewhat less likely to attend. In the multivariate model all gainfully employed women were combined into one category (thus creating the new variable employment status), and women who were not gainfully employed were found to be twice as likely to be non-attenders as gainfully employed women. Among women renting their home, non-attendance was 75% higher than among those owning their home. Foreign-born women were less likely to attend than women born in Sweden, with those born outside the Nordic countries being least likely to attend. Univariately, women with the lowest income (0–99 thousand SEK per year) and the highest income (300 thousand or more) were found to have the highest odds of non-attendance.

A total of seven significant second-level interactions were found and included in the final model. A closer look at selected interactions showed that among non-gainfully employed women, those between the ages of 40 and 69 years were less likely to attend than older women.

**Table 4.** Multivariate logistic regression analysis of factors regarding their prediction of non-attendance at mammography screening\*

<b>Variables</b>	<b>Groups</b>	<b>OR (95% CI)†</b>	<b>P value for likelihood ratio test</b>
<u>Sociodemographic factors</u>			
Marital status	Non-single	1.00 (Reference)	<0.001
	Single/divorced/separated	2.11 (1.48–3.00)	
	Widowed	0.72 (0.41–1.26)	
Employment	Employed full- or part-time	1.00 (Reference)	0.06
	Not employed	1.62 (1.02–2.60)	
	Retirement pensioner	0.81 (0.43–1.52)	
<u>Health behavior</u>			
BSE frequency (currently)	Once a month or more often vs. seldom/never	1.69 (1.25–2.29)	<0.001
Visits to doctor (within previous 5 yrs)	Never vs. ever	1.73 (1.08–2.78)	0.02
Use of oral contraceptives	Never vs. ever	1.61 (1.13–2.29)	<0.01
Use of hormone replacement therapy	Never vs. ever	2.00 (1.43–2.79)	<0.001
Cervical smear test	Never vs. ever	3.89 (1.65–9.18)	<0.001
Smoking (during previous 5 yrs)	Regularly part of period or more vs. never	1.74 (1.27–2.37)	<0.001
Present alcohol use	Never vs. ever	2.22 (1.51–3.27)	<0.001
<u>Experiences</u>			
Breast cancer in the family	Never vs. ever	1.78 (1.19–2.66)	<0.01
Breast cancer among friends	Never vs. ever	1.50 (1.09–2.06)	0.01
Own breast problems	Never vs. ever	2.40 (1.49–3.87)	<0.001

\* Based on 417 non-attenders and 504 attenders in interview-based study.

† Adjusted for age and all other variables included in the multivariate logistic regression analysis

OR, odds ratios; CI, confidence interval; BSE, breast self-examination

**Table 5.** Multivariate odds ratios (OR) and 95% confidence intervals (CI) of non-attendance at mammography screening by sociodemographic factors (n=43,170, of whom 4,198 were classified as non-attenders and 38,972 as attenders), in register-based study.

<b>Variable</b>	<b>Non-attenders n (row %)</b>	<b>Attenders n (row %)</b>	<b>OR (95% CI)*</b>
<u>Age group</u>			
40–69 yrs	3,600 (9.2)	35,414 (90.8)	1.00 (Reference)
70–74 yrs	598 (14.4%)	3,558 (85.6)	1.29 (1.03–1.62)
<u>Number of live births</u>			
0	840 (16.3)	4,301 (83.7)	1.75 (1.55–1.97)
1–4	3,099 (8.5)	33,504 (91.5)	1.00 (Reference)
5 or more	259 (18.2)	1,167 (81.8)	2.18 (1.77–2.68)
<u>Cohabitation</u>			
Yes	2,510 (7.8)	29,877 (92.3)	1.00 (Reference)
No	1,688 (15.7)	9,095 (84.4)	1.69 (1.53–1.87)
<u>Employment status</u>			
Gainfully employed (including self-employed)	2,792 (8.0)	31,997 (92.0)	1.00 (Reference)
Not gainfully employed (including retired)	1,406 (16.8)	6,975 (83.2)	2.07 (1.85–2.32)
<u>Home ownership</u>			
Owning	2,985 (8.4)	32,511 (91.6)	1.00 (Reference)
Renting	1,213 (15.8)	6,461 (84.2)	1.75 (1.55–1.97)
<u>Country of origin</u>			
Sweden	3,490 (9.1)	34,860 (90.9)	1.00 (Reference)
Nordic country	316 (11.6)	2,406 (88.4)	1.27 (1.07–1.50)
Other	392 (18.7)	1,706 (81.3)	2.39 (2.00–2.84)
<u>Interactions</u>			
Age * employment status			p = 0.004
Live births * employment status			p = 0.03
Live births * home ownership			p = 0.005
Cohabitation * employment status			p = 0.006
Cohabitation * home ownership			p = 0.04
Country of origin * employment status			p = 0.03
Country of origin * home ownership			p = 0.0002

\* P-values for the seven included interactions are for likelihood ratio test, type 3.  
Hosmer-Lemeshow Goodness-of-fit statistics = 2.36, df = 3, p = 0.67.

The difference in screening attendance between women owning and renting their home was smaller among single women than among non-single women. Women who rented their home were much less likely to attend if they had five or more children than if they were childless.

### 5.1.1 Immigrants

In the register-based case-control study we conducted separate analyses among women born abroad. The overall rate of non-attendance in foreign-born women was 15.8%, compared to 9.6% among Swedish-born women. In this subgroup of foreign-born women

additional univariate analyses showed that women who were 50–74 years of age at first immigration were almost three times more likely to be non-attenders compared to younger women, and that immigrants who had spent less than 26 years in Sweden were 78% more likely to be non-attenders compared to those who had spent a longer time in the country. Number of years spent in Sweden was chosen for inclusion in the multivariate model together with number of live births, cohabitation, socioeconomic status, home ownership and country of origin. Overall, the influence of sociodemographic factors was somewhat less pronounced among immigrants, but did not differ substantially from that among all women (see Table 5). Among women born outside of Europe those owning their home were somewhat more likely to be non-attenders than those renting their home.

## **5.2 HEALTH BEHAVIOR AND HEALTH STATUS (PAPER I)**

In the interview-based case-control study we also examined the effect of health behavior and of self-perceived health status on non-attendance at mammography screening. There was some indication that non-attendance was more common among women practicing breast self-examination; an association that was significant among blue-collar but not among white-collar workers. Age-adjusted attendance rates were significantly lower among women who had never had a clinical breast examination, those who never visited a dentist, those who had paid no visits to a physician during the last 5 years, and those who had never had a cervical smear test. Never-users of oral contraceptives or HRT were also less likely to attend. However, no association with HRT use was found among women with university education. Similarly, a positive association between smoking (ever having smoked regularly during the previous 5-year period) and failure to attend was modified by education and was found only among women with no university education. Women who reported that they never drank alcohol were significantly more likely not to participate. When tested in a multivariate model, all health behavior variables, except clinical breast examination and visits to a dentist, were significantly associated with non-attendance and included in the model (Table 4).

Non-attenders tended to rate their health status as poorer than attenders. The likelihood of non-participation was almost three times higher among women with very poor self-rated health than among those who stated that their health was very good. However, this variable was not included in the final multivariate model.

## **5.3 EXPERIENCE OF CANCER AND BREAST PROBLEMS (PAPER I)**

The association of non-attendance at mammography screening with experience of cancer and breast problems was examined in the interview-based case-control study. We found that the age-adjusted likelihood of non-attendance was about 80% higher among women with no experience of breast cancer in the family or among friends, and almost three times higher among women with no personal experience of breast problems compared to women who had such experience. A similar pattern was found for lack of experience of other cancers among family or friends. Women who had never breast-fed their children were 88% more likely not to attend when adjustment was made only for age. When adjustment was made for other factors in the multivariate model, previous experience of breast cancer among friends and of own breast problems remained significant (Table 4). The association between experience of breast cancer in the family and non-attendance remained stable.



## 5.4 ATTITUDES AND KNOWLEDGE (PAPER II)

In the interview-based case-control study we also evaluated the effects of attitudes, knowledge, and social support on attendance at mammography screening. When the different items related to the HBM were analyzed in a dichotomized form, all of the barrier items except pain at the mammography examination and knowledge of others' negative experience of the examination were positively associated with non-attendance. All items measuring perceived benefit, perceived susceptibility, advice, and self-efficacy were positively associated with attendance, while a less consistent pattern was found for perceived severity.

The 17 single- and multi-item subscales were significant in univariate analyses and were all subsequently tested in a multivariate model (Table 6). The best-fitting multivariate logistic regression model was based on 347 non-attenders and 496 attenders. Eight subscales remained significant and were retained in the model. Attenders were more than twice as likely as non-attenders to have ever received advice from a health professional to undergo mammography. Non-attenders were more likely than attenders to have very poor trust in the ability of the health care services to help in the event of illness. Women who considered the out-of-pocket mammography expense too high were over three times more likely to be non-attenders than those who did not. Furthermore, women who were dissatisfied with being invited to a particular screening clinic were three times more likely to be non-attenders. Out-of-pocket cost and screening clinic were the only two practical barriers included in the multivariate model.

A barrier subscale, consisting of six emotional barrier items, was positively associated with non-attendance. Women in the highest quartile of barriers (i.e., with the highest barrier scores) were almost five times more likely to be non-attenders compared to women in the lowest quartile when adjustment was made for other factors. Within the highest quartile there was a strong linear effect (data not shown).

Five items were retained in the benefit subscale; women in the two highest quartiles (with the highest benefit scores) were about four times less likely to be non-attenders than women in the lowest quartile. The subscale depicting worry was positively associated with attendance; women in the fourth quartile were approximately 10 times more likely to be attenders compared to women in the lowest quartile.

In the multivariate model we detected and included a significant interaction effect between benefits and worry. This effect indicated that among women with the greatest worry, non-attendance was less likely to be decreased further by perceived benefits than among women who worried less. Among women with the lowest perceived benefits, non-attendance was more likely to be decreased further by greater worry.

**Table 6.** Univariate and multivariate odds ratios (OR) and 95% confidence intervals (CI) of non-attendance at mammography screening for single- and multi-item subscales of HBM variables, other attitudes, knowledge and social support, in interview-based case-control study.

Variables	Groups or scores	OR (95% CI)	OR (95% CI)*
Have received advice to have mammography from health professional (advice/cue to action)	Ever vs never	0.25 (0.14–0.45)	0.46 (0.22–0.98)
Trust in the ability of the health care to help if ill	Good or quite poor vs very poor	0.12 (0.03–0.55)	0.11 (0.01–0.97)
Mammography is too expensive (cost barrier)	Agree vs disagree†	4.24 (2.29–7.84)	3.59 (1.50–8.62)
Dissatisfied with being invited to a particular screening clinic	Yes vs no	3.51 (1.87–6.59)	3.12 (1.14–6.39)
Others think one should undergo mammography	Yes vs no	0.33 (0.17–0.63)	
Breast cancer cannot be treated successfully even if detected early (severity)	Agree vs disagree†	1.68 (1.09–2.59)	
Perceived severity of breast cancer treatment	Hard vs easy	0.58 (0.38–0.90)	
Satisfied with own knowledge about breast cancer and mammography	Yes vs no	0.51 (0.30–0.89)	
If I see a news articles about breast cancer I usually read it	Agree vs disagree†	0.44 (0.33–0.59)	
Impression about benefits of mammography from mass media	Positive	1.00 (Reference)	
	Neither positive nor negative	1.82 (1.19–2.80)	
	Negative	3.48 (1.84–6.58)	
Emotional barrier subscale	6	1 (Reference)	1 (Reference)
	7–7.2	1.08 (0.67–1.75)	1.36 (0.73–2.58)
	8–10.8	1.01 (0.72–1.42)	1.17 (0.74–1.84)
	11–30	4.36 (3.08–6.17)	4.81 (2.96–7.82)
Benefit subscale	5–24	1 (Reference)	1 (Reference)
	25–27.5	0.47 (0.32–0.69)	0.53 (0.17–1.66)
	28–29	0.25 (0.17–0.39)	0.26 (0.08–0.86)
	30	0.29 (0.20–0.43)	0.35 (0.08–0.75)
Worry subscale	3–4	1 (Reference)	1 (Reference)
	5–8	0.40 (0.28–0.58)	0.42 (0.14–1.27)
	9–12	0.34 (0.23–0.50)	0.24 (0.08–0.77)
	13–18	0.38 (0.26–0.56)	0.09 (0.02–0.31)
Knowledge subscale	0–2	1 (Reference)	1 (Reference)
	3	0.47 (0.32–0.70)	0.43 (0.25–0.75)
	4	0.41 (0.28–0.61)	0.58 (0.34–1.00)
	5–8	0.26 (0.18–0.39)	0.40 (0.23–0.70)
Susceptibility subscale	2	1 (Reference)	
	3	0.60 (0.38–0.95)	
	4	0.39 (0.26–0.58)	
	5–8	0.29 (0.19–0.45)	
Self-efficacy (perceived control) subscale	1–2	1 (Reference)	
	3–4	0.38 (0.26–0.55)	
	5	0.56 (0.36–0.87)	
	6	0.61 (0.42–0.89)	
Social support subscale	3–14	1 (Reference)	
	15–17	0.48 (0.32–0.70)	
	18	0.56 (0.40–0.77)	
Interaction between benefits and worry			p < 0.05

\* Adjusted for age, all other variables included in the model and background factors (from Table 4).

† Agree, 4–6 on Likert scale; disagree, 1–3 on Likert scale.

Non-attenders were less likely to know the correct answers to the seven knowledge questions about mammography and breast cancer. Women in the upper quartile with the highest score were 2.5 times less likely to be non-attenders compared to women in the lowest quartile.

In addition to the emotional and practical barrier items, other practical aspects were addressed at the interview. First, two questions were asked about factors that had ever resulted in non-attendance. As these two questions were irrelevant to absolute attenders, they were not considered for inclusion in a multivariate model. However, in a univariate analysis comparing present attenders and all non-attenders, non-attendance was positively related to both “distance to screening clinic” (OR=6.70; 95% CI: 1.60–28.08) and “opening hours at screening clinic” (OR=2.82; 95% CI: 1.16–6.80). These estimates became even stronger when adjustment was made for all variables in the final multivariate model. We also asked about previous experience of mammography examinations. An analysis restricted to present non-attenders and all attenders showed that non-attendance was positively associated with being dissatisfied with a previous mammography examination (OR=1.75; 95% CI: 1.23–2.48). Among women who had phoned the screening clinic, those who experienced difficulties in getting through were more likely to be non-attenders (OR=3.27; 95% CI: 1.99–5.35). When adjustment was made for all variables in the final multivariate model, all of these associations remained significant.

## 5.5 RESULTS FROM FOCUS GROUP DISCUSSIONS (PAPER III)

To further the understanding of women’s concerns and to probe more deeply into attitudinal factors related to mammography screening, we conducted focus group discussions among women in the county of Uppsala. Through inductive analysis of the FGDs, we identified six different themes (Table 7) that separately or in combination played an important part in the women’s rationales for attending or not attending mammography screening.

**Table 7.** Main themes identified in the focus group discussions.

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1. Negative experiences
2. Perceived risk factors
3. Knowledge of one’s own body
4. Perceived problems with mammography
5. Political, ideological and moral reasoning
6. Involuntary non-attendance

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### 5.5.1 Negative experiences

Negative experiences were the most frequent theme in the FGDs. The women described such experiences not only with the mammography examination, but also with earlier health care encounters from childhood, through pregnancies, through their own and family members’ illnesses, and also through experiences recounted about others. Judging from the intensity of the descriptions, these various experiences appeared to have affected the women deeply and had later inhibited some of them from seeking health care. Notably, positive descriptions were sparse even among women who had chosen to attend

mammography. Although the strongest negative descriptions came from groups of present non-attenders, attenders also described the mammography examination in a variety of negative terms.

### **5.5.2 Perceived risk factors**

Heredity, which is one major risk factor for breast cancer, was mentioned in all but one group. Some women explained their non-attendance by saying that they did not believe they had any hereditary risk for breast cancer. Women in attender groups also to some extent discussed heredity as a risk factor for breast cancer.

Most of the women in the groups were peri- or postmenopausal, and HRT was mentioned in all but one group. However, HRT as a risk factor for breast cancer was only addressed in a few groups. Other factors that the women related specifically to breast cancer etiology were stress, oral contraceptives, trauma to the breast, pressure and radiation from mammography, and environmental toxins. Factors related to ill health in general included increased longevity of the population, smoking (causing lung cancer), excessive drinking, and lack of adequate sleep, diet and physical exercise.

Furthermore, the unpredictable nature of cancer and a sense of helplessness in relation to breast cancer and other cancers were addressed by some women, mostly in non-attender groups, but also by one attender. They reasoned that you cannot predict whether and where cancer will strike, and that you can have a very healthy lifestyle and still get cancer.

### **5.5.3 'I know my own body'**

Among some women in non-attender groups there was an obvious belief that mammography screening is unnecessary in the absence of symptoms. This issue was spontaneously raised in four of the five non-attender groups. Some of these women viewed themselves as having expertise in interpreting their bodily signals, an expertise which they wished to maintain in contact with health professionals. These women tended to argue that they would discover symptoms themselves. Furthermore, in this study the women who did not attend mammography seemed to express more reliance on their own ability to detect symptoms through self-examinations than did women who attended. Some women seemed to compensate for their non-attendance at mammography screening by self-examination of their breasts or by having a clinical examination by a physician.

### **5.5.4 Perceived problems with mammography**

Negative technical aspects of mammography were one kind of problem identified in the FGDs. These aspects were mentioned only in the non-attender groups and regarded concern that the pressure and the radiation might be harmful, that the test might fail to detect some cancers or lead to an incorrect diagnosis of cancer in some women, and that the procedure does not save enough lives. Another type of problem related to the degree to which knowledge of the result of the examination is desired. Several women explicitly said that finding out that they had breast cancer would be undesired knowledge and would cause too much worry. Some non-attender groups mentioned problems that arise as a consequence of the broadening spectrum of health controls in our society, problems ranging from increased worry/anxiety, on the one hand, to a false sense of being totally

protected from disease, on the other. In contrast to this skepticism, there was generally a belief in the benefits of screening and in the test result among attenders.

### **5.5.5 Political, ideological and moral reasoning**

One of the women in a non-attender group expressed a strong opinion that tax money should not go to different kinds of screening, especially since the value of mammography screening is still questioned, and that health care should only deal with diseases and ill health. She placed the responsibility on the individual woman to examine herself and to contact a doctor when she experiences symptoms.

Contrary to this view, other women in both non-attender and attender focus groups expressed the view that mammography screening is an asset. The non-attenders generally thought that it was positive that women were offered this opportunity. Screening was regarded as a societal expression of care for women, even if women choose not to participate. The acknowledgement of freedom of choice was important to some women in non-attender groups, but in one non-attender group the participants particularly expressed a sense of responsibility to attend at mammography screening, at least in the abstract.

### **5.5.6 Involuntary non-attendance**

In one group there was a woman whose non-attendance we considered to be involuntary. She had had breast implants for over 30 years and she had attended screening several times before being told at the screening unit that it was unnecessary for her to be screened as the implants obstructed the visualization of the mammograms. She seemed worried about getting breast cancer, relating her concern to her use of HRT and her mother's death from breast cancer.

### **5.5.7 Opinions on information**

Information represents an important aspect of future intervention studies, and as such is of general interest. Relevant results concerning the women's views on information about mammography and breast cancer are therefore incorporated here.

Opinions about the amount of information included in the invitation to mammography were mainly discussed in the non-attender groups and varied quite widely. One attender group briefly discussed this issue on the moderator's initiative, and all women present agreed that information about time and place is all that needs to be included in the invitation. Two women in separate groups of non-attenders wanted information about how beneficial mammography screening is for the individual. In two of the non-attender groups there were women who wanted fairly detailed information about the examination, the procedure, and its potential benefits, and about how it might be experienced, including the information that it might be painful and why, and what time during the menstrual cycle the breasts are least sore and when it therefore might be best to attend mammography in order to avoid pain. However, another group generally agreed that detailed information should not be given, as the details may be frightening, and since too many details might discourage them from reading the invitation. This group also reached a consensus in agreement with one participant's suggestion that the name of the radiology nurse/technician or doctor should be included, to make the invitation more personal.

In all of the eight FGDs, influences from mass media were mentioned. The news articles the participants reported reading appeared to be highly skewed in the sense that women in non-attender groups tended to note things that supported their negative view of mammography, while those in attender groups had heard or seen things that confirmed their fear that the continuation of the screening program was threatened. Information about the benefits of mammography had caught the eye of a few non-attenders, but was generally questioned and did not affect their opinion about mammography.

## **5.6 SOCIOECONOMIC FACTORS AND BREAST CANCER SURVIVAL**

### **(PAPER V)**

In a cohort study the effect of socioeconomic factors on survival among breast cancer patients was examined. The mean age of the women who died of breast cancer during follow-up was 65.0 years, which was slightly older ( $p=0.005$ ) than that of survivors (63.5). Moreover, 16.9% of the women with a low SEI died during follow-up, as against 10.4% of the women with a high SEI; a survival difference that translates into 82 additional deaths in the group of women with a low SEI. Information on the socioeconomic status was not available among those who were not gainfully employed; the proportion of missing data amounted to 57% among women, and 51% among households. Some data were also missing for the education (47%) and parity (42%) variables. Information on tumor size was obtained for 70% of the women, on lymph node status for 63%, and on estrogen receptor status for 55%.

Kaplan-Meier overall and stratified survival curves for a maximum of six years of follow-up are shown in Figure 1. A total of 772 women had died of breast cancer up till the end of 1998 (survival rate 83.4%). No difference in survival was seen between pre-menopausal women (<50 years of age) and women between 50 and 79 years of age, but women diagnosed at the age of 80 or later had clearly poorer survival. The survival rates were higher among women with a high SEI and among home-owners. Women with smaller tumors and no lymph node involvement at diagnosis had a clear survival advantage.

When hazard ratios were computed, a similar pattern was seen for all socioeconomic indicators (SEI, education, income, and home ownership) after adjustment for age; with higher survival rates among women with a higher socioeconomic status. However, after additional adjustment for tumor size at diagnosis, SEI remained the only socioeconomic factor significantly associated with survival. Women from other Nordic countries had a significantly lower survival rate than Swedish-born women. Compared to the youngest age group, women between the ages of 50 and 59 had higher survival, and women above the age of 80 had significantly lower survival. Among women with larger tumors at diagnosis, with positive nodal involvement and with a negative estrogen receptor status, the prognosis was clearly poorer. In addition, women living in counties that had introduced population-based mammography screening in 1993 showed a significantly higher survival than women who lived in counties without screening. This difference, however, could not be explained by differences in tumor size at diagnosis. In a stratified analysis, the effect of SEI was more pronounced among women not covered by screening in 1993.

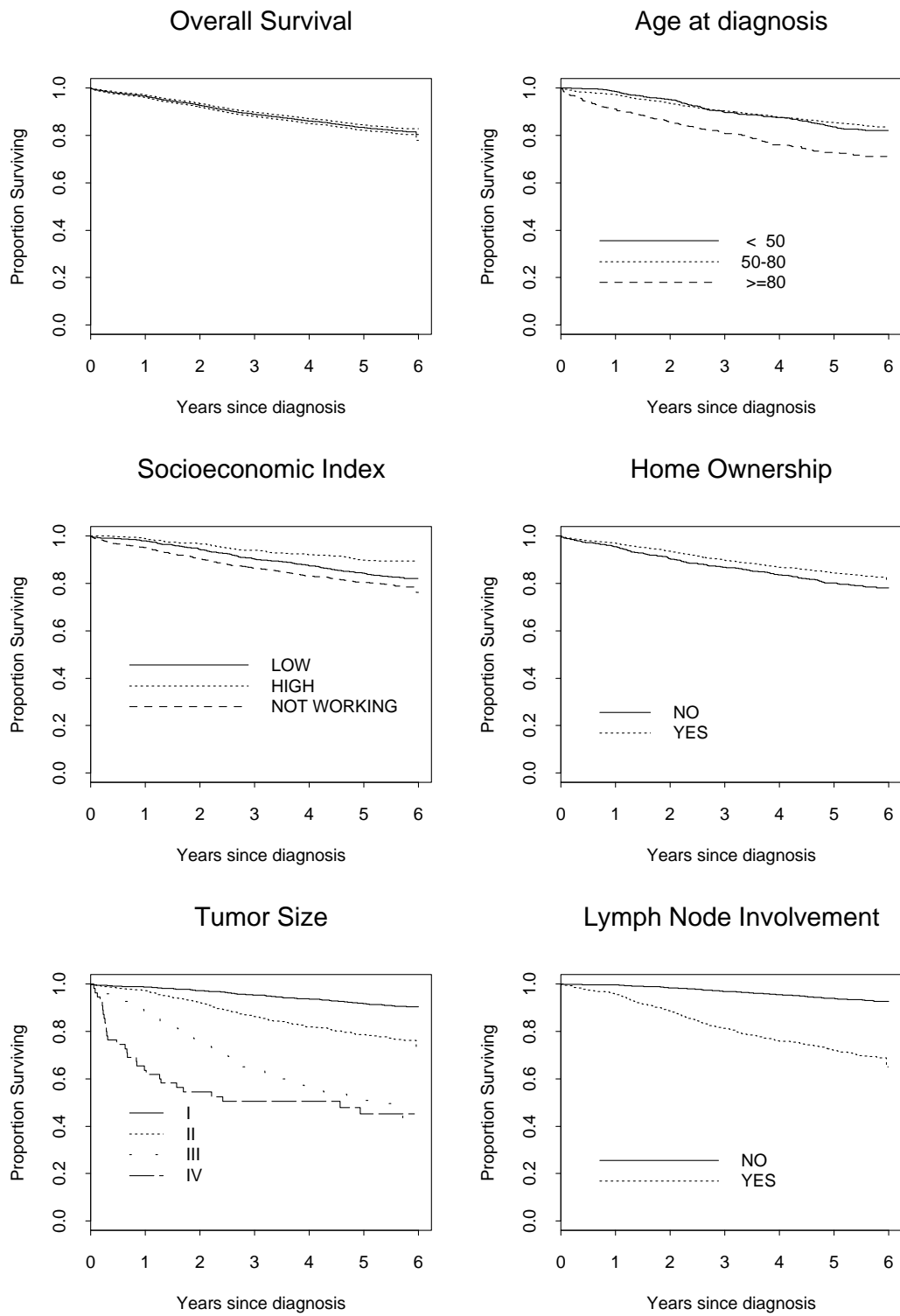


Figure 1. Survival after diagnosis of breast cancer

In multivariate proportional hazards models, SEI of the woman was used as the main socioeconomic indicator. The ‘best-fitting’ multivariate proportional hazards model showed that women with a low SEI had 59% (1/0.63) lower survival than women with a high SEI (Table 8).

**Table 8.** Multivariate proportional hazards model stratified by tumor size at diagnosis.

Variable	Hazard ratio (95% CI) n = 1426
Socioeconomic index (woman)	
Low	1 (Reference)
High	0.63 (0.46-0.88)
Age at diagnosis (linear term)	1.05 (1.01-1.09)
Age at diagnosis (quadratic term)	1.002 (1.000-1.003)
Lymph node involvement	
No	1 (Reference)
Yes	3.66 (2.61-5.13)

Global test:  $\chi^2 = 5.71$ ,  $p = 0.22$



## **6 GENERAL DISCUSSION**

### **6.1 METHODOLOGICAL CONSIDERATIONS**

#### **6.1.1 Focus group discussions (Paper III)**

In considering the implications of the focus group study, it should be recognized that this was a qualitative investigation including a small number of women, which did not aim at generating conclusive findings for direct implementation. Focus group participants very rarely are random samples representative of the target population. As opposed to the quantitative studies described in this thesis, the purpose of the focus group study was to raise issues for consideration and to generate questions of relevance for further discussion. The main themes illuminate existing concerns in the target population. However, focus groups are limited to people that are able and willing to express their views. Furthermore, as well as producing a rich material, the group setting may also suppress some views and opinions. It is therefore possible that other important influences on mammography attendance exist both among the focus group participants and in the wider population.

The women participating in the focus groups represented a wide range of socio-demographic characteristics. However, we did not succeed in recruiting as many older women, particularly non-attenders, as we had hoped. The findings reported in Paper IV showed that women above the age of 70 years were found to be somewhat less likely to attend mammography screening, and their rationales for attending or not attending may differ from those of younger women. It was not clear whether our intention to separate present non-attenders and never-attenders succeeded, since some focus group participants gave information that did not correspond to the register data. The discrepancies were not further investigated, since we did not consider that they interfered with the aim of this study. Our main concern was to separate the attenders and non-attenders, which we did successfully.

In the following discussion about precision and validity, the focus group study will not be included, since the common meanings of these concepts do not relevantly apply to qualitative research.

#### **6.1.2 Precision/Chance**

High precision of estimates makes chance a less likely explanation of findings. Important determinants of precision are sample size, prevalence of exposure, and extent of exposure misclassification. We used p-values and 95% confidence intervals as a measure of the precision of our results. If the confidence interval does not include the null value, it is unlikely that the findings will be a product of chance. Furthermore, a narrow confidence interval implies a small variability in the estimate of exposure. However, we cannot rule out the possibility that positive findings may be due to chance. When several exposure-outcome associations are examined simultaneously, as was the case in the studies described in Papers I, II and IV, the potential role of chance in producing a particular result should not be ignored. There is also a possibility that null results will be due to chance, i.e., that there is an association between an exposure and an outcome that we did not have the statistical power or appropriate tools to discover. When the exposure is rare, a larger sample size will give us more power to detect an existing association. However,

small but statistically significant risk differences may not always be clinically important, and should therefore be interpreted with caution.

In general the findings reported in Papers I, II, IV and V supported our hypotheses and were also in line with previous studies. There was also an internal consistency in findings between our different studies.

### **6.1.3 Validity**

#### *6.1.3.1 Selection bias*

Selection bias is a systematic error that results if the mode of selection of participants for a study differs between cases and controls and that difference is related to the outcome. Selection bias is a particular problem in case-control studies and retrospective cohort studies.

In our interview-based case-control study the response rate among non-attenders was significantly lower than that among attenders (70% vs. 89%) (Papers I and II). It was not unforeseen that non-attenders would be more difficult to enroll for the interviews. Our request for an interview could have been perceived as yet another attempt to persuade reluctant women to attend the screening program. When we compared the women in the random sample who were included in the analysis with those who were not (because they were not interviewed or not eligible), we found no significant differences by age or place of residence. However, we cannot rule out the possibility that the non-responders differed in other ways. Compared to responders, they may have belonged to a category with poorer health, more extreme behaviors and social conditions, and more negative attitudes toward mammography and health care in general. Attenders and non-attenders differed with regard to reasons for refusal to participate in the study, whether they had missing or ex-directory phone numbers or not, and whether they stated ill health or not as a reason for not participating in the study (Table 2), which further implies that non-responding non-attenders may differ systematically from non-responding attenders. However, if anything, this would have led to an underestimation of the true differences between attenders and non-attenders.

In the register-based case-control study the whole population of women invited at least twice to mammography screening in the county of Uppsala was included (Paper IV). These women were identified in the Mammography Register in this county. Exposure data were collected from the Census 90 and the Fertility Register. In these registers the amount of missing data was zero for some specific variables and rather small for others. However, the non-response was higher among non-attenders. When the non-responders (with a missing observation for one or more of the variables cohabitation, employment status, and home ownership) were compared with women who had complete data on all of these variables, we found that they were significantly more likely to be over 70 years of age, to rent their housing, to be non-employed, to be of non-Nordic origin, to have a low level of education, and to have a low income. They were more likely to be childless or to have five or more children, but did not differ regarding cohabitation. This suggests that we underestimated the true differences between attenders and non-attenders. Reasons for not providing complete information in the Census may coincide with reasons for not attending mammography screening, e.g., unwillingness to follow rules or obey authorities.

In retrospective cohort studies selection bias may result if the outcome influences the way in which the exposure status is defined. In the study described in Paper V information on outcome and exposure was collected from different population-based registers, and it is therefore unlikely that the outcome would have influenced the exposure data. Breast cancer cases were identified in the more than 98% complete Swedish Cancer Register, which should minimize the possibility of selection bias in this cohort study. There is a possibility that some breast cancer cases are not diagnosed and registered in the Cancer Register, and are detected for the first time at autopsy. Furthermore, it cannot be ruled out that social class might affect the probability that the cancers remain undetected until death. With this in mind, we decided to include cases first diagnosed at autopsy and we actually found that these women were more likely to be of lower socioeconomic status than the rest of the population. There is a possibility that increased medical awareness among women with a high socioeconomic status causes these women to be diagnosed at an earlier stage of the disease and thus have a true or artificial (the time of diagnosis is advanced but the death is not delayed) survival advantage. Tumor characteristics at diagnosis did not eliminate the effect of socioeconomic status. A survival advantage due to early diagnosis is therefore an unlikely explanation for our findings.

In the survival study reported in Paper V, observations were missing for some of the sociodemographic factors (SEI, education, and parity). Non-working women were found to have lower survival. Analysis of missing data showed that women without information on SEI were more likely to be renting their housing and to have a lower income compared to women with complete information on SEI. Thus, it cannot be excluded that absence of data on SEI was systematic. However, the great majority of women with missing information on SEI (as well as on education and parity) were older and retired (above 68 years in 1993), and thus more likely to have a lower income and possibly also to rent their housing, even if their socioeconomic index might have been high earlier in life. Some data were also missing on tumor size, lymph node involvement and estrogen receptor status, but the presence or absence of these data did not vary systematically by socioeconomic category.

#### 6.1.3.2 *Information bias*

Errors in measurements, both regarding exposure and outcome, may lead to information bias.

Whereas other studies have mainly relied on self-reports, we based our information on participation in mammography screening on register data (Papers I, II and IV), which would reduce the risk of misclassification of the outcome. In the interview-based study, 21% of the non-attenders and 2% of the attenders gave reports concerning their participation that did not correspond to information obtained from the Mammography Register. In accordance with other studies (Eaker *et al.* 2001; Fulton-Kehoe *et al.* 1992; Paskett *et al.* 1996), we also found a tendency for women to underestimate the length of time since the most recent screening. Moreover, in the subgroup of absolute non-attenders, 41% incorrectly stated that they had participated in the screening program. This may reflect the women's difficulties in distinguishing between screening and diagnostic

mammograms and in estimating time lags, thus highlighting a potential problem in studies that have relied on self-reports regarding attendance.

In the same three studies we were also able to exclude women classified as non-attenders but who had had a diagnostic mammography in the catchment area during the last five years. In the interview-based case-control study we were able to exclude women who reported that they had had a mammography examination elsewhere (Papers I and II), but in the register-based study no such information was available (Paper IV). Thus, the possibility cannot be excluded that some of the women categorized as non-attenders may have undergone mammography elsewhere. However, any such misclassification would have led to underestimation of the true differences between attenders and non-attenders (Rothman and Greenland 1998).

Information bias is a potential problem, especially in interview studies. It is conceivable, for example, that the interview questions might have made women think of reasons for non-attendance when in fact they previously had had no clear or specific motives (Paper II). Thus we might have overestimated the importance of some factors. Reporting of exposure may differ between attenders and non-attenders at mammography screening (Papers I and II); either attenders or non-attenders might be more thorough than the other group when they answer the interview questions. But we have no hypothesis on the direction in which this might have affected the reported exposure information. Possible under-reporting of alcohol consumption among non-attenders might have led to the finding that non-attenders are teetotalers to a greater extent than attenders. Non-attenders may possibly also have had more difficulties in recalling having been advised to attend mammography screening, which would then have led us to overestimate the effect of advice from health professionals.

In the studies described in Papers IV and V we also based our exposure information on high-quality population register data, which would reduce the risk of misclassification. However, it cannot be ruled out that the available data on home ownership to some extent overestimated the proportion of women who owned their home, but we have no reason to believe that such misclassification, if any, among attenders and non-attenders was other than non-differential.

In cohort studies on kind of information bias may result if we have incomplete follow-up. In the study described in Paper V, women diagnosed with breast cancer were followed up concerning emigration through the Emigration Register and concerning death through the Cause of Death Register. If a woman was not found in either of these two registers, we assumed that she was alive. There is a slight possibility that some of these women had actually died without being registered in the Cause of Death register. If for some reason this had been more common among women of low socioeconomic status, we would have underestimated the true survival difference. However, with the high quality of these population-based registers in mind it is unlikely that we lost more than a very few women to follow-up. Non-random misclassification was not an issue, since information on outcome was collected independently of information on tumor characteristics and socioeconomic indicators. There is no reason to believe that the reliability of death certificates varied by social groups. Also, it is unlikely that there would have been differences in the quality of assessment of tumor characteristics by social factors or by

urban or rural residence. In a sample of all breast cancer cases diagnosed in 1993, no differences in the distribution of tumor size and lymph node involvement were found between large hospitals (serving urban areas) and smaller hospitals (serving rural areas) (G. Tejler, personal communication, November 27, 2001). When degree of urbanization was examined among all cases, women living in the two biggest cities were significantly more often lymph node positive, and had less often the smaller tumor size (<20mm) at diagnosis. This is likely to reflect a greater survival heterogeneity in the urban centers, and not a difference in diagnostic accuracy. Furthermore, degree of urbanization did not affect the socioeconomic gradient in survival.

#### 6.1.3.3 *Reversed causality*

With a few exceptions (Calnan, 1984; Sutton *et al.*, 1994), most European studies of mammography uptake have had a retrospective design, which could have had a negative effect on the validity; differences between attenders and non-attenders may represent a function of compliance. It is unlikely that the major predictive variables sociodemographic factors, general health behavior, experience of cancer and breast problems, reported in Papers I and IV, would have been affected by the previous attendance pattern and experiences of mammography. In the study described in Paper II, however, we examined the association between attitudes and attendance at mammography screening. Inherent in studies of this kind is the question of whether attitudes influence behavior, or whether, conversely, undergoing a mammography influences one's attitudes and knowledge. For instance, it cannot be ruled out that some of the predictive variables (attitudes, beliefs, and knowledge) might have been attributable to previous attendance pattern and experiences of mammography.

#### 6.1.3.4 *Confounding*

Confounders are factors that are associated with the exposure, and in themselves are predictive of the outcome, but they are not intermediate steps in the pathway from exposure to outcome. Lack of relevant information on confounders is common in retrospective cohort studies. In the study described in Paper V we only collected information on sociodemographic factors and tumor characteristics at diagnosis, and we did not have information on possible confounders such as initial breast cancer treatment received, detailed information on social support, and distance to the treating hospital. These factors may also be intermediate steps in the pathway between socioeconomic factors and survival, and thus it is unclear whether adjustment for these factors is appropriate. However, they might help to explain the survival difference between women of low and high socioeconomic status.

In Sweden true causes of attendance at mammography screening are not known. It is also difficult to ascertain the direction of associations, for example, between attitudes and behavior (as mentioned in the previous section). Assuming that some of the factors that have been proven to affect mammography attendance in studies in other countries also apply to Swedish women, we collected information on many potential predictors in the interview-based study (Papers I and II). In the register-based study (Paper IV) we gathered information only on sociodemographic factors and were not able to assess the possible confounding effects of general health behavior, experience of breast cancer in the family or among friends, attitudes, or knowledge.

### 6.1.3.5 *External validity*

Assuming that the roles of chance, bias and confounding have not seriously affected our results, we can assess the applicability of our findings to other populations. The studies included in this thesis were all based on population-based data, and all included women were recruited from a well-defined region with a similar health care system and quality of care.

In the study described in Papers I and II, factors affecting mammography attendance were assessed in a sample of women who had been invited to mammography screening in one Swedish county. The participation rate in this study was fairly high and, given internal validity, it is likely that the results are applicable to the target population, i.e., Swedish-born women invited to mammography screening in the county of Uppsala. In the register-based study (Paper IV) the whole target population in this county (including foreign-born women) was examined. Although the county of Uppsala has a somewhat higher level of education compared to the rest of the country (Official Statistics Sweden 2001), we believe that the results can be generalized to other regions, with the possible exception of the largest urban areas, where conditions may be different. In the study described in Paper V survival of breast cancer cases was assessed in the whole of Sweden, and the results should thus be applicable to all women in Sweden. However, the data on the socio-economic index, education and parity were incomplete. This mostly concerned women who in 1993 were above the age of 68, which limits the value of our findings in older women. The results of these studies may also to some extent apply to other countries that have outreach population-based mammography screening, but such generalizations should be made cautiously, as many issues may be culture-specific and dependent on a specific health care system and tradition.

## **6.2 INTERPRETATIONS AND IMPLICATIONS OF FINDINGS**

By means of different complementary methods we have been able to gather information on factors associated with attendance at mammography screening in Sweden.

### **6.2.1 Sociodemographic factors (Papers I and IV)**

Our results show that marital status and cohabitation constitute important predictors of participation in mammography screening (Papers I and IV). This could imply that non-single women have better social support, greater concern about their own health, and a sense of responsibility toward their partner or family. In the study described in Paper IV we also found that both childless and high-parity women were less likely to attend. A possible explanation for this finding is that childless women have had fewer previous contacts with health care, and that among high-parity women practical barriers are more prevalent. The group of childless women constituted as much as 12% of the study population and appears to be an important target group, especially as childlessness is a well-established risk factor for breast cancer.

Regardless of the socioeconomic measures (attained educational level; blue-collar vs. white-collar work; non-employment vs. full- or part-time employment, income, and home ownership) used in the univariate analysis, we found a social gradient in the likelihood of

attendance at mammography screening (Papers I and IV). However, in the multivariate analysis the only socioeconomic factors that remained predictive of non-attendance were employment status (Papers I and IV) and home ownership (Paper IV). Women with part- or full-time employment were found to be more likely to attend than non-employed women. Apart from being an economic factor, the employment status may serve as a proxy for interaction with other people, and degree of social integration. Another possibility is the 'healthy-worker effect' (Wang and Miettinen 1982); namely, that health problems may be over-represented among non-gainfully employed women and, in this case, take priority over screening. Home owners were found to be more likely to attend. A plausible explanation for the disappearance of an effect of other sociodemographic characteristics in the study described in Paper I is that they represent 'carriers' of certain health-related behaviors, which were also included in the multivariate model. Also, in both studies different socioeconomic indices tended to cancel each other out, implying that to a large extent they measured the same thing. The out-of-pocket fee for the patient is an unlikely explanation for any difference in use by socioeconomic level. Since the start of the mammography program, the cost has been relatively low. Furthermore, during periods when screening was offered at no cost, the attendance rates were not affected (Thurfjell and Lindgren 1996). In a Finnish study it was found that screening attendance decreased, irrespective of socioeconomic status, when an out-of-pocket fee in certain age groups was introduced (Immonen-Raiha *et al.* 2001).

In conclusion, our results show that although the overall attendance at invitational mammography screening is high, there are identifiable sociodemographic subgroups in whom the attendance can be increased. Despite the lack of insurance-related economic barriers, some socioeconomic discrepancies seem to exist between attenders and non-attenders.

#### *6.2.1.1 Immigrants (Paper IV)*

We found that immigrants, especially those from non-Nordic countries, were less likely to participate. Although non-attendance was more than 50% higher among immigrant than among Swedish-born women, the determinants of non-attendance were fairly similar in the two groups. The percentage of the women's lifetime spent in Sweden did not explain mammography utilization as indicated in US studies of immigrant women (Maxwell *et al.* 1998; Maxwell *et al.* 2000; Peragallo *et al.* 1998), although women living in Sweden for less than 26 years were somewhat more likely to be non-attenders.

The lower attendance rate among immigrants from non-Nordic countries is of special concern. This is likely to reflect language and cultural barriers, and the possibility that the standardized outreach efforts used to date are inadequate. Immigrant women are probably served better by a contact system tailored to their specific situation. Most immigrants come from countries with a lower breast cancer incidence than in Sweden (Ferlay *et al.* 2001). This may contribute to lower awareness of breast cancer in this group.

#### **6.2.2 Health behavior and health status (Paper I)**

Positive health-related behaviors such as having had cervical smear tests and visits to doctors were more common among attenders. For both BSE and contacts with physicians, we found an indication of a U-shaped association in that both a low and a high frequency

appeared to be related to non-attendance. Use of HRT and of OC – regular use of both of which is dependent on medical follow-up – was positively related to attendance.

Sparse contacts with doctors could reflect good health as well as repression of health problems, fear of the health care system, poor economy, and lack of time. Very frequent contacts, on the other hand, could imply chronic disease, and possibly less concern about other health problems. Thus, both these extremes could be related to a lower attendance at mammography screening. Regular dental check-ups, smear tests and mammography all represent behaviors that serve to monitor one's state of health or to detect illness and involve periodic contact with health care professionals. Common factors underlying these behaviors could be concern about health problems or a tendency to comply with invitations from health professionals. It has been suggested that experience of smear testing may lead to changes in attitudes and beliefs that make women more positive to the idea of going for breast screening (Sutton *et al.* 1994).

Contrary to several reports (Maclean *et al.* 1984; Ore *et al.* 1997; Sutton *et al.* 1994), we observed a difference in attendance in relation to smoking habits, possibly reflecting differences in general health behavior. Somewhat surprisingly, the likelihood of non-attendance was significantly higher among women who reported that they never drank alcohol (teetotalers). At least one investigator has previously reported that non-drinkers are less likely to participate in mammography screening programs (Sutton *et al.* 1994). There is no clear explanation for this finding, but it may indicate that these women represent a selected group of women with, for example, religious, social or medical reasons for their teetotalism, which in turn may influence participation. Our data indicate that some characteristics associated with non-participation (being single, blue-collar worker, non-employed, never-user of OC or never visiting a dentist) were significantly more common in teetotalers. However, it cannot be excluded that drinking may have been underreported by some non-attenders.

Our results suggest that also in the setting of a low-cost, outreach mammography program, encouragement from the medical profession represents an important determinant for participation. In Sweden, efforts to promote breast cancer screening have had a broad approach, not targeting special groups. Our findings indicate that in future promotional activities there is a need to develop methods to reach and inform women with sparse contacts with the health care system.

### **6.2.3 Experience of cancer and breast problems (Paper I)**

We found that attenders were more likely to have breast cancer in the family or among friends. A larger proportion of attenders also reported a history of non-malignant breast disease or other breast problems, such as complications during lactation. It is likely that such experiences lead to familiarity with the health care system and greater breast awareness, both of which may positively affect participation.

### **6.2.4 Attitudes and knowledge (Paper II)**

Our main findings were that barriers, benefits and worry represented the major determinants of participation in mammography. Both perceived out-of-pocket cost and emotional barriers increased the likelihood of non-attendance. We also found that the



more the perceived benefits and the greater the worry the higher the probability of attendance at the screening program. Likewise, knowledge, cues to action and trust in health care were all positively associated with attendance. Women who were dissatisfied with having been invited to a particular clinic within the regional screening program were also more likely to be non-attenders.

#### 6.2.4.1 Barriers

Among the items relating to attitudes, perceived barriers represented the most prominent predictor of non-attendance. The item ‘mammography produces worry about breast cancer’ emerged as the single most important barrier in the subscale and the strongest predictor of attendance. Thus, it cannot be ruled out that the invitation to mammography may induce rather than reduce worry among non-attenders. Perceptions of ‘harmful radiation’ and of the examination being ‘too expensive’ represented other types of salient barriers. However, it is not clear how many of the women in this study were aware of the real cost. In an earlier Swedish study, addressing participation rates and out-of-pocket costs in different counties, there was no obvious correlation between these factors (Olsson *et al.* 1995).

Elimination of barriers would seem to be an attractive way to increase attendance. For example, the belief that mammography is harmful or too expensive could be changed by information. However, elimination of perceived barriers may not necessarily lead to increased attendance. Rather than pointing to actual barriers, our findings and those of other investigators may reflect efforts both among attenders and non-attenders to rationalize and justify their previous screening behavior. This phenomenon has been explained in the theory of cognitive dissonance (Festinger 1976); when thoughts and actions do not coincide, cognitive dissonance is experienced. To relieve this tension, people tend to bring their attitudes into line with their actions.

#### 6.2.4.2 Worry

Worry represented another important predictor of non-attendance. We found that attenders appeared to be more worried about breast cancer, possibly indicating that worry leads to self-protective behavior. This is in line with results from the study described in Paper I, which showed that women with experiences of breast cancer in the family or among friends, or of their own breast problems, attend to a greater extent. Another possibility, however, may be that non-attenders and attenders differ in the way in which they cope with worry. It is well known that when faced with a certain amount of worry or anxiety, some individuals tend to cope with this situation by cognitively and behaviorally avoiding anything related to the topic in question (Krohne 1993). Attenders’ experience of worry may serve as a cue to action, whereas non-attenders may cope with their worry in a way that might be termed cognitive avoidance. By ignoring any cognition relating to breast cancer and mammography (e.g., information from the health sector, letters of invitation to mammography, news articles, informal talk among friends and family), their worry would be reduced and hence the risk of non-attendance behavior could be increased. If this is the case, it may prove difficult to reach these women with information about breast cancer and mammography. Thus, efforts to enhance their breast cancer awareness and knowledge about the risk should be made with caution. A paradoxical finding in the present study was that the barrier item ‘Mammography makes me worry

about having breast cancer' showed a negative association with attendance. A probable explanation for this is a reversed causality, i.e., that it is more likely that the invitation to mammography produces worry among women who have previously not attended than among those who have.

#### 6.2.4.3 *Benefits*

Our results showed a positive association between perceived benefits and the likelihood of attendance. Furthermore, our results indicated that the effects of benefits and the effects of worry strengthen each other. Great worry together with high perceived benefits was especially advantageous to attendance, except in the highest quartile, where they seemed to cancel each other out; women with the greatest worry about breast cancer do not seem to be further encouraged to attend by the highest level of perceived benefits.

#### 6.2.4.4 *Advice (cue to action)*

According to experiences in the US, advice from health professionals to have a mammogram is a leading determinant of attendance. This was also a significant predictor in our study, though not as markedly so as in the US. The relative importance of physician advice in Sweden is likely to be reduced because of the population-based system of invitations to screening and the organization of the national health care system.

In conclusion, the findings reported in Paper II indicate that increased attendance may be achieved through enhancement of breast cancer awareness, by emphasizing the benefits of mammography, and possibly by reducing some of the modifiable barriers. Attendance rates may also be improved by greater flexibility in the program with regard to availability by phone, opening hours and free choice of screening clinic.

### **6.2.5 Qualitative findings from focus groups (Paper III)**

The results from the focus group study are largely in line with findings in our quantitative studies (Papers I, II and IV) and the main themes discovered broadly corroborate observations in other focus group studies (Bobo *et al.* 1999; Schechter *et al.* 1990; Straughan and Seow 1995; Tessaro *et al.* 1994). Factors that seemed to be more pronounced in other studies were procrastination (Bobo *et al.* 1999; Schechter *et al.* 1990), physician's influence (Schechter *et al.* 1990; Tessaro *et al.* 1994), knowledge about screening guidelines (Schechter *et al.* 1990), and practical barriers (Schechter *et al.* 1990; Straughan and Seow 1995; Tessaro *et al.* 1994). Although the results reported in Paper II showed that advice from health professionals is associated with attendance, it is likely that the influence of physicians and knowledge about screening guidelines are somewhat less important in Sweden, with its population-based outreach mammography screening. The written screening invitations remind women that it is time for the examination and serve as a strong cue to action. Practical barriers, such as out-of-pocket cost, distance to the screening clinic, opening and closing hours, caring for family members etc., were not mentioned in the FGDs. More likely than reflecting a true absence of practical barriers, this may reflect a possible self-selection to the focus groups, i.e., women with these practical barriers may also have experienced the same barriers in relation to attending FGDs.

The focus group study was also found to provide an important complement to the quantitative findings (Papers I, II and IV), since two aspects, new to us, of particular interest in the context of population-based screening programs, were brought up in the FGDs. These were the political and ideological views of mammography, and the fact that the program fails to provide an adequate screening examination for some women, i.e., women with breast implants, a group that is becoming increasingly common in Sweden as in other countries. It is important to find a solution for these women, even though at present they constitute a relatively small group. To tell these women that it is useless for them to come for mammography screening without giving them reasonable alternatives, besides self-examination, is not compatible with the goal of population-based screening, which is to embrace the whole population.

We identified two extremes regarding ideological views of mammography. One was the strong opinion that prevention is the responsibility of the individual rather than of society. At the other extreme, there were women who expressed the opinion that the society is obliged to offer population-based screening, and that all women who are offered screening also have a collective responsibility for the future existence of the mammography screening program, hence a moral obligation to attend. Between these extremes we located the view that the society's offer to provide screening is positive, but that the individual has the right to choose whether or not to attend.

Another area of interest was the opinions expressed about the form and content of information. We gained some insight into the lack of consistency existing about what kind of information the women would like to receive about the mammography examination. The demand for information is not consistent within the separate groups of attenders and non-attenders. In order that written invitations to mammography screening shall have the potential to be successful, they probably need to be carefully tailored with different needs in mind. Furthermore, it is important to keep in mind that categorization into attenders and non-attenders might be temporary – 'attenders' can indeed become 'non-attenders', and vice versa, and the 'non-attenders' in this study consisted of a heterogeneous group ranging from self-defined attenders to persistent never-attenders.

Other findings in the focus group study indicate the necessity for informing women that mammography is an examination aimed at detecting illness at an asymptomatic stage, i.e., when lumps are too small to detect by self-examination or palpation. There also seems to be a need to inform women why the firm pressure from the mammography apparatus is necessary; the focus group participants seemed to be unaware that this mechanical pressure is needed in order to achieve a sharp mammographic image. Furthermore, many women seemed to lack knowledge regarding the nature of breast cancer and its risk factors. Although two of the established risk factors for breast cancer, heredity and HRT (McPherson *et al.* 2000), were mentioned in most of the focus group discussions, age, for example, which is a major risk factor, was never mentioned in the focus groups.

In accordance with the findings reported in Paper I, women in non-attender FGDs gave the impression of practicing self-examination to a higher extent than did women in attender FGDs. It is noteworthy that some women seemed to compensate for their non-attendance at mammography screening by self-examinations and clinical examinations by a physician. These alternative actions quite possibly reflect an awareness of the breast

cancer risk. However, the value of these screening methods is less well established than that of mammography (Holmberg *et al.* 1997; Jatoi 1999).

As experienced elsewhere (Bobo *et al.* 1999) the liveliest discussions, particularly among non-attender focus groups, occurred when prior mammography examinations were described. It is not possible to undo prior negative experiences that women may have had during a mammography, and it is even harder to control other health care situations where negative experiences might be generated. If the quality of the encounter with the women coming for a mammography has improved, as we have been informed, a major challenge for the screening program lies in attracting women who stopped attending because of negative experiences of mammography in the past.

A certain amount of worry or anxiety, and a certain amount of radiation and pressure may not be avoidable, but efforts should be made to make the examination situation as comfortable and convenient as possible for each individual. Inviting 'healthy' women for screening makes special demands on routines, since an examination that has the character of a conveyor belt risks alienating women from the health care system. An improved dialogue appears an attractive way of adapting the screening situation to meet the varied needs and expectations of the women who attend (Forss *et al.* 2001). A more individualistic approach may also be a way of making the examination less monotonous and more agreeable for both the attending women and the radiology nurses/technicians.

No obvious differences in reasoning were found between Swedish and foreign-born women. However, the study was not designed to allow conclusions to be drawn relating to cultural similarities or differences. To better understand the relationships between different cultures and conceptions of breast cancer prevention, we have also conducted focus group discussions among Iranian immigrant women in the same region. These results will be published separately.

#### **6.2.6 Socioeconomic factors and breast cancer survival (Paper V)**

In the population-based cohort study (Paper V), we found evidence of socioeconomic differences in breast cancer survival. Our results support the findings in a majority of previous studies addressing the influence of socioeconomic status based on occupation (Auvinen *et al.* 1995; Bassett and Krieger 1986; Karjalainen and Pukkala 1990; Stavrayk *et al.* 1996; Vågerö and Persson 1987). In our study, consideration of tumor characteristics did not eliminate the socioeconomic gradient in prognosis, which corroborates the findings described in Paper I that there are no substantial socioeconomic differences in screening attendance or diagnostic delay in Sweden.

It seems unlikely that our observation of a social gradient in survival could be attributed to artifacts generated by lead-time bias, age, calendar date of diagnosis, or competing risks. Tumor characteristics at diagnosis were used as a proxy for lead-time, but no clear socioeconomic differences in tumor size or nodal status were found. Adjustment was made for age at diagnosis in all analyses, and calendar date of diagnosis was not an issue, since all cases were diagnosed in 1993. As information on cause of death was available, we were able to calculate cause-specific survival rates by censoring women who died from other causes than breast cancer.

Economic barriers are also an unlikely explanation for our findings, in view of the principle of equal access to care in Sweden. Furthermore, the uniformity of treatment programs within and between regions should minimize the possible influence of differences in accuracy of diagnosis and quality or appropriateness of treatment. However, it cannot be excluded that there may be subtle inequalities in care or follow-up, related, for example, to rapport between the physician and the patient, to demands and expectations from the patient, and to communication skills on both parts. There may also be social differences in the acceptance of, or compliance with treatments, such as prolonged chemotherapy regimens. Distance from the mammography clinic could possibly also play a role as a barrier; women of lower socioeconomic status may on average live further away from hospitals where diagnoses are made and treatments performed.

In order to minimize the influence of differences in tumor biology, we focused on adenocarcinomas, and adjusted for tumor size, lymph node status, and estrogen receptor status. However, there might still be clinically important differences in tumor behavior related to cancer-host interactions. Host characteristics such as nutritional status, weight, smoking, alcohol use, tolerance of therapy, general health, other diseases, and the immune state, might all affect the ability to combat malignant disease. It has been suggested that both smoking and overweight decrease survival (Haybittle *et al.* 1997; Reeves *et al.* 2000; Tominaga *et al.* 1998). Findings in Swedish studies have indicated that a low educational level is associated with low fruit and vegetable consumption (Wallstrom *et al.* 2000), obesity (Lissner *et al.* 2000), and an unhealthy lipid profile (Wamala *et al.* 1997).

Psychosocial factors such as social support, feelings of well-being, control over one's life situation, problem-solving skills, and ability to cope with a cancer diagnosis are factors that have been postulated to reduce stress, which in turn may enhance immune surveillance (Pompe *et al.* 1994). In one study factors such as psychological distress, anxiety and hostility were found to have a negative effect on breast cancer survival (Gilbar 1996). Recurrence-free survival was reported to be more common among patients who reacted to cancer by denial or a fighting spirit than among those who responded with stoic acceptance or feelings of helplessness or hopelessness (Pettingale *et al.* 1985). Similarly, high scores for depression, helplessness and hopelessness as early responses to breast cancer have been associated with a reduced chance of survival (Watson *et al.* 1999). Psychosocial factors possibly differ between socioeconomic groups. However, the association between psychosocial factors and socioeconomic status has rarely been assessed (Auvinen and Karjalainen 1997).

Several studies have shown a survival advantage gained by social support (Maunsell *et al.* 1995; Waxler-Morrison *et al.* 1991). In a Japanese study it was found that having a hobby, increased number of hobbies, and increased number of female children positively influenced the prognosis (Tominaga *et al.* 1998). However, the indicators of social network that were used in that study (marital status, parity and size of household) did not alter the effect of the socioeconomic index. Furthermore, their univariate effect on survival decreased further after adjustment for tumor size at diagnosis, which may indicate that being married, having children and not living alone actually make these women somewhat more likely to be diagnosed at an earlier stage. This is in accordance with findings in the present studies (Papers I and IV) that living without a partner and

being childless decreased the likelihood of attending mammography screening. Other indicators of social network, such as the quality of the relationships, may be more important in explaining the association between socioeconomic status and survival.

In conclusion, we found evidence of a social gradient in breast cancer survival in a region with presumably equal access to a uniform health care system that also offers outreach mammography. The present findings indicate that there are prognostic factors, unevenly distributed in the population, that might be amenable to intervention.

## **6.3 IMPLICATIONS FOR FUTURE RESEARCH**

### **6.3.1 Interventional strategies**

Based on our findings described in Papers I-IV, we have reason to believe that attendance at mammography screening can and should be increased in certain subgroups. Different possible ways of increasing the attendance could be tested and evaluated in a randomized intervention study.

According to the findings reported in Paper I it appears important to reach women who have only sparse contacts with the health care system. The only practical way of succeeding with this task would be to reach them through the written invitation and in a second step possibly also by telephone. The results described in Paper II indicate that increased attendance may be achieved through enhancement of breast cancer awareness, by emphasizing the benefits of mammography, and possibly by reducing some of the modifiable barriers. Relatively simple means of increasing the attendance could be tested in the subgroups of non-attenders and women who are invited for the first time. The invitational letter is an important and modifiable factor that must be given great care and thought. One strategy may be to complement the written invitation with information that aims at improving women's knowledge about mammography and breast cancer, at increasing their awareness of breast cancer and the importance of regular mammography examinations, and at reducing perceived practical and emotional barriers. Specific issues that could be addressed in the invitation are the benefits of mammography, factors that are known to cause worry or anxiety, a description about the examination procedures, reasons why a certain amount of mechanical pressure is needed at the examination, and the time during the menstrual cycle when the breasts are likely to be least sore and when pain during the examination might be avoided. It also seems important to emphasize that the aim of the examination is to find cancer as early as possible, before any symptoms have developed and before the cancer would be detectable by self-examinations or clinical examinations of the breasts.

In addition to improved information, another possible intervention might be to include a personalized letter from the woman's general practitioner either in the invitation or in a reminder. This method has been successfully tested in earlier studies (Richardson *et al.* 1994; Sharp *et al.* 1996; Turner *et al.* 1994; Yabroff and Mandelblatt 1999). In this letter women can, for example, be encouraged to contact their health care provider regarding any special concerns or questions.

We also believe that reminders, both by mail and telephone, might increase the attendance. A first written reminder would serve those women who may have had

temporary barriers to attendance when the first invitation was sent out. A second reminder by telephone could be tailored in response to the individual needs of each specific woman. Written reminders have been successfully tested in several studies (Hayes *et al.* 1999; Irwig *et al.* 1990; King *et al.* 1994). Reminders by telephone have been tested with varying results. In an American study it was found that telephone reminders were twice as effective as written reminders (Taplin *et al.* 2000), while in a study in New Zealand no difference in effect was detected between written and telephone reminders (Richardson *et al.* 1994). A British study showed promising results in tests of personalized re-contact of non-attenders by specially trained general practice staff (Atri *et al.* 1997). In several American studies telephone interventions, of a more consultative character, have been tried, generally with good results (Davis *et al.* 1997; Janz *et al.* 1997; King *et al.* 1994; Ludman *et al.* 1999; Saywell *et al.* 1999). However, in one study no difference in effect was found between a telephone call where barriers were discussed and telephone calls aiming only at reminding the woman that it is time to make an appointment for an examination (Taplin *et al.* 2000). A recent review article pointed out five potentially effective interventional strategies: written invitations, educational material sent by mail, written invitations in combination with telephone calls, telephone calls alone, and training activities in combination with direct reminders (Bonfill *et al.* 2001).

### **6.3.2 Additional questions**

The results of the studies described in this thesis give rise to additional issues that need to be resolved in future research.

Our findings indicate the importance of reaching women who have only sparse contacts with the health care system (Paper I). Possibly interventional strategies to achieve this purpose could include more informative invitational letters, written and telephone reminders, and perhaps also personal letters from the women's general practitioners.

Ideally, to determine the causal influence of attitudes and knowledge on mammography attendance, these exposures should be assessed before the first invitation to mammography screening in a prospective study. The complex nature of the relation between the intensity of worry and mammography attendance also needs further investigation (Paper II).

Additional exploration of the relation between culture and conceptions of breast cancer prevention is warranted (Paper III). Our knowledge about older women's perceptions of mammography should also be increased. In recruiting and conducting focus group discussions with elderly participants, their special needs and abilities should be considered.

Further research is needed to investigate reasons for non-attendance among women born abroad, since their attendance rate was found to be lower than that of Swedish-born women. If possible, future research should also address the question whether reasons for not providing complete information to the Census coincide with reasons for not attending mammography screening, e.g., unwillingness to follow rules or obey authorities (Paper IV).

Future exploration of detailed information on treatment received and of the possible role of psychosocial factors and tumor-host interactions in breast cancer prognosis is warranted (Paper V). The women in the present study were only followed up for a maximum of six years, which is a relatively short period. It is of interest to extend the follow-up in order to assess 10-year survival after diagnosis and to determine whether the socioeconomic difference in survival persists.



## 7 CONCLUSIONS

- Some socioeconomic discrepancies seem to exist between attenders and non-attenders at mammography screening; non-employed women and those renting their housing are less likely to attend the screening. Other sociodemographic characteristics positively associated with attendance are being married or living with a partner, and being below the age of 70 years.
- Immigrants, especially those from non-Nordic countries, are less likely to attend mammography screening than Swedish-born women.
- Positive health behavior, such as regular performance of breast self-examination, visits to a doctor within the last 5 years, attendance at cervical screening, and non-smoking, is related to screening attendance. Furthermore, women who have ever used oral contraceptives or hormone replacement therapy are more likely to attend mammography screening.
- Experiences of breast cancer in the family or among friends, or of own breast problems, are positively related to mammography screening attendance.
- Attitudes, such as perceived barriers, benefits, worry, and trust in health care, as well as advice from health professionals and knowledge, are related to attendance.
  - Perceived barriers are negatively associated with attendance.
  - Perceived benefits, worry, trust in health care, advice from health professionals to attend mammography, and knowledge are positively associated with attendance.
- Important issues in women's reasoning about attendance or non-attendance at mammography screening are negative experiences, perceived risk factors, knowledge of one's own body, perceived problems with mammography, political, ideological and moral reasoning, and involuntary non-attendance.
- There is a socioeconomic gradient in breast-cancer survival; women of high socioeconomic status have a higher survival from breast cancer independently of tumor characteristics and age at diagnosis.

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