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Women's experiences of mammography screening:

Decision making, participation and recall

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List of papers

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1. Introduction

This is a thesis about breast cancer screening. Screening is searching for disease in a population free of symptoms (Forsmo, 2003). Breast cancer is the most common cancer among women in the western world. In Norway, the most recently published statistics on cancer showed an age adjusted incidence rate for breast cancer of 72,4 per 100.000 (Cancer Registry of Norway, 2007). There were 2735 new cases of female breast cancer in average every year between 2002 and 2006, while 694 women died of breast cancer in 2004. The wish to reduce mortality from breast cancer resulted during the 1990's in a political will to initiate a screening program for breast cancer in Norway (NOU, 1987), even though experts were sceptical to its benefit (Westin, 1989; Mørland, Lund Håheim, & Linnestad, 2002; Holst et al., 1989). The initial breast cancer screening project started in four counties in 1996, and became nationwide in 2004 (Hofvind, 2005). In the Norwegian Breast Cancer Screening Programme all women aged 50-69 are invited to mammography every second year. Nearly 80% of the target population participated during its first round. Later there has been a decline in participation rates (Feiring, 2004).

Mammography is an x-ray examination of the breast. The result of the examination is black-and-white images that are interpreted by radiologists in search for abnormalities that may be indications of cancer. Research on mammography screening has primarily been randomized controlled trials to establish the effect of screening upon mortality. Women's experiences as participants have not been much studied, with only three studies in Norway – of which all are survey studies (Ekeberg, Skjauff, & Kåresen, 2001; Gram, Lund, & Slenker, 1990; Hofvind, Wang, & Thoresen, 2003). Yet, not all aspects of the experience of mammography screening can be explored through surveys and quantitative studies.

Lay women who receive an invitation to participate in a screening programme are likely to have experiences of mammography that are somewhat different than those of medical professionals working with breast cancer or of policy-makers discussing effects from randomized controlled studies. It is worth noting here that screening is primarily an examination of the non-symptomatic. The implication of this is that participants in a screening programme may have an experience of going from well to unwell – not due to symptoms experienced in their bodies, but through technological

detection of non-symptomatic abnormalities. This raises questions about experiences of screening, health and breast cancer, as well as questions about these experiences' relation to other aspects in our society. I will attempt to answer some of these questions in this thesis.

My Ph.D project has been part of the umbrella project "Screening and health examinations – the path to improved health?". When starting the research project there were few articles to be found on Norwegian women's experiences and knowledge about mammography. Therefore, our research group wanted to explore how women experienced being participants in a national screening program for a potentially lethal disease. We wanted to gain knowledge about women's experiences of mammography screening, as well as study their knowledge of breast cancer and attitudes towards screening programmes, medical technology and examinations for a disease of which they were non-symptomatic.

The focus of my part of the project has been on how women experience their participation in a public screening programme and what it is that makes them experience mammography screening as they do. Furthermore I wanted to look into how women experienced meeting the consequences of screening participation, that is, how they experienced being recalled for further examinations due to an abnormal mammogram.

The field of mammography screening has many agendas and different statements. As a member of a Canadian provincial government committee planning the implementation of a breast cancer screening programme, Patricia Kaufert discovered that there were two discourses at the field. One discourse was about whether mammography satisfies the formal rules of screening, while the other was about faith, emotions, responsibility, morality, compliance and guilt (Kaufert, 2000). Kaufert found that she had to read medical rather than social science literature since the discourses of screening were much neglected by social scientists. This has also been the case when exploring the field surrounding women's experiences of mammography screening in Norway. It has been necessary to define the field while looking at it. I will discuss this at greater length in the final article of this dissertation, a methodological article on focus group research. Meanwhile, it is necessary to present

the field quite thoroughly in this introduction to give the reader an impression of how I perceive the context of mammography screening.

The two discourses Kaufert (2000) identified in the field of mammography screening will be mentioned in the different parts of this thesis. Continuing the introduction, I will present themes from the “first” discourse: the discourse about the formal rules of screening. I will present medical debates about mammography screening and look into its implications. Furthermore, I will present prior research about participation and experiences of mammography screening, issues related more to Kaufert’s “second discourse of screening”. In the following chapters I will discuss more issues about both these discourses on mammography screening; issues that show the relations between them and how they are present in women’s experiences.

First in this chapter I will give a presentation of the term screening, and questions rising from its definition that concerns screening in general and mammography screening in specific.

What is screening?

Screening for preclinical disease has a short history. Defining screening through questions of validity of the screening test, prognostic benefit from early treatment and the existence of a screening service, screening has existed no longer than the 20th century (Morabia & Zhang, 2004). The term “screening” was originally meant to describe the process in which particles of different sizes were separated by filtering them through a screen, for instance in coal mines (Brodersen, 2006). The mesh width through which particles were screened, determined which particles were let through the net, and which were left behind. This is also the case with medical screening: the mesh width, or rather the precision of the test, decides who are classified as well and who are in need of further examination.

Using screening to describe a medical practise has generated many definitions of the term, with the search for non-symptomatic disease as its main aim (Holland, Stewart, & Masseria, 2006). Summarizing them, one can say that screening is searching for a defined disease, using a specific tool, in a whole population free of symptoms (Forsmo, 2003). It is based on the assumption that diagnosing a disease in an early stage improves its prognosis, and its main aim is to reduce morbidity and mortality

among those who are screened (Hofvind, 2005). Mass screening is the large-scale screening of whole population groups (Holland et al., 2006). The National Screening Committee in the United Kingdom defined screening to be:

“a public health service in which members of a defined population, who do not necessarily perceive that they are at risk of, or already affected by, a disease or its complications are asked a question, or offered a test to identify those individuals who are more likely to be helped than harmed by further tests or treatment to reduce the risk of disease or its complications” (Holland et al., 2006).

Different definitions of screening can thus, as we see from these examples, include different values and insinuate a variety of consequences from screening practice. An implication of this last definition is that the public health service defines people to be at risk or even diseased when perceiving themselves as well and healthy.

In 1968, the World Health Organisation (WHO) established ten principles of early disease detection (Hofvind, 2005; Wilson & Jungner, 1968; Holland et al., 2006). These principles can be seen in all debates on mammography screening, but with emphasis on different elements in different discussions, and also depending on the position of the discussant.

Figure 1: The World Health Organization's ten principles for screening for disease (Wilson & Jungner (1968), used in Hofvind (2005)).

1. The condition sought should be an important health problem
2. There should be an accepted treatment for patients with recognized disease
3. Facilities for diagnosis and treatment should be available
4. There should be a recognizable latent or early symptomatic stage
5. There should be a suitable test or examination
6. The test should be acceptable in the population
7. The natural history of the condition, including development from latent to declared disease, should be adequately understood
8. There should be an agreed policy on whom to treat as patients
9. The cost of case-findings (including diagnosis and treatment of patients diagnosed) should be economically balanced in relation to possible expenditure on medical care as a whole
10. Case finding should be a continuing process and not a "once and for all" project

Whether mammography screening fulfils all these principles has been, and still is, subject to debate. Here I will only give a short outlining of difficulties of some of the principles; that is the ones I perceive as most important for women's experiences as screening participants. As for the first three principles, breast cancer can be stated as an important health problem as it is the most common cancer among western women today. Incidents are still rising (Hofvind, 2005), although there are claims that the rising incident can be blamed on over-diagnosis due to screening (Zahl, Strand, & Maehlen, 2004; Zackrisson et al., 2006). Furthermore, accepted treatments for breast cancer exist, and in Norway there are facilities for diagnosis and treatment – facilities that have been further developed due to the implementation of the breast cancer screening programme. Also the tenth principle about a continuing process of screening is attended to by having an ongoing screening programme. The ninth principle of an economically balanced cost of case-findings is a large and major question, but is outside of the problems to be addressed here and will not be further

discussed in this thesis. This leaves five principles (4-8) to which I will give some more attention.

Principle 4 of “The WHO’s ten principles of early disease detection” is that there should be a recognizable latent or early symptomatic stage. Cancer has for a long time been seen as a disease where patients might benefit from early detection, even before symptoms occur. This has made cancer screening attractive for health service providers. Cancer screening has for many years been viewed as a public health task aimed at disease prevention through early discovery and cure (Jepson et al., 2005). Breast cancer, as well as cancer of the cervix, has been seen as especially suitable for early detection as they occur near the surface of the body rather than “deep below” as in other organs (Kaufert, 2000).

The question of whether cancer has a recognizable early symptomatic stage is also closely connected to the seventh principle about how the natural history of the condition should be adequately understood. The natural history of breast cancer includes for instance development from latent to manifest disease, its lead time bias and its potential to spread to other organs. Viewing cancer test results as a trajectory with normal at one end and cancer at the other is a theoretical construct (Kaufert, 2000). One dilemma concerning breast cancer is the issue of ductal carcinoma in situ (DCIS). This is a precancerous stadium that is relevant for breast cancer examinations. DCIS may, or may not, progress to invasive cancer (Hofvind, 2005; Evans et al., 2001; Kaufert, 2000). This is not necessarily common knowledge among screening participants. Women in an American study were found to know little of DCIS, even after being diagnosed with it (Schwartz et al., 2000). Another claim that has been raised about the nature of cancer is a theory of cancer as potentially regressive (Zahl & Maehlen, 2005). Even though this claim has met resistance in medical journals, it points to uncertainties in knowledge of the nature of breast cancer. Both the question of regressive cancer and issues of DCIS are indications of a certain amount of over-diagnosis of breast cancer from having a screening programme (Zahl et al., 2004; Zackrisson et al., 2006). These are important questions when discussing the eighth principle of early disease detection from the WHO about an agreed policy on whom to treat as patients.

The problems with not knowing the natural history of breast cancer with complete certainty is that medical personnel have a moral obligation to act upon symptoms or signs of disease. Once a potential cancer is discovered, it becomes unethical to maintain a “wait and see”-approach (Kaufert, 2000). This implies that when searching for pre-symptomatic disease, interventions will be made on more individuals than would have been necessary if symptoms were discovered at a later stage. Interventions may save lives, but they do also alter women’s lives and identities (Kaufert, 2000).

A question of particular importance is the issue of whether you have a suitable test or examination (WHO’s fifth principle for early detection of disease). A criterion for the suitability of a test is its accuracy: its sensitivity and specificity. A test’s sensitivity depends on its ability to find those who have the disease, so that no one with a disease is left undiagnosed. Its specificity concerns the test’s ability to avoid diagnosing those who are healthy. There are thus four outcomes of medical screening (Figure 2). Either the test is positive, or it is negative. And the person tested can either be healthy or have the disease.

Figure 2: The outcomes of medical screening

	Person with disease	Healthy person
Positive screening test	True positive	False positive
Negative screening test	False negative	True negative

In a screening with low sensitivity, many persons with disease are missed, while in screening with low specificity many healthy persons will test positive and either be diagnosed or have to go through further unnecessary testing. This can be seen in medical screening as well as for crime surveillance technologies (Sætnan, 2007). Debates about mammography screening have most recently been concerned with the question of false positives, and the amount of wrong diagnoses acceptable while maintaining a screening programme (Brodersen, 2006; Zahl et al., 2004). The percentages of false negative and false positive results are difficult to estimate. What can give an impression of the accuracy of the test is the positive predictive value. This is the number of true positives from all those who test positive in the screening test.

During the initial mammography project in four counties in Norway, the positive predictive value were 16,2 per cent (Wang, Hofvind, & Thoresen, 2000). This means that out of 100 women with an abnormal screening mammogram about 16 women were subsequently diagnosed with breast cancer. However, false positives and false negatives will always be an issue when using probabilistic reasoning to determine the treatment of individuals (Rose, 2001).

The sixth WHO-principle on early detection of disease, and the last to be discussed here, is the principle that the screening test should be acceptable in the population. This means that the negative consequences should not outnumber the positive, and should not be more severe than the positive consequences. The disadvantages of screening are harms that would not appear without participating in screening (Hofvind, 2005). Hofvind (2005) points to the 76 per cent attendance rate in the Norwegian breast cancer screening programme as indicating that mammography is an acceptable screening test in the population. Nevertheless, little is known about what lay participants know about the problematical aspects of screening as discussed above. The question is thus not only about the acceptability of the test in it self, but also what kind of implications that are acceptable for lay participants when there is an ongoing debate among experts about the benefit from mammography screening. An implication of screening is that it might provide large gains for those few whose lives are saved, while disadvantages from screening influences many women but are probably smaller for each woman going through recalls and potential false positive diagnosis. It is thus a simple task to name benefits from screening, but discussing its disadvantages is a more complex question (Holland et al., 2006). I will therefore ask how benefits and disadvantages from screening are interpreted among lay users of a screening programme, and whether false-negatives and false-positives are seen as comparable positions. A disease is only appropriate for screening if its benefits exceed the disadvantages (Hofvind, 2005). But who are the ones who should decide when the benefits exceed the negative consequences? And what information is seen as needed as a basis for that decision?

Screening for pre-symptomatic disease is an attempt to reduce mortality and morbidity. The discussions for and against a screening programme for breast cancer can be seen as a discussion about “good intentions”: all parties want the population provided with the best means for securing its health. The purpose of detecting the

abnormal within a normal population is well intended (Kaufert, 2000). But, a screening programme initiated by a national health authority by targeting healthy individuals nevertheless raises questions. A national public screening programme can be understood as a technology for governing the health of the population (Hydle, 2003). Meland (2007) says that these are not about the paternalistic nature of the programme, but also about how the programme is a means for the authorities to shepherd the population. I will return to this question in the second chapter of the thesis, but first I will go more into the specific debates about mammography screening.

Mammography screening – the debate continues

Breast cancer is seen as appropriate for screening because its lethality is related to clinical stages of diagnosis (Hofvind, 2005). The need for detecting lumps early to give better prognoses for survival from breast cancer made mammography screening a good alternative to other interventions, that had been primarily radical mastectomy¹ (Lerner, 2001). Mammography screening was initiated in the United States during the 1960's (Lerner, 2001). A randomized controlled trial (RCT), the HIP-study, was launched in 1963, becoming the only RCT carried out in the United States (Shapiro, 1977). Other studies would follow in other countries, such as the Canada trials (Miller et al., 2000; Miller et al., 2002), the Edinburgh trial (Alexander et al., 1999), and studies in several counties in Sweden – Malmö (Andersson et al., 1988); Kopparberg and Östergötland (WE-study) (Tabar et al., 1995); Stockholm (Frisell et al., 1997); and Göteborg (Bjurstam et al., 1997).

Most of the studies have reported some reduction in breast cancer mortality among women participating in mammography screening compared to control groups, with reductions up to 30 per cent in the WE-study (Tabar et al., 1995). The WE-study has later been criticised for bias (Gøtzsche & Olsen, 2000), and the Kopparberg part of the study was not available for the meta-study of the Swedish randomized controlled trials up to 1996 (Nystrom et al., 2002). The Canada trials and the Malmö trial found

¹ Mastectomy is the surgical removal of the breast. For a description of the historical variance in the degree of “radical mastectomy” as breast cancer treatment and prophylactic mastectomy as prevention of breast cancer, see Lerner (2001).

smaller benefit from mammography screening – respectively 20 % from Malmö (Andersson et al., 1988), and no effect from mammography in the Canada trials (Miller et al., 2000; Miller et al., 2002). The Norwegian breast cancer screening programme has not been conducted as a randomized controlled trial. Nevertheless, an evaluation of the mammography project in four counties estimated an expected mortality reduction of 30 per cent compared to breast cancer mortality in the population without mammography screening (Wang et al., 2001).

RCT's have become the “gold standard” for medical decision making in the western world since the 1960's, even though they cannot always solve controversies (Weisz, 2005). This has not least been the case with RCT's on mammography screening. Claims for evidence can be somewhat different between clinicians and epidemiologists, with epidemiologists favouring specific forms of quantified data (Johansson, Risberg, & Hamberg, 2003). But, in a data material of published papers on mammography screening, Sætnan (1992) found no significant difference in conclusions about the benefit of mammography between epidemiologists and clinicians. Both clinicians and epidemiologists seemed to be in favour of mammography screening (Sætnan, 1992).

Without having made a similar study on recently published papers, there are indications that the tide may have turned. Lately, critics of mammography screening have made their voices heard, especially questioning the validity of hitherto published RCT's (Gotzsche & Olsen, 2000; Zahl et al., 2004; Welch, 2004). Debating the evidence of mammography's effects also implies debating whether or not mammography screening is worthwhile (Nystrom et al., 1993; Gotzsche & Olsen, 2000; Nystrom et al., 2002). Critical voices on mammography screening were heard in the United States already in 1976 (Lerner, 2001), and have later had an impact on debates, but obviously not enough impact to prevent screening programs. Screening programmes have been initiated in several countries, including most countries in the EU, but with some difference in target group and organization (Holland et al., 2006). Evaluations from screening programmes indicates reduction in breast cancer mortality, even though effects varies in groups of women with different characteristics (Gabe & Duffy, 2005; Banks et al., 2004).

The research focus on randomised controlled trials for evaluating mammography screening can be claimed as a feature of medical research per se, but it is not always the medical, quantitative research based evidence that wins ground. May (2006) found that argumentation for implementing new technologies in health care systems in UK has become more a matter of practice-based evidence than evidence-based practice. Evidence-based studies were seen as too distant to practical problems, as well as taking too long to provide for practitioners and politicians on the field of local health care (May, 2006). Similarly, politicians in Norway did not take the time to await evaluations from the initial project of mammography screening in the four counties before deciding upon a nationwide screening programme. The 1989 Norwegian consensus conference on mammography screening would not recommend a mammography screening programme at that time (Holst et al., 1989; Ertzaas, Hofvind, & Thoresen, 2001). Nevertheless, the focus on early cancer detection, combined with the increasing status of randomized controlled trials, seems to have made mammography screening a possibility for the public health authorities and policy makers. If politicians are evaluated by their ability to act, technologies that allow interventions that pursue better health may be welcomed with or without scientific evidence. That at least some of the RCT evidence in this instance supported their decision to implement a screening programme must have been a welcome factor even though not a necessary condition.

I will now turn to how the medical perspective may influence participation in mammography screening, and further down I will look into what is known about lay women's experiences of mammography screening.

Participation – more than medical logics

A question of importance for mammography screening is the question of participation in the screening programme. How many and who it is that participates is of interest to both screening providers, policy makers and researchers as it can tell us about the screening programme's acceptance in the population, or about the distribution of health service use in the population. It can also tell us something about women's choices about participation, but the rates of participation cannot tell how women make their decisions. I will go more into this later in this chapter.

Participation rates have indeed been much studied, both by service providers and by others. A number of characteristics relevant for participation rates among invited women have been found, such as education and high income as positive predictive values, while increasing age and poor health are negative predictive values (Lairson, Chan, & Newmark, 2005). Even though these predictive factors may have different impact in different countries, one can expect the main variables to have an effect in most of the western countries. Place of residence seems to have an effect on screening uptake, both as an urban-rural gradient (von Euler-Chelpin et al., 2006) that may be explained by distance to the screening unit as well as an outcome of the connotation between place of residence and socioeconomic factors (Pelfrene, Bleyen, & De Backer, 1998). Uptake is also connected to ethnicity and cultural beliefs about breast cancer (Yi & Reyes-Gibby, 2002; Pfeffer, 2004b; Garbers & Chiasson, 2004).

A number of studies have been directed towards the issue of screening uptake. Some have explored reasons why some groups have particularly low participation rates, for instance immigrants in the UK (Ahmad, Cameron, & Stewart, 2005). Others have proposed organizational models that make it easier for underserved women to overcome barriers towards using health services (Lillquist, 2004). Knowledge of breast cancer risks and effects of mammography are concerns for ensuring equal uptake in screening programmes among different socioeconomic-, geographical- or age groups. Knowledge of breast cancer and prior acquaintance with mammography can be connected to questions of family history of cancer (Unic et al., 1997).

Both lay and professional knowledge has been a concern for those attempting to increase uptake. Johnson et al (1998) found for instance that physicians in Seattle had relatively low knowledge about breast cancer screening, even though most of them saw themselves as competent to answer patient's questions on the subject. This ought to be of importance to screening providers, since another American study (from Wisconsin) found recommendations by a physician about annual mammography to have an effect on patient's use of mammography (Brown et al., 1996). Physician's advices might be of greater importance for mammography uptake in countries where breast cancer screening is organized through the primary health care service than in Norway and other countries where screening is provided by a separate health authority. Nevertheless, it could be an indication of the health service's ability to influence people's choices about mammography screening.

Information from interest groups or from screening service providers is thought to influence participation and women's ability to make an informed choice. A question raised by critics is whether the information provided is biased, for instance in invitation letters (Jørgensen & Gotzsche, 2006) or on websites (Jørgensen & Gøtzsche, 2004). Biased information may increase participation rates, but does not enable people to make an informed and autonomous choice. Making an informed choice is not only about having access to relevant and unbiased information, but also about autonomy enabling decisions that reflect personal preferences (Jepson, Hewison, Thompson, & Weller, 2005). There might still be practical obstacles or value-determined barriers towards carrying out the preferred choice, and indeed there is also the question about whether it is possible, or even desirable, to make an individual informed choice. This is also discussed in the first article of this thesis.

Nevertheless, lay women's knowledge about breast cancer, mammography and screening have been put forward as important factors in questions about informed choice, as well as about reasons for participation. For instance, beliefs about breast cancer and screening among lay women can be seen as a hindrance for making an informed consent (Denberg, Wong, & Beattie, 2005). The knowledge and beliefs of breast cancer and screening that Denberg, Wong and Beattie found in their study did not fit with biomedical knowledge and well-known risks of screening, such as false-positives or false-negatives, psychological harms or going through diagnostic procedures, were hardly mentioned by the interviewed women.

So, the factors that influence participation are not always given. An Israeli study (Hagoel et al., 1999) found that groups of Israeli women participating in mammography when invited were more similar to those not participating than to those who initiate mammography by themselves, based on a set of structural, behavioural and perceptual variables. This may indicate that participating in mammography is connected to a lifestyle marker (Hagoel et al., 1999). A question arising here is how participation is connected to the organization of a public screening programme as opposed to private health service screening. In this research project the focus is on a public screening programme, even though it is known that Norwegian women also attend private mammography screening (Hofvind, 2006). Statistics for attendance at private mammography screening is not available. We can thus only assume that many of those who decline the public screening programme attend a private clinic to have

non-symptomatic mammography. Private screening will not be discussed in this thesis.

Other important factors for participation in a mammography screening programme seems to be whether one has prior experience with mammography (von Euler-Chelpin et al., 2006), and how the prior mammography examination was experienced (Hofvind et al., 2003; Peipins et al., 2006). There are conflicting views on whether fear of cancer acts as a facilitator or inhibitor of breast cancer screening participation. Worries about breast cancer have been found to influence screening behaviour (Hay, McCaul, & Magnan, 2006). In their meta-analysis, Hay et al (2006) found that there was a positive relationship between breast cancer worries and participation in mammography screening. However, one of the studies in the meta-analysis found a negative effect of breast cancer worries on screening participation.

Studies on the effect of false-positive mammograms on screening attendance also varies in their results (Brewer, Salz, & Lillie, 2007). While some studies conclude that false-positive breast cancer screening participants are more likely to participate in the following screening rounds compared with those experiencing a normal mammogram (Ganott et al., 2006; Lampic, Thurfjell, & Sjødén, 2003; Schwartz et al., 2000; Gram et al., 1990), other studies found women with a false-positive mammogram to be less inclined to participate in routine screening (Brett & Austoker, 2001; Hofvind et al., 2003). Brewer et al's review (2007) found unexpectedly that re-attendance was higher among women with a false-positive mammogram in the United States than in Europe and Canada – where a false-positive mammogram gave less re-attendance in routine screening. The reasons for this can be ascribed to structural factors of screening in Europe and the United States respectively, with screening interval, accuracy of mammography readings, national screening programs and “opt out” versus “opt in” systems (Brewer et al., 2007).

Even though Brewer et al (2007) found that the studies in their review showed variance in the effects of having a false-positive mammogram, having a false-positive screening result can give other long-term consequences, such as a higher degree of breast cancer worries, higher degree of performance of self-examinations and anxiety when facing the next mammography screening (Brett & Austoker, 2001; Aro et al., 2000; Lampic et al., 2003). Nevertheless, measurements of anxiety levels have been

criticized for being inadequate. One response to this has been the development of a specific questionnaire (PCQ) to measure breast cancer screening anxiety in particular (Cockburn et al., 1992; Brodersen, Thorsen, & Cockburn, 2004). A Swedish study using the PCQ found anxiety levels among recalled women to be significantly higher than among women with a negative screening result (Olsson et al., 1999).

Yet, women's perspectives on (their own) health are not only based on their knowledge and this knowledge's connections with biomedicine. On the contrary, life experiences, everyday life and cultural interpretations may influence how biomedical knowledge is perceived. Lay women do not necessarily see cancer as connected to an organ or cell as biomedicine does, but rather categorize its causes as a mixture of cultural and normative claims (Pfeffer, 2004b). These culturally conditioned understandings of cancer can also influence participation in, and experiences of screening for cancer. For instance, if cancer is seen as a curable disease when detected early, screening can be worthwhile, but if cancer is seen as always fatal, early diagnosis might be seen as a waste of time (Pfeffer, 2004b; Straughan & Seow, 2000). Thus, even though knowledge of biomedical facts might be necessary for enabling an informed choice as defined by medical ethics, it is not necessarily enough. As presented in article I in this thesis, there remain questions about whether women want to make an autonomous choice about participation in medical screening, or if autonomy is secondary for women's concerns of their own health.

Lay experiences of screening

Lay women who are invited to and who participate in mammography screening not only have to make choices about participation, but are also facing experiences of a mammography examination, as well as a period of waiting for the results, receiving a recall or being diagnosed with breast cancer. Women's experiences from screening can be seen from different perspectives and levels. Experiences of mammography screening can be understood as experiences of the mammography examination in terms of waiting time, pain or care, as well as experiences of anxiety and relief from a "good" result (Hofvind et al., 2003).

But, there are also other elements to women's experiences of screening. Participating in screening can be seen as a moral obligation (Howson, 1999). Howson found women participating in cervical screening to see the screening as a routine, as well as

a possibility to fill one's responsibility to oneself, and an obligation to participate when called. Responsibility for health can be seen as both as a matter of individual's responsibility for their own body and health, as well as a question of good citizenship (Willis, 2004). Women's experiences of screening are thus closely connected to the attribution of meaning. If we perceive screening as a moral obligation towards ourselves, others and the state, choices about participation are no longer solely an issue of rational choice based on statistical health effects. Rather, the meanings attributed to screening are part of a social process, dependent on relations to others.

The interaction between women's responsibility for both good health and good citizenship can be seen as made possible by the government providing a screening service. Women in rural Australia saw the government as "reaching out to them" when communities were provided with a mobile screening unit for breast cancer (Willis, 2004). Governmental "reaching out" can also be seen when talking about the letter of invitation for a screening programme. A Swedish study of cervical screening found that the letter of invitation gave incentives for two types of reasoning about participation in the screening (Forss et al., 2001). On the one hand, the letter of invitation catalysed thoughts about the beneficial aspects of attendance, and on the other hand it became a means to overcome hindrances to attendance. Also, participating in the cervical cancer screening programme was described by some as part of their own contact with the health care system that made it possible to maintain their active role in personal health promotion (Forss et al., 2001).

Women's responsibility for their bodies and health is not a new issue in medical thought. The American Journal of Nursing wrote as early as 1923 that "only neglected cancer is incurable" (Jasen, 2002). In 1977 this utterance seems to have maintained its validity, when one of the "fathers" of the HIP-study², radiologist Philip Strax, claimed that women declining to be screened were "playing Russian roulette with their lives" (Lerner, 2001). One can ask whether or not the idea of women's responsibility for breast cancer is different now.

In a Danish study, women participating in screening believed that "early detection of cancer will save lives" (Lunde, 1997). A qualitative study from the United States

² The HIP-study is the randomized controlled study of mammography screening in New York.

found women's beliefs about early detection of breast cancer as so essential for saving lives that it overshadowed any doubts the women might have about mammography screening (Silverman et al., 2001). Women who have recently had a mammography have also been found to overestimate the benefits of mammography (Domenighetti et al., 2003; Ganott et al., 2006). Whether this would apply to Norwegian women were unknown when we started this research project.

Different groups of women may have different experiences from being the target of a screening programme for breast cancer. Some are "just" participants in the mammography examination while some women feel the consequences of participation in mammography screening through being among those recalled. A few of these women are even diagnosed with breast cancer. About 20 per cent of those recalled eventually have a breast cancer diagnosis.³

Recalled and diagnosed women may have a more complex experience than those who receive an "all well"-notice after the mammography examination. Recalled women in Montreal seemed to overestimate their own risk of having a malign tumour when having a breast biopsy following an abnormal mammogram (Lebel et al., 2003). Anxiety rising from the recall letter as well as other aspects of being recalled may influence these women's experiences. Relief over having a good result in the end can be mixed with doubts about whether it was worth the trouble (Padgett et al., 2001).

There are also some women who decline the invitation to mammography screening. It is possible that many of these non-attenders are women who choose private mammography clinics instead of participating in public screening, leaving only a small group of women as actual non-attenders. Little is known about these non-attenders. A Swedish telephone-interview study of non-attenders found that barriers, benefits and worry represented the major determinants of participation in mammography, and that knowledge could overcome barriers to screening participation (Lagerlund et al., 2000). In a pilot interview to a third part of this research project that was never carried through, I found that there can be small differences between attendance and non-attendance in terms of arguments for or against participation. But, the interview showed that there are other kinds of aspects

³ Information given in the recall letter sent to screened women in Central Norway.

of women's everyday lives and life experiences that are perceived as more important than mammography screening or other medical tests. However, even though knowledge of non-attending women and their reasons for declining an invitation to a health examination is interesting for many parties, there are also ethical questions about whether or not they ought to be explored. Giving non-attenders a voice in the public debate is one side of the coin; the other side is whether non-attenders rather should be allowed to maintain a space of non-regulation without counter-arguments from screening providers.

The exploration of how women interpret their participation, mammography and breast cancer is indeed important for the discussion of cancer screening. Cultural aspects of how women understand breast cancer and the fact that mammography screening had just been initiated in Norway were some of the research group's reasons to be curious about Norwegian women's perceptions and interpretations of being participators in a screening programme for breast cancer.

Aim and approach of the study

As I have shown in this introduction, mammography screening is a multifaceted research field, and a field where both policy and research base their credibility on several discourses. Prior research has had its main focus on the effect of cancer screening on mortality and participation. But, as shown above, there has also been some research on individual choice and autonomy in screening programmes, as well as some research on how women experience participating in screening programmes. Of the three studies conducted on women's experiences of mammography screening in Norway (Gram et al., 1990; Hofvind et al., 2003; Ekeberg et al., 2001) none are qualitative studies.

The kind of problems that has been addressed in research on mammography screening has primarily been from the "first discourse on mammography screening" pointed to by Kaufert (2000). But, one might ask what other answers one would produce if the questions were posed from a different position than the dominant one (Bacchi, 1999). Researching mammography screening, I will ask what is left unproblematized when mammography screening is represented as a medical, statistical or "rational choice" problem. It will be relevant to ask whether these representations of screening influence women's experiences of being the target population for a mammography

screening programme. Furthermore, there might exist a “second discourse on mammography screening” (Kaufert, 2000); a discourse that is about faith, emotions, responsibility, morality, compliance and guilt. In the midst of these discourses we find the lay women who are invited to, and who participate in the mammography screening programme. The aim of this study is to explore how women experience participating in a public mammography screening programme. Different groups of women have different experiences of mammography screening, and I have chosen to study women who go through the mammography screening and receive an “all well”-answer, as well as those women who have to go through further examinations due to an abnormality at their first mammogram. The research question is thus:

What are the experiences of women who are invited to join the screening programme when making their decision to participate, when participating, and when facing a recall letter?

Structure of the thesis

This thesis consists of four articles plus a “framing section”. The four articles that are the result of the analyses from my PhD-project are presented in the end of the thesis. The first article is an exploration of how women experience being invited to a public breast cancer screening programme and what it is that has the greatest influence on their decision to participate. The second article examines if and why women have trust in mammography to save them from cancer. Article three is about participants in mammography screening who receive a recall letter due to an abnormal mammogram. It asks how they interpret the recall letter and how information influences their experience of facing a potential cancer diagnosis. The fourth article is about the use of a qualitative methodology on a research field primarily dominated by medical research with its focus on statistical generalization and evidence-based research.

The framing section in turn provides four cornerstones: 1) This chapter, in which I present features of the field that form a background for my study, 2) A discussion of the theories undergirding my approach, 3) Methodological reflections, going somewhat deeper into these issues than the article format allows, and 4) an overarching discussion and conclusions tying the four articles closer together than when each stand alone in separate publication contexts.

In the next chapter I will thus give a theoretical framework to the analyses that are given in the four articles. The theories are used more implicit than explicit in the articles, except for discussions of trust in article II. The article format has not given room for explicit theoretical discussions, and the perspective of governmentality that is the main point in both the theoretical framework and discussion is used more implicitly in the articles. Nevertheless, the theoretical framework will present a perspective on how we can understand women's experiences of mammography screening in a wider social context. The theoretical framework will also explore themes concerning the "second discourse of mammography screening" (Kaufert, 2000).

The third chapter of the thesis presents the methods used to sample and analyse the data material for the study. As the thesis is built upon two studies where one is a focus group study with women invited to a breast cancer screening programme, and the other contains data from individual interviews with women recalled after participating in mammography screening, I will present both these methods respectively.

In the final chapter I will draw the lines between the articles and the introductory chapters of the thesis. I will discuss how women's experiences of mammography screening draw on both the first and the second discourses of mammography screening that have been presented by Kaufert (2000). I will also lean on the fourth article in the thesis to see how these discourses influence how we study women's experiences of mammography screening.

2. Theoretical framework

As mentioned in the introductory chapter, Kaufert (2000) has identified two discourses about mammography screening. The first discourse is about whether mammography satisfies the formal rules of screening, whilst the other was about faith, emotions, responsibility, morality, compliance and guilt (Kaufert, 2000). In the first chapter of this thesis I looked into aspects of the “first” discourse of mammography screening. In this chapter I present a theoretical approach for understanding the latter and how these two discourses are connected and work together. However, I do not use one single theory from sociology or other fields. Rather, I have taken a pragmatic stand and will use elements from different theoretical perspectives to give a framework for interpreting how women experience mammography screening.

When analysing the data material, the women’s ways of talking about their up-coming participation in the mammography screening programme and their following experiences with worries and relief came out of the material as complex relations. These were the relations between concrete experiences, obligations in everyday life, perceptions of health and risk, and women’s trust in the health authorities, expert advice and the mammography technology. This led me and the rest of the research group to look more into explanations of women’s experiences of mammography screening. In the previous chapter I presented a background for understanding problematic aspects of individual choice in screening. Difficulties of individual choice can be explained through the concept of governmentality (Foucault, 1991). The concept builds on an alliance between the individual and the collective which gives a sense of individuality and choice. This is a reason for why I have chosen this approach. Governmentality gives a framework to analyse how individual women choose and experience participation in mammography screening. However, it also provides us with explanations of the limits of autonomy.

A main point when using the concept of governmentality is to explore and understand how technologies of governance work together with individual’s self-governance. In order to study how we govern and are governed within different regimes one must study the characteristic ways of seeing and perceiving, knowledge, techniques, practices and identities within a regime of government, since all these parts presupposes the others, but are not reducible to them (Dean, 1999). In this chapter I

will describe the elements that appeared as most relevant for understanding women's experiences of mammography screening. I will explore how, in the case of mammography screening, the axes of visibility, knowledge, techniques, expertise and identities (Dean, 1999:23) are expressed through expert knowledge, statistics, technology and medicalisation. Furthermore I will go into how trust can be a part of how women's health is governed. In the last sequence of this chapter I will discuss the gendered aspect to the experiences women have when enrolled in a mammography screening programme. But first I will develop how society is governed and present how government in our society follows a logic that can be called liberal.

Governmentality

The concept of government provides a way of analysing the concerns of social authorities in administering the lives of individuals (Miller & Rose, 1990). Government is a general term for calculated direction of human conduct while the concept governmentality seeks to distinguish mentalities and regimes of government and administration that have emerged since "the early modern period" in Western Europe (Dean, 1999). More than the direct regulation or inference by the state, governmentality refers to the government of populations through agencies and techniques, for instance when experts identify healthy practices (Brownlie & Howson, 2006) that the public then follows on their own accord. Thus, it is not possible to reduce government to the intentions of one actor. Rather, regimes of practices have a logic that is irreducible to the intentions of any one actor but the logic still has an orientation toward particular ends and purposes (Dean, 1999).

A problem with an analysis that looks into government is what kind of power one can attribute to the state (Neumann, 2003). More than understanding the state as giving rise to government, one can say that the state is a particular form that government has taken (Miller & Rose, 1990). A central part of the formation of the state was the recognition by the state that the health and welfare of its population were among the key objectives of its rule (Dean, 1999). Governmentality is thus a kind of power which is in a productive relation to the population's well-being (Hammer, 2008). The question is not how much power the state inherits but what governmental techniques the state mobilizes to maintain a specific governmental regime (Neumann, 2003). Government is accomplished through multiple actors and agencies rather than a

centralized set of state apparatuses, without any a priori distribution of power and authority (Dean, 1999). We can rather see a number of techniques that have a common goal; namely to hold the population within the boundaries of normality (Hammer, 2008). These techniques make it possible to lead the population to do what is considered best for the state and the population, but nevertheless leaving the individuals with a sense of making their own choices. So governmentality is a mobile and changeable set of technologies and rationalities that is different from both law and individual discipline and works in a complex manner as a productive relation to secure the population in the best way (Hammer, 2008). The state is the “good shepherd” with its responsibilities to guide each individual in the population to its best possible level (Rose, 2001; Neumann, 2003).

Governmentality is about the processes through which the body and populations are managed and governed (Brownlie & Howson 2006). The discipline of bodies as a technique at a micro level has transformed into a continuous self-controlling technique in our modern society (Hammer, 2008). The concept of governmentality can thus be understood as a point where technologies of the self and technologies of domination meet (Petersen, 1997). Government presupposes the activity and freedom of the governed, and to govern individuals is thus to get them to act on their particular wills with ends imposed upon them through facilitating models of possible action (Burchell, 1991). Government is thus not only how we exercise authority over others but about how we govern ourselves through practices of the self (Dean, 1999).

This view of governance involves seeing power and autonomy not as opposites, but as intertwined facets of one another. Power is only effective if the subjects are able to react in certain ways which do not suppose that individuals are passive (Nettleton, 1997). One can for instance see individuals as reflexive agents who are active when facing modern medicine and technological developments (Williams & Calnan, 1996). Nevertheless, this does not mean that subjects are free as outside discourse, but rather that they are free to act within the discourses that constitute the subject (Neumann, 2003). The mentality of government is the way in which thought involved in practices of government is collective and taken for granted, but not necessarily open to questioning by its practitioners (Dean, 1999).

Individuals are recruited to take care of themselves with techniques deployed by experts, techniques that inevitably shape how individuals think about themselves (Nettleton, 1997). The liberal art of governance explained through the concept of governmentality is thus about disciplining and regulating the population without direct intervention but rather steering discourse through setting agendas, legitimating statements and authorizing technologies, etc, so that actors perceive problems in similar ways and accept responsibility to transforming their position themselves (Flynn, 2002). Given the power of discipline and surveillance it is difficult to see how one can explain opposition (Williams & Calnan, 1996). But, the concept of governmentality is also an answer to a critique that Foucault's theories of discourse deprived individuals of their status as acting subjects (Foucault, 1991; Neumann, 2003). The practices of the self are only possible through the freedom of the individual, and can also be means of resistance to other forms of government (Dean, 1999). Governing at a distance is moreover dependent on individuals' internalisation of governmental perspectives and self-governance.

Foucault implied that our society is characterized by particular ways of thinking about which problems can and should be addressed by the authorities, rendering fields open to intervention (Miller & Rose, 1990). It might thus be in its place to ask why breast cancer has become one of the problems that health authorities should address and what it is that makes screening a solution to the problem. A frame to this question is that in the liberal society, health has formed a zone between political concerns for the fitness of the nation and personal techniques for the care of self (Rose, 2001). There is however, a danger of exaggerating the control modern medicine has over people's experiences in contemporary society (Williams & Calnan, 1996). Medicine and medicalisation is rather one among several instances by which liberal societies are governed, but may still be a rather important one.

The liberal society

Self-governance and autonomy are values of liberalism. In the welfare state however, the main focus has been on solidarity and equality (Christensen, 2005). Although Norway is a welfare state, its government structures have been influenced by liberal ideas on how to govern by governing as little as possible. This implies that a central power in our society is indirect power, that is, a power that works through its

definitions of normality, rather than by forcing individuals to do what they initially did not intend to do (Neumann, 2003).

The liberal character of our society is exemplified by an analysis of the white paper on public health from 2003. Norwegian health policy was characterized as “social liberal” in comparison with Danish and Swedish white papers that were characterized as “liberal” and “social democratic” respectively (Vallgård, 2007). There has been a change from the white paper on public health in 1993 where focus was on institutions and structures, to the white paper in 2003 with its focus on individual responsibility (Stenvoll, Elvbakken, & Malterud, 2005). During the 1980s and 1990s Norwegian politics, where a rationality of the welfare state had been dominant, was supplemented with a liberal rationality (Neumann 2003:238). Rather than substituting other forms of power, liberal rationalities supplemented ways of ruling, so that one can identify a trilateral ruling power in society; strategic power, discipline and governmentality. Traditional relations of power such as strategies and dominance are developed with technologies that allow governing at a distance (Neumann, 2003). The development of government as a central logic of power has to be understood as part of an established framework where the state is the carrier of sovereignty, but with the presupposition that there exist freedom and social spaces independent of the state because otherwise it would not be possible to govern in the direction of less state dominance (Neumann, 2003). Liberal modes of government attempt to work through the freedom of the governed (Dean, 1999).

The discussion of whether there should be spaces in society free of state power can hardly be settled in the area of health care. Studying issues of health rather raises questions about the complexities of self-government and individual choice than give solutions to it (Burchell, 1991). Health is thus an example of an area which consists of strategies from the welfare state and at the same time has a space free of state government. Moreover, Rose (2001) sees health politics today as strategies following arguments such as economic cost-benefit of ill-health, or moral terms such as reducing inequalities in health. Health indicators are seen as nations’ rates of success but it is nevertheless citizens who must take active responsibility for their own health, with the state governing at a distance (Rose, 2001).

A question here is how the liberal society with its governing at a distance affects mammography screening and women's experiences of it. Mammography screening in Norway is – as in most western countries (see Holland et al (2006) for a description of the organization of European mammography screening programmes) – managed by the health authorities in order to reduce mortality from breast cancer (Cancer Registry of Norway, 2007). Even though the national mammography screening programme can be seen as a strategic initiative from the welfare state, it is voluntarily to join. Breast cancer screening is not imposed on the population as screening for tuberculosis was. It has nevertheless been claimed that mammography screening emphasizes individual choice, but that there exists a framework around this choice such that those choosing non-attendance come to be seen as irresponsible (Hydle, 2003).

It is exactly the voluntary aspect of mammography screening that makes it interesting to look at it from the perspective of governmentality. In a recent editorial in the British Medical Journal, opposition towards direct government and expert advice about mammography screening were put this way: "Women should be encouraged to decide what is right for them, rather than being told what to do" (Schwartz & Woloshin, 2007). I will thus ask how it is possible to choose what is right for oneself if we are all surrounded by a multitude of expert advice and governmental discourses and techniques – discourses that point to ones obligation to secure ones health.

It is important to investigate empirically how members of the lay population respond to and even seek out the medical gaze rather than seeing them as passive bodies (Lupton, 1997). Women attending mammography screening are in my opinion a good example of a lay population submitting themselves to health surveillance, yet at the same time they constitute an example of individual choice and resistance. In order to analyse the mobile, changing and contingent assemblages of regimes it is necessary to give attention to what is put into these assemblages: i.e. the routines of bureaucracy, the technologies of recording and transporting of information, the programmes, knowledge and expertise that compose a field to be governed, the ways of seeing and representing embedded in practises and the different agencies with various capacities that practices of government require and form (Dean, 1999:27). I will therefore now go further into which techniques and technologies it is that make the process of governing the population's health work so "smoothly".

Elements in the government of health

In this part of this chapter I will provide a framework for the analysis of women's experiences as participants in a mammography screening programme. This sketch is not meant to be a complete representation of influences on women's experiences of mammography screening. Even though other elements could be mentioned, such as the division of labour and the care obligations women have in our society, I have chosen to focus on expert systems, technology, statistics, medicalisation and risk, and trust.

Expert systems are relevant as providers of knowledge. When we exercise self-government, we draw upon certain forms of knowledge and expertise provided by for instance health professionals (Dean, 1999). It is also an arena for professional power. Experts have knowledge that is valued by society, and this knowledge can give them monopoly of truth and intervention. For instance can experts have monopoly over technology, and technology is an important asset for power and knowledge in our society. Statistics is relevant as part of the expert system for mammography screening, as shown in chapter one. And statistics forms a basis for making risk estimates, which in turn are one of the undergirdings of medicalisation. In other words, these elements are tightly intertwined with one another.

The medicalisation of society is closely connected to risk because medical expertise is called upon to solve questions of risk. When facing uncertainty individuals and society turn to the experts for solutions, and medicine has provided or promised solutions. One consequence is thus that the medical profession and medical knowledge has become "the" solution to questions about human life that previously was seen as the purview of other institutions. However, the liberal society with its focus on individual autonomy could not function without individuals trusting the expert's solutions to be the best for them. In order to "lead" individuals to participate in self-governance - applying expert advice - it is necessary for individuals to trust the practices which they are presented. I will now present the elements mentioned above. Keeping the intertwined whole in mind as a backdrop, I will examine the elements one by one.

Expert systems

Expert systems are systems of a technical and professional expertise that organize larger areas of our material and social environment (Giddens, 1990). The language of expertise plays a key role in governmental networks as expertise provides norms and values with claims of disinterested truth (Miller & Rose, 1990:10). The complex mechanisms which make it possible to link calculations at one place with action at another makes expert systems relevant for governance.

Expert systems are abstract systems which functions on the basis of exclusive knowledge of which lay people are likely to understand very little (Giddens, 1990; Brown, 2008). Those who are in position to provide and interpret a given area of this knowledge are deemed experts, or professionals. One definition of a profession is an occupational group characterized by sharing skills based on theoretical knowledge, provision of training and education, testing of competence, organisation and adherence to a professional code of conduct (Witz, 1992). However, a profession could also be seen as an occupation which has successfully struggled for a right to control its own work (Freidson, 1988). Also, professionalism can be seen as a strategy of exclusionary closure to limit and control the entrance to an occupation (Witz, 1992), thereby also controlling knowledge possessed by that profession and having jurisdiction over the field in question (Abbott, 1988).

However, in this thesis I will not go into issues of professionalism per se. Rather, my perspective is how the medical profession and professionals are part of a larger system of experts and expertise that are providers of knowledge that induce practises and technologies of government. Thus, the first point here is how experts and expert systems take part in the government of individuals. However, medical (and other professions) expert systems are also part of the liberal society and its governance technologies. I will therefore also briefly look into how surveillance technologies, such as audits and clinical governance, enrol the medical expert system into practices of self-governance.

Expertise can play a vital translating role between general politico-ethical principles and the self-regulatory activities of individuals (Miller & Rose, 1990:26). This links rationalities of personal autonomy to technologies of regulation. Within these rationalities new relations can be formed between the health of the nation and the

private choices of individuals, and the power of expertise has shaped and normalized the self-regulation of subjects (Miller & Rose, 1990). Expertise has thus become a resource for liberal democratic governing at a distance.

But, in order for lay individuals to follow expert advice, it is required that they have trust in the experts to have their best interest at heart. Expert systems embody faceless commitments (Giddens, 1990) of professional judgements to which lay users are dependent in order to assess future risks and products available to meet them (Stevenson & Scambler, 2005). We need to trust doctors because medical knowledge is too complex for each of us to grasp fully, or even adequately, on our own (Greener, 2003). A key dimension of public trust in health services is, among others, the assessment of whether the doctor behaves professionally and gives patients enough attention, and the perceived level of professional expertise (Calnan & Sanford, 2004). A decline in trust in the health care system can be part of a general lack of certainty in a post-modern era, where medical knowledge is highly questioned and de-privileged (Brown, 2008; Scambler & Britten, 2001). In current day society, much of our trust in the medical profession has come to be in response to risk: Experts tell us what we are at risk for, and how we can reduce or avoid those risks.

However, scientists frequently disagree about the significance of statistical correlations on which estimates of risk are based (Petersen, 1997). This makes expert advice generate its own uncertainties even though it is meant to create security and help avoid risks. An increased sensitivity of risks has been accompanied by an awareness of the limitations of medical expertise (Alaszewski & Brown, 2007). Control of the access and application of medical knowledge has been one means of ensuring a perception of expertise (Brown, 2008; Abbott, 1988). Thus, the medical profession's status has depended on its management of privileged knowledge, even though a growing focus on risk has contributed to the yielding of power away from the experts (Brown, 2008; Castel, 1991). However, medical knowledge remain privileged but the focus on risk in health-care has led policy makers to necessitate regulation of professional practice and a systematisation of knowledge (Flynn, 2002). Audit of has become a large-scale activity for governing the activities of experts at a distance (Flynn, 2002; Rose, 1999).

The concept of governmentality (Foucault, 1991) enables us to understand the institutionalisation of expertise as part of the operation of systems of power (Flynn, 2002). But, it can also show how expertise and expert systems are governed. What can be named “clinical governance” imply the monitoring and auditing of medical experts. Clinical governance is a tool by which the risks of negative consequences in healthcare are minimised (Brown, 2008). It marks a transition in knowledge from “embodied knowledge” held by the individual to “encoded knowledge” by which knowledge is spread across a community of doctors in the form of guidelines, directives and standards (Brown, 2008). It is thus not the individual autonomy of the medical doctor that is in focus but rather a strong organisational control. It is the system itself that will play the main part in identifying failings (Flynn, 2002). In the rationality of clinical governance, little emphasis is put on access points (Giddens, 1990) as influencing public trust in the health care system. Rather, the communicative trust where patients believe that professionals place their best interest above all others is seen as secondary to the instrumental trust provided by the instrumental systems of clinical governance (Brown, 2008). It thus becomes necessary for the system to imply self-governance. Through clinical governance regulations are monitored by the system itself.

The question is how knowledge provided by expert systems – systems being governed themselves – influence and become part of how individuals govern their health. The monopoly experts have on providing knowledge on their field of expertise, as well as on the use and interpretation of that knowledge, give experts a unique position as translators on knowledge to the lay population and policy makers. Experts can communicate through mobile inscriptions (Latour, 1990) which can be numbers and images – also meaning number *or* images. For mammography screening, statistics provide numbers and the technology provides images that need interpretation by experts.

Technology

Mammography screening is not only about experts debating statistical evidence or political decisions. It also involves a machine that must be handled by experts and that provides the medical expertise with images to interpret. Mammography’s visualising aspects can have a persuading power (Willis & Baxter, 2003). The visual aspect of

mammography is developed further in article II of this thesis (“You Have to Have Trust in Those Pictures”. A Perspective on Women’s Experiences of Mammography Screening), but it is important to highlight how women feel visual proof more trustworthy than perceptions from other senses. The imperative of objectivity and visual modes of representation link together as instruments of “truth” in medical knowledge (Reventlow, Hvas, & Malterud, 2006).

However, it is not only the mammographic machine that can be explored through the term technology. It is also tempting to see even the screening programme as a technology. The workings of the screening programme has similarities to Bruno Latour’s fable of the metal key holder (Latour, 1991). Latour tells a story of how a hotel manager makes more and more people surrender to his wish that they should leave the hotel key at the reception when leaving the hotel. First the hotel manager asks his guests to leave the key. A few polite guests follow his request. Next he puts a notice at the reception, urging people to leave the key. Now also the polite but forgetful guests leave the key. Finally he attaches a heavy and bulky metal keyholder to each key. Suddenly most people leave the key at the reception, eager to get rid of the heavy weight in their pocket or purse. In my opinion it is possible to interpret mammography screening in similar terms. Mammography equipment has been around for a long time, and some women have made use of it. Expert advice about its use has added some more women as users of mammography. But, it seems to be some aspect of the screening programme that leads nearly 80 per cent of women in the target group to become users of mammography.

What separates the public screening programme from other kinds of mammography screening is the personal letter with a preset appointment that is sent to all women in the target group. This can be described as an “opt-out” strategy (Junghans et al., 2005). “Opt-out” is a term primarily used in recruitment of research participants. It refers to practices whereby research participants are included unless they choose to withdraw from the study. This is opposed to the recruitment strategy of “opt-in” where research participants must take a more active part in joining the study to be included. A randomised trial on “opt-in” versus “opt-out” strategies for recruiting participants to a research project on angina found that there was a significantly higher recruitment rate with the “opt-out” strategy, and that the “opt-in” strategy provided a more biased sample (Junghans et al., 2005). Nevertheless, “opt-in” strategies are

considered more ethical when recruiting participants to research. The question when choosing between these strategies is whether it is most important and ethical to put individual choice first, or whether the perceived requirements for valid research hold a morally higher ground since research results presumably serve the common good (Hewison & Haines, 2006).

A similar comparison can be used when considering screening participation as well. Screening programmes are dependent on high participation rates in order to reduce mortality from cancer, and this will presumably serve not only society as a whole but also individuals who participate. Also, the opting-out strategy in a screening programme can overcome the participation bias that an opting-in strategy may provide, for instance through minimizing a socio-economic gradient and thereby securing an equal distribution of health care services in the population. Nevertheless, an “opt out” structure of the screening programme is likely to influence the choices of those invited into the programme, thereby inflicting on their autonomy and thus the individualistic values of the liberalistic government.

Statistics

One of the manners in which expert systems can influence practices is through the use of statistics. The function of statistics is to generalize, to move from the individual towards the larger picture. At the same time there is a more hidden effect. Statistics provide us with a position along a scale, a personal connection to certain categories (Hammer, 2008). This double edge has made it possible for the welfare state to combine long-term planning with direct intervention towards those outside the statistically defined normal range (*ibid*). Drawing the limits of normality narrowly can open for the inclusion of large groups of individuals into programmes of intervention. Calculations of risk as deviance from statistical normality can thus contribute to medicalisation (Skolbekken, 2007). Statistics make persons and actions governable through turning them into numerical sizes that makes uncertainties predictable (Hammer, 2008; O'Malley, 2004). Numbers can be understood as mobile inscriptions that make it possible to transfer knowledge into symbols and signs that are (presumably) interpreted similarly by all their readers (Latour, 1990). Statistics are thus not only about formal methods or techniques; they are also a co-producer of knowledge and technologies for the governing of society (Hammer, 2008).

This is not least evident in medical knowledge. Quantification of medicine is indeed part of the growing trust in numbers that has affected all aspects of social life during the past centuries; it is part of a process of objectification in clinical medicine that has been going on since the eighteenth century, even though counting had a rather low epistemological status in the latter half of the nineteenth century (Weisz, 2005). But, the objectification of medicine is indeed not only visible through the focus on numbers, but also as images in living patients through visualizing technologies (Weisz, 2005). Visualization and quantification may both be seen as part of the objectifying of medicine. For instance did Keating and Cambrosio (2005) find that cancer pathology has gone through a process of objectivation through which the more subjective visual elements has been eliminated in exchange for quantitative dimensions in the analysis of pathological lesions. One example of this is the quantification of cancer pathology of cervical cancer through the Pap-test (developed in the 1920's by George Papanicolaou). The quantification of the cervical cancer test made it possible for those promoting the early detection of cancer to provide not only diagnostics but also a pre-diagnostic test (Keating & Cambrosio, 2005). The history of the Pap-smear has been a long and winding road (Bryder, 2008). Its success has been attributed to a number of assets, for instance its ability to be standardized (Casper & Clarke, 1998). I will not look further into the example of cervical screening. Nevertheless, it provides a good example on how the merging of biological aspects and quantitative techniques can pave the way for pre-diagnostic screening (Keating & Cambrosio, 2005). The objectivation of medical practice through use of numbers and visualizing techniques has thus been a basis for the development of medical screening, and may also have had an impact on the acceptability of screening in the population.

In medicine quantification is especially evident in randomized controlled studies which has become the gold standard for evidence based medicine (Weisz, 2005; Makela, 2004). This has not least been the case with mammography screening (Lerner, 2001). Even though mammography screening is visual rather than numerical, the evidence of the usefulness of mammography screening has been randomized controlled trials. Numbers and statistics, as well as recorded images, can be understood as mobile inscriptions. Mobile inscriptions give a unique advantage when it comes to proving that ones science is right or true (Latour, 1990). Statistics and images can thus be used to prove the truth of science and medical practise such as

screening. When experts are arguing that mammography screening is saving lives through providing the most truthful statistical evidence, discussions can centre on whether the numbers are obtained correctly rather than on whether statistics are the best proof for mammography screening's superiority. Studying women's experiences of mammography screening, it is exciting to see whether the focus on statistics that exists in expert debates is also present in lay perceptions of mammography screening or whether it is rather taken for granted as truth.

A part from giving a scientific knowledge base statistics are also used in information and invitation letters that are presented to the population which are in target of participation. For instance women in the Norwegian breast cancer screening programme are presented with numbers and statistics for their risk of having breast cancer and their risk of being recalled. This is an example of how statistics provides us with a personal connection to certain categories (Hammer, 2008). The accumulated numbers of those saved from breast cancer if participating in mammography screening are returned to the women and thereby inflicting upon them a choice of which statistical group they want to belong to – those following statistical expert advice or those taking the risk to do otherwise. Again, we can see how utterances based on expert advice have a potential for governing individual choice. Moreover, statistics used for the development of risk estimates for potential disease can contribute to medicalisation.

Medicalisation and risk

One supporting beam of medical activity in our society is preventive medicine, attempting to avoid morbidity and mortality. To achieve the goal of “a long healthy life”, there has been a rise of surveillance medicine (Armstrong, 1995).

Mammography screening can be seen as surveillance of un-symptomatic individuals through its periodic mammography examinations. A screening programme does not only provide one examination for the potential disease but rather monitor individual's health at specific times during a period of time. Frequent periodic examinations are at the core of screening. In order to optimize the advantage of screening the interval between two consecutive examinations is based on a statistical estimate on a minimum lead-time of the disease (Forsmo, 1997). For mammography screening, the

recommendations for screening interval range from one to three years.⁴ A screening programme is thus a thoroughly calculated way of surveillance of the health of population and individuals.

Surveillance medicine as a dominant form of medicine in the twentieth century is connected to the medicalisation of life (Armstrong, 1995). A characteristic of the medicalisation process⁵ is the widening of who is in need of medical attention. This also implies enrolling individuals free of symptoms into medical attention (Skolbekken, 2007). Even when accepting breast cancer as a medical problem, enrolling a whole population free of symptoms into a system of medical examinations can be interpreted as medicalisation.

Surveillance of healthy populations can be seen as the problematisation of the normal and pointing to potential future disease as pieces in a chain of risks (Armstrong, 1995). A risk is thus not only the presence of danger. It is also the probable occurrence of an effect of a combination of abstract factors (Castel, 1991; Petersen, 1997). Health risks are estimated by the use of epidemiological data. Nevertheless, there are challenges to communicating what may look like causality at the epidemiological group level as uncertainty at the individual level (Skolbekken, 2007; Hollnagel, 1999). Communication of risk is also a question of how lay people understand risk and concepts related to risk. Interpretation of risk can even vary among socio-economic groups (Woloshin, Schwartz, & Welch, 2007). I will not go into how women in this study perceive of their risk for breast cancer, but it is studied in another part of the research project (Østerlie, 2008).

Nevertheless, when enrolled into a screening programme for a disease of which the women have no symptoms, it might influence how women perceive their own bodies and health. Risk is not perceived through bodily experiences but through

⁴ Recommendations varies in different mammography screening programmes: every year is recommended in the United States, biannually mammography is recommended in Norway, while the mammography screening programme in the UK invites women every third year.

⁵ The causes of medicalisation has been attributed to professional dominance; industrialization and bureaucratization; as a means of social control – both from the ruling class and to serve a heterogeneous array of interests; and as a patriarchal means to control women's bodies (Williams & Calnan, 1996). Medicalisation can thus be seen to happen through the actions of a multitude of actors,

measurements and calculations which makes individuals dependent on medical knowledge and technology to have knowledge of their own body and health (Skolbekken, 2007). Pre-symptomatic diagnostics can thus become part of the practices women must do in order to control risk. The urge to control mortality and morbidity are part of a need to make the future predictable and manageable (Rose, 2001). Thus, risk becomes an existential parameter for structuring life both for experts and lay people (Williams & Calnan, 1996).

A characteristic of governance is that it consists of a variety of strategies to identify, treat or administer those individuals where risk is seen to be high (Rose, 2001). For risk to be a tool of governance it must not only communicate uncertainty but promise a solution to control that uncertainty (Skolbekken, 2007). Estimating risks may be one way to govern ourselves in the moment and towards the future. Thus, medical expert systems provide technology and statistics as solutions to problems of life and death. But, these are not only solutions to medical problems felt on citizen's bodies. Rather they are also solutions to questions that come out of the problematizations of normality that arise from liberal discourses. More than seeing experts and health authorities as agents for medicalisation, I see them as providers of utterances and mobile inscriptions that are both creators of and created by discourse. Thus, expert systems with their technology and statistics are among what makes government of a population possible. A mammography screening programme can thus be interpreted as a medical and governmental solution to a health risk estimated by experts.

But, since individuals are not forced to participate in mammography screening, there must be something making governance possible. What is it that makes it possible for women to do self-governance in the manner suggested by the health authorities? One answer to this may be trust. I will now discuss whether and how trust can be the cement holding elements of governance and self-governance together.

Trust

The previous parts of this chapter have presented elements that are relevant for the techniques of government in a liberal society. What these elements have in common is

such as the medical profession, the pharmaceutical industry, the mass media, politicians, lay people and patient organizations, as well as the health authorities (Skolbekken, 2007).

that they are about knowledge and how knowledge is closely connected to power. Nevertheless, looking into knowledge is not enough when studying women's experiences of mammography screening. In our modern society we cannot know all aspects of relations, authorities or systems. Our modern society is complex and personal knowledge is more difficult to attain than in a traditional society (Giddens, 1990; Möllering, 2001). In order to make sense of abstract knowledge it is necessary to trust. One can claim that the complexity of modern society results in active trust (Giddens, 1990). It is not possible for lay women to test all aspects of expert claims about the usefulness of mammography screening, and accepting expert knowledge must therefore involve trust.

The aim of screening is to precede symptomatic diagnostics of breast cancer, and anticipation about what the future might bring middle aged women is a reason for the initiation of mammography screening. Anticipation of the future is the nature of trust (Brownlie & Howson, 2008). Trust about the future must be based on some form of knowledge which may be personal (as when we trust in a person based on our previous experiences with him or her), or abstract (as when we trust in institutions, rules, science) (Hardin, 2001; Tyler, 2001).

If we accept that we live in a complex society, we need simplifying processes, and risk estimates have been mentioned above as one way to predict an unknown future. Risk estimates are attempts at rational prediction, which is one strategy for reducing complexity. But, even if one assumes a determinant universe we do not have the time and resources to predict all actions (Lewis & Weigert, 1985). Trust is an alternative to reduce complexity since trust enables us to live as if certain possible options will not happen (Lewis & Weigert, 1985). This certainty can be grounded in security about one's social position, for instance arising from a context of group identity (Tyler, 2001).

Furthermore, relations and acknowledgement can create trust between the trusted and the trustee. How people are treated gives them information of their own status in the social group they belong to, and of the status of their social group in society (Tyler, 2001). When people are treated well they get the feeling of having a valuable identity and being acknowledged as an important part of society. Thus, in Tyler's account, acknowledgment of social status can make people trust authorities. People receiving

good treatment from the authorities are more likely to defer to group authorities and group rules. This interpretation of trust might explain women's trust in mammography. The invitation to participate in mammography screening and the mammography examination itself can both be seen as communication between women and the authorities, acknowledging the importance of these women's health.

Trust can be seen as something we do every day, as a routine we do since it would be unthinkable to act otherwise (Möllering, 2006). The routine aspect of trusting can indicate that individuals are passive, but also that individuals do not see the need to make a fresh choice to trust on a regular basis. A new decision may only be made if and when some unusual event disturbs the routine. Moreover, routines may enable action when facing uncertainties and are moreover an element of social life - in which agency and identity should not be overlooked with regard to routines (Möllering, 2006).

Trust enters the picture when something remains unknown (Möllering, 2001). That is when knowledge and rational action based on that knowledge is insufficient. If all options and their contingent outcomes were known there would be nothing left to trust. It is thus not knowledge and security that are essentials for trust, but rather uncertainties that has to be overcome in order to trust (Giddens 1990). Yet trust does not eclipse rational action; rather, it is a cognitive process that combines "good reasons" with an emotional dimension (Lewis & Weigert, 1985). Knowledge can give good reasons for trusting, but good reasons are more a rationalisation of one's trust than what actually constitutes trust since good reasons do not produce trust by themselves as there are mostly good reasons for the opposite as well (Lewis & Weigert, 1985).

Trust is thus something more than reasoning, and can be seen as a process of the three elements of expectation, interpretation and suspension (Möllering 2001). Expectation is the presumed future outcome; interpretation is how one makes knowledge one's own; and suspension mediates between interpretative bases (good reasons) and certain expectations. Möllering (2001) describes suspension as a mental "leap" from interpretation into expectation, that is, the point where we accept our interpretations and suspend our awareness of the unknowable. Suspension overcomes uncertainties and makes it possible to make the "leap of faith" into trusting (Brownlie and Howson

2005; Lewis and Weigert 1985; Möllering 2001). Indeed, the leap into trust can not happen from nowhere, it needs to be made from a place where interpretation leads us even though we cannot be entirely certain (Möllering, 2001) .

A question when researching trust is of course who it is that trusts and what it is they trust. Health issues are marked by uncertainties which make it a special analytical opportunity to researching trust (Brownlie & Howson, 2008). A relevant question here is whether or not women trust mammography screening, and what it is that they trust if they trust it. Their trust or distrust in a screening programme or medical technology with its interpretations and its surrounding expert systems is likely to be connected to how they experience their participation in the breast cancer screening programme. And here is where all the strands meet and intertwine. Expert systems provide knowledge and interpretations of technological outcomes and statistics. These statistics are also the basis for risk estimates which again can be a vehicle for medicalisation. Through these elements it becomes possible for women to imply self-governance, choosing practises that minimizes risks and thereby securing their future health. Government of women's health through self-governance is thus made possible when women have trust in experts and health authorities to have the expertise and their best interest at heart when offering medical screening for a disease of which they have no symptoms.

One last aspect is worth mentioning when theorizing about women's experiences of mammography screening. This is the aspect of gender. Mammography screening is an initiative directed at women only. Even though this thesis does not have a particular gendered perspective, I understand gender as an implicit element in how women experience their screening participation. The last sequence of this chapter will therefore focus on the gendered elements of women's experiences of breast cancer screening.

Women's experiences

An assumption when studying women's experiences of mammography screening is that participation in a screening programme will influence and be influenced by aspects in people's lives. Another assumption is that women's experiences might be gendered, especially when concerning a "women's disease". The place of women in society is likely to influence experiences of screening, as well as women's decisions

for participation in screening. Statements about beneficial medical surveillance technologies such as cervical or mammography screening seem to place women as care-givers for others, and thereby making their participation in self-surveillance and preventive health programmes an obligation towards both themselves and others (Howson, 1998; Lerner, 2001). Wanting medical screening is, however, not solely a feature of women's relations to medicine. The prostate specific antigen test is widely used to screen men for prostate cancer even though its value is controversial (Chapple et al., 2008).

Theories about women, womanhood and femininity have changed over time. I will not go into these theories and scientific debates here, neither will I explore or explain how women's positions in society and women's rights have developed. Nevertheless there are aspects about women's experiences of breast cancer screening that need to be discussed with a gendered focus. Breast cancer screening is one of only two screening programmes for cancer in Norway, with cervix screening as the other. Indeed, both screening programmes have women's health and bodies as their target. Thus, not all bodies receive the same inscriptions. Rather, different inscriptions target different kinds of bodies (Sandell, 2001).

Women's bodies as a target for medical practice are not a new invention. Biological perspectives to the feminine body have resulted in different kinds of interventions - for instance the extensive use of hysterectomy, or other surgical interventions. What part of biology that has been seen as determinant for femininity, has varied in different epochs. Apart from the breast, also bone structure, the uterus and hormones have been seen as signifying the feminine at different times (Forsmo, 1998).

Feminist writers have described the ways in which women's health is controlled by a male technology-dominated medical system, but to analyze women's roles as passive is to perpetuate the kind of assumptions about women that feminists have been challenging (Riessman, 1983). In Riessman's view, women collaborate in the medicalisation process due to their own needs and motives. She exemplifies the co-constructive position of women through the medicalisation of childbirth which was part of a struggle for professional dominance, but at the same time the demand for anaesthesia can be seen as part of a social process where pregnancy no longer was

seen as a condition that women should endure with fatalism and passivity (Riessman, 1983).

Indeed, there has tended to be a fit between women's interests in having their experiences acknowledged and medicine's interests in expanding its jurisdiction, and medicalisation is thus part of the problem and at the same time part of the solution for women (Riessman, 1983). Also breast cancer screening can be seen as part of this complex relation between women's health and experiences on the one hand and medicalisation and governance on the other hand. Furthermore, one can not see women's experiences of screening solely as the internalisation of disciplinary techniques but should maybe rather focus on these complex relations. For instance did Howson (1998), in her study on cervical screening, find that even when women expected to subject themselves to medical surveillance, they also developed a critical response to their experiences.

Breast cancer

Of course, one gendered aspect of the mammography screening experience may stem from larger discourses on the breast, discourses which render breasts central to women's gender identities (Broom, 2001; Davis, 2008; Wilkinson & Kitzinger, 1993).

The breast has been an issue for politics and commercial interests, and a sign for femininity in a multitude of ways, as well as a site for medical intervention (Yalom, 1999). Yet despite medical "eagerness" to intervene on women's bodies, the breast was initially characterized by radiologists as too soft, too irregular and too changeable to image clearly with x-ray technology (Cartwright, 1995). According to Cartwright, such characteristics were classified as feminine, showing how the feminine breast was unsuitable for standardized screening. Instead of adapting the technique some radiologists tried to adapt the breast to the technique (ibid). This may explain the technical solution of squeezing the breast between two glass plates while performing the x-ray examination. This technical choice was critiqued dramatically by Schei (1989) in her parody where she modified defence of mammography by exchanging references to women's breasts with a reference to men's testicles.

Breast cancer, with its treatments and detection strategies influencing women and their bodies, has been subject to feminist critique. The medical gaze with its male

dominance is credited for focusing on the breast as an object for male desire more than the woman's sensation of loss or anxiety for a severe disease (Wilkinson & Kitzinger, 1993). Characterizing the female body after mastectomy as mutilated, defective and not normal is for Wilkinson & Kitzinger (1993) a construction of femininity connected to women as medical and sexual objects. They show how women are represented in both mainstream medical and alternative health discourses, with medicine as male dominated and alternative health care as a blame-the-victim mentality accusing women of failing.

One can claim that breast cancer is at the centre of at least four discourses: those relevant to life-threatening illness, those surrounding cancers, those of female-specific conditions and discourses on the breast specifically (Broom, 2001). These discourses will presumably also influence the experiences of women invited to a breast cancer screening programme. In addition, one can talk about the discourses of "the imperative of concealment" and "personal blame and responsibility for illness" (Wilkinson, 2001).

To lose a breast due to breast cancer influences a woman's image of her self, her bodily experience and her sexuality, while a reconstruction of the breast may reset her experience of her body as a whole (Sandell, 2001). Losing a breast can thus, according to Sandell, symbolize the loss of a body part, but also an abnormality and lost femininity and health. In Sandell's study women's experiences of losing a breast influenced their decision about breast reconstruction but Sandell also found the term "the male gaze" important when analysing her data. "The male gaze" saw the missing breast as deviance and a sign of a lack of femininity and influenced the ideals for size and appearance of a breast after breast surgery (Sandell, 2001). These discourses on the breast and femininity are also part of what women participating in breast cancer screening relate to, and that may influence their experiences of mammography screening. Knowing that early detection of breast cancer can influence the degree of surgical intervention on the breast might also be a reason for women's decisions about participating in mammography screening. Breast cancer experiences have been studied by many (see for instance (Sandaunet, 2008) or (Davis, 2008)). I have chosen to not go more into the subject. Nevertheless, survival stories from breast cancer patients can influence how women experience breast cancer screening.

I will pursue the question of a particular female experience – whether social or bodily - with some caution in the analysis. Working inductively from my respondents' own words, I will keep an open mind as to whether they present their experiences of the mammography screening programme as somehow specific for women. Also, the gendered experience may be both implicit and explicit in women's stories of their participation in the mammography screening programme.

Conclusion

Women's experiences of mammography screening can be interpreted in a framework of governmentality and liberal ways of governing. When approaching this research project, we knew little about how women experienced being enrolled in a mammography screening programme. The elements of expert knowledge and statistics, technology and medicine appeared as important for women's interpretations of their experiences when analysing the data. Each article does not focus on all the theoretical aspects of mammography screening that has been discussed here. Writing articles do not always allow extended theoretical explorations, and each of the articles is a result of an analytical process with focus on only one or few of the elements discussed in this chapter. The analyses of the data had different steps and levels of theoretical interpretation. Nevertheless, each article can be seen as within the theoretical framework of governmentality – showing a piece of the whole picture of how women's health is governed and how women govern themselves.

Theoretical approach to the research question

In the introductory chapter I asked “what are the experiences of women who are invited to join the screening programme when making their decision to participate; when participating; and when facing a recall letter?”. In this chapter I have provided a theoretical framework for the analyses of women's experiences of mammography screening. Putting the research question into the theoretical context, I will outline a theoretically based research question that I attempt to answer in the concluding chapter of this thesis:

How do technologies of government influence women's experiences of mammography screening?

The theoretical framework's relevance for the articles

In the first article in this thesis the discussion is whether or not women's decisions to participate are made following the rational ideals that are inherent in discourses on medical interventions. In the article we can see how women's knowledge about breast cancer and the health authorities' techniques for information and enrolment into the screening programme give practises of government and self-government that at the same time use and oppose the liberal ideals of individual freedom that are pursued in discussions about screening.

The second article is an analysis of how women's knowledge about the mammography technology makes them question the screening programme's ability to work in a trustworthy manner. Both the technology and the expertise involved in practising it are questioned as too uncertain. Nevertheless, the visualising aspect of mammography persuades women into trusting it to find breast cancer. I interpret how "ways of seeing and perceiving, knowledge, techniques and practices" (Dean, 1999) are woven together into knowledge that can be interpreted and accepted by the women in order to suspend of doubts and make the "leap of faith" (Möllering, 2001) into trusting mammography screening to save them from breast cancer.

In the third article I explore women's experiences of a recall after mammography screening. This article analyses how information and efforts made to comfort the recalled women are interpreted in several manners by the women who find themselves in a somewhat unexpected situation. It shows how the routinization of mammography screening that makes the government and self-governance of women's health possible influences how women experience a recall. Trusting the expertise and the technology, and seeing screening participation as the "normal" thing to do render the recall all the more surprising and frightening. In this light the "rationality" of numbers and a short waiting period becomes irrelevant or even distorted into something frightening. Nevertheless, the recalled women were glad to be part of the screening programme, and only one of the women in the study was in opposition to the screening programme.

The fourth article is an article about how qualitative research can be done and how it can contribute in the research field of mammography screening that has been primarily quantitative and dominated by medical perspectives. The medical

perspective that has been identified as “the first discourse on mammography screening” by Kaufert (2000), influenced how our research group did our research even as we studied “the second discourse on mammography screening”. This raises questions about how one can study the field in question, and I will explore this more in the next chapter of the thesis; that is the methods chapter.

3. Methods

Research on women's experiences of mammography screening has been dominated by survey studies, as shown in the introductory chapter. In spite of the number of such studies, many aspects from experiences of screening are overlooked when using surveys. In this study, our research group chose to do a qualitative, prospective interview study. We wanted to use research methods that would let women tell about their experiences in their own words and about their own perspectives on the subject. Using qualitative methods such as open-ended interviews give women an opportunity to tell the stories they consider most important rather than telling about their views on issues considered important by the researchers.

Moreover, qualitative interviewing was the best option in order to know more about how women's decisions and experiences turned out as they did. Listening to how women talk about their experiences and feelings can show which discourses women draw upon when making their decisions, and which discourses that influence their experiences. In this chapter I will give a short presentation of why qualitative interviewing was seen as the most relevant method for studying women's experiences of mammography screening. I will give a presentation of the studies that provided the data material for this thesis and discuss aspects of focus group interviews and individual interviews. Furthermore, I will present the process of analysis and discuss whether and how these analyses can be generalised to a larger population, as well as reflect upon how I might have influenced the data material and the analysis. Finally I will discuss the ethics of the research project.

Qualitative research on mammography screening

The main strength of qualitative research is that it allows those who are studied to give their perspectives and interpretations of the phenomenon in question. This is an advantage when studying people's experiences and ideas, as well as when studying issues that concern personal matters (Edwards & Ribbens, 1998). Health is an example of a personal matter in our culture. Personal aspects of health are people's bodies and psyche, as well as individual and social experiences related to having a body. At the same time health and citizen's bodies are a matter of public concern in the welfare state, thereby presumably drawing on public discourses on what it implies

to be a citizen with a body that require health services. Researching experiences of mammography screening mean dealing with women and their bodies in both private and public spheres. Considerations of mammography screening's double-sided position ought to be important before, during and after deciding how to do research on the field.

Since mammography screening is a screening programme that invites all women at a certain age, and of whom nearly 80 per cent participate (Feiring, 2004), experiences of being invited and participating could be expected to be relevant for most women. Furthermore, this relevance can be seen as constructed through public discourses. Data are bound to context and a person is likely to answer differently when set in a focus group than in an individual interview (Kitzinger & Barbour, 1999). It was therefore both possible and desirable to study women's experiences of screening in a group setting. Focus groups are better than individual interviews for examining how knowledge, stories and self-presentation operate in a given cultural context, while individual interviews are more effective for getting information about individual biographies (Kitzinger & Barbour, 1999).

The research group thus chose to see the experience of being invited to a population based screening programme as a "public" event, suitable for being studied by group interviews. Being recalled, on the other hand, is something extraordinary, and something that might be experienced as more private, and thus more suitable for being explored in individual interviews. Even though group interviews can give participants a chance to discuss personal experiences, individual interviews are probably more appealing for conversation about personal thoughts, anxieties and life experiences. Nevertheless, women talking in a group might experience solidarity with each other and thereby give room for another kind of intimacy. In the following I will present the parts of this study and the data material, as well as discuss aspects of focus groups and individual interviews.

The study

This thesis consists of data from two data sampling processes. The first part of the study is a focus group study with women participating in the national breast cancer screening programme. I will call this part of the research project "the focus group study". In this part of the study we conducted a series of focus group interviews with

women invited to the Norwegian Breast Cancer Screening Programme for the first time. Even though more than half the women had prior experience with mammography, this was the first time they had received an invitation letter with a set appointment in the public screening programme. The second part of the study consist of individual interviews with women recalled for further examinations due to an abnormal mammogram after participation in the breast cancer screening programme. I will call this study “the recall study”.

The focus group study

The focus group study had its first round of interviews during the spring of 2003. As the national screening programme expanded, the spring of 2003 was the last chance to talk to women over enrolment age in Central Norway the first time they were invited. The thought behind this haste to talk with the screened women was that their experiences would be somewhat different when they participate in mammography screening for the second time than for the first. We wanted to know about their experiences as first time participants. This was a somewhat optimistic expectation since most of these women had already had one or even several experiences with mammography. Some women had been to a private clinic on their own initiative, others had joined “health tours” organized by The Norwegian Women's Public Health Association⁶. Nevertheless, participating in a public screening programme for breast cancer was a new experience for all the women. Seeking to explore women’s personal experiences in a relatively unexamined area, we opted for a semi-structured focus group study.

Design

The design of the study was prospective. Eight groups from four different municipalities were gathered three times. The first round was held about a week before the women were going to their mammography examination. The second round of meetings was held between two and four weeks after the mammography. Half of the groups had received their answers before the second focus group meeting, while

⁶ In Norwegian: Norske kvinners sanitetsforening (NKS); known among the women in our study as “Sanitetsforeningen” – an organization with 1324 local branches across the country, with over 52.000 members doing voluntary work.

the other half had not yet received the result of the examination. This dissertation is primarily based on analyses of data from the first round of focus groups. Only article IV draw on data from the second round of groups. The third round of focus groups has been analysed in another part of the project, see Østerlie, W et al (2008, forthcoming).

The point with choosing a prospective design was to see whether women felt differently about mammography before and after they had participated in the screening program. The experience of joining a screening program for a potential lethal disease can make women change perspective on their own health and on screening per se. It was also important for us to talk with the participating women before they went for the mammography examination to hear how they interpreted the experience at that moment, not how they saw the experience in retrospect. 69 women participated in the focus group study, unequally distributed in the eight groups, as shown in table 1.

Table 1: Distribution of participants in focus groups

Group	Age	Number of invited women	Participants 1. focus group (pre-screening)	Participants 2. focus group (2 weeks after screening)	Participants 3. focus group (6 months after screening)	Women with no previous mammography experience
1	50-59	35	8	7	4	0
2	60-69	35	8	7	6	3
3	50-59	36	8	8	7	3
4	60-69	30	10	10	10	3
5	50-59	40	10	8	7	5
6	60-69	38	6	6	5	4
7	50-59	36	9	8	7	2
8	60-69	36	10	8	7	2
Total		286	69	62	53	22

Sampling

To be able to have a prospective design in the focus group study, we cooperated with the Cancer Registry of Norway - the agency in charge of setting up the screening

invitation lists. This made us dependent on their procedures concerning time and place for the focus group meetings, selecting communities according to the Cancer Registry's screening calendar. Since the screening programme is based on inviting women municipality by municipality, we chose to do the same. From a list of municipalities scheduled for mammography screening during the upcoming months we chose four communities. Since parts of Central Norway have large areas of low population density, we chose municipalities that had a population density that made it probable that we could gather enough women for group interviews without them having to drive for hours to meet. Four municipalities were chosen on a rural-urban scale, with groups in one city, one small industry town, and in two rural communities; one near the fjord and one in the mountains. The rural municipalities we chose had populations from about 6.000 inhabitants, while the city in the area had a population of about 150.000.

We divided the women in each municipality in two groups, aged 50-59 and 60-69 since discussions of health issues may have variations in connection to age and generation. We assumed that women would feel that more subjects would concern them when talking to other women in the same age group. Researchers using focus group methods seem to agree that homogeneity in each group is the best environment for group discussion, while heterogeneity between groups can generate variation in responses and get a broader representation of existing meanings on the topic in question (Kitzinger, 1994; Morgan, 1996; Barbour, 2005). In this study we knew only the women's age and place of residence unless they revealed more about themselves it during the interview.

Based on the mammography screening calendar and the project's selection criteria we received randomly selected lists of women who were going to be invited to the public mammography screening program. From each of the four chosen municipalities we invited 30-40 women in each age group (Table 1). Which women that should be invited were thus selected strategically at the group level (communities and age groups), while individuals within the groups were selected randomly.

Women who were invited to the research project received a letter of invitation to the focus group in their community. The letter consisted of information about the project and how the group interview would proceed as well as time and place for the

interview, a form of consent and a reply note with pre paid postage. This stage of the sampling process was thus dependent on self-recruitment by the women. For each group between 6 and 18 women replied. One can only theorize about the reasons for the variety in the number of answers, but we had a hint of one reason when one of the women in the less-participating parish was delayed due to a sheep in labour. The research group consisting of city dwellers had not thought about May as a busy month for farmers. Another reason for not answering the research invitation might be a lesser degree of interest in research of this kind in the rural district than in municipalities closer to the university and colleges, but this will always remain as qualified guessing.

The variance of response in different communities gave different challenges. Even though the number of participants in each focus group may vary, we had to gather enough participants to carry out each group. The preferred number of participants is between three and twelve (Kitzinger & Barbour, 1999). For the most eager population we had to withdraw a few of the invitations to participate so that the focus group would have no more than twelve participants. The selection of who should not participate even after accepting the invitation was based on their addresses, withdrawing the invitation to those being the closest neighbours. In the end no group ended up with more than ten participants since some women were prevented from participating. Despite our assumption that twelve would be a suitable number of group participants, even ten turned out to be a bit too many for one group.

Recruiting participants from sparsely populated areas or small towns gave us neighbours, friends or relatives in each group. This can be viewed as positive or negative for the data collection and analysis. Some researchers, especially in market research, see a group of already well known participants as polluting. The positive interpretation is that this makes the group more similar to an ordinary situation and can give the researcher a better glimpse of how this question is handled in a real social context, but at the same time group participants may avoid sharing sensitive information (Kitzinger & Barbour, 1999). It is impossible to know overall in what way our data were “biased” by the composition of each group, but “bias” is not a central issue here. We were not searching for “the truth” per se. Rather we wanted to hear different voices with somewhat different characteristics. But, in one instance the influence was positive since it made it easier to recruit participants to the focus groups. Some of the women told they would not have come without a neighbour to

drive them to the group meeting room, and also to make them feel safe about participating. We thus experienced one of the advantages of focus groups when the research method allowed the inclusion of voices that would otherwise have been left out (Kitzinger, 1995).

When putting a group or a series of groups together, it is important to consider the number of groups and the number of people that will be necessary to find both patterns and diversity in the material. Focus group studies can contain from 3 or 4 groups to more than 50 groups (Kitzinger & Barbour, 1999). When deciding on the number of focus groups we drew on the research group's experiences from an earlier study on osteoporosis (Skolbekken, Østerlie, & Forsmo, 2008). In order to find common features of the participant's experiences and illuminate the ways in which participants identify discourses (Starks & Trinidad, 2007), our previous experience suggested that eight groups would be sufficient for this kind of study.

Our experience turned out to be that even six groups might have been enough as the last two groups added little new to the analyses, but rather supported what was found in the previous groups. Still, if the order of the municipalities represented in the material had been different we might have missed important information with only six groups since the two groups from the most rural municipality gave a different perspective than the other groups (Saracevic, 2003).

Procedure and conduct of focus groups

The focus groups were held at a meeting place near where the women lived. Groups 1 and 2 met at the University, groups 3 and 4 at a research centre, while groups 5-8 met at community centres. The place for the group sessions were primarily determined by the access of localities. Since some of the municipalities were low-density areas there were not many places to choose from when we wanted to be undisturbed from others outside the group and at the same time at a place the women would easily find. Each group meeting lasted for approximately two hours.

The focus group interview is a qualitative group interview that focuses on a specific topic, selected by the researchers (Sim, 1998). The focus group can be more or less structured with preset questions. The group sessions in this study were structured by an interview guide. Each interview guide consisted of five questions (Appendix 2).

They were copied and given to the participants, one at the time. Some were repeated across the focus group meeting rounds, others were specific to each of the three sessions with each group. A facilitator read the questions and kept control of the discussion so that it stayed within the research themes. Apart from this, the women were encouraged to speak freely about the subject in question (Kitzinger & Barbour, 1999; Bender & Ewbank, 1994; Sim, 1998).

The women in the focus groups were also encouraged to ask one another questions rather than asking the researchers, and to share their opinions, stories and comment on each others point of view (Kitzinger & Barbour, 1999). This means that we could study the interaction between the participants while discussing their expectations and experiences of mammography screening, drawing on discourses that they saw as relevant for the topic (Hyde et al., 2005; Kitzinger, 1994).

It has been argued that participants in group interviews give their answers according to what they believe to be the most common attitude in the group (Brandth, 1996). This might be a problem if one attempts to use focus groups to measure attitudes, but not if one uses group interviews to talk about experiences, since most people like to talk about their experiences with others (Brandth, 1996). Even though the research group setting was unfamiliar to the women, most of them exceeded their shyness during the first session. Moreover, there were of course also some women who talked about their opinions and experiences from the very beginning of the focus group. Some of these extrovert women even dominated their group to some extent and the facilitator had to make sure other women could have their turn talking.

As we experienced, the group interview setting might give an advantage to participants familiar with the dominant culture and to talking in groups of a certain size (Pfeffer, 2004a). Differences in participation during the group discussion can influence the results. Whereas differences between participants can create hierarchical structures that make participants avoid expressing their opinions, we chose age as a means for creating internally homogenous groups. Nevertheless, there were differences between participants. In the small communities the other women knew who was the nurse, the school teacher or in the local council. This influenced some of the interviews, especially when one of the women came out as a nurse with knowledge to answer the other women's questions.

When making focus group interview guides about mammography screening, we could not know whether the topic would be an issue for conflict or for consensus between the group participants. Nevertheless, the group discussions turned out to focus on consensus between participants. Even though experiences varied between the women on issues such as pain and fear, the women agreed on the usefulness of mammography screening. Disagreements between the women were also solved by themselves by attempting for consensus.

One example of the group seeking consensus was a discussion about risk factors for breast cancer where some women emphasized the importance of having children, as seen below. One of the women told that she had never given birth, and this led the other women to reconsider their statements:

- A: *I have read something about... [...] it has been said that those of us that have children early and breastfeed are less at risk [for breast cancer]. Or am I confusing things here?*
- B: *I have read exactly the same, yes I have.*
- C: *It is more natural to have children at 20 than at 40.*
- D: *What about the ones who have never given birth then?*
- A: *Yeah... what about them, I wonder....*
- D: *Yes?*
- E: *That is a question too....*
- D: *I have never given birth. But I do have a son....*
- A: *No... But we are not all the same... So we can't say that, if it was like that... well, it doesn't apply to all women....*
- B: *One reads all kinds of stuff you know....*

(Group 4,1,25)

Consensus oriented group interviews can thus tell us about participant's mutual attitudes to a theme, and maybe show discourses that all group participants can agree on. A second example was from another group where one woman who had never been to mammography earlier was sceptical and asked critical questions to the researchers and the other group participants. She was met with both laughter and discussion, but the group seemed to reach consensus as this woman also wanted to participate in mammography screening and admitted that one reason for not being to mammography earlier were her fear of breast cancer.

It is not only the utterances of each participant that produces relevant data in focus group interviews, but also interaction between the participants. Discussions, negotiations of meaning and presentations of selves is what makes focus group

methodology special (Wilkinson, 1999). One can say that it is a process of collective sense-making that happens in the interaction between focus group participants (ibid; 67). The group interview brings about processes where meaning is created between the participants in the group (Crossley, 2002). Different understandings of the subject can come forward, as well as argumentation that seeks to legitimate views from different angles (Søndergaard, 1996). Focus group interviews are in this manner a tool for constructing data, as these data would not have been created without setting up the focus group study. Still one can claim that these data-creating processes are similar to how people talk about such topics amongst themselves in other contexts.

The researchers present during the focus groups made a choice to avoid answering questions from the group participants. The facilitator rather turned questions back to the group to facilitate more discussion. Putting the researchers outside the group process probably influenced the group discussions. The idea of researchers staying out of the discussion can be seen as an argument from the position of a focus group as a construction site for data. The choices made about researcher participation during focus groups interviews are discussed more thoroughly in article IV.

The presence of the facilitator might influence how participants talk and what they talk about. For instance it might be an advantage if the researcher has some similar features to the group participants, such as gender, ethnicity or manner of using the language (Kitzinger & Barbour, 1999). This was the reason why we chose to have one of the female researchers as facilitator even though she was not the most experienced focus group facilitator in the research team. Having a man as facilitator might have influenced which subjects the women would have talked about. In addition to the facilitator, we were several women from the research group present. I was in charge of the technical equipment and assisted the facilitator in asking follow-up questions to the group participants. We also brought a secretary who took notes while the women talked. In some groups a researcher from the Cancer Registry of Norway was present. The presence of a group of researchers may have influenced how the women felt about participating in the discussions, but after the initial awkwardness we could not spot any direct influence of our presence. Nevertheless, in one manner my appearance influenced the relation to some of the women. During most of the focus group sessions I was visibly pregnant, and this seemed to influence how the women talked

to me. For instance one woman talked about the pain of having mammography, but then told me (and the rest of the group) that it wasn't as bad as giving birth.

Similarities between researchers and informants can give two kinds of knowledge. The informants may tell a woman what they would not say to a man. But, being part of a collective can on the other hand imply that knowledge is implicit in what is said, instead of being said out loud. Expecting the others to already know about certain experiences can have made it unnecessary to express all thoughts that the women had when participating in mammography screening. It is important that the facilitator knows when to let group participants talk freely and letting them introduce themes important to them that the researcher(s) had not imagined beforehand (Kitzinger & Barbour, 1999). During the focus groups the facilitator attempted to make women develop their statements when conscious about implicit knowledge. But, the data is still left with both utterances and silences open for interpretation.

All interviews were recorded by cassette or minidisk. They were transcribed by an assistant that had also been resident during the interviews, taking notes. The interviews were transcribed in dialect, but were later standardized. Translating the dialect into standard Norwegian was done to make them more accessible to the reader. For the English articles and this thesis the excerpts have been translated into English.

The recall study

“The recall study” was conducted during the winter of 2004/2005. Women who had a recall letter were invited to participate in individual interviews, assuming they would prefer to talk about their experiences privately. Also, it would be difficult to sample groups of women in the short time span between women receiving the recall letter and their follow-up examination. None of the women in the recall study had participated in the focus group study.

Design

The recall study was also a prospective study, with interviews both before and short time after the follow-up examination. Women who are recalled after mammography screening in Central Norway receive a recall letter four or five days prior to their follow-up examination. Performing individual interviews in the short time gap

between the recall letter and the follow-up examination, I have studied the women's "real time" experiences of being recalled. Women's experiences of recall while awaiting the follow-up examination are underexplored. Only few studies have looked into this part of the screening experience. So far, I know only of three studies on the subject. Two of these were conducted through a self-report questionnaire or questionnaire interviews (Pineault, 2007; Austoker & Ong, 1994). The last study consists of qualitative interviews for a pilot trial of a questionnaire (Cockburn et al., 1992).

I wanted to study recalled women's experiences told in their own words. The purpose of interviewing women in the waiting period was to see what had the greatest relevance for women waiting for a follow-up, rather than interpreting the experience retrospectively. Qualitative interview method has been advocated as particularly well suited to collecting data on sensitive topics (Hewitt, 2007).

Sampling

Informants for the recall study were sampled among women who were recalled for further examinations after participating in the national breast cancer screening programme. Criteria for being invited to the research interview were to be free of self-detected symptoms of breast cancer and live within 45 minutes drive from the hospital. A total of 35 women met the inclusion criteria during four months of sampling. They received a recall letter four to five days prior to the scheduled examination. An invitation to join the research project was presented in the same envelope. Women joined the project by calling the interviewer and making an appointment for an interview. Eight women actively agreed to participate in the first interview while waiting for the follow-up examination. Six of these women took part in a second interview after having the follow-up and result. Three of the eight women were diagnosed with cancer, while four women were "false-positives". The diagnostic status of the last woman remains unknown as she never got in touch for the second interview.

The low response rate for participating in the research project can have several explanations. First, the information provided may have been too vague. Some women had come to the outpatient breast cancer clinic with the intention to join the project on the day of their appointment for the follow-up examination. This can be due to

insufficient information in the invitation letter, or because the invitation to participate in a research project was presented in the same envelope as a letter about an abnormal mammogram. In order to avoid recalled women to feel pressured into participation in the research project, an important point was to let them recruit themselves when receiving the invitation. Thus, this was the only way to get in touch with recalled women.

Another reason for the low response rate can be that receiving a letter about an abnormal result of an examination for a potentially fatal disease can be scary. For some women it may not be the best time to make a decision about participation in a research project. Being anxious from the recall letter can prevent women from participating in the research project. The period between receiving the recall letter and the follow-up appointment may be the time of greatest anxiety during the screening process (Austoker & Ong, 1994). And yet, this is exactly why the experience of awaiting a follow-up examination is important to study. I have looked more into this in the third article of this thesis.

Procedure of individual interviews

The eight women who responded to the interview invitation were presented with options to where they could be interviewed. All eight women preferred to be interviewed in the researcher's office at the university campus. Each interview took between 10 minutes and an hour. Most of the second interviews were shorter than the first interview with the same woman. All interviews were audio taped and transcribed verbatim by research assistants or researcher.

The interviews followed an interview guide (Appendix 4). After offering each woman coffee and biscuits, I told about the purpose of the project and then asked questions from the interview guide. Sometimes the questions were rearranged due to the interviewee's storyline. Some of the women talked about the subject almost without me asking the questions. Other women were quiet and provided short answers for my questions. A goal of the qualitative interview is to explore the meanings of topics central to the interviewee (Kvale, 1997). During the interview I was opting for nuanced descriptions of different aspects of the interviewee's life world and experiences. An open or semi-structured interview might bring out unexpected perspectives to the topic, or other topics related to the primary research question.

Since the interview will create new insights through the interaction between the interviewer and the interviewee, different interviewers can co-produce different discussions on the same topic (Kvale, 1997).

I was considerably younger than the women who were interviewed. Conducting individual interviews with the women, my personal characteristics may have influenced what the women told about. In which direction my person may have influenced the data I can for the most part only guess. Some of the recalled women used the fact that I was at their children's age to talk about mutual experiences in life; but it is not unlikely that some women chose to keep quiet about experiences or feelings that they thought I could not understand. Several of the women told me stories from their lives that were very personal; but some women seemed to feel uneasy in the interview setting and were not very talkative.

Interviewing women who were awaiting their follow-up examination after mammography screening can be, as in all qualitative research, intrusive on the interviewees. In order to know more I used follow-up questions during the interview. It was however important for me to highlight how I wanted to know about their experiences as recalled, without intruding on the women's lives and feelings. Even though a qualitative individual interview is a conversation between a researcher and an informant, the research interview is not a conversation between equal parts as the researcher is defining and controlling the situation (Kvale, 1997). Nevertheless, it is the interviewee who decides what information she will give to the researcher.

Also, when doing individual interviews about issues of health it can be difficult to draw the line between therapy and research (Hewitt, 2007; Kvale, 1997). I had invited women to the research interview by using the hospital channel for communication. This could have given the interviewees the impression of the research interview as part of the therapeutic procedure of being recalled. Even though some of the women said that they appreciated to have a chance to talk about their experiences, none of them seemed to perceive the interview as therapy.

Analyses

Analysing qualitative interview material can be done in different manners. Qualitative approaches can be classified as phenomenology, discourse analysis and grounded

theory (Starks & Trinidad, 2007).⁷ These approaches have in common the analytical methods and processes of coding, sorting, identifying themes and drawing conclusions, but their methodology differs in that they have different focuses when formulating a research question (Starks & Trinidad, 2007). In this project we have not situated ourselves exclusively in grounded theory, discourse analysis or phenomenology. Rather, we have drawn upon all these approaches. Even though the goals and epistemologies of the approaches are different, they have been used at different stages of the project. Asking about women's experiences of a screening programme can be a phenomenological project in the way that its goal is to describe meanings and the lived experiences of a phenomenon. At the same time, I have opted to describe how discourses on the field of mammography screening shape and are shaped by women's experiences.

In this study with two different interview materials, I had to treat the two materials differently, but nevertheless, most of the analytical tools and analytical methods were the same. Both the focus group material and the individual interviews from the recall study were analysed as written text. The interviews were read by all authors to the articles in which the analysis were to be presented. After reading one of the interviews, analytical categories were discussed by the research group. The categories were found on the basis of what the interviewed women said in the texts. Categories were thus found inductively from the data, rather than pre-determined. But at the same time, we had of course some thoughts of potential findings from theory and research made by others (Forss et al., 2001; Willis & Baxter, 2003; Lagerlund et al., 2000). Nevertheless, analytical topics arose that we had not expected in advance. This happened for instance with the topic of trust that appeared as an analytical category after analysing the whole focus group material.

After discussing the categories, the two PhD-candidates in the research project (me and Wenche Østerlie) categorised the transcripts from the focus group interviews. During this process, we discussed and re-defined categories and their connection to each other. For the material with individual interviews, I did the sorting of data after

⁷ Other classifications of analytical approaches add narrative methodologies, ethnographies, participatory action research and different case study approaches (Carter & Little, 2007). It is a question whether these should be called methods or analytical approaches. I will only mention this, not discuss it further.

discussing categories with the co-authors for the article on recalled women's experiences. When analysing, we used both categorizing, condensation and interpretation (Kvale, 1997). First the data were categorized. Then we looked more into the most relevant quotations and condensed their meaning. Lastly we interpreted the quotes from theoretical perspectives, looking for patterns, paradoxes and discourses.

Analysing the focus group material

A question arising when using group interviews as data material is whether it is the group or the individual that is the analytic unit. In this study both groups and individuals have been treated as subjects in the analysis. Each statement by a woman has been seen as an utterance with its own meaning. But, each of the women has not been followed during the three focus group sessions in which she participated. Rather, each utterance has been seen as part of the group discussion and discourse. In this way the groups stand out as analytic units. Each woman in the group and the interaction within the group has thus become part of the presentation of the group in the material.

As the facilitator of each group opted to make the women discuss with each other rather than with us, there was interaction between the participants. The degree of interaction varied between the groups; nevertheless, all the groups had some degree of discussion between participants. These discussions gave insight into different perspectives that the women had towards mammography screening. When analysing the material the discussions provided important information on which discourses the women draw upon when making their decisions for mammography screening. Both disagreement and consensus has become focus points during the analyses as they both provide strong hints about what is most important for the participating women.

Another issue concerning the analysis of these data is that the groups differed in the way they discussed the subject. These were eight different groups with dissimilar characteristics. Even though their attitudes to mammography screening pointed in the same direction, their interpretations of breast cancer and mammography nevertheless differed. This especially became visible when analysing the issue of trust as presented in article II. While doing the data collection, trust was not an explicit issue for the research. Rather, it was during the process of analysing the data that it became clear that many of the focus groups discussed questions of mammography and trust.

Researching trust explicitly is difficult. The concept is complicated to discuss as trust is implicit in our daily lives and doings (Brownlie & Howson, 2008). It would thus have been difficult to ask the women directly about whether or not they had trust in mammography, and what it was they had trust in. When the women themselves started to discuss their trust in mammography as a technology and as an expert system, I considered this a unique opportunity to study trust.

Not all the focus groups discussed their trust in mammography. The two groups from the most rural district in our sample differed from the other groups in this regard. In these two groups trust and the potential “untrustworthiness” of mammography were not mentioned at all. This does not mean that these women have less trust in mammography than the women in the other groups. Rather, their approach to the discussion insinuated that they may have more trust in mammography than the other women, or that problematizing the subject was irrelevant. Since fewer of these women had previously had mammography than in the other groups, it may also be that these women were less familiar with mammography than the other groups. If women are unfamiliar with mammography, they may not have any expectation of what it is, or know of its critical points. With no expectations, there are also no doubts. If these women had no doubts to suspend, then their unproblematic relation to mammography may be better explained as acceptance rather than trust. Or rather, they trust, but their point of suspension is for instance that the invitation to mammography is issued by the national health authorities. I still chose to interpret the remaining six focus group interviews from the perspective of visualization and trust. It gave a good explanation to why these groups of women had trust in the mammography screening program. This is developed further in the second article.

A weakness of my analysis is that I have not used the data material to its full extent. Even though there is evidence of differences between the focus groups, I have chosen to focus on the similarities between them. This can give an air of a unity in the data material that is not real. But, the ways in which the groups differed were vague, and difficult to spot. One impression is that there was more of a “wait and see”-attitude in the two most rural groups than in the other groups, with the city groups as most proactive (Saracevic, 2003). So, there is some indication of an urban-rural dimension in this material.

Furthermore, neither analysis on the prospective design, nor of the age specific groups has been developed in this analysis. These paths of analysis are left unexplored for now. This is a consequence of the article-based dissertation format, but I hope to be able to pursue these paths later on.

Analysing the individual interviews

When doing the interviews of the recalled women I did not know what I would find about their experiences. Since there was little knowledge about women's experiences of a recall, particularly during the time span of waiting for the follow-up examination, I had asked the women open questions to allow them to give their perspectives. When analysing the data I therefore chose an open inductive approach.

Reading the interviews after the transcript, it was the ambivalence in each woman and between the women that struck me. That the women were worried about the result of the test while at the same time hoping for the best was not a surprise. Rather, it was what could be expected for persons awaiting a follow-up examination. Thus, I looked for other aspects of the data material. Categorizing what the women had talked about, the issues of numbers and time struck me as important for the women's experiences of being recalled. This was not expected in advance; neither did I have a theoretical perspective to lift these issues out of the material. Rather, it was an inductive analysis with themes rising out of the interview material. Then, when these themes had emerged in the analysis I looked for theoretical explanations.

Other subjects from the data could also have been developed in the analysis. For instance many of the women talked about their relation to family members and who they told about the recall while others were spared from knowing about it. Also, some women talked about earlier disease and how other experiences in life influenced their perception of the recall. Even though these subjects could have been developed in an analysis, I chose to focus on the aspects of surprise, numbers and time. Even though the data material of the recalled consisted of only eight interviews, I opted for issues that could be generalized as important topics for other women than the eight women in the material. In this study I chose to focus on patterns in the material. Focusing on individual stories and family relations could have given another perspective, but would also have given a story of unique histories rather than focusing on what the women had in common.

Generalizability

Statistical generalization is not a goal of qualitative research (Kvale, 1997). More important is giving new perspectives to a subject, and letting the persons who are studied give their stories in their own words. The claim in qualitative research is to represent a version of reality, not the “truth per se” (Hewitt, 2007). Nevertheless, a scientific study must provide information interesting for more people than the researcher and the informant. Generalization can thus be different processes, even opposed to statistical generalisation.

When starting this study the goal was to gain data that could tell us how women experiences to be part of a mammography screening programme. The sampling procedures for the study were thus made in order to provide a material that would both give homogeneity and heterogeneity. The procedure has been discussed further in article IV. One question is, however, how the age- and municipality-specific sampling has influenced the generalizability.

The material for both parts of this study is sampled from the same two-county area of Norway. Whether women from Nord- and Sør-Trøndelag are different from women in other parts of the country is impossible to say. The Norwegian culture is homogeneous, but there may still be differences between groups of women based on class, education, or regional differences. For instance, we found some differences in women’s attitudes toward the importance of mammography screening between the urban and the rural groups. This can probably be applicable as an indication of differences across the country as well. Age was another classification in our sampling in the focus group study. The data consists of women from the whole age range in the target group for mammography screening, and the analyses are thus probably liable to be generalized to the mammography screening population.

In the recall study the age span was narrower. Only women aged 50-59 volunteered to join the study. This is a weakness when stretching the results to the whole population. Rather, I will claim that the recall study is only valid for the age group that was interviewed. We cannot know if older women have different perspectives to being recalled than those in the youngest group. Also, the small material with only eight informants makes it difficult to generalize. Nevertheless, Patton (2002) argues that sample size depends on what you want to find and how it is to be used when you have

found it. The recall study has provided important knowledge about how women interpret information in a difficult situation – or rather how they find information with numbers as out of place when worrying about having a diagnosis for a potentially lethal disease. This perspective can provide researchers, health personnel and policy makers with a different perspective than a “rational decision-making”-perspective.

Studying women’s experiences of mammography screening with qualitative interview methods gave a large and multifaceted data material. When analyzing the data I found both patterns and special cases. A question I had to relate to was whether I should focus on universals or particularities, whether the focus was to find patterns or to exploit complexity (McPherson & Thorne, 2006). Whether the results of the study can be generalized is dependent on how the analyses deal with the variance and paradoxes in the data material. When doing the focus group interviews the women seemed to search for consensus but the interaction between the women also showed diversity. We were conscious of the diversity between groups and between women in the groups when analysing. Despite our wish to provide analyses that gave insight into both commonalities and diversity, I see our analyses of the focus group material as primarily seeking patterns in how women experience mammography screening.

When analysing the recall study interviews I also focused on both commonalities and diversities, but with individual interviews the diversities became more salient. Even though there were many aspects of the women’s experiences of a recall that were similar to most of the women, such as having ambivalent thoughts about the recall and its result, there were also apparent diversities between their experiences.

Especially one woman stood out as an exceptional case when compared to the others. She was the only one who had a negative attitude towards the recall and who was more irritated about joining the screening programme than glad to have an extra check-up as the other women were. In order to give a new perspective from the data on recalled women it is important to give the woman with a different voice a place in the analyses.

No matter how valid or reliable the data from a research study is, when its results are made public, social researchers who are concerned with intimate issues are also involved in the social construction of knowledge within public and academic discourses (Edwards & Ribbens, 1998). When researching women’s experiences of

mammography screening I experienced the problem of translating personal experiences into academic and public knowledge. How can I as a researcher standing outside the experience say that the women's experiences represent governmentality? This is probably an interpretation none of these women would offer on their own. It is my own theory-based interpretation. Its credibility stands or falls on my ability to argue for it through deploying the data as supportive or critical evidence.

Ethics

The project was acknowledged by the Regional Committee for Medical Research Ethics (REK IV). Information about the project was sent to all participants before interviews were conducted, and they signed an act of consent before joining the group or participating in the individual interview. We also emphasized the importance of a non-disclosure agreement between participants in the focus groups. Women joined the project by their own initiative after receiving a letter of invitation. Those invited to the recall study were anonymous to the researchers until they chose to participate and those participating remained anonymous to the staff at the hospital unit. Women were informed that whether or not they joined the research project would have no impact on their follow-up examination or on further treatment. Interviews were conducted outside the hospital area to obtain a neutral environment. Nevertheless, some ethical challenges arose.

A question when interviewing women who are about to have an examination for a potentially lethal disease is if it is a burden to participate in a research interview. This became visible at some of our focus group sessions. During the first focus group the women discussed hormone replacement therapy. At the second group session some of the women told that they had begun to worry about what impact their hormone medication might have on breast cancer risk. One of the focus group women stopped taking her hormone replacement therapy following the discussion at the first group session.

That anxiety may increase because of reflections during a research interview was to some extent also visible in the recall study. One of the women going for a follow-up examination expressed that she got more nervous after being interviewed than she had been before she came to the interview. Nevertheless, most of the interviewed women

expressed that it was good to talk to someone during the waiting period and few participants dropped out of the study.

These observations represent ethical challenges with the chosen research design. At least it says something critical about the decision to remain passive in the discussions. In the women's own discussions they sought to soothe fears as these arose. When choosing the passive role for the facilitator we blocked us off from the consoling role. But, a few times during the focus groups the facilitator neglected the passive role and offered explanations to women who were worried. The role of the passive facilitator in the focus group interviews is discussed more in article four. In the individual interviews I did not attempt to maintain a passive role and I attempted to comfort those who expressed anxiety in many of the interviews. However, not all of the recalled women expressed the need for consolation.

4. Discussion and conclusion

When initiating this research project, I asked “What are the experiences of women who are invited to join the screening programme when making their decision to participate; when participating; and when facing a recall letter?”. The four articles have offered some answers to how women make their decisions to participate, and how they experience to participate – also when receiving a recall letter. Furthermore, the second article explores women’s trust in mammography screening – a trust that is closely connected to issues of knowledge and technology, as well as to expert practices. Even though the study is not completed, nor have all paths of the data been explored or mapped, it is time to wind up this thesis.

During the previous chapters of this thesis I have painted a picture of the field of mammography screening. The field has been described as filled with at least two discourses (Kaufert, 2000), of which a medical and statistical discourse is the dominant in discussions about mammography screening. Based on the medical discourse and its statistical proofs it is rational for the health authorities to initiate a screening programme. Not surprisingly, women’s own perspectives were, at least to some extent, reflections and interpretations of the dominant medical discourse. However, the other discourse described by Kaufert (2000) – the discourse about faith, emotions, responsibility, morality, compliance and guilt - was also influencing women’s experiences of mammography screening. My own conclusions wrap their way around the medical perspective and women’s acceptance of it, seeing both as instances of “governmentality”. This interpretation does not invalidate the medical perspective or women’s acceptance of it. I remain agnostic as to the medial value of mammography screening. My perspective merely adds a layer of interpretation to the medical and popular discourse, in terms of the role of that discourse in society. Also, my interpretation allows me to explore the experiences of the recalled that are among those taking the consequences of participation in a routinised mammography screening programme. In this chapter I will show the details of this argument. I will furthermore give a short discussion about how the research design may have given priority to one of the discourses on mammography screening. In the last part of the chapter I will conclude this thesis and presents some thoughts about further research.

Mammography screening: government or self-governance?

When invited to the public mammography screening programme, women receive a letter of invitation with a preset appointment. This invitation seems to be an important contribution to how women choose participation in the screening programme. For many of the women the invitation became a means to overcome the “threshold mile” (dørstokkmila). In their busy lives, women delay mammography even when they say they ought to have it done, but when receiving an invitation with a preset appointment, they make it their priority to attend.

Women who participated in the focus groups were unsure about the nature of breast cancer. They described cancer as a frightening disease, with breast cancer as one of the most lethal types of cancer, as well as a disease with a high incidence rate among Norwegian women. Their perceptions of breast cancer influenced how they interpreted the screening invitation letter and how they made their choices about participation in the screening programme. Although a bit worried about their own risk for breast cancer, these women saw mammography screening as a chance to have certainty about not having breast cancer. The possibility of receiving an “all well”-notice seemed to be just as much in focus as actually receiving a diagnosis of breast cancer. The women in this study saw it as their own responsibility to take care of their health. Having regular mammograms was part of what they thought they ought to do in order to safeguard their health, but at the same time many of them expressed a lack of ability to make mammography a high priority on their own initiative.

Even though the letter is highlighted as an invitation from the screening providers, it was seen as a call-in by the participating women. The letter of invitation to mammography with the preset appointment was understood as advice from medical experts about what women should do to maintain their health. Seeing the invitation as a result of expert advice made the choice of participation easy. Moreover, they were glad that the health authorities and the welfare state (as they expressed it) had taken the decision about their participation. Women in our sample were grateful that someone had made the choice for them, rather than having to initiate breast cancer screening by themselves. Receiving a letter with a preset appointment seems to overcome obstacles women see for their participation, even though some women have

to change their appointment, which can take somewhat more effort than just showing up at the preset time.

The women expressed that participating in screening was a responsibility towards themselves, but also as a responsibility towards others. Their responsibility towards others was related to taking care of their own health so they could take care of their families, but also related to showing solidarity with other women who could have breast cancer. Similar aspects of women's compliance to screening was also found in a study of cervical screening where the invitation made the screening a routine aspect of female embodiment (Howson, 1999). In Howson's study, compliance was associated with responsibility to oneself and emerged with a sense that one was obliged to participate. Compliance towards a screening programme expresses thus complex obligations that women see as relevant for their participation.

Nevertheless, the invitation influences women's participation in and experiences of mammography screening. The invitation letter is part of the communication between the health authorities and the women, and part of the technology surrounding the screening programme. This technology brings more women into compliance with the screening programme as it helps women overcome the obstacles they have for having mammography when they have no symptoms for breast cancer. Some women would nevertheless use mammography as a means to detect pre-symptomatic breast cancer without a screening programme. Others have been to mammography since their women's health promotion organization⁸ has arranged trips to a private mammography clinic. Some continued to attend when the private clinic sent them a letter reminding them how long it has been since their last mammography examination. For others these factors are not enough to make them participate, and one can see the preset appointment in the invitation letter as a technology that glues more and more women into compliance with the programme, like "Latour's key" (Latour, 1991). The letter of invitation with its preset appointment thus leads Norwegian women between 50 and 69 years of age to participate in the public mammography screening programme.

⁸ Norske kvinners sanitetsforening, see page 54.

There is of course reason to ask whether the invitation actually has such a big influence on women's participation and experiences of mammography screening. The belief women have about breast cancer as curable if detected early is essential for their choice to participate. But, this knowledge has not been enough to make all women have mammography as often as recommended by the expertise. The fear of cancer that some women say leads them to go to mammography, may lead others to postpone mammography. Furthermore, in their busy lives and without symptoms to make it seem urgent, many women don't make mammography their priority, but the invitation with the preset appointment overcomes their lingering.

Even though the women are glad to have mammography in order to detect breast cancer early, most women do not expect to be diagnosed with breast cancer. The women interpret mammography as a way of reassuring good health as much as they see it as a technology to detect disease. This does not mean that women believe that mammography will prevent breast cancer. Rather, it seems to give them an opportunity to let their feeling of being without breast cancer dominate and get rid of their fears of breast cancer. Indeed, I cannot know whether they already had a fear of breast cancer or whether it was initiated or increased by receiving the invitation to mammography screening.

In one aspect women experienced the screening programme as less positive than going to private screening. That aspect was the social bit of going to mammography. Before enrolled into a programme, many of the women who lived far from the city had as mentioned above been on mammography screening tours organized by a women's organization. There were other attractive aspects to participation in that setting than in the more individualized screening invitation. When going on an organized screening trip with a busload of women to the nearest city, there was a social aspect and a women's health solidarity-aspect that partly made women participate. The social aspect is gone in the national screening programme, but the solidarity-aspect was found in the data in this study as well. Some of the women told during the focus groups that they were sure they were well themselves, but they still saw it as important to participate to maintain the programme, and to have solidarity with those women who actually have breast cancer. Indeed, there are several reasons for women to participate in the breast cancer screening programme. The choices they make are not only influenced by the wish to confirm that they themselves are free

from breast cancer or at least found early if diagnosed. Their experiences of being participants are also coloured by their relations to other women who have breast cancer.

One question here is whether the screening programme manages to obtain screening participation as an informed choice. According to Miller and Rose (1990), programmes of government are evaluated in terms of the extent to which they enhance personal choice. Individual choice is in focus in the liberal society. We asked women about their individual choices and they presented themselves as choosing. Nevertheless, the results of this study show that there are other factors that influence women's participation in and experiences of mammography screening.

The Norwegian breast cancer screening programme provides information to its target population along with the invitation to participate, and have designed their quality manual in order to follow the WHO's ten principles for screening. I will not go into the discussion of whether information provided to the targeted group is biased or not, as others have done (Jørgensen & Gøtzsche, 2004). Rather, questions about bias in information may come second when women make their choices about participation. Despite receiving information about pros and cons for mammography screening, women in this study seems to make their choice about screening participation based on other aspects of screening than what was meant to enable their personal choice. Their screening participation was perceived as decided by someone else due to the preset appointment in the invitation letter, and the fact that the invitation came from the public health authorities and the welfare state which they trust. The process of choosing to have mammography without having breast cancer symptoms is thus made easy. The opting-out structure of a population based mammography screening programme were not seen as threatening the women's autonomy, rather it was perceived with gratitude from the invited women. Participation in mammography screening can be seen as less of a choice women make and more as an obliging act where women submit themselves to compliance into a technique of governance.

In the liberal society being a good citizen through doing self-governance, implies taking care of one's own health (Brownlie & Howson, 2006). The women in this study felt as if the health authorities' agenda and their own wishes coincided. Seeing a screening programme as a technology of governance, we can see how the values

which influence how we are governed overlap with those which shape how we govern ourselves (Nettleton, 1997). There is a connection between what is wanted by the state and what the individuals want for themselves. Women's wishes about finding cancer early to avoid death from breast cancer encourage them to embrace the screening programme, even though they are un-symptomatic. The connection between women's wishes and the solutions put forward by the health authorities and the medical expertise are thus not characterized by opposition but rather by consensus (Riessman, 1983). The consensus is made possible by ethical, epistemological and ontological appeals of political discourse about what is possible or desirable – and the plans, schemes and objectives that seek to address specific problematizations within social, economic or personal existence (Miller & Rose, 1990). This does not mean that all parties have the same agenda. Rather, the consensus can be different perspectives that coincide but that nevertheless brings about similar practices.

The consensus between the health authorities and the women can be explained as governmentality. Through the perspective of governmentality we can see how individuals are taking care of themselves through choosing to follow expert advice or not. Thus, expert advice shape how individuals think about themselves (Nettleton, 1997). Individuals are not forced into specific practises but rather guided through expert advice to ensure their health. This does not mean that all women are lead headless into mammography screening. Although processes of government leave problems with explaining individual choice, the concept of governmentality is also a way of making room for the individual in the process (Neumann, 2003). Even though this study has highlighted the compliance of Norwegian women in the mammography screening programme, there is also room for resistance. Some women decline the invitation to mammography, and others drop out of the programme after one or several mammography examinations. Nevertheless, the way a screening programme defines normality makes little room for those resisting it (Hydle, 2003). If the normal and sound thing to do is to participate in mammography screening, resistance can be difficult. By initiating a population-based screening programme the health authorities have pointed out breast cancer as a health problem for both symptomatic and non-symptomatic women. Screening is thus an example of governance embedded in preventive initiatives and discourses where women are enrolled through practices of the self (Howson, 1999).

To compare the benefit of those receiving a diagnosis with the benefit of those who are well is complicated. When women perceive their risk for breast cancer as being so high that they need to have mammography every second year, there may be something to gain for all women who participate in screening. The assumptions that prevention and early detection are of a common good for all individuals imply that even non-symptomatic women are better off under surveillance of a medical expert system. This can be seen as part of the medicalisation of society that teaches us to think about risks and acting in a way that helps avoid risks. Risk estimates for breast cancer are, however, based on estimates from experts who have a specific base of knowledge: a medical knowledge based on natural science and statistics. The screening programme thus offers women expert advice and a medical examination at the same time. Seeing this union as simplifying their own health care, the women in this study experienced it as a good thing. In my interpretation, the screening programme providing medical advice simplifies the process of self-governance that the women feel they ought to do.

Trusting mammography: between expert advice and uncertainty

Mammography is understood by women as a means to detect cancer early, thereby presumably saving (their) lives. Feeling that self-examination of their breasts is inadequate for detecting small lumps and not trusting the doctor to examine them either, mammography is left as the best way to detect breast cancer lumps early. Nevertheless, women know about some weaknesses in mammography technology. Without prompting from us, they mentioned that even mammography can miss finding some lesions – what medical text refer to as false negative results. They acknowledge that mammography cannot be trusted 100 per cent. However, while expert discussions mostly concern questions of false positives, the women primarily worry about false negatives and to a lesser degree about false positive results. These women worry about whether mammography screening might give them a false safety when they receive an “all-well”-notice. Still, women trust mammography screening to save them from cancer. This gave reason to ask what it is that leads women to trust in mammography screening.

For the women who were mammography screening participants, two things were seen as necessary for detecting lumps with mammography. The first concern was how the technology works. The construction of the mammography technology raises questions for the women since they perceive it as impossible to get the whole breast into the machine, thereby leaving parts of the breast unexamined even when having a mammography examination. Secondly, a question of doubt is related to how medical personnel interpret the pictures from the mammography. The number of mammograms examined by each radiologist is assuring for the women but at the same time screening participation gives them a sense of being one of many at a busy production line. They ask if lesions are missed due to inattention or rushed and routinised work. Detecting pre-symptomatic breast cancer is thus perceived as a complex task, but mammography's visualizing technology seems to tip the scales, persuading women to trust mammography to save them from cancer.

Familiarity with X-ray images from other parts of the body is an indication for lay women of how mammography works. Knowledge of the technology gives women an expectation about what will come out of having mammography, an expectation of how mammography may influence their future. The technology and the expertise interpreting the images are good reasons to trust mammography screening to find lumps; but knowledge of errors and an understanding of how such faults are possible make some women sceptical towards trusting mammography. Nevertheless, the visualizing mammogram is seen as a proof of the breast beneath the skin, allowing women take the "leap of faith" (Möllering, 2001) into trusting mammography even while acknowledging its weaknesses.

Also, interpretation of complex knowledge is difficult. Having trust is a way to simplify complex systems (Lewis & Weigert, 1985). When trusting mammography screening to detect pre-symptomatic breast cancer, women do not have to estimate its pros and cons. Rather, they can use mammography as a way of doing their own self-governance; taking care of their health in a way that is perceived as simple by the women. Thus, the visualizing technology is part of how screening programmes simplifies women's lives and their self-governance. When choosing to trust mammography participation in the screening programme to which they are invited becomes the right choice for the women.

When talking of trust in mammography as a “leap of faith” that is made possible through the visualizing technology, I am treating the women in this study as a homogenous group. Nevertheless, I cannot assume that the trust women seem to have in mammography screening is experienced in the same way by all women, neither that the process of trusting is the same for all the women. Some of the other explanations of trust are more accurate for some women, for instance that trusting the health authorities is more a routine than an actual act (Möllering, 2006). Due to the vital nature of health care, people need to trust health care providers (Taylor-Gooby, 2006). But, most women who are enrolled in a screening programme do not perceive that they have symptoms in need of treatment. Nevertheless, the women see it as so important to detect un-symptomatic breast cancer that they choose to have mammography screening. Even for those women who discuss reasons not to have trust in mammography to save them from breast cancer, there is some issue that makes them trust, and that seems to be the visualizing technology that makes it possible to look at the breast beneath the skin.

A striking point in women’s discussions about the trustworthiness of mammography is that they never raise questions about the specificity of the examination, that is, the possibility of having false positive diagnoses. Women did not raise doubts about the content of what an expert might claim to see, that is whether or not signs on the mammogram actually are cancers. It seems that women trust the expert’s findings of cancer to be correct, precisely because of mammography’s visualizing ability. The picture of a potential lump becomes a proof of the state of the breast. This interpretation was also found in another study where a woman who was shown a potential lump in her first mammogram could not believe that it could disappear on the second mammogram (Willis & Baxter, 2003). It is interesting to ask how such faith in mammography’s visualising ability influences Norwegian women’s experiences when recalled due to an abnormal finding at the mammogram. Having trust in the mammography image can make such an experience even more frightening.

Mammography screening as routine

Modern society is characterised by surveillance which is institutionalised and routinised in every aspect of economic and social life (Flynn, 2002). The screening programme becomes a technique through which the health authorities may shepherd

the population for its own good, guiding the individuals to do what is considered best for the “herd” (Neumann, 2003). The women in this study talk about mammography as something they ought to do in order to take care of their own health. The normality of having mammography even when non-symptomatic is clearly present in their discussions at the focus group sessions. Through receiving the letter of invitation with a preset appointment to mammography, women can take part in early detection of breast cancer without too much effort. The mammography programme makes mammography a routine for invited women. It becomes something to be done regularly, like going to the dentist. Women’s experiences of mammography screening are strongly influenced by their perception of it as a routine. The routinization of the mammography examinations makes participating seem normal, and the adequate thing to do for the women who are invited. It becomes just another examination that women at a certain age are due to do.

Mammography screening is not unique in building on routinization of a medical test. It can be compared to how the prostate specific antigen (PSA) test – when performed without discussion or alongside other routine health tests – is seen by men as “just another blood test” (Chapple et al., 2008; Pfeiffer & Laws, 2006). The study of the PSA-test found that it was perceived as a routine since taken alongside with other tests, and this blurred its potential for giving a consequential result. Moreover, when men are informed about uncertainties of treatment and side-effects, fewer are willing to partake in cancer screening than when solely informed about prostate cancer risk (Gattellari & Ward, 2004). This can also yield to mammography screening. When mammography screening is perceived as routine, the potential for receiving a cancer diagnosis is obscured. Most of the women in the focus group study perceived themselves as unlikely to be among those actually diagnosed with breast cancer. The routinization of mammography contributes to reducing the sense of risk.

However, routinization of an examination for breast cancer has consequences. Firstly, it takes much of the fright out of the experience. Of course anxiety varies but even though many women worry about the results letter; this was not a big issue for most of the women. The routinization of the examination contributes to a sense of “nothing to worry about”. This seems to increase the shock of receiving a recall letter, the sense of being “thrown for a loop” experienced by those who are recalled or even subsequently diagnosed with breast cancer. Even though women worry and are aware

of how mammography is a test for breast cancer, the aspect of routine seems to make a recall all the more of a surprise. The experience of mammography as a routine becomes a trap for those recalled. They too have wanted to make sure they are as healthy as they feel, and suddenly they are one of those potentially ill.

Recall after mammography screening – a routine “trap”?

Women who participate in mammography screening run a cumulative risk of 20 per cent of being recalled (Hofvind, Thoresen, & Tretli, 2004). The Norwegian Breast Cancer Screening Programme has a recall rate of about three per cent per year. However, when receiving the recall letter women reacted with surprise. Even though they had been informed about the purpose of the initial mammography, only one of the women had expected to be among those recalled. Receiving the recall gave the women ambivalent thoughts. Some felt anxious, some wanted to take it in stride, and most of the women found themselves on an emotional “roller coaster” ride between different kinds of thoughts and feelings. Facing the possibility of having breast cancer the women thought about the seriousness of the disease and imagined the worst outcome.

The experiences of the women who were recalled were coloured by their earlier expectations of each being one small member of the large group of women going through the routine of mammography screening with a routine “all clear” message as outcome. Thus they expressed surprise from being recalled. The women’s surprise might come as a surprise to us. They had just participated in an examination developed to find breast cancer lumps at a stadium prior to what they could know themselves. But, it seems like healthy women participating in the mammography screening programme are joining the programme to have certainty about being free of breast cancer as much as they see it as searching for cancer. Even when knowing the purpose of the screening program most women assume they are among the healthy ones.

Though the form of the recall letter points back to an intention of consoling those recalled, these women found little comfort in the numbers and risk estimates presented in their recall letter. The information in the recall letter was rather interpreted in several manners by the recalled women. Being among the three per cent recalled made the experience frightening. Information that only one fifth of those

recalled were likely to have breast cancer was comforting to some, while others felt this to be a high number. The leap from 3 per cent to 20 per cent felt as a frightening large one. For others again the numbers made no sense since the important issue was whether one was well or not. The recall is experienced as difficult to interpret in “rational” terms when the only answer wanted is to know whether one is well.

Information on risks and consequences of screening was perceived as important among participants in a British study on patient perspectives on information and choice in cancer screening (Jepson et al., 2007). But, information was not seen as most important when making ones decision to participate. Rather, the main reason for wanting information was to reduce anxiety when waiting for a result or if receiving an abnormal result. Information can thus serve to help with coping strategies (Jepson et al., 2007), but in my study this is contradicted. The recalled women read the received information, but when awaiting a follow-up examination for a potential cancer diagnosis many of these women saw the information as irrelevant for their situation, or even as frightening.

The notion of time became important for those who were recalled. Since many women had waited many weeks for the recall letter, they perceived it as worrying that the follow-up examination was scheduled so quickly after receiving the recall letter. The short time frame for the recall made some perceive it as highly prioritised and thereby an indication of a serious situation. Also, the weeks passed since the initial screening mammogram were suddenly cast in a new light. Some had come to see the slow response as an indication that nothing urgent had been found. With the arrival of the recall letter, those weeks became a source of fear rather than comfort. The women’s understanding of the nature of cancer made them think about whether they might now have had cancer for too long without being diagnosed.

Although worried before the follow-up examination, most of the women said they were glad to have participated in the screening programme. Those who were diagnosed with breast cancer expressed they were glad to have been caught early, while those who were false-positives were glad to have been checked out. Only one woman said she was annoyed by the recall and that she would not participate in the next screening round. This woman had had benign cysts before and expected the same again. In her view, this predictable false positive result was an annoyance. For some

of the women there remained an uncertainty after the follow-up. One woman did not receive the result during the follow-up examination due to a biopsy test that had to be double checked. Two other women were told they had benign cysts, and that made them worry about whether they could be really certain about their “all well”-answer.

European women are less inclined to participate in the next routine screening than American women after having a false positive result (Brewer et al., 2007). Following the results of our study, it is a surprise that women in Europe are less inclined to participate in the next screening round. Even though not directly comparable, in this small material all but one of the women were certain they would return for screening in two years time. One explanation for the fall in participation rates among recalled women is that they may find the two-year span too long to wait for a new mammography after having a false positive mammogram, and therefore joined a private clinic with mammography screening instead of following the national programme. However, Brewer et al's claim is that the "opt out" screening system of European countries may explain the difference. While the “opt in” system may require a minimum of reflection before joining a screening programme, the “opt out” system gives women a chance of overcoming obstacles to screening without relating so much to its potential consequences. Rather, it is exactly the “opt out” system that gives screening participation the air of routine and natural behaviour that overcomes “the threshold mile” that had kept the women from initiating mammography themselves. Facing the consequences of screening through a recall can make some women revise their thoughts about mammography screening as a mere routine.

Research design and the priority of discourses

Academic discourses on mammography screening have primarily been conducted as a biomedical discourse, which is also to say a discourse legitimated by quantitative methodologies, especially RCTs. Even though there had been done some research on lay experience of mammography screening, the research field was underexplored and our research group chose to explore the field by conducting qualitative focus group interviews. The question is what we obtained by choosing qualitative methods.

As we wanted to explore women's experiences of mammography screening both before and after participating in the screening programme, the research group chose a prospective design. While doing the data collection, we experienced for instance that

women's focus changed from uncertainty about what to expect at the mammography examination, to seeing the examination as obvious but still being excited about how their result would turn out. A prospective design can be seen as improving validity by grasping the women's experiences as they occur rather than as understood in hindsight. Even when not using the prospective design to its full extent in the analyses, the focus on women's experiences "here and now" have probably given important information that would not have been found if studying the same experiences in retrospect.

Sampling and recruitment to the study were done using both random and strategic sampling. This may have made the data communicable to several parties in the field, satisfying both medical and qualitative discourses on recruiting informants. Women participating in the research project partially interpreted our project as connected to the screening programme, and that might have influenced how they talked in the focus groups. Also, this can have influenced which discourses that were drawn upon by the women in the group discussions. If accepting, as I have done, Kaufert's identification of two discourses of mammography screening (Kaufert, 2000) it is interesting to ask to what extent this research design has given priority to either one of these discourses. The interview guide for the focus group sessions might have given priority to one of the discourses. When asking about women's thoughts prior to the mammography examination, we might have given priority to the discourse on faith, emotions, responsibility, morality, compliance and guilt. However, when asking how women perceived their own risk for breast cancer we probably gave priority to the first, medical discourse. But, throughout the analyses of the focus groups and the individual interviews, the medical discourse has appeared more as a black box in the women's experiences – that is, knowledge that is accepted rather than reflected upon. The discourse on obligations, morality, compliance and guilt did, on the other hand, become more and more evident as relevant for the reflections the women had on their own experiences of mammography screening.

Conclusion

In this thesis I have studied women's experiences of mammography screening. Women who participated in this study experienced participation in mammography screening as the right choice, rendering non-participation almost impossible. The

medical reasoning about how “early detection saves lives” is experienced as the rational way to make a decision. Expert systems provide knowledge and technology which women value and trust. When mammography is offered as a routine examination it helps women to govern their health. But when facing the possibility of having a breast cancer diagnosis it is not statistics or technology that is in focus. Rather, all women want to know is whether they are well or not. The routinization of mammography which takes the fright out of the breast cancer examination when all is well makes a recall a disturbing surprise. However, the experience of screening participation which gives some women pain and anxiety while waiting for the result seems to be outshined by the relief when receiving an all well-notice.

Further research

Women’s experiences of mammography screening are complex and multifaceted. However, the format of a thesis and four articles does not give room for presenting more than parts of the picture. There are of course other aspects of mammography screening that could have been studied. I have for instance not focused on how the women experience the examination in itself. Neither have I looked much into how they experienced meeting with the staff at the mammography clinic. Exploring these issues could give a broader picture of women’s relations to the screening programme, and also show other aspects of what it is that encourage them trust mammography screening to save them from cancer.

Moreover, mammography screening may have consequences for more women than those recalled. Even though some of the women in the recall study in this thesis were diagnosed with breast cancer, I chose to focus on the experiences of those women who were “false-positives”. The experiences of non-symptomatic women receiving a diagnosis after mammography screening, could add interesting perspectives to screening. A study on this subject is currently taking place in Denmark, but would also be interesting in a Norwegian context.

Furthermore, there are also other groups of women who face consequences from the screening participation. That is women with a “false-negative mammogram” or “interval cancer”. The false-negative women are undiagnosed with breast cancer even though having a lump at the time of the mammography, while the last group consists of women who discover a lump in between screening rounds. It is possible that having

trust in mammography screening and being part of a screening program can delay diagnosis for women who experience one of these two scenarios. Further research questions can thus be whether or not participation in a screening programme gives a delayed diagnosis for some women, and not least how these women interpret the experience.

Finally, it would be useful to know how health personnel working in the mammography screening programme experiences and interpret their position and debates about mammography screening. How do health personnel relate to “the two discourses on mammography screening” that Kaufert (2000) identified? Do health personnel and decision makers solely relate to a discourse on scientific knowledge, statistics and principles for screening? Or, do health personnel and decision makers also, as the women themselves, relate to discourses on morality, responsibility, compliance and guilt? An interesting question following from the latter is how these discourses on health and women’s lives are part of political agendas and decision making. Through studies of women’s experiences as participants in a screening programme, and of health service providers’ perspectives to the programme and technology, we can understand more of the processes of medicalisation that occur in our society when our bodies, regardless of symptoms, are subjected to medical surveillance.

An evaluation of the Norwegian breast cancer screening programme is scheduled to start in 2008. It will be exciting to see what aspects are included in the evaluation, how they are studied, and what conclusions will be drawn. It will also be exciting to see what impact these results have on public discourse and public policy. Given what we know today, the influence of the evaluation is far from certain. Moreover, it will be even more interesting to imagine a scenario where the effect of the mammography screening programme is questioned by the evaluation. The consensus conference on mammography screening in Norway in 1989 did not recommend a mammography screening programme at that time (Holst et al., 1989). Nevertheless, this did not influence the initiation of a national mammography screening programme. It will be surprising if a potential negative evaluation will make health authorities remove a public health service already running. Also, it is interesting to ask how the potential scenario of a negative evaluation may influence women’s participation in the programme. Maybe women governed by expert advices are letting themselves being

governed as long as the advice fit with how they perceive of mammography screening themselves?

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Appendix 1: Invitation letter - focus groups

Dato: 18.02.03

Forespørsel om å delta i forskningsprosjekt

Du har i disse dager mottatt invitasjon til mammografiundersøkelse fra Kreftregisteret. I forbindelse med dette er det startet et forskningsprosjekt, hvor vi samler noen kvinner i mindre grupper for å høre hvordan de opplever slike helseundersøkelser. Grunnen til at du mottar denne forespørselen er at ditt navn tilfeldig ble trukket ut blant kvinnene som inviteres til mammografiundersøkelse. Vi håper du har anledning til å være med i dette forskningsprosjektet og ber deg i så tilfelle fylle ut og returnere vedlagte svarslipp.

Gruppesamtalene vil foregå på følgende måte:

Mellom 7 og 10 kvinner som har mottatt invitasjon til mammografi, møtes og utveksler tanker og synspunkter omkring undersøkelsen. Gruppen vil bli samlet tre ganger: Noen dager før undersøkelsen, noen uker etter og den siste ca. 6 måneder deretter. To til tre forskere fra Norges teknisk-naturvitenskapelige universitet (NTNU) vil lede samlingene.

Samtalene tas opp på lydbånd for å sikre en mest mulig korrekt gjengivelse av det som blir sagt. Senere blir opptaket skrevet ut, deretter blir alt slettet. Intervju-utskriftene skal kun oppbevares i anonymiserte versjoner, dvs. de vil ikke inneholde navn på personene som deltar. Utskriftene blir kun tilgjengelig for forskerne, som alle er underlagt taushetsplikt. Publisering av resultatene skal skje i vitenskapelige tidsskrift. Alle deltagerne vil få tilsendt et sammendrag av resultatene.

Vi håper at du har tid og lyst til å sette av et par timer tre ettermiddager/kvelder i løpet av det neste halvåret for å møte til gruppesamlingene. Gruppene vil samles på nærmere angitte steder i nærheten av ditt hjemsted. Det vil bli en enkel servering.

Det er helt frivillig å delta i disse samlingene, og du kan når som helst trekke deg uten å måtte forklare hvorfor du gjør det. Vi vil presisere at opplysninger som framkommer i gruppen ikke må fortelles til personer utenom gruppen. Det blir ikke registrert noe sted om du velger ikke å delta, og du vil fortsatt motta invitasjoner til mammografiundersøkelse (for kvinner under 70 år).

Vedlagt finner du en svarslipp som vi ber deg returnere innen **25.februar** dersom du ønsker og har anledning å delta på den første gruppesamlingen **onsdag 5.mars kl.19.00** (se vedlagt kart for sted). I den forbindelse ber vi deg krysse av for om du har vært undersøkt med mammografi tidligere. Du finner også vedlagt et kort spørreskjema og to eksemplarer av en samtykkeerklæring som vi ber deg fylle ut. Det ene eksemplaret sender du sammen med svarslippen i vedlagte konvolutt, det andre beholder du selv. Dersom du sender inn svarslippen, vil du bli kontaktet over telefon for nærmere avtale. Den andre gruppesamlingen vil bli gjennomført i **uke 12**, nærmere avtale om dato og tid gjøres på den første samlingen. Informasjon om innsending av spørreskjemaet er opplyst på skjemaet.

Prosjektet er vurdert av Regional komite for medisinsk forskningsetikk, region Midt-Norge.

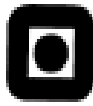
Med vennlig hilsen



Siri Forsmo
Lege dr.med.
Inst. for samfunnsmedisin,
NTNU
Tlf. 73597582



Steinar Thoresen
Overlege dr.med.
Kreftregisteret
Oslo



SVARSLIPP

Jeg ønsker å delta på gruppesamlingene: Kryss
(Første samling er onsdag 5.mars)

Jeg ønsker mer informasjon pr. telefon

Jeg har vært til mammografiundersøkelse tidligere

Navn:	
Adresse:	
Postnummer:	Postadresse:
Telefon:	Evt. mobil:

Retureres sammen med undertegnet samtykkeerklæring (nedenfor) i vedlagte frankerte svarkonvolutt.

SAMTYKKEERKLÆRING

Jeg har lest vedlagte informasjonsskriv om mammografiprojektet, og er villig til å delta i gruppesamlingene.

Min deltakelse i prosjektet er frivillig. Jeg er ikke forpliktet til å svare på spørsmål eller fortelle om egne opplevelser og erfaringer dersom jeg ikke ønsker det. Jeg kan når som helst trekke meg uten begrunnelse og uten at dette skal ha noen form for negative konsekvenser for meg. De opplysningene jeg allerede har gitt kan imidlertid brukes til prosjektets formål. Ved deltakelse i gruppesamlingene vil jeg kunne få innsikt i de andre deltakernes helseforhold. Jeg samtykker i at slike opplysninger ikke bringes videre.

..... den .../.... 2003

.....
Gruppedeltaker

Appendix 2: Interview guides - focus groups

Intervjuguide fokusgrupper 1.samling

Introduksjon

Velkommen

Presentasjon av staben

- Marit og meg: Sosiologer ved NTNU, to forskningsprosjekter (ende ut doktorgrader). Hittil har mye av forskningen vært konsentrert rundt hvor mange som får brystkreft, hvilke aldersgrupper etc. Det er for lite forskning knyttet til hvordan kvinner opplever det å delta i slike helseundersøkelser.
- Transkribør
- Solveig: Fra Oslo, holder også på med forskning rundt mammografi. Er bisitter her i dag.

Hva skal dere gjøre her i dag:

Innkalt til mammografiundersøkelse. Skal kanskje på undersøkelse om kort tid.

Dere har kanskje gjort dere noen tanker rundt dette nå i forkant.

- Som gruppeintervju der dere kan utveksle tanker og erfaringer med hverandre.

Temaer - leveres ut etterhvert: ark

Svar: Ingen riktige og ingen gale

Snakke fritt, men ikke i munnen på hverandre med hverandre.

Snakk med hverandre - ikke til oss.

Spørsmål:

Dere har kanskje sp.mål, eller det kan dukke opp sp.mål underveis: Spør hverandre, ikke oss.

Samle opp: Vi kommer ikke til å svare på disse sp.mål nå. Vi noterer dem og dere kan notere ned selv også. Ved siste samling (3. gang) vil en representant for Kreftregisteret komme, og da kan dere stille sp.mål og få svar.

Taushetsplikten

- ikke formelt, men tillitsforhold.

Varighet: Inntil to timer

To båndspillere: Fordi transkripsjon. 2 stk pga kvaliteten.

Fornavn på navneskilt

Mat og drikke. Pappkrus pga unngå støy

Toalett-besøk/pause - når vi snur båndet.

Ny avtale før dere går.

Før start:

Stemmeprøve for båndet, Kjenne igjen når skrives ut.

Presentasjon med fornavn og om vært til mammografiundersøkelse tidligere (snakk tydelig)

Spørsmål på første samling

1. Hvilke tanker har dere gjort dere i forkant av mammografiundersøkelsen?

Tenkt mye/lite? Opptatt dere mye – eller ikke tenkt i det hele tatt?
Forventninger? Pos./neg.
Spenning? Engstelig? Snakket med andre?
Usikkerhet?
Hatt mer fokus på brystene i det siste (pga innkallelsen)?
Snakket med noen?
Utført mammografi før?
Hva tenkte du da du fikk screening-invitasjonen?
Motivasjon for å delta?

2. Hvilke tanker har dere gjort dere om egen risiko for brystkreft?

Høy/lav?
Disponerende faktorer – tanker om hvorfor noen får brystkreft (årsaker)
Atferd/ arv/ alder

3. Hvilken betydning har masseundersøkelser som denne mammografiundersøkelsen for deres helse?

Ingen/stor betydning
Betryggende/skremmende
Viktigere enn blodtryksmåling?
Viktigere enn bentetthetsmåling?

4. Hva kan man gjøre for å forebygge brystkreft?

Mat/mosjon/røyking
Medisiner (Vaksine? Østrogen?)
Mammografi
Selvundersøkelser
Besøk hos fastlegen
Når bør man få barn?
Amming

5. Vil dere anbefale andre kvinner å foreta mammografi?

Hvilken anbefaling?
Til hvem? –alder?
Hvordan?
Privat eller offentlig?

Spørsmål på andre samling

1. Hvordan gikk mammografiundersøkelsen?

Prosessen – undersøkelsen

Smerte?

Kommunikasjonen

Informasjonen underveis

Hvordan følte du deg tatt vare på?

Resultatet (For de som er på 2. Samling etter mottatt svar)

2. Hvordan opplever du ventetiden før resultat? (Hvordan opplevde du ventetiden før resultatet?)

Tanker?

Tanker om kroppen din/opplevelser av kroppen

Følt på om det er noe?

Mer oppmerksom?

Usikkerhet? Ubehag?

Snakket med noen andre?

3. Hvilket utbytte har du hatt av mammografien?

Stort / lite?

Begrunnelse

Betydning for egen helse

Trygghet nå?

Trygghet for fremtiden?

4. Hvilke tanker har du om å gå til mammografi igjen?

Behov?

Planer?

Hvor ofte tenker du å gå?

Begrunnelse for å gå?

Kostnader?

5. Bør helsemyndighetene gi alle kvinner tilbud om mammografi?

Tanker om prioriteringer?

Hvem: Alle/ noen? Alder?

Ift. Ressursbruk

Hvem har ansvaret for kvinners helse?

Vil du anbefale andre kvinner å ta imot tilbud om mammografi?

Privat eller offentlig?

Appendix 3: Invitation letter – recalled



Til deg som skal til undersøkelse
på mammapoliklinikken.

Stipendiat
Marit Solbjør
Telefon 73 59 89 05
E-post marit.solbjor@medisin.ntnu.no

Forespørsel om å delta i en vitenskapelig undersøkelse

Du som får dette brevet har nylig vært til mammografi, og har i dag fått innkalling til videre undersøkelser på mammapoliklinikken. Vi ønsker å snakke med noen av kvinnene som blir innkalt til nye bilder/nye prøver **en av dagene før timen på mammapoliklinikken.**

Formålet med samtalen er å høre om deres egne tanker rundt denne opplevelsen. Kunnskapen om dette håper vi kan bli til nytte i arbeidet rundt forebygging av brystkreft. Dette er et forskningsprosjekt, og deltagelse er helt frivillig.

Deltagelse i prosjektet består i å bli intervjuet 2 eller 3 ganger. Første intervju gjøres **en av dagene før** undersøkelsen på mammapoliklinikken. Andre intervju blir gjennomført noen dager etter at du har fått svaret på undersøkelsen. Intervjuene behandles konfidensielt, og ingen andre vil vite hvem intervjupersonene er. Den som intervjues kan når som helst, og uten begrunnelse trekke seg fra intervjuet og prosjektet uten at det får konsekvenser for videre medisinsk oppfølging. Alle opplysninger vil da bli slettet fra prosjektet. Forskningsgruppen arbeider ved Institutt for samfunnsmedisin ved NTNU, og ikke på sykehuset. Derfor vet vi foreløpig ikke hvem du er. Vi får kun vite navn på dem som kontakter oss.

Prosjektet er et samarbeid mellom NTNU, St. Olavs hospital og Kreftregisteret, og er finansiert av Norges forskningsråd. Prosjektet er vurdert og godkjent av Regional komite for medisinsk forskningsetikk, Region Midt-Norge.

Dersom du kan tenke deg å delta i dette prosjektet må du ringe oss så snart som mulig på telefon 73 59 89 05 (arbeid) eller mobil 98 84 52 62 (når som helst), slik at vi kan avtale et tidspunkt og sted for den første samtalen før undersøkelsen. Vi beklager den korte tiden.

Vennlig hilsen

Marit Solbjør,
Stipendiat i medisinsk sosiologi

Siri Forsmo,
Lege, dr.med.
Prosjektleder

INFORMASJON OM INTERVJUET

Dette intervjuet vil inngå som del av et forskningsarbeid i medisinsk sosiologi og er en del av prosjektet "Screening og helseundersøkelser – veien til god helse?". Prosjektet tar for seg kvinners møte med mammografiscreening, og det vil bli gjennomført intervjuer med kvinner som har møtt til mammografi. Spørsmålene vil være åpne, slik at de kan besvares med den intervjuedes egne ord, og det finnes ingen riktige eller gale svar

Deltagelsen i intervjuet er frivillig. Den som intervjues bestemmer selv når intervjuet kan skje, hun kan når som helst trekke seg fra intervjuet uten å gi noen begrunnelse for det og kan unnlate å svare på spørsmål hun ikke vil si noe om. Den som intervjues kan underveis spørre om ting hun lurer på.

Forskeren kan notere underveis i samtalen, og samtalene tas opp på lydbånd for å sikre en mest mulig nøyaktig gjengivelse av det som blir sagt. Senere blir lydopptaket skrevet ut, før opptaket slettes. Intervjuene oppbevares kun som anonymiserte utskrifter, dvs. de vil ikke inneholde navn på personene som deltar. Utskriftene blir kun tilgjengelig for forskerne, som alle er underlagt taushetsplikt. Resultatene fra forskningsarbeidet vil bli publisert i vitenskapelige tidsskrift og i avhandlinger.

SAMTYKKEERKLÆRING

Jeg har lest informasjonsskrivet og har hatt anledning til å stille spørsmål. Jeg samtykker i å delta i prosjektet.

..... den / 2004

.....

prosjektdeltaker

Dette eksemplaret beholdes av prosjektdeltager

Appendix 4: Interview guides – recalled

Intervjuguide etterundersøkte: 1. intervju

Kvinner som skal til etterundersøkelse på mammapoliklinikken.

Introduksjon:

Du har vært til mammografi og har nå fått brev om at bildene ikke var entydige, slik at du skal på mammapoliklinikken i morgen/senere i dag.

1. Kan du fortelle om dette?
 - bekymret?
 - Trygg?

2. Hvordan har ventetiden vært?
 - etter mammografien
 - etter å ha mottatt brevet fra mammapoliklinikken

3. Hvilke forventninger har du til etterundersøkelsen?
 - Hva tanker har du gjort deg om utfallet av denne undersøkelsen?

4. Hvordan opplever du din egen helse?

Intervjuguide etterundersøkte: 2. Intervju

Kvinner som har vært til etterundersøkelse på mammapoliklinikken

Introduksjon:

Nå er det 3 dager/en uke siden vi snakket sammen, og du har fått svar på prøvene fra mammapoliklinikken.

1. Kan du fortelle om det?
 - hvordan gikk undersøkelsene?
 - Positive og negative opplevelser av resultatet?
 - bekymret ?
 - trygg?

2. Vil du gå til mammografi igjen?
 - hvor ofte?

3. Vil du anbefale andre å gå til mammografiundersøkelse?
 - Hvem?
 - Hvor ofte?

Paper I

Is not included due to copyright

Paper II

3 “*You Have to Have Trust in Those Pictures*”

A Perspective on Women’s Experiences of Mammography Screening

Marit Solbjør

3.1 INTRODUCTION

Breast cancer is the most frequent cancer among women in the industrialized world, and screening—systematic examination of asymptomatic populations—is increasingly a part of public health services. In Norway a screening program for breast cancer was initiated in 1996 and became nationwide in 2004 (Cancer Registry of Norway 2005). The screening program biannually invites all women aged 50 through 69 to mammography. Women receive a letter of invitation with a preset appointment for the examination. Nearly 80 percent of those invited participated during the first round of public screening, excluding women who sought mammograms through private clinics (Hofvind 2005). In part, fear of cancer, along with the old slogan “Early detection saves lives” (Lerner 2001), might have contributed to the high participation rate, because mammography screening is widely viewed as beneficial (Sætnan 1992).

But there are also sceptical voices within medicine and among the public that question whether lives are actually saved or prolonged: early diagnosis may simply mean knowing of one’s cancer for a longer period. These voices also question whether all cancers diagnosed are truly cancers; whether mass mammography screening leads to overdiagnosis and overtreatment; and whether interventions may lead to increased numbers of cancers (Baines 2003; Gotzsche and Olsen 2000; Zackrisson et al. 2006). Therefore, one can ask what fosters the high participation rate in mammography screening. We live in a society dominated by expert systems and technologies that we trust to control the inevitable risks we face (Giddens 1990). Mammography screening is such a technology and expert system, designed to reduce the risk of breast cancer deaths. The high number of participants in the Norwegian screening program may be an indication of trust in mammography as a means to reduce their risk for fatal breast cancer.

Trust in social institutions, as well as in fellow citizens, is high in Norway. In the European Social Survey 2002, Norway was top of the trust rankings of European countries, together with the other Nordic states and

Switzerland. Norwegians seem to place trust in the police, in parliament and in the legal system (Listhaug 2005). When asked about trust in sources of information about modern biotechnology in 2006, 47 percent trusted public authorities, compared to 13 percent among European Union members (Nielsen 2007). It is not clear whether Norwegians also trust health authorities when given advice about preventive health examinations.

In order to explore this question, this chapter commences with theorizing trust and introducing mammography screening as an expert system and a technology. Mammography is a visualizing technology that makes it especially interesting to explore whether and how technological aspects and expertise influence participation and trust in the efficiency of the screening program. The empirical project presented in this chapter is based on focus group interviews and explores mammography technology, expertise and visualization as connected to women's trust in mammography screening.

3.2 THEORIZING TRUST

Trust as a sociological concept maps onto the everyday, intuitive usage of the word, which may be a problem if social scientists follow suppositions, rather than looking at causal accounts and explanations of trust (Hardin 2001). What makes trust a meaningful and important concept is that it shows the process by which we reach a point where our interpretations are accepted and our awareness of the unknown is suspended (Möllering 2001). In other words, trust enters the picture when rational action is insufficient—when something remains unknown. We speak of trust when there is an element of risk and uncertainty (Giddens 1990). Yet, following Möllering (2001), trust does not eclipse rational action; rather, it is a cognitive process that combines "good reasons" with an emotional dimension (Lewis and Weigert 1985). Trust is thus based on some form of knowledge which may be personal (as when we trust in a person based on our previous experiences of him or her) or impersonal or abstract (as when we trust in institutions, rules, science). Some claim that we have more trust in those with whom we have an ongoing relationship and probably act more trustworthy ourselves if the relationship is important to us (Hardin 2001). So how is it that we trust social institutions or abstract systems?

3.2.1 Trust and Expert Systems

Our modern society is complex, and personal knowledge is more difficult to attain than in a traditional society (Giddens 1990; Möllering 2001). What is needed in the complex modern society is a strategy to reduce complexity. Trust is a strategy to reduce complexity because trust means living as if certain possible outcomes will not happen (Lewis and Weigert 1985). It is a paradox that there is less personal knowledge to base trust upon

(Möllering 2001), and at the same time this very complexity requires that we exercise more trust. One can claim that this results in a more active trust in our modern society (Giddens 1990) and more deliberate leaps of faith.

At the same time, the complexity of modern society involves abstract systems that may reduce uncertainties because they guarantee that expectations can be fulfilled independent of time and space or social relations (Giddens 1990). An expert system can be defined as a technical or professional system that organizes more or less specific areas of our social and material environment (Giddens 1990). Trust in abstract expert systems must then be something other than what Hardin (2001) calls an encapsulated interest of trust, that is, trust in other individuals with whom we have relations.

Nevertheless, abstract systems, such as expert systems, and lay people meet at particular access points (Giddens 1990), where the abstract system is represented by a specific person who provides the connection between personal trust and system trust. However, the access point is a place of tension between lay scepticism and expert knowledge and is a vulnerable area of abstract systems because it involves what Giddens (1990) refers to as facework and faceless obligations and, therefore, includes both personal trust relations and trust in the abstract.

Facework is expressed and developed through personal relations and co-presence, whereas faceless obligations are developed through faith in impersonal principles that provide statistics rather than individualized results (Giddens 1990). Trust in abstract systems takes shape as faceless obligation when knowledge of that system is unknown by lay participants, yet faith in the knowledge system is maintained. Because the expert system is complex and difficult to grasp due to its abstract character, it is especially interesting to explore what reasons and knowledge make suspension and trust possible.

3.3 MAMMOGRAPHY SCREENING AS EXPERT SYSTEM

As early as the beginning of the twentieth century, physicians claimed that early detection of breast cancer was necessary for survival (Lerner 2001). The physician made treatment decisions, and, as late as the 1960s, many physicians relied more on their own clinical experience and judgement than on statistics when deciding on breast cancer diagnosis and treatment. Still, the 1960s saw the onset of mammography screening: concomitantly, randomized controlled trials provided statistical evidence of whether or not mammography had any effect on breast cancer mortality. Results from these studies vary in their degree of support for mammography screening, and they are still being debated (Alexander et al. 1999; Andersson et al. 1988; Bjurstam et al. 1997; Frisell et al. 1997; Miller et al. 2000; Miller et al. 2002; Shapiro 1977). Discussions focus on whether or not mammography has an effect on mortality (Gotzsche and Olsen

2000; Welch 2004), false positives (Brodersen 2006) and overdiagnosis (Zackrisson et al. 2006; Zahl and Maehlen 2005). Despite the ongoing discussions it seems clear that, at least for now, those in favour of mammography screening have won this health policy debate (Sætnan 1992) as screening programs have been initiated in most Western countries. It is a paradox that governments are willing to initiate extensive and expensive screening programs while there are still ongoing scientific discussions about their effect. Questions of health policy and different parties' agendas will not be further discussed here, but a question arising from this is to what extent lay participants in screening programs are aware of these discussions and uncertainties.

Mammography screening is designed to reduce mortality by detecting presymptomatic lumps and is a complex expert system involving different kinds of experts. Radiographers manage the X-ray machines; radiologists interpret images and decide who needs further examinations; and statisticians and other scientists evaluate the program's accomplishments and effects. Lay users meet the expert system when enrolled into a screening program. The invitation letter, examination and later correspondence between the system and the women can be seen as places where face-dependent trust can be developed. Yet it is unclear whether women are aware of the complexity of expert knowledge and how they interpret these complexities and possible uncertainties.

3.4 MAMMOGRAPHY—A VISUALIZING TECHNOLOGY

Mammography is not only an expert system but is also a technological artefact. Mammography was developed as an extension of X-ray technology, photographing the breast beneath the skin by placing the breast between two glass plates. The outcome of the examination is an X-ray image of the internal breast, shaded in black and white, and its goal is to detect small lumps or condensed tissue that is apparent in the image. This image is interpreted by radiologists looking for abnormalities, and a system of cancer experts are ready to intervene with women who have abnormal mammograms. The visual interpretation by the experts can therefore entail further interventions on the bodies of screening participants.

Visualizing aspects have become invaluable in diagnostics, treatment and preventive medicine. Cartwright (1995) and Blume (1992) have explored the discovery of the X-ray and its implications in the development of medicine. After Roentgen's discovery in 1895, the X-ray technique was met with excitement as a diagnostic tool (Cartwright 1995). The X-ray provided images of the skeleton but was also used to image other parts of the body. Torso X-ray screening for tuberculosis eventually became common. Cancer screening was not the issue at that time, but some had already suggested that X-rays on healthy subjects could detect unsuspected cancers

(Cartwright 1995). This logic was not immediately embraced by radiologists, as the breast was characterized as too soft, too irregular and too changeable to image clearly with X-ray technology. Today some radiologists see the visibility of breast cancer on mammograms as clinical evidence of mammography's effect (Kaufert 1996).

There are other visualizing techniques in medical practice, such as screening for cervical cancer, osteoporosis and ultrasound imaging of the foetus. Blume (1992) studied how the standardized thermometer was introduced into medical practise and shows how technology permits delegation of the diagnosis from the sole physician to a material artefact that is embedded in a larger social setting (Blume 1992). Delegation happens when a technician performs the act of examination, for instance by using the mammography machine. The machine produces a result that is apparently objective, ready to be read and interpreted by a knowledgeable professional. The process of delegation and diagnosis presents an air of objective certainty and confidence in the result for both lay and professional users, perhaps obscuring the fact that skilled readings of mammograms are also—necessarily—interpretations. Måseide (2002) found for instance that diagnostics based on X-ray images of the lung region were negotiated between radiologists, oncologists and specialists in pulmonary medicine by discussions of thorax images at diagnostic meetings.

All these techniques require expert knowledge to interpret the results (Atkinson 1995), and visualization techniques create images for expert interpretation, requiring a high degree of abstraction (Howson 2001). For instance, the bone density scan gives its outcome in both pictures and numbers, where the numerical estimate calls for a professional interpretation, adding a 'subjective' element to the 'objective' numbers (Reventlow, Hvas, and Malterud 2006). Even though we can think of pictures as persuasive proof of objective facts, the outcome of visualization of medical procedures on bodily parts is not always predictable to its lay 'users.' For instance, Howson (2001) found that patients who were given the option to watch their own cervix on a screen during cervical colposcopy did not experience this as 'getting in touch with their body.' Rather, the process defined the cervix in medicalized terms. The women in Reventlow, Hvas and Malterud's (2006) study were influenced by the bone scan and the visualization of the bones and started interpreting their bodily experiences in relation to the bone scan. Similarly, women have various responses to ultrasound images of the foetus, sometimes 'diagnosing' the foetus as healthy or not depending on what they themselves see on the screen, sometimes puzzled by the images and dependent on medical personnel's interpretations (Sætnan 2000).

The goal of screening mammography is not to diagnose breast cancer but to separate normal from abnormal mammograms (Elmore et al. 1994). What is seen on mammograms varies, even though radiologists in charge of reading the images develop a somewhat standardized perspective through their education and experience. Debates exist, however, as to the necessary number

of readings to assure quality (Moss, Blanks, and Bennett 2005). Leaving aside issues of varying image quality, differences are apparent in radiologists' interpretations of visual images (Hofvind 2005); in how abnormality is perceived; and in the concern about perceived abnormalities (Elmore et al. 1994). Mammography images are not usually shown to patients, but women know they exist, yet it is unclear how women might react to such images.

3.4.1 Visual Images as Truth

One might claim that we are living in a visual culture with sight as the primary sense: medicine is no exception in privileging the visual (Cartwright 1995; Mirzoeff 2006). The imperative of objectivity and visual modes of representation link together as instruments of 'truth' in medical knowledge (Reventlow, Hvas and Malterud 2006). Visual proof may feel more trustworthy than perceptions from other senses, perhaps because it offers a way of making concrete information that is hitherto hidden or unseen. Or maybe the image is a comprehensible object as opposed to prognoses, imperceptible lesions or the contents of test tubes, all of which contain knowledge that must be interpreted and translated by the experts? Mammography images must also be interpreted by experts, but lay users may think it is easier to spot abnormalities on a picture than to interpret other medical and scientific procedures.

To explore how women participating in a mammography screening program understand mammography technology, I now turn to empirical material, which examines whether the visual culture that we live in influences how women think about mammography and their own health. What reasons do these women have for trusting or not trusting mammography? Do the women trust in mammography as an expert system—and if so, do they trust the experts they encounter personally, or the system in the abstract?

3.5 METHODOLOGY

To explore how women experience participation in a screening program for breast cancer, it was important to hear about their perspectives and interpretations in their own words. The research group invited women due to be screened to participate in focus groups to talk about mammography and breast cancer. A total of sixty-nine women met, unequally distributed in eight groups. Each group met three times: shortly before, shortly after and six months after their mammography examination. In order to conduct a prospective design, we cooperated with the Cancer Registry of Norway—the agency in charge of the organization of the screening program. This made us dependent on their procedures when choosing a time and place for the focus group meetings. The spring of 2003 provided the last opportunity to talk to first-time participants over enrolment age in mid-Norway, and

we wanted to know about their experiences as first-time participants. As it turned out, this did not imply that these women had no experience of mammography. Many had already had mammography on their own initiative. However, this was their first time responding to an invitation to participate in the public mammography screening program.

Women were sorted in groups depending on age and municipality: 50–59 and 60–69 year olds were put in different groups due to the expectation that they would have different knowledge and experiences of cancer and risk factors for breast cancer. Four municipalities were selected to represent an urban–rural dimension. Recruiting participants from sparsely populated areas or small towns gave us neighbours, friends or relatives in each group. The fact that some participants knew each other became an asset for both participation and discussions in our groups, as other researchers on women's health have found (Kitzinger 1994).

Focus group interviewing is a qualitative method that allows participants to talk freely about the subject in question (Bender and Ewbank 1994; Kitzinger and Barbour 1999; Sim 1998). A group discussion is centred round an interview guide with questions preset by the researchers but where participants' discussions with each other are in focus. All interviews were tape recorded and transcribed, and analyses were based on text transcripts. Methods used for analyzing the data were categorization, condensation of the material and interpretation (Kvale 1996). The analysis in this chapter is based on the first round of focus groups. Our research group did not primarily study women's trust in particular but rather women's experiences in general. As it turned out, trust became part of what women talked about during the first focus group sessions. None of the groups were asked directly about trust; rather, it sprang from discussions about technology, medical expertise and from talking about breast cancer and screening participation among themselves and others. Some women used the word 'trust' directly; others talked about certainties and uncertainties.

The groups differed in their discussions of this subject. The eight groups had dissimilar characteristics, and their interpretations of breast cancer and mammography differed. The analyses are centred on six of these groups, as the last two groups were less concerned with questions of trust in technology and concentrated more on other issues, such as prior and recent diseases among themselves and their families. Women in these two groups did not necessarily have less trust in mammography than the other groups who were more articulate on the subject. Rather, trust in medical expertise and technology is even stronger among these women, but more difficult to grasp in an interview, as it is more implicit in how the groups talk and what they talk about. *Not* talking about something may reflect a lack of interest or awareness, but it might also suggest that a matter is so taken for granted that it need not be mentioned. It is a challenge to grasp what people themselves may not be aware of and especially the "unknowable" knowledge

that makes them trust (Möllering 2001). In what follows, I therefore concentrate on the groups where bases for trust were explicitly discussed.

3.6 TRUSTING MAMMOGRAPHY—OR NOT?

Participators in the Norwegian Screening Program for Breast Cancer hope that mammography screening might help them avoid a severe cancer experience. Women know mammography's task is to find cancer, but they most of all hope for and expect to have an 'all clear' notice. Trusting mammography to find lumps if there are any and the expectation of a message with a good content are two reasons for participating in the program. As one woman put it:

O1: Yes, I too believe it to be very positive to have those examinations with mammography. I believe so. Because if you don't find anything it will influence you afterwards in terms of [. . .] then you'll at least feel safe. And that, that is important to me.

If nothing is found at the mammogram, women feel assured that they are well, and this may affect how they think about their own health. The safety women feel, or expect to feel after having a mammography examination makes some women neglect their own breast self-examination, and this is a concern for women in the focus groups. Some of the women in the groups ask if mammography makes it unnecessary to do the self-examination. This opened a discussion in one focus group session:

E1: So are we going to avoid doing self-examinations then . . . because we have been to mammography?

E2: No, I don't think we should, but for those of us who aren't really good at doing the self-examination it is good help.

E1: But should we trust mammography 100 percent? Isn't it true that there have been mistakes made there as well? Things have been overlooked [. . .] I have this idea that I'm not going to leave everything to them. I'll keep track a bit myself as well. But that is my way of thinking. It is my body.

E1: We can't trust this 100 percent. That has been proven.

E2: I've heard that they have been there and not found anything, and then there has been something wrong after all.

E3: That's the way it is with most examinations.

Women who feel unsure about whether or not they do the self-examination properly are especially glad to have the mammography screening program undertake the responsibility for finding lumps. Feeling insecure in one's own ability to detect lumps makes women welcome having a technology to help them with this chore. Women's experiences of themselves as less reliable (when doing self-palpation) than professionals doing an examination (using mammography technology) may also influence their perception of which method is best. Still the importance of doing self-examinations is highlighted by some of the women. They mention women's responsibility for their own health and body, and how this responsibility must be continued also after having the mammography examination. Seeing mammography as fallible, self-examination offers a good supplement; but, on an individual level, self-examination might feel more complex and difficult than having mammography. Many women do not trust self-examinations to provide a trustworthy result. These women trust mammography to detect cancer more than they trust themselves, but they know also of the possibility that mammography might give a wrong result.

R1: But . . . can it be like a false safety that . . . doesn't have to be sure that they can find it, if there is anything. That you kind of think when one has been to an examination like that, then it is . . . is it certain that it is nothing? If they say so? Is it 100% certain?

R2: It isn't that, is it? No, not 100% certain.

R3: You hear about cases, when it has appeared after all, don't you [. . .] You must have heard that [. . .] it has appeared anyway. They are [. . .] well, heard about it. Should be quite safe anyway [. . .] so it must be safer than not having it. [. . .]

R4: Must be special cases that.

R3: Yes, but I believe that is . . . because it is like that with everything. One hundred percent, that's almost impossible.

Some women worry that mammography can give a false sense of security. They know that mammography is less than 100 percent certain. The women manage the uncertainty inherent in screening, however, by, to an extent, normalizing it: everything is uncertain, and no examination can be trusted one hundred percent. There are persistent worries that they might have breast cancer without mammography detecting it, but they find comfort in the explanation that only special cases are overlooked during the screening process. These women place trust in mammography and manage to turn their discussions about distrust around, ending up at trusting again. This raises questions of what it is they trust and what it is that makes them put their

doubts aside. Is it the mammography machine as a technological artefact or the medical professionals interpreting the pictures that are trusted? Scientific discussions of what one can see from the mammograms do exist. Do women know about these discussions, and do they care about them? Is it the pictures themselves that evoke lay users' trust in mammography, and if so, why?

3.7 TRUSTING THE EQUIPMENT? THE EXPERTS? THE SYSTEM?

Women in the screening program see mammography as equipment that simplifies the process of early detection. For some it feels like the only way to gain knowledge about their own state of health when it comes to breast cancer. In other words, they trust mammography more than they trust themselves as self-examiners. Understanding cancer as a sneaking and mortal disease makes it important for them to be certain of the condition of the breast even before they can feel the potential lumps themselves.

O2: I've heard of many who have been to mammography now, or rather, know some who've been to mammography and found lumps that are in that stage [. . .] so tiny that they couldn't be felt. So I think many have been saved by it . . . that mammography.

Mammography becomes a means to find smaller lumps than the women expect to find themselves, and thereby mammography hastens cancer detection, diagnosis and treatment compared to what would have happened if the cancer had to be found without mammography technology. Indeed, women's knowledge of breast cancer and mammography also comes from the stories of others who have been saved from severe cancer, because mammography found smaller lumps than would have been detected during self-palpation. The slogan 'early detection saves lives' (Lerner 2001) not only appears to be 'common knowledge,' but women interpret stories about cancer using this knowledge to make sense of their own experiences with breast cancer screening. Understanding cancer survival as dependent on early detection makes it necessary to lean on the technology that can obtain the earliest diagnostics for breast cancer. In this way mammography becomes a mediating technology between the women and their breasts, helping women to know the inside of their body. To what do these women ascribe mammography's superiority? Why is it better at knowing their bodies than they themselves are? Is it the machine or the experts who operate it that deserves the credit?

As far as the women are concerned, two things are necessary for finding the lump when having mammography. One is how the machine works, and the other is how medical personnel interpret the pictures. Although they know both of these to be reliable, the women are not without misgivings. The mammography machine is understood by most women as safe, even though some question the radiation they receive when having the examination. What is

more important to the women is whether or not the technology is constructed to cover the whole area that has a potential for breast cancer. What can be seen when using mammography technology and what is difficult to detect are both important to the women, and they question if the reason some cancers go undetected by mammography is due to the design of the equipment.

G1: I find it is a small amount of the breast that goes into the machine when they take the pictures. Can it still be trusted? Those are the thoughts I get.

B1: I know of a case [. . .] a woman who has been to mammography, had her green light. But afterwards she found a lump far up in the breast [. . .] Probably wasn't part of the image.

B2: No, because it depends on how they do when they put the breast into the machine. They only get [. . .] They don't see the tops.

The machine is seen as neglecting certain areas of the breast, for instance, its upper parts. These women understand that the plates of the mammography machine exclude parts of the breast and view this as a defect of the technology. The knowledge about how mammography technology functions is interpreted by these women and may be a reason for distrust in mammography screening. They know of other women who have been to mammography and had a breast cancer diagnosis a short time after, even when the result of the mammography was interpreted as normal. The question is whether or not the undetected cancer should have been detected or whether it was outside the mammography image.

The other question raised by the women is how the pictures from the mammography are interpreted. Women seem to put less emphasis on this than on the technology in their talk about having doubts about mammography. There is not much discussion about the expertise of those interpreting the mammograms nor about how mammograms can be interpreted in different ways, as is well known in medical research (Elmore et al. 1994). There is still, however, a worry about whether or not a mammography examination can find every lesion of potential breast cancer. The number of examined mammograms by each professional interpreter is seen as reassuring for the sensitivity of the examination. Still some women point to the feeling of being in a busy production line and just a number in the queue.

B2: But then you can say that they examine so many breasts that they should have good knowledge of it. They look and they look and they look. The more images they see, the more knowledge. But at the same time maybe it is so many and so busy that they maybe don't use enough time on each picture? So it's double edged. But obviously they might get more statistics on how many it is.

Being part of the production line for better health makes women see themselves as one of many, and they acknowledge the necessity of statistics as part of the mammography screening expert system. The discussion brings forth reflections on how the number of screened women can make the examination and its results more accurate, even if it means having less time for each specific woman participating in the screening program. So women are aware of how the screening program, with its opportunity for experts to collect statistics and develop expertise, can make interpretations more accurate, but at the same time they point out their impression of each woman as a small piece in the system. Nevertheless, their primary focus is that routinization contributes to expertise and better diagnostics.

The above discussion, then, suggests that women know that mammography screening is complex. Yet they see the mammography examination as a way to gain knowledge of a potential breast cancer as early as possible, even before they have symptoms they can notice on their own. They also know that the technology sometimes misses breast cancer. Women in this study blame missed breast cancer primarily on the design of the technology and secondly on professional interpretations of the pictures. Being part of a screening program makes women aware of being one amongst many, and this can give reasons both for and against trusting mammography to find lumps.

Women point to good reasons for both trusting and not trusting mammography screening. From the focus group data, it appears that when women discuss the technology's materiality, the organization of the program, or the expertise involved, it leads to new rounds of doubts. Yet through these discussions, the women eventually come around to a conclusion of trust in mammography after all. They interpret their knowledge and weigh up the case for and against. Dealing with questions of technology and trust in professional knowledge, however, still do not show what it is that makes women suspend their doubts and trust mammography. What then is the suspension point? Can it be the visual aspect of mammography that somehow persuades women to trust technology and expertise?

3.8 TRUSTING THE IMAGES?

The significance of the visualizing aspect of mammography for how women come to trust is apparent in the comparison of mammography with other means for finding breast cancer. For some women the possibility of finding breast cancer is dependent on a seeing technology. They are aware of three means to locate the cancer lump in the breast: self-examination, a doctor's palpation of the breast and mammography. Ranking these, mammography, because of its visualizing technology, is thought to be the most trustworthy:

V1: Really, it is only mammography that can examine it, find it. Cause if we [. . .] I say that I'm not so certain of myself, then maybe the doctor can

do it, but then that isn't certain either. So you can't trust that either. And we are . . . the breasts are different from each other, so how can we trust it. There isn't any lump here . . . I can't find a lump, and you can't find a lump. The doctor can't find a lump . . . but then . . . I don't know what mammography is, I believe it is some sort of X-ray, and when it comes to other X-rays they usually find things . . . So I have to trust it. They take a picture and it is an X-ray; you have to have trust in those pictures.

Familiarity with X-rays used on other parts of the body indicates that these women picture for themselves how mammography works. They have seen X-ray pictures before and know the effect of seeing one's bones. This knowledge influences their views on mammography and leads women to trust mammography more than the other methods for finding breast cancer. Breast self-examination is considered difficult, and several of these women say they do not trust their own examination. Some of them trust their doctor's breast exam more than their own, but still there can be margins of error since breasts can feel different, as noted by the women in the extract above. Finding breast cancer at an early stage, then, appears to come down to understanding the visualizing mammography as a technology that eliminates the differences between breasts and differences between examiners' experiences, whether it is a medical doctor carrying out the examination or a woman doing breast self-examination. Knowledge of different means for finding breast cancer early is interpreted by the women and weighted to find the best and most trustworthy way of saving women from breast cancer. The point of suspension seems to be rooted in the belief that it is mammography that can best find breast cancer, as the only way of eliminating uncertainties is through seeing what is really beneath the breast surface. Visualization becomes the trustworthy aspect of mammography technology, the feature that helps women put their doubts aside and trust mammography to find breast cancer so early that they can be saved from a serious disease.

One can see this more clearly in the discussion of ultrasound technology as a diagnostic tool compared to mammography. In one of the groups, two women start to discuss whether mammography or ultrasound is best for detecting breast cancer.

V1: Can you find the same thing with ultrasound as with mammography?

V2: Ultrasound is a more expensive and more thorough examination.

V1: More thorough?

V2: It looks further in, you could say. But if one should start to have all women take ultrasound, like a mass examination . . . it would be very expensive.

V1: I wouldn't mind that!

Ultrasound is classified by these women as a better but more expensive examination, and, therefore, not likely to be used in a mass screening program. When arguing for the superiority of ultrasound to mammography, it is said that ultrasound can see even deeper into the breast—a feature that makes it all the more appealing for some women in the focus groups. Even though greater efficiency does not necessarily lead to higher level of trust, for some women, better visualization techniques do give a more trustworthy result. This too indicates that visualization is the final suspension point: the point where doubts, even if they are not eliminated, can be put aside or bracketed.

3.9 CONCLUSION

This chapter has examined how and why women participating in the Norwegian screening program for breast cancer place trust in mammography as a screening technology. Other aspects of women's experiences with mammography screening are discussed elsewhere (Østerlie et al., forthcoming), but here I have chosen to compare three aspects of trust in mammography: technology, expertise, and visualization. I have chosen these aspects not only because they are theoretically interesting but also because they are prominent in the data itself.

As expected from previous research, Norwegians have trust in public institutions (Listhaug 2005), and women receiving an invitation to participate in a public screening program may trust the public health service to do what is best for them. At the same time they have, as shown above, knowledge of weaknesses in the system. Trust in public services, in and of itself, cannot explain how and why women suspend their interpretations of missed cases in breast cancer diagnostics and choose to trust mammography after all. Moreover, Giddens's (1990) faceless obligations are not enough to explain why women trust mammography before entering the program and after their first examination.

One can ask whether the mammographic image is something different from other forms of "proof" evinced through medical examinations, such as tests used on blood or urine samples, measurements of bone density or ECG. All of these are techniques for obtaining objective results about the body of the patient. We cannot answer this question from our data, but one can reflect upon it as others have done (Blume 1992; Cartwright 1995; Howson 2001). What it is possible to say is that the focus group material suggests that mammography's visualizing aspect could be the last instance of persuasion. Living in a predominantly visual culture (Mirzoeff 2006) is one way of explaining why these women suspend their doubts about the machine and the experts to place trust in the mammography program. One can claim that we are more likely to be convinced by visual proof than by other senses, such as touch (necessary

for self-examination or clinical palpation). The mammogram's image of the internal breast and its lumps is seen as better proof than anything else. When the trained medical professionals look at the pictures from the mammography, lay women have to trust that the experts can see what the breast is really like.

Preventive medicine gives us the message that one might be diseased without feeling ill, leaving bodily signals untrustworthy and making us dependent on medical technology (Sachs 1995). But being dependent and trusting is not necessarily the same thing and for many women, trust co-exists—indeed is necessary—because of an awareness of uncertainty.

Trusting the technology can arise from faith in the objectivity of results, because machines can be seen as more accurate than persons. But mammography does not work by itself, it requires experts to handle it and interpret the results. The delegation of diagnosis from the physician to the machine is only partial, because the radiologist still has to interpret the images (Blume 1992). Women worry about false negatives and how certain it is that every sign of cancer is found on the mammogram. Knowledge of others who have had undetected breast cancer after participating in the screening program makes women reflect on how this can happen. Failure to detect cancer make them question mammography and its interpretations. Some of the women explain false negative diagnoses and other uncertainties in terms of how the technology works, in particular that it leaves parts of the breast unexamined. Experiencing the mammography examination as an assembly line makes women reflect on whether or not it is positive for radiologists to have so many images to interpret. The women appear to be aware of the possibility of human error whether expert or not, although awareness of uncertainties about how to interpret mammograms are less present in the focus group data than in scientific debate generally (Elmore et al. 1994). Women participating in the Norwegian mammography program seem to have faith in this expert knowledge, even when acquainted with uncertainties and are, at some point, persuaded by aspects of mammography. The image is seen as visual proof of the breast beneath the skin, leading them to take the "leap of faith." Therefore, what can be seen and what is not seen is essential for the success of the screening program.

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Paper III

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Paper IV

Article

Focus Groups in a Medicine-Dominated Field: Compromises or Quality Improvements?

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Abstract

Mammography screening has traditionally been viewed as a field for medical research. The medical science discourse, however, is highly quantitative, and its claims for validity somewhat opposed to those of qualitative research. To communicate research in a cross-disciplinary field, it is necessary to adapt one's research to several paradigms. The authors conducted focus group interviews with women due to be screened in a national breast cancer screening program. Their prospective design, both strategic and random sampling, and free discussions during focus groups are all questions of satisfying a medical science discourse in the frames of qualitative research. Focus group research showed itself adaptable through the data collection phase in a cross-disciplinary research project on mammography screening.

Keywords: focus groups, qualitative methodology, mammography, screening, multidisciplinary research

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In this article we present reflections on our experiences regarding the role, design, and effectiveness of a qualitative research project on mammography screening. In Norway, as in the world at large, mammography and screening have traditionally been seen as located within the medical field. Although qualitative research in medicine is far from a new invention, the medical discourse is dominated by a quantitative, evidence-based logic (Grypdonck, 2006). Clinical and epidemiological studies have dominated research on mammography screening. These have focused mainly on the core issues for policy, namely the safety and effectiveness of mammography screening (Gotzsche & Olsen, 2000; Nystrom, Andersson, et al., 2002; Nystrom, Rutqvist et al., 1993). Throughout these discussions arguments are focused primarily on numbers and survival estimates. Other issues addressed have been treatment options in connection with screening; psychological research, which has also to some extent been included through research on anxiety levels for participants (Brodersen, Thorsen, & Cockburn, 2004; Brunton, Jordan, & Campbell, 2005); and how information about medical screening should be given to secure participation in the screening programs (Ahmad, Cameron, & Stewart, 2005). These kinds of research can be seen as playing a supporting role in a field where medical expertise has had the leading role in decision making, execution, and research, even though recent decades have seen a rising consciousness of patient or lay rights in what traditionally have been seen as medical questions (Lerner, 2001).

A question is how medical dominance of the discourse affects how and why research on subjects is carried out. One might also ask what the pursuit of other research questions and methods might give to the dominant medical discourse. Even though quantitative, evidence-based research gives important information on biomedical issues (Hetlevik, 2004), it has clear limitations when it comes to producing knowledge about, for instance, patient experiences or lay perspectives on health issues.

A screening program for breast cancer had been initiated in Norway in 1996 and was becoming nationwide during 2003, when we conducted our study. We knew of only one study of women's experiences as participators in the program (Hofvind, Wang, & Thoresen, 2003). Hofvind's study was survey based and quantitative, and our multidisciplinary research group chose to carry out focus group interviews to explore women's experiences and lay perspectives on mammography screening. Because of the strong dominance of numerical arguments on the field of screening, we opted to provide "new" knowledge to both medical professionals and policy makers. Despite several studies using focus groups on health issues (Bender & Ewbank, 1994; Waldorff, Bulow, Malterud, & Waldemar, 2001), including studies of mammography (Pfeffer, 2004b; Willis, 2004), throughout the project we were frequently faced with critical questions concerning the qualitative nature of the research. This led us to ask how our qualitative research might be secured and what impact it might have in a field where quantitative studies are the norm.

Communication problems between paradigms

Different research methods have somewhat different theoretical bases and different views on what it makes sense to study. There is not one standard approach to qualitative research, but one might claim that a constructivist approach dominates, just as there is not one standard approach in medical research, although a natural science ontology dominates (Silverman, 1993). The main features of qualitative research might be said to be that it involves examining social phenomena in their natural environment, attending to commonsense assumptions about what constitutes a field, and doing theoretically driven research rather than research driven by technical considerations (Silverman, 1993).

One assumption that qualitative methods share is an acknowledgement of the role of the researcher in both creating and analyzing the data. Although there are different approaches to researcher presence in qualitative research, there is a certain acknowledgement of the researcher as the analytic interpreter of the material (Gubrium & Holstein, 1997). This has led critics of qualitative research to point to what they see

as the lack of objectivity in data materials and analyses. For instance, Weinberger et al. (1998) have discussed the reliability and generalizability of interpretations of focus group material. One response to this is that qualitative data can be said to take better care of objectivity when studying “objects” existing in a context of language and social relations than methods developed to study nonhuman spheres, such as the methods of the natural sciences (Kvale, 1996).

One aspect of medical discourses is the use of numbers such as statistics in medical arguments, with emphasis on evidence-based medicine and randomized controlled trials (Hetlevik, 2004; Makela, 2004). In a Swedish study physicians were shown to evaluate quantitative and qualitative research differently (Johansson, Risberg, & Hamberg, 2003). Quantitative abstracts were acknowledged for their scientific accuracy, whereas qualitative abstracts were seen as less scientific and accurate but nonetheless clinically relevant. This can give us a notion of how medical professionals think about science and its status. Nevertheless, qualitative research is not unknown in medical journals. Both *The Lancet* and *BMJ–British Medical Journal* have published papers on qualitative research methods during the last decennials (Malterud, 2001; Mays & Pope, 1996). Still, without pushing too far, we will claim that medical science discourse is primarily quantitative and oriented toward naturalism and realism.

Even within this general orientation, however, different medical specialties have different approaches to quantification of data. Different orientations can be exemplified by looking at how tools to deal with breast cancer risk have been met with uneven acknowledgement by different medical groups. Breast self-examinations, “breast awareness,” and public mammography screening all have their supporters in different strata of the medical profession, where epidemiology and radiology are most in favor of mammography (Pfeffer, 2004a). One reason for support from epidemiologists is that mammography can be seen as innovative among screening programs for having been evaluated by means of randomized trials to estimate the potential for reducing breast cancer mortality (Morabia & Zhang, 2004).

Epidemiology is based on the use of large amounts of quantitative data materials (Rothman & Greenland, 1998). Epidemiological evaluations of randomized controlled trials have been one of the main sources of arguments in medical science discourses both in favor of and against organized screening. Randomized controlled trials have been seen to generate facts, as opposed to nonscientific or “emotional” arguments (Lerner, 2001). Nevertheless, when clinical and epidemiological arguments are in confrontation, clinical research tends to “trump” epidemiology, but in material on mammography screening it was difficult to test splits between epidemiologists and clinically oriented authors, perhaps because both directions have reached the same conclusions in this case (Sætnan, 1992).

Our choice to use qualitative methods to study lay perspectives on mammography screening was based on the fact that it had not been much studied, so there were no clear hypotheses to be “tested.” Rather, we wished to gather whatever meanings were out there, with only loose reins on the discussions. Quantitative methods presume that one knows in advance the relevant categories and that these can be measured accurately. We wanted to open up space for unknown categories of lay participant experiences and consequently chose to do qualitative research by using focus groups.

Nevertheless, even when exploring a new field, it is the researcher who formulates the questions for the interview. He or she is thereby setting an agenda and at least in part deciding the kind of knowledge that is relevant for the research question. One strength of the qualitative interview is still that the researcher may alter the design or add questions to the interview guide when knowledge of new issues is developed. The interview participants can also challenge the assumptions underlying a question, thus changing the direction of an interview. The possibility of altering questions according to responses among interviewees has been questioned by quantitative researchers asking how one can generalize from such data. Trying to communicate with research participants and other scientists in a way that made sense, we experienced

ourselves as in “a squeeze” between different discourses. In the following we discuss some paradoxes that emerged during our study.

Our study

During 2003 we conducted a set of focus groups to study how women invited to a mammography screening program interpret screening and breast cancer. Focus groups were chosen primarily because we wanted to get in touch with how women experience being part of a screening program for a potentially fatal disease and hear how they talked about their experiences while among their peers. The study focused on women’s conceptions of mammography screening, breast cancer, and risk; on trust and technology; and on being cared for or being frightened. Our findings will be reported elsewhere (Solbjør, in press).

The design of the study was prospective. We followed eight groups of women through their experiences of a screening, from invitation, through examination, to results and reflection. We did this by interviewing the groups at three points: before, shortly after, and 6 months after their mammography screening examination. Referring to previous experiences, we assumed that eight groups would be enough to reach data saturation. Selections from each of the four municipalities were split in two age groups: 50 to 59 and 60 to 69 years. Municipalities were selected to represent an urban-rural dimension, although we chose only communities that had population densities that made it likely that we could gather enough women for group interviews without them having to drive for hours to meet. Each group had 6 to 10 participants, with a total of 69 women participating in the study.

The group sessions were structured by an interview guide. The interview guide consisted of five questions, some repeated and some specific to the three respective sessions with each group. The questions were copied and presented, one at a time, to the participants. A moderator read the questions and kept control of the discussion so that it stayed within the research themes. Aside from this, the women were encouraged to speak freely and ask each other questions rather than asking the researchers. This will be discussed more thoroughly later in this article.

The prospective design

Our prospective design acknowledges the possibility of changing constructions over time. New experiences can change the way we feel and talk about our opinions and attitudes. It was therefore our goal to catch the women’s experiences of and opinions on mammography screening both before and after they had participated in the screening program. This choice was based on two influences. In the literature on psychological distress related to mammography screening, it is common to apply psychometric measures at various times in relation to the screening to measure the psychological effects of the screening (Brett, Bankhead, Henderson, Watson, & Austoker, 2005; Brodersen et al., 2004). The other influence was prior experiences with studying screening experiences with retrospective interviews. Such a design would also give interesting and valuable data, but they represented the participants’ reconstruction of their screening experiences rather than their constructions at the time of the screening.

For instance, during the first focus group interviews we found that women expressed uncertainty about how they would experience the mammography examination and what consequences it could have for them:

First group session

Interviewer: What are your expectations to the examination?

G: I hope they don’t find a lump . . . because yesterday I had a lot of lumps . . .

E: Did you check [your breasts]?

G: Yes, it [the invitation letter] said I should. "Tick this box if . . ." Found some lumps yesterday, but today it was gone. Thank God.

//

E: But about something else . . . I haven't been there, so I don't even know how it is done. So it is a question I would like to ask those who have been there before. Well, is it as . . . bad . . . like . . . It isn't that it is dangerous, I can take pain, right? But, is it good to be squeezed like that? So hard as they tell you it is?

G: It has been discussed. I saw a program about it on the television about this research that's been done in Denmark. And it wasn't good.

The experience of uncertainty was more or less marginalized during the second round of interviews. At that time women were more concerned about their experience of the particular examination and the work of those in charge of the program as well as about having the answer. The woman concerned about her potential lumps and participating in the discussion of negative consequences from mammography during the first focus group session seems to be little concerned when interviewed after the mammography examination:

Second group session

G: I thought it was all right . . . I hadn't expected any information either, so . . . not much more than about having the result in about four weeks. We don't need any other information, I can't see that. And about being called again [in 2 years' time]. . . . So I can't see what other information we should have had either. If we should have had any more.

Having women talk about their experiences with mammography screening at two different times during the experience gave somewhat different results. It is impossible to claim that one of these interviews gives the correct picture of women's experiences over the other. Our choice, therefore, addresses the validity of the data. Both constructions and reconstructions of one's life experiences should be seen as representing valid data, but they should also be seen as representing different phenomena. We wanted to study women's experiences as they developed in the context of medical screening and thus opted for a prospective design.

In medical research prospective designs are preferred over retrospective ones, as they are seen as superior with respect to both to validity and reliability. Our design might, hence, have a greater appeal to medical researchers than some other qualitative designs would, as it can be seen as created on a common ground, although from quite different epistemic perspectives. Nevertheless, one can ask whether the prospective design actually obtains greater validity or reliability than a retrospective study would have done. Is the assumption that women's notions of mammography can be grasped before they are influenced by an intervention like a screening program also acknowledging data as naturally given, as something that can be found in its natural state? We, rather, chose to see data as a changeable construction. This can be solved as a practical problem while collecting data, but it is important to discuss and be clear about one's perspective when doing analyses, not least when communicating results to different parties. We will look into this in more detail in the discussion.

Sampling and recruitment

As mentioned above, we chose to recruit focus group participants using both strategic and random sampling. Choosing a sampling process that gave credibility in both qualitative and medical discourses seemed like a good choice and has given us data material that can be communicated to several parties. When we were inviting women to participate in the project, our purpose was to inform them about our intentions and the nature of the project so that they could make an informed choice as to whether to

participate. An invitation letter was sent to women due to be screened for breast cancer. In it we gave a brief introduction to the project and a short description of how the focus groups would be carried out. We also made it clear that this was a cooperative project between our university and the Norwegian Cancer Registry.

Women wanting to participate returned a signed statement of consent to us and were later called to be reminded of the time and place of the focus group interview. During the phone conversation they were invited to ask questions. Despite our efforts to give sufficient information, we experienced that some of the women were unsure about the purpose of the project at the beginning of the focus groups. Some women understood it as being part of the breast examination, and some expressed that they participated because they wanted to contribute to medical research on breast cancer or as an act of solidarity with women who had breast cancer. This made us ask how our research project could be interpreted as having a strictly medical benefit and how these preconceptions might have influenced the data.

One answer to the first question is that we informed potential participants that our project was accepted by the Regional Committee for Medical Research Ethics, which initially locates the project in a medical context. Another potential answer is that lay perspectives on mammography screening are influenced by medical discourses, leading women to assume that all research in the field of breast cancer is rooted in medical science. This might have influenced how women talked and what they saw as important to report to researchers. A further question is whether it is possible to inform participants properly about how data will be used and interpreted (Bosk, 2001). Even though we informed the participating women of the purpose of the project, we cannot expect them to see the potential interpretations that will occur. After all, as researchers we discover new interpretations as we write up our results. This merely reflects that information will always be interpreted within a context.

Researcher participation and participator communication

The focus groups were conducted as discussions but still following an interview guide with preset questions. Questions were put forward in a standardized manner and in a set order. Each question led to a group discussion where the participants spoke freely about the issue in question. In this manner a focus group can be said to be both an interview and a discussion group.

As mentioned earlier, groups were directed by a moderator, who kept the discussion on topic by asking questions, inviting silent participants to join the discussion, and asking women to elaborate on their statements. Still, the main strategy at each group was to let the women discuss in their own ways so that we could hear their stories and perspectives. We chose to inform them that we (as researchers) would participate as little as possible during the discussion and that they were welcome to speak freely. Many women addressed the researchers with questions, especially during the first group session, as we can see in the example below:

S: I thought it was very good to have the invitation [to the examination], that is, it is like a push . . . I am trying to examine myself sometimes but . . . it's never on a regular basis, it's like now and then. Ought to do it more regularly . . . Don't know how often? Once a month or what? Can someone answer that? (*S is turning towards the interviewer*)

Interviewer (looking at the group): Anybody know? Anybody have thoughts about this?

A: I got this advice at the GP's once.

The group moderator turned the question toward the other participants in the group, and the discussion developed further through the other women's advice and knowledge. One choice that we made was to refuse to answer questions from the participants until the set of three focus group sessions was completed.

After the last session the women were given information about mammography screening and breast cancer based on the questions they had brought forward during the focus groups.

It is interesting to ask about the influence that a decision such as not answering questions might have on the group discussion and, furthermore, on the data we obtained. It is a paradox that although we were trying to obtain a normalized conversation between the focus group participants, as researchers we did not act in a manner normal to conversation in a group. In an ordinary group of people it would probably be considered impolite to refuse to answer a direct question. By choosing to observe more than participate in the conversation, we probably put ourselves at a distance from the participants, influencing how the women talked to us and to each other.

Participants were a bit reserved at the beginning of the focus groups. Eventually they spoke more freely as the first session progressed and even more freely during the second and third group sessions. Sometimes discussions wandered away from the issues put forward by the moderator, and she had to turn the conversation back on track. At other times they brought up themes that the researchers did not cover in their interview guide, such as issues related to family structures and “descending from healthy people” as well as the use of alternative medicine and their relations to general practitioners while living in a small community. All of these subjects were brought forward in connection to women’s experiences of participating in mammography screening and could hardly have been anticipated by a researcher.

This shows how focus groups are discussions to which the participants bring their knowledge, experiences, and attitudes but where these presumptions are stirred together with those of the other participants’ stories and opinions, thereby creating data from discourses and negotiations. Information lost in this process includes thoughts that are considered unsuitable in a group setting but that might have been revealed in a personal interview. The idea of focus groups as a construction site for data is therefore an argument for the researchers’ staying out of the discussion.

On the other hand, one can see the choice to interfere as little as possible as a question of data biases. The idea of the researcher’s role as involving as little interference as possible to avoid bias is relevant in the more quantitative medical discourse. Another choice that was made early on was to omit the two most experienced focus group moderators in the research team from these groups. We saw the mere presence of a male moderator to be an unfortunate intervention considering the subject in question, no matter how the role was played. Having a doctor as moderator might also influence how focus group participants act during the discussion (Reventlow & Tulinius, 2005). Again, this choice can be defended from two points of view. From a natural science standpoint, using moderators less likely to evoke specific notions as to the topic of discussion can be seen as restraint from intervention. However, we did see that having two young women as moderators had some effects on conversations: The participants often took a motherly, instructive, or protective tone toward the moderators, a form of bias but a data-productive one. From a constructivist standpoint, our choice of moderators could be viewed as avoiding putting constraints on participants’ data-building conversations. From that standpoint, too, the choice can also be critiqued: What interesting exchanges, shifts of focus, and elisions might we have seen by inserting a man or a physician into the setting?

Discussion

Our research group aimed to perform multidisciplinary research acceptable and valid in both medical and qualitative fields of science. Using focus groups to find out how women experience participating in a screening program for breast cancer means accepting certain scientific perspectives. The choices we made were influenced by both medical discourses and our qualitative approach, and have presumably influenced the data material. Wilkinson (1999) has pointed to the loss of epistemological clarity when interpreting focus group data. For us it has been a challenge to stay true to the philosophical ideas of qualitative

research while opting for communication of our results to several parties participating in the field of mammography screening. In the end, our project design became something of a compromise, with elements that can be interpreted in both realist and constructivist terms. One can ask why it is necessary to approach two methods with different, perhaps even contrasting, theoretical bases. We wished to communicate results so that they could be seen as scientifically valid and relevant to all parties in the multifaceted field of mammography screening.

It is relevant to ask whether it is possible to satisfy different epistemologies at the same time. The answer to this question is not a simple one and can be discussed on many levels. Others have seen data from focus groups as open to both essentialist and constructionist interpretations (Wilkinson 1999). We chose to approach the question in a practical manner; finding our way and testing possibilities in both directions while doing our research project. Our main choices have been presented in the previous sections of this article, and we will now discuss further the applicability of our approach to a multidisciplinary research field.

In an attempt to make our research communicable to others, sampling and recruitment of focus group participants had to be done according to the claims for validity in different scientific traditions. Our strategic grouping by age and an urban/rural community dimension could be seen as a tool for producing variation, in keeping with a qualitative tradition, or as a tool for testing specific hypotheses, for example about the effects of age and closeness to “nature” as influences on health attitudes.

Where the most widely accepted medical perspective might be to avoid bias and variation in the data material, qualitative theories acknowledge the idea of methods as practice, craftsmanship that is shaped and recreated during the situation. How, then, can we manage to maintain validity and reliability for both qualitative and medical researchers? Perhaps the answer is that it is impossible to satisfy strict methodologies—the one way or the other—and that validity and reliability can be treated as more open concepts. For instance, validity is not destroyed by this variation in approach to the object under study. Rather, the multiple experiences and attitudes that women present during a focus group session are valuable to the research field of mammography screening. Nevertheless, researcher presence will probably always be a bias, and data’s reliability can never be guaranteed when the researcher behaves differently in each unique situation. Rather, one could ask about the concept of reliability’s relevance for a qualitative study. This challenge seems inescapable when one is presenting qualitative research to an audience favoring natural science epistemologies.

Our prospective design can also give room for more than one scientific perspective. It can be seen as showing how the experience of mammography screening becomes an element in the construction of the meanings of cancer and health. It can also be seen as isolating the invitation, the examination, and the results letter as separate factors influencing opinions.

An obvious question, then, is how this might have influenced our data and analysis. Is it possible to analyze data at the same time both as constructions of meaning among those studied and as determined by interventions from the outside? Our choice when interpreting the data has been to see the data as a process whereby women’s interpretations and constructions of meaning are influenced by the intervention; that is, the screening invitation, examination, and results letter. However, instead of looking at the data as isolated before and after the screening intervention, we chose to focus on how women use the invitation and the screening program as part of their ongoing, dynamic constructions of meaning about, for instance, cancer and health.

Whether our analyses will be accepted by either constructivist social scientists or realist natural scientists remains to be seen. It might be that in trying to obtain data on common grounds for both constructivists and naturalists, we have rendered it impossible for either to accept our study’s reliability or, even more, its

validity. Maintaining validity from two perspectives, namely the medical and the qualitative, seems possible with minor adjustments in both directions. Although this looks like a good hybrid between qualitative and medical research, one can ask whether it, rather, turned out as a bastard.

Conclusion

Mammography screening is entangled in medical discourses. Focus group research is based on theories of science that are partly opposed to the quantitative, or positivistic, medical discourse. Our research stands in the middle of a cross-disciplinary field, and our methodological and analytical choices reflect how qualitative research on mammography screening is in a squeeze between theories of qualitative research and medical discourses. The design of a study, sampling procedures, and researcher presence during data collection have different implications depending on the epistemological perspective of the researcher. It is therefore necessary to find a way to communicate to several discourses at once without rejecting one's own perspective. Focus groups can be seen as a solution to a desire to do qualitative research in a field dominated by medical discourse. As we have shown, the process of focus groups and analyses of the data can be interpreted from a qualitative, constructivist point of view as well as from a more naturalist, or objectivist, perspective. Nevertheless, when we are analyzing data, the question of data perspective always remains. This makes focus group data valuable in a field of complex knowledge such as mammography screening.

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