

**WOMEN'S EXPERIENCES WITH MAMMOGRAPHY SCREENING
THROUGH SIX YEARS OF PARTICIPATION – A LONGITUDINAL
QUALITATIVE STUDY**

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ABSTRACT

In this article we explore women's experiences with six years of mammography screening. Regular and repeated mammography screening is promoted as an important tool for disease prevention among women worldwide. The purpose of the present study was to explore how continued participation in screening influence how women perceive screening and breast cancer. We carried out focus groups with 24 screening participants in 2003 and 2009. Our analysis highlights that while women were excited about the examination in 2003, it was perceived as routine in 2009. Waiting for the result became easier over the years, while stress related to receiving the results letter did not diminish. Knowledge of risk factors for breast cancer did not change. Personal risk assessments remained low, though high incidence of cancer among acquaintances suggested high risk for breast cancer among women in general. Analysis of participant experiences suggests that continuous participation in screening have led surveillance medicine to become a part of ordinary life.

Keywords: Mammography, screening, medicalization, breast cancer, qualitative, focus group, longitudinal, Norway.

Breast cancer is the most frequent female cancer in the Western world, and is the leading cause of death in middle-aged women. As a consequence its prevention has become a pertinent issue in modern medicine, which at present is offering a variety of preventive approaches to save women from dying from breast cancer. Selected groups of women, identified as having a high risk of getting the disease, are offered such preventive measures as prophylactic mastectomy or chemoprevention (i.e. in the form of Tamoxifen, see for instance Fosket 2003). Due to a lack of medical knowledge identifying risk factors reducible by lifestyle modifications, the vast majority of the female population is left with the option of early detection of cancer lumps by means of self-surveillance, check-ups by their doctors or mammography. In this article, our aim is to explore how repeated mammography screening affects screening experiences of women who participated in several rounds of a national screening program.

Medical screening emerged during the twentieth century as part of the rise of surveillance medicine (Armstrong, 1995), making healthy populations eligible for medical intervention. The key element of screening is the pursuit of an early diagnosis to be made among asymptomatic individuals (Armstrong, 2012), leading to therapeutic measures that are believed to have risk reducing, life prolonging or even lifesaving outcomes. Although heavily contested among medical experts, mammography is among the most widely spread forms of screening in the western world today. In current health discourse mammography screening is presented to women as a means of protecting themselves from the embodied risk of breast cancer (Kavanagh & Broom, 1998).

Addressing the healthy population, surveillance medicine is regarded as a vital contribution to the rising medicalization of life in the modern society (Conrad, 2007). Surveillance is about securing future health outcomes, about reaching for health through acting in the present to secure the future (Alexias, 2008). Historically medicalization has been seen as a means of social control in the hands of the medical profession, and women's bodies have often been portrayed as the favourite subject of this control. More recently, however, the pharmaceutical industry has been attributed a more central role, as the 'engine' behind current medicalization processes (Conrad, 2007). Acknowledging

the intensifying and increasingly complexity of medicalization in latter decades, the term biomedicalization has been introduced in the analysis of a set of intertwined processes (Clarke, Shim, Mamo, Fosket, & Fishman, 2003). In these developments patients in general have taken more active roles, as consumers and health activists, thus transforming them from victims of medicalization to promoters of it. Though biomedicalization rest upon the coproduction of sciences, technologies and social forms, for instance through randomized controlled trials as a gold standard for medical knowledge (Clarke et al., 2003), its impact on lay women's opinions is contested (Barker & Galardi, 2011).

In the biomedicalization era, health is an individual goal and a moral responsibility which opens up for routine biomedical intervention and surveillance practices (Clarke et al., 2003). Individual responsibility for attaining a healthy lifestyle and the internalization of such responsibility include self-surveillance and technological surveillance (Green, Thompson, & Griffiths, 2002). The ideals of autonomy and rational choice connect individual responsibility to words like prevention and prophylaxis, which have positive connotations in our society (Beck & Beck-Gernsheim, 2002). Beck & Beck-Gernsheim suggest the term *testponsibility* to describe the responsibility of individuals to participate in available health examinations. Women who are invited regularly to mammography screening seem to perceive participation as responsible behaviour (Willis, 2004; Howson, 1999).

Through the focus on risk and medical surveillance individuals have been presented with a new form of identity, depicting them as neither healthy nor sick, leaving them with the liminal status of being at-risk (Kenen, 1996). The at-risk identity takes various forms, however, depending on whether a person identifies his/her self as being at risk as an unavoidable consequence of belonging to a mortal species or has been identified as having a special risk that sets them apart from other humans (Scott, Prior, Wood, & Gray, 2005). In the case of mammography screening it thus becomes relevant to study how women who regularly participate in screening mammography integrate this knowledge into their identity.

Mammography screening

An important context for understanding women's participation in mammography screening is provided through current descriptions of breast cancer aetiology and the history of breast cancer treatment (or lack of it). Breast cancer history has been thoroughly described within the North-American context (Aronowitz, 2001; Lerner, 2001; Kaufert, 1996; Klawiter, 2008; Montini, 1996). For a long time the only option against breast cancer was a symptomatic diagnosis followed by radical mastectomy (Lerner, 2001). Its history is described as a move from "heroic" surgeons conducting radical mastectomies and personal secrecy among cancer patients, towards campaigns to make women take part in early detection, women's rights to choose treatment, increased public attention, and the surveillance of risky populations. In Klawiter's account, the development through the first three quarters of the 20th century was a process of medicalization of breast cancer, while more recent developments could be framed within the concept of biomedicalization due to its focus on risk and surveillance (Klawiter, 2008). Mammography was initially developed as a diagnostic tool for breast cancer, but during the 20th century it was increasingly used to search for pre-symptomatic disease. Such use contributed to a movement of the mammographic gaze into asymptomatic populations, constituting adult women as risky subjects in need of surveillance (Klawiter, 2008).

This development saw the rise of organizations embracing screening. What is now labelled as the breast cancer movement has been a force in health policies in the US in recent decades (Lerner, 2001), campaigning for breast awareness and early detection to save lives. From 1991, the National Breast Cancer Coalition has worked to increase research funding, treatment for all women, and the role of women in health policy decisions, as well as increased access to screening (Lerner, 2001). In Norway the Norwegian Breast Cancer Association which was founded in 1992 has been pro-screening. Politically, various women's associations made unified efforts to ensure the national implementation of a public and national program for breast cancer screening in Norway during the 1990s. One important argument for such a program was to avoid "wild" screening, which involved privatised screening without proper systems for timespan, follow up of findings, and social

stratification of screening uptake. Prior to the national programme, women's health organizations organized mammography screening group travels from rural areas to private mammography units all over Norway. As such, the public program was perceived as overdue, and received strong support among its target group when the national mammography program was initiated. This support is reflected in its participation rates, which have remained above 75 per cent after four rounds of screening (Hofvind et al., 2007).

Publicly financed mammography screening programs are running in most European countries (Holland, Stewart, & Masseria, 2006). In Norway, all women aged 50-69 are invited to mammography biennially. Receiving an invitation to screening seems to influence women's decisions about participation (Østerlie et al., 2008; Forss et al., 2001). When self-surveillance is not enough, screening allows women to take further responsibility through accepting participation in a screening program when invited (Howson, 1999; Pfeffer, 2004a). Especially within the European context, the framing and timing of screening invitations might be of importance. Another contributing factor is the public's trust in authorities, which is high in Norway, as in the other Scandinavian countries (Listhaug, 2005). Perceptions of breast cancer risk and early detection as important for survival have been identified as reasons for participation in mammography screening (Hay, McCaul, & Magnan, 2006; Lagerlund, Hedin, Sparen, Thurfjell, & Lambe, 2000; Willis, 2004; Saidi, Sutton, & Bickler, 1998; Pfeffer, 2004b; Silverman et al., 2001), although government recommendations have been described in some contexts as sufficient for participation despite little knowledge about breast screening (Prinjha, Evans & McPherson, 2006). Women may perceive breast cancer screening as a reassuring preventive initiative (Brodersen, Siersma, & Ryle, 2011). Women's beliefs in the benefit of mammography screening's remain strong even when facing statistics indicating otherwise (Barker & Galardi, 2011).

In order to increase its effectiveness, screening should be performed repeatedly. The routine aspect of screening participation may, however, influence how women experience cancer surveillance (Howson, 1999). Reoccurring tests such as mammography might even be a (bi)annual reminder that

the body is, or should be, under surveillance (Kaufert, 1996; Kaufert, 2000). Seeing participation as a routine or habit may contribute to give screening an air of a normal and naturalised practice in women's lives, maybe even an obligation (Howson, 1999; Willis, 2004). Such routinization may be understood as how medicalization becomes a feature of daily living: what was a contested medical intervention when it first appeared in lay peoples' lives has been transformed into a normal life event as time goes by (Anderssen, 2010).

Women who have participated in mammography screening during several rounds are examples of individuals who have been submitted to - and submitted themselves to - organized medical surveillance. Long-term screening participation may not only potentially influence women's lives but also our cultural interpretations of health and illness. Therefore, we asked how such long term surveillance influence knowledge of breast cancer and screening, and women's rationales for participation. In this article, our aim was to explore how women experience long term participation in mammography screening, how it influences their perceptions of personal risk for breast cancer, and how it has become another example of medicalization in their lives. Drawing on data from repeated focus groups with mammography screening participants, we asked how their experiences of mammography screening participation developed during six years and three rounds of screening.

THE STUDY

Focus groups are particularly suitable for exploring how individuals who have similar experiences interpret such experiences (Barbour & Kitzinger, 1999). As all Norwegian women aged 50-69 are invited to mammography screening, focus groups would enable the exploration of dominant discourses. We thus performed a prospective focus group study of women's experiences with mammography screening during a six year period. The prospective design allowed us to explore how their experiences with mammography had developed after three rounds of screening.

The first rounds of focus groups were conducted in 2003, following the implementation of the nationwide mammography program (Østerlie et al., 2008). Women from four municipalities in the

counties of Sør- and Nord-Trøndelag who were first time invitees to the screening program were randomly selected and received an invitation to the study by mail. Participation was based on their written response to a personal invitation to participate in our study. In 2003, 35 women aged 50-59 participated in four focus groups. Each group met three times: right before, right after, and six months after their first screening in the Norwegian breast cancer screening programme. In 2009 we approached these 35 women again to recruit them to a new round of focus groups (see flow-chart, figure 1). Two women were not found, and another two who were reached by phone did not wish to receive further information. Thirty-one women agreed to receive an information letter about the new focus group study. Twenty-four women agreed to participate. In 2009, these women had become 55-64 years old, and had, if not dropped out, participated in three screening rounds.

All focus groups took place at a meeting room in a public building in each of the four municipalities. Each group consisted of 8-10 women in 2003 and of 4-7 women in 2009. Groups were put together according to age and geographical criteria. Homogeneity within a group is often necessary to have access to participants' personal experiences (Morgan, 1996). Each group meeting lasted for about two hours. The interviews were conducted as conversations between the participants about their experiences with mammography screening. The conversation themes came from a semi-structured interview guide and participants were given one question at a time. The interview guide for 2009 was a modified version of the three interview guides that had been used for the three rounds in 2003. Authors MS and WØ acted as moderators in all of the groups.

All group discussions were audio-recorded and transcribed verbatim. The transcriptions from each round were read by at least one researcher, and all authors read at least one transcription. Themes rising from the first reading were discussed within the group and a list of codes was developed. All interviews were categorised within these codes. We used an interpretative approach to the analysis through identifying codes, categorising data and interpreting the meaning content of the categorized data within each code (Kvale & Brinkmann, 2008). In 2003 we had identified twelve main codes and several sub-codes, of which analyses have been presented previously (Østerlie et al., 2008; Solbjør,

2008). These analyses became a backdrop for analysing the 2009 interviews. We did, however, attempt to read the new interviews without referring to the old codes, in order to detect new themes that might have developed since the first data collection. After identifying new themes and coding the newest interviews, we re-read the first set of interviews to interpret them in light of the new codes from the 2009-interviews. During the analysis of the 2009-data and re-analysis of the 2003-data, we used NVivo 8.0 for cataloguing purposes.

The study was approved by the Regional Committee for Medical Research Ethics and was based on the participants' written informed consent. All names have been altered to secure anonymity.

FINDINGS

In 2003 more than half of the interviewed women had been to mammography on their own initiative, but the public screening programme was new to all. The invitation letter to screening had led them to overcome the threshold mile and guided them into participation (Østerlie et al., 2008). In the following we present findings from the development of these women's screening experiences from 2003 until 2009, and their reflections on their continued participation. There were two meeting points with screening services that will be described in this article: the mammography examination, and receiving the results letter. In the presentation of quotes, individuals are identified by reference to woman (anonymized), group number and interview round (round 1: before first screening, round 2: shortly after screening, round 3: six months after screening, round 4: six years after first screening).

The examination

Being first time screening participants was exciting. Before the first mammography examination, those new to mammography had many questions about how it was done and how it would feel. After participating for the first time, being part of a production line was a frequent description of screening participation. Communication with staff at the mammography clinic was experienced as

friendly, but effective. For some women, this meant having too little time to ask questions or being soothed from their worries.

“...so, when I met the first one – she was very talkative and had plenty of time- but the others were quicker and wanted to..., cause there was a queue, you know, inside them boxes, I was about to say, where we sat waiting. So clearly they, there wasn’t much communication with them, then. There was no need for it either. I reacted a bit then ... they talked too little to me, I felt like being on a production line, as it were. I felt that... think they could have made more conversation.” (Else, group 1, interview round 2)

Screening providers and participating women may have different needs when they meet at the mammography examination. Screening participants need information and reassurance about the examination, whereas screening providers need to secure production. The first meeting with the production line was uncomfortable for the participants. After six years, the production logic had become familiar. Marianne, who had been curious and anxious about mammography as a first time participant had learnt how to behave during the examination, not asking too many questions that would delay the screening production.

“Well it may be, if you’ve got any queries it might be a bit too effective, but I haven’t had many questions anyway. The first time I was more concerned, but then you become like them after a while. You know how to adapt and just listen, that’s how it is.” (Marianne, group 2, interview round 4)

Through continued participation the women adapted to the rationality of the screening programme. Their individual needs came second to the effectiveness of the system that could save lives. Such adaptations also encompassed issues of pain. Pain during the examination had been an important theme for the women in 2003 but knowledge of how it would feel decreased worries about pain. Moreover, improvements were credited to new technology, though some still experienced

considerable discomfort. However, when deciding upon continued participation pain could not trump the perceived benefits.

“When you see the big picture, my view is that this examination is just a triviality you must go through.” (Laila, group 3, interview round 4)

A short time of pain had to be endured in order to have the benefit of screening. In comparison to making an effort in preventing serious breast cancer, women’s bodily sensations became secondary to the perceived benefits of having the medical examination.

Waiting for and having the result

During the first round of screening, all had not been well informed about how they would receive the result if suspicious findings were seen to have appeared on the mammogram. Having the result could take up to five weeks in this hospital district, which felt long for first time participants. For those who worried most during their first round of screening, waiting for the results letter meant a prolongation of their worries. By 2009 most participants gave screening little thought while waiting for the results. After six years, they had become “professional” participants who knew the course of a screening round, including having the examination and waiting for the result. Continued participation had led to the routinization of screening. However, waiting for the letter provided a paradox. Screening as a routine examination did not hide that breast cancer could be a possible outcome. Thus, waiting was a mixture of oblivion and sudden glimpses of unease.

«No, I don’t think about it every day, but ‘Dearest, shouldn’t there be an answer now’, I thought to myself one day.” (Anita, group 4, interview round 4)

What was left un-routinized was receiving the results letter, which had become more stressful over the years. Having the envelope was a reminder about breast cancer, and the necessity of screening became materialized in the results letter.

«I don't give it much thought, really, but as you say, it's good to be called in cause then you don't have to take care of it yourself. But of course, when you receive that letter you're a bit tense anyway about what it'll tell. [...] Before you open the envelope you feel a sting, like.»
(Eli, group 3, interview round 4)

«You were really tense when you got that envelope. [...] Cause it may change a lot in two years. Even if you're healthy once you don't need to be in two years' time.» *(Britt, group 2, interview round 4)*

Breast cancer developing without symptom presentation was a source of worry when receiving the results letter. Having had mammography previously did not guarantee being free from breast cancer two years later, which was a reason for continued participation in screening. This left women with uncertainties about their own judgements of being well. Those who had experienced a previous recall from screening expressed increased anxiety from having the result letter. But a false positive finding was also reassuring. It indicated that the screening services actually paid attention to changes in the breast.

«They're keeping tabs. But as you said, they look... there was something they saw. I remembered when you said it. I can't remember anymore what it was but it was something they pointed out: "there you've got something that you haven't had before", but I can't recall what it was, so it wasn't anything dangerous. But they were very scrupulous that way. But then I thought about if it is false reassurance, really. Is it like "well, now I can just relax?" I don't go around being scared, really.» *(Vigdis, group 2, interview round 4)*

Vigdis, who had previously been recalled, worried about screening providing a false sense of security for women. For those who had never been recalled, having the results was re-assuring. It felt good to know that one had been tested with available tests, and to receive a confirmation about being without breast cancer. The worry some had when receiving the response was dismissed after reading

the good result. Ultimately, medical technology had provided safety and a good feeling for those participating in mammography screening.

"yes, I feel good when I receive that letter and all is well. Then I feel safe. Now I've been examined and... Yes, that makes me feel good." (Mette, group 4, interview round 4)

Why continue screening - breast cancer risk and reassurance

In 2003, risk factors for breast cancer appeared diffuse for these women. They referred to general views on cancer risk, such as genetics, nutrition, smoking and exercise. Among the specific factors mentioned for breast cancer were pregnancy and breast feeding. It was, however, established among the women that preventive measures against breast cancer were difficult to find.

«One knows very little about it. You've never heard what to avoid, what not to avoid, and so on. You know it should be five fruits a day. It's sort of what... Prevention of breast cancer, I've never heard of it, not at all. The only thing is that if you discover a lump, one should react instantly and have it dealt with. But whether there's something one could positively do one self, such things I've never heard about. Cause there are people who've been healthy and well and exercised and done everything, and suddenly they get it anyway."(Solveig, group 1, interview round 1)

Among the first time participants in the national mammography screening program, breast cancer risk was seen as part of a general argument for mammography screening. Knowing other women who had cancer led to a perception of cancer as a high incidence disease, but this knowledge rarely influenced how they saw their own risk. Individual risk factors played a subordinate role in their reasoning about screening. Rather, arguments contained general descriptions of women's health risks and solidarity with others who had breast cancer. Moreover, the fact that the health authorities spend resources on a mammography screening program was seen as an indication of women being at risk.

«It has sometimes occurred to me that it's important, and that you examine yourself.

Maybe I've thought a bit more about it as I've been once before too. But when you've been there and you hear there's a lot of breast cancer around, and the authorities go for it, it's struck me as important, that you must be careful to examine... (May, group 3, interview round 3)

After six years of participation, changes in breast cancer knowledge were negligible and their knowledge about risk factors for breast cancer remained vague. Personal experiences influenced which risk factor they focused upon. Hormone replacement therapy and breast feeding were discussed by those familiar to it. Genetic disposition remained the most important risk factor for breast cancer, which freed most from feeling at risk since it did not "run" in their family. Age was acknowledged as a risk factor but not all saw older age as implying increased risk. All knew younger women who had been diagnosed with breast cancer, indicating that age had a modest influence on breast cancer risk.

«I must say the same, cause I've never considered it, cause no one in my family has had it, so I don't go around thinking about it. I don't think I'll have it. Besides, I'm too old now, anyhow (laughter)». (Else, Group 1, round 4)

«I have a niece who's waiting to die [from breast cancer] any day now. She is 52." (Jorunn, group 2, interview round 4)

As they had grown older, incidence rates of breast cancer had raised among their acquaintances. Some had relatives with cancer. Others had heard frequently about people having cancer, although this observation was not restricted to breast cancer. Knowing others with cancer gave them a sense of being at risk. The impression of cancer striking in what appeared to be a random fashion provided a source of alert. If cancer could strike others, they could not be certain to walk free themselves. Cancer appearing fast, without being detectable by one self was particularly frightening. Medical and technological surveillance became the solution.

Ragnhild: «Should have sent us all through a machine every second year, checked everything.»

Eli: «When you hear about everybody that has cancer, we should've done so, for sure.»

(Group 3, interview round 4)

Not only had other persons' experiences influenced their views on breast cancer risk. Having been recalled after screening strengthened these women's views about the necessity of screening. But also participation in itself had a reinforcing effect. Marianne had been one of only a few sceptics before participation in round one. After six years, participation had convinced her about the benefits of screening, even though she had not worried about breast cancer before participation. Her turn from sceptic to pro screening was saluted by the others.

«No, I didn't feel insecure before. I started late, you know, too late really, but I wasn't insecure. I thought it was a strange kind of nagging they were at. Everybody was talking about going to the city by bus to have an examination. I thought it was nonsense. I did it, so I wasn't feeling insecure.[...] Now I think that.. I understand that we are at risk and why I probably get to know now. But I knew that we were at risk from fifty or so, or in relation to menopause, but if I'd have done it anyway, I think I would have waited a bit longer.[...] It wasn't really because it was mammography, but no one ever spoke about what it really was about. "...but now I've woken up" (laughing).» (Marianne, group 2, interview round 4)

Participating was not so much about detecting cancer as of getting reassurance about being free of cancer. With breast cancer being perceived as unpreventable by means of life style, screening participation was the sole option to act on it. Participation gave a sense of gratefulness towards a system that took care of them. Though not seeing themselves as being at high risk, they relied on mammography screening to confirm that they were healthy, as presented by the conversation from group 1, interview round 4:

Solveig: «I go there to get the confirmation that I am well.»

Ingrid: «Feel safe, yes.»

Else: «So do I.»

Ingrid: “Safety, quite simply.”

After three rounds of participation, the reassuring feeling of having an all right-answer trumped negative sides of participation. Having participated led to a sense of tranquillity, of having done what could be done. Even when knowing that mammography is a fallible technology, having professionals conducting and interpreting results led to a feeling of safety, of confirmed security – at least for now.

“Something may arise in the meantime and it isn’t one hundred per cent certain, it’s not one hundred per cent guaranteed that they spot it on mammography. But it is better to do it anyway, that’s my opinion.” (Hilde, group 3, interview round 4)

In the end, it was the feeling that “you can never know” that led these women’s urge for reassurance. Detection of asymptomatic breast cancer was impossible without submitting to the screening regime. The need for reassurance suggests that women are dependent on mammography screening. If they would not be called in, they would make other arrangements in order to be on the safe side. But being inclined to have screening mammography did not imply being anxious. Rather, being at risk for breast cancer left every woman with a worry for breast cancer that was perceived as a normal state of mind. As one woman put it, her worries about breast cancer were just “average”.

Ann: «I feel the standard worry about breast cancer.”

Interviewer: “And what is the standard worry?”

Ann: «We are all a bit anxious, I believe. But we don’t go around thinking “what if we get it any day soon”, never like that.” (Ann, group 3, Interview round 4)

The average worry for breast cancer was not about high levels of anxiety. It was not breast cancer risk factors that worried them, but rather an all-embracing sense that women are at risk for breast cancer. Within such a discourse, the benefits of screening became indisputable.

DISCUSSION

In this study we have explored how women experienced participation in mammography screening through three rounds and six years from being new to screening in 2003. To our knowledge, no other studies with repeated interviews with mammography screening participants have been conducted.

Our main aim was to explore how women's experiences with screening developed. Secondly, we aimed to study how long-term screening participation contributes to medicalization.

Participation in mammography screening through three rounds and six years left screening as a naturalized part of these women's lives. It served as a reminder of their mortality at regular intervals, but only for a limited amount of time, thus making the burden bearable. It can soon be forgotten and remain out of mind until the next screening round appears, which is quite similar to the reaction to mammography described by British women (Griffiths, Bendelow, Green, & Palmer, 2010). The naturalization of such experiences has been described as medicalization by Anderssen (2010), who by studying the medicalization of everyday life in a rural society over three decades found that despite being contested initially, changes in lifestyle were gradually accepted until nobody questioned them anymore.

In the present study, participating in mammography screening hardly changed these women's perceptions of their personal risk for breast cancer as being low. They did, however, introduce the term "average risk" based upon the apparent randomness of breast cancer which defined all women to be at risk, even without specific individual risk factors. Recent discourses on breast cancer include all women as being at risk of breast cancer (Fosket, 2010; Klawiter, 2008). Participation in mammography screening programmes is for most women initiated by an invitation informing women about the risk of breast cancer and completed by the reception of the screening outcome. Feeling at risk, screening might provide a degree of ontological security, a "peace of mind", at least symbolically (Willis, 2004; Howson, 1999). When health authorities initiate such programmes, it indicates that all women are involved in what has been described by Petersen (1997) as "the process of eventually becoming ill". Being at risk for a disease may leave individuals in a liminal status between health and

illness, causing people to seek out further health surveillance (Scott et al., 2005). Scott et al (2005) found that recognition of the liminal status was sharpest among those at “low risk”, leaving them to seek surveillance to avoid uncertainty. Timmermans and Buchbinder (2010) also suggest that patients who await a diagnosis following an ambiguous screening result are left in a liminal state with the term “patients-in-waiting”. Waiting for screening results did, however, not leave women in the present study in a liminal state. Screening could, however, be said to leave them with a sense of all women being “patients-in-waiting”, since all women (in their age group) were seen to be at risk for breast cancer. Womanhood itself thus became a state that eventually would lead to becoming ill.

The risk of becoming ill in the future may lead individuals to aim for the most prominent way to detect disease early. Visualizing technology is trusted to show correct results (Willis & Baxter, 2003; Solbjør, 2008; Griffiths et al., 2010). Women who participated in the 2003-study had high trust in the mammography’s ability to detect cancer (Solbjør, 2008). Even when having interval breast cancer, women seem inclined to trust mammography screening as a beneficial initiative (Solbjør, Skolbekken, Saetnan, Hagen, & Forsmo, 2012). The context of the Norwegian mammography programme is the welfare state which assures all inhabitants with health insurance, and high trust in public institutions (Listhaug, 2005). We argue that through having an invitation to the screening programme, participants are convinced of its relevance, thereby contributing to perceptions of all women being at risk for breast cancer. Having an invitation to participate is known to influence women’s decision making about screening (Østerlie et al., 2008; Forss, 2001).

Medicalization happens when medical explanations replace other interpretations of reality. In the context of medical screening this can be the case when a person that hitherto has perceived herself as healthy perceives herself as a person at risk of a potentially lethal disease. Mammography screening results are seen by the women to provide more security than simply feeling healthy. The possibility of having cancer without being aware of it may provide uncertainty about knowing one’s own body (Forss et al., 2001). Also our present results support that trust in technology might replace trust in one’s own body. Especially after having the answer from a follow-up examination, women

might feel uncertain about whether their body is actually cancer free (Solbjør, Skolbekken, Sætnan, & Forsmo, 2011). A false positive screening result leaves women with less trust in their own interpretations of bodily signs, which again lead them to opt for more screening. Previous research varies in conclusions about how recall influences participation (Brewer, Salz, & Lillie, 2007). Women in the present study were convinced about the benefit of screening from having had a recall as it became proof of the importance of continued monitoring for pre-symptomatic cancer. It was difficult for these women to understand that some women refused to be screened. For women who are invited regularly to mammography screening, participation is seen to be responsible behaviour (Willis, 2004; Howson, 1999). Interpreting the acceptance of available health examinations as responsible action indicates that “responsibility” was accepted among the screening participants (Beck & Beck-Gernsheim, 2002). In late modernity, individual responsibility for health is vital. Though participation is an individual choice, the invitation indicates a moral obligation to do what is recommended by the experts (and health authorities). With few other options against breast cancer, participating in screening appears to be not only a responsible act, but perhaps the only viable action. Submitting their bodies to medical surveillance thus becomes a rational choice.

The women in our study base their participation on information acquired as a form of lay epidemiology rather than more scientifically based epidemiological risk estimates. Their everyday observations tell them that breast cancer strikes in what appears to be a random fashion, leaving little room for a clear cut identification of a ‘candidacy’, which has been the case with coronary heart disease (Davison, Smith & Frankel, 1991). Apart from genetically related forms of breast cancer, there is no hard medical evidence contradicting their notions, thus making participation in the screening programme an obvious choice as trustworthy alternatives have thus far not been provided. Trusting mammography to be beneficial may be seen as negligence of scientific debates over side-effects of screening, such as whether it leads to overdiagnosis of cancer (Jorgensen, Zahl & Gotzsche, 2009). Presented with information about overdiagnosis, British women were cautious about whether such information would deter other women to participate in mammography screening – a scenario

they would not wish for (Waller, Douglas, Whitaker & Wardle, 2013). Different forms of knowledge might give different answers to questions about the benefit of screening. Based on their own experiences of having been saved by mammography screening, American women with breast cancer argued against statistical data suggesting screening had minimal effect (Barker & Galardi, 2011). In Norway, the critical debate on screening effects have been carried out more in scientific circles while lay voices have been rather unison in their support of mammography. As long as mammography screening is also supported in governmental recommendations and policies of cancer organizations, individual opposition might be difficult or futile. Such common pro-screening alliances might also convince women to continue their trust in the dominant discourse on mammography screening.

Limitations

This study of women who had participated in a national mammography screening program through three rounds is limited by its lack of participants who had dropped out of screening. We have no information on whether study drop-outs also had continued screening. Two women who were approached in 2009 refused to participate due to anxiety in connection to screening. Apparently, those accepting the second research invitation were screening supporters. These analyses could therefore be understood as based on a dominant, but not exclusive, view on mammography screening.

A second limitation concerns the design with repeated focus groups. First, the repeated design gave “trained” group participants who had an impression of what researchers were after and who knew the kind of responses that would be sanctioned by other group members. One ideal for focus groups is that it consists of individuals who are unfamiliar to each other (Morgan, 1996). When seeking to illuminate experiences in relation to health it makes sense to have groups that might have occurred naturally (Barbour, 2005). In rural Norway, finding participants in the same age segment that do not know about one another is rather difficult. When they met again in 2009, women in all groups remembered and referred to each other. The conduct of the 2009-groups was influenced by

participants who already knew each other. However, such familiarity could also have contributed to expanded disclosure within the groups.

Conclusion

This is the first longitudinal qualitative study with focus groups that has been conducted with women participating in mammography screening. For these women who had been participants in the Norwegian mammography programme for six years, participation and waiting for the results became routinized. However, receiving the results letter remained stressful as it reminded them of the serious nature of the routine examination. As time went by, these women introduced the term “average risk” about their risk for breast cancer, pointing towards an understanding of all women being at risk simply through being female. This fits with what Klawiter (2008) has named the “biomedicalization” of breast cancer. Our results suggest that continuous participation in screening may contribute to surveillance medicine becoming part of ordinary life.

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