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Could screening participation bias symptom interpretation? An interview study of women's interpretations of and responses to cancer symptoms between mammography screening rounds.

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Title page

Title: Could screening participation bias symptom interpretation? An interview study of women's interpretations of and responses to cancer symptoms between mammography screening rounds.

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Article summary:

Article Focus

- Interval breast cancer comprises 28 per cent of cancers among screened women in Europe.
- Women who participate in mammography screening may delay acting upon breast cancer symptoms if they trust screening results to be correct.
- We asked women with interval breast cancer how they had reacted to detecting symptoms of breast cancer in-between screening rounds.

Key Messages

- Women who had participated in breast cancer screening interpreted lumps as symptoms of breast cancer and sought medical advice rapidly, despite having had a screening negative result. Some did, however, interpret themselves as delayers when seeking medical advice less than three months after symptom presentation.
- Only few women who detected a symptom of breast cancer in-between screening rounds delayed seeking medical advice due to being participants in mammography screening.
- It is essential that health care services take women's symptom interpretations seriously.

Strengths and limitations

This qualitative interview study is unique in studying the experiences of women with interval cancer and how they related their experiences with breast cancer to mammography screening. A limitation to the current study is that it is based on women's retrospective reports. Self-selection in responding to the invitation present a selection bias, women with advanced cancer might not have participated in the study, and participants could have been more resourceful than average.

ABSTRACT

Objectives To explore whether participation in mammography screening may have contributed to diagnostic delay among women with interval breast cancer.

Design Semi-structured individual interviews with women who have been diagnosed with breast cancer during mammography screening intervals.

Setting Two breast diagnostic units covering two counties in Norway.

Participants 26 women diagnosed with interval breast cancer.

Results Women with a screening negative result react in two ways when experiencing a possible symptom of breast cancer. Among 24 women with a self-detected palpable lesion, 14 sought medical advice immediately. Their argument was to dispose of potential cancer as soon as possible. Ten women delayed seeking medical advice. Practical reasons, uncertainty about having a symptom and previous experiences with illness or with medical personnel were reasons for delaying. Also, a recent negative mammography scan made some women assume that the palpable lesion was benign and wait for the next screening round.

Conclusion Participating in mammography screening could be a reason for a postponed reaction to a breast cancer symptom, though most women acted rapidly when detecting a palpable breast lesion. The participation in mammography screening does not necessarily increase awareness of breast cancer symptoms.

Keywords: Breast cancer, interval cancer, oncology, mammography, screening.

INTRODUCTION

Mammography screening aims to provide a pre-symptomatic diagnosis of breast cancer. Nevertheless, interval cancer, which is cancer detected between screening rounds, comprise 28 per cent of cancers among screened women in Europe.[1] Survival rates for interval cancers have improved during recent decades, [2] but remain worse than for screening detected cancers.[3;4] Such rates may be due to the aggressive nature of interval cancers, but may potentially also be caused by diagnostic delay.

Diagnostic delay does occur at many stages of the cancer detection process.[5] We will here concentrate on the patients' interpretation of symptoms and help-seeking. Early detection of breast cancer has been promoted throughout the 20th century, including women's responsibility to react upon a palpable breast lesion.[6-8] Recognizing a symptom of breast cancer is not always a straightforward process. Cultural contexts influence symptom experiences and bodily signs become symptoms only after an interpretation that they are abnormal.[5;9;10] The process from onset of symptoms until recognition that the symptom may represent a pathological condition may be the period of time accounting for the greatest proportion of patient delay.[11;12] Interpreting symptoms as cancer do not automatically lead to taking action. [10;13;14]

Mode of detection is associated with diagnostic delay, favouring mammography over self-detection.[15] The positive effect of mammography must be balanced against wider issues about whether patient delay could be induced by the reassurance given following a false negative screening.[16] A previous qualitative study indicates that women trust mammography screening to provide true results about their breast status.[17] The question addressed in this article is whether screening participation interferes with the women's symptom interpretation and help seeking. This study aims at exploring how women with negative mammography screening results react when they observe breast symptoms that could indicate malignancy in-between screening rounds.

METHODS

This was a qualitative interview study with women who had experienced interval breast cancer within the Norwegian breast cancer screening programme. This is a nationwide, public

screening programme that offers mammography biannually for all women aged 50-69. The study was approved by the Regional Committee for Medical Research.

Recruitment

Forty women diagnosed with interval cancer at two hospitals in Central and Northern Norway received an information letter about the study from their hospital. They were the twenty last women diagnosed with interval breast cancer at each hospital, living in or nearby one of four cities (inhabitants 9.500-150.000), counting back from six months before the study invitation was sent. Totally, 26 women accepted the invitation by returning a form of consent to the research group.

The interviews

Semi-structured interviews were carried out in 2009 by the first author (MS), at a hospital, a university, a hotel meeting room, or in the woman's home or workplace if requested. The women were invited to tell their breast cancer story, including how they detected the breast cancer symptoms. Each interview lasted 45 to 60 minutes, and was audiotaped prior to being transcribed in verbatim. All informants have been given fictitious names to secure anonymity.

Analysis

Two researchers read all the interviews independently, and all co-authors read some of the interviews. We used a method of constant comparison, comparing themes within and between interviews. All authors discussed themes arising from the interviews. We conducted thematic analysis.[18] Data were categorized using NVivo 8.0. Within each theme we found sub-themes which were subjected to meaning interpretation.[19]

RESULTS

Participants

The 26 participating women were aged 53 to 69 years, in average 59.4. Twenty-four women had discovered the symptoms of breast cancer themselves. Two were detected during other medical examinations. The women were diagnosed with breast cancer between three and 23 months after their last screening mammography and were interviewed from six to 36 months after having their diagnosis. At the interview, all had been surgically treated, either with mastectomy or with breast conserving surgery, 21 women had gone through radiation therapy,

and 14 had chemotherapy. Few women knew whether their malignant tumor represented a false negative mammography scan or a true interval cancer.

Fourteen women contacted the health care services within a week after noticing a palpable lump (Table 1). Eight women waited between two weeks and three months before seeking medical advice, and two delayed more than three months. There were no differences in type of symptom between the immediate help-seekers and those waiting for weeks or months, as all talked about having a lump. At least two women retrospectively reported symptoms such as mastalgia or breast contour change, but as they had not related it to breast cancer before being diagnosed. In the following we will present the women's own explanations for their timing when seeking medical advice.

Seeking medical advice immediately

Those who saw themselves as having sought medical advice promptly had all called their doctor's office or the mammography clinic at the first opportunity or at least within a week of feeling a lump.

"I detected it at eleven p.m. And there I was, with a glowing phone at eight a.m. (Laughter) Next morning, straight to the GP." (Johanne, 56)

The women who contacted their doctor immediately had no doubt about the possibility of having cancer. For them delay was no option after detecting a lump. In retrospect they had been certain that it could be a symptom of breast cancer. Thoughts about having cancer made acting upon it the rational option.

"I was very quick to get to the GP. I was certain it was cancer right away. […] I became very rational: Go to the clinic, make it go away."(Vigdis, 62)

Postponing seeking medical advice

Ten of the women had waited between two weeks and six months before seeking medical advice. Some of the women reported that they reinterpreted embodied sensations as possible cancer symptoms in retrospect, after being diagnosed. Prior to feeling a lump, they had either not noticed these symptoms or at least not interpreted them as symptoms of cancer. The women offered multiple explanations for what they saw as delay; neither explanations nor the help-seeking steps they refer to are mutually exclusive.

Uncertainty about symptom

All these women admitted that breast anomalies could often represent symptoms of breast cancer. However, their own bodily changes did not always stand out as definite symptoms. Being uncertain about the etiology of the breast change, it was initially interpreted as something imagined or something that could change back to normal.

"No you can't date it because you just sense it and consider it, and eventually it grows, so it could maybe have been a month or so. […] Yes, because it could potentially regress." (Cecilie, 67)

Olaug (63) and Eva (57) explained their lesions due to sore skin from a tight bra or to an inflammation of some kind, sensations and observations the women later interpreted as possible early symptoms of cancer. These women delayed seeking medical advice as the symptoms appeared too vague, for instance having an unpleasant sensation in the breast, nausea or tiredness. They interpreted their bodily sensations into everyday experiences. In retrospect, different bodily experiences were re-interpreted as breast cancer symptoms.

Previous experiences

Even once a bodily sensation was identified as a potential symptom there were many reasons to postpone seeking medical help. Previous negative experiences with health care services contributed to reluctance towards what might turn out to be an unnecessary medical examination. Those with multiple experiences with illness and disease were tired of being in the patient role. Prior negative encounters with health care services following diffuse symptoms gave a threshold for seeking help with diffuse breast cancer symptoms.

"I thought it might be an inflammation because I have had arm inflammations before and maybe that could have spread. And it was sore too. And one isn't too happy to go running to the doctor either. I did that all the time when I was younger, before I was diagnosed with arthritis, and with all that pain, so I'd rather not go (laughter). I got so tired when they never could detect what was wrong with me and I got all kinds of medications which damaged... […] So I am glad when I feel healthy and don't have to go."(Eva, 57)

Having had frequent visits to the GP made them uneasy about being seen as whimpering. This suggests that "being whimpering" or occupying health care services unnecessary were incoherent with their identity.

Practical reasons

There were also practical reasons given for delaying seeking medical advice. Two women had already a scheduled appointment with their GP when they detected a lump. Both waited until the appointment before bringing the lump to the doctor's attention.

"I had an appointment with the GP a few weeks after, so I waited until then. It was probably nothing anyway."(Gudrun, 60)

Noticing a lump during holidays also led to a delay in seeing the doctor. Actions after finding a lump were not solely about the lesion, but also about their social situation. Practical reasons were intertwined with other explanations such as interpreting the mass as benign or non-existent.

Mammography screening

For some of the women the essential argument for delaying was related to having participated in mammography screening. Two different time frames were important for this argument. One was about having had a negative mammography in the recent past. The other was about an upcoming mammography. Having recently had a mammography scan led some to interpret the newly discovered lump as harmless. Having trusted mammography to detect even non-palpable lumps, some of the women experienced as strange that cancer had not been found when attending screening. Petra, for instance, detected a lesion in April, but delayed acting upon it until October.

"I wonder if it [last mammography screening] wasn't in January that year. And that was probably the reason for my interpretation. Because I thought that when they hadn't seen anything then, it could not be anything now." (Petra, 66)

Being part of a screening programme made some women interpret bodily signs as not being breast cancer symptoms. One woman presented a forward-looking argument for delaying. She had started to wait for a screening invitation, but after several months with a growing tumour she called the screening unit asking for mammography.

"I started to wait for the [mammography] bus that used to come, but it never came. Right? It was too long to wait, because I felt this… […] Yes, because I'm usually called in. So I called

the hospital and asked them when the bus was due, and they said that it would not come until later that year, and she asked me if there was something specific I had on my mind? So I told her I had pain in a breast, but that I knew it isn't any danger when it hurts. "Go see a doctor", she said. So I called my GP that day, and got an appointment the next day." (Inger, 56)

Even when interpreting her lump as potential cancer, Inger delayed acting on it as she waited for the screening programme to act. The two women who had waited six months before seeking medical advice both justified their delay with their status as screening participants.

DISCUSSION

From this qualitative interview study we found that ten of 24 women who had been mammography screening participants put off seeking medical advice when detecting a palpable lump. Medically defined, diagnostic delay is waiting more than three months with a symptom before help-seeking. Though only two among 26 women with interval cancer were within this definition, the women who had not acted immediately considered themselves to have delayed the diagnosis. The four main reasons for waiting to seek medical advice for a breast cancer symptom were uncertainty about symptom interpretation, practical reasons, previous experiences, and being participants of mammography screening. To self-detect cancer, individuals must sense a symptom, acknowledge it as a symptom, and take action to seek medical advice.[20] It has hitherto not been known whether participating in mammography screening could influence any of these processes. What was unique in the present study was that all study participants had been participants in a mammography screening programme, and we explored whether screening participation could have contributed to a diagnostic delay.

Symptom interpretation of breast cancer can cause patient delay.[5;9-12;21;22] Palpable lumps are a well-known symptom of breast cancer that should induce seeking medical advice. All women in a Dutch study associated lumps with breast cancer.[5] However, studies vary in their conclusions about whether having a palpable lesion is associated with more or less delay than non-palpable symptoms. [13;23] In the present study, all the women referred to lumps when asked what had led to seeking medical advice. Other symptoms had only been subject to interpretation in retrospect after the cancer diagnosis. For these women, participation in mammography screening might have increased awareness about self-examination for lumps but had apparently not increased knowledge of other symptoms.

Delay in seeking medical advice cannot be explained solely by lack of knowledge.[24] All the women knew that a lump could be a sign of cancer, and yet some delayed seeking medical advice. Patient delay can depend on the patient's interpretation of bodily signs as related to cancer.[20] Although they knew in general that a lump could be a sign of cancer, some of the women did not immediately make that connection in their own case. As found in earlier studies, they did not expect to be ill and their current situation provided alternative explanations for their bodily experiences.[9] The present study indicates that participating in mammography screening may provide other explanations for bodily signs, since cancer had not been detected by mammography. Retrospective interpretations of bodily sensations as symptoms of breast cancer suggest that some had been reluctant to trust their own bodily sensations. In this sense mammography may contribute to medicalisation, leaving women to trust medical technology over their own bodily sensations. Another interpretation is that they were too frightened by the prospect of having cancer to react to potential symptoms, in which case screening programme participation was not so much a contributing factor to delay as it was an available excuse to avoid contemplating cancer.

The two arguments about mammography screening as reason for delaying seeking medical advice about potential breast cancer did suggest that having a public screening programme may lead to too much trust. Though only few women expressed such arguments, our study has revealed their existence in the population. Trusting previous screens to be correct may have led to non-cancer interpretations of symptoms. Waiting for the next screening round instead of acting upon a palpable lump indicate high trust in the correctness of a biannual design. The regularity of screening programmes offers to take responsibility for detecting cancer.

Delay has been an essential concept throughout breast cancer history in the US.[8] Cultural studies of breast cancer have been scarce in Norway, but media campaigns against delayed diagnosis have been implemented. These women's delayed actions must be understood within such a broader cultural context. Dominating the last decennials are discourses seeing breast cancer as a continuum, with one consequence being that women's breasts must be under constant surveillance both by themselves and by others.[7] As a consequence, surveillance becomes the sole option for responsible health behaviour. Though ten women in the present study claimed having delayed, only two women delayed more than three months. Those who saw themselves as having delaying had varied and complex arguments explaining their (in)actions while women who sought medical help immediately were certain they were doing

the right thing. Initiating mammography screening programmes may have increased the understanding of the importance of early detection, leaving individual women with responsibility for pursuing early detection between screening rounds.

Strengths and limitations

This qualitative interview study is unique in studying the experiences of women with interval cancer and how they related their experiences with breast cancer to mammography screening. Being interviewed about delaying seeking medical advice when detecting symptoms that later were diagnosed as cancer could be discomforting for those feeling guilty about delaying, leading to answers masking guilt. A limitation to the current study is that it is based on women's retrospective reports. Some had been diagnosed up to 3 years prior to the interview. "Pre-cancerous" experiences may not be the most important to remember after going through intensive cancer treatment, and could have been reinterpreted several times since experiencing them.

Nearly 65 per cent of those invited to the study chose to participate. All women with interval cancer within a specific period in these communities were invited, but self-selection in responding to the invitation present a selection bias. Women with advanced cancer might not have participated in the study. Despite their age and cancer diagnosis, only six of these women were fully retired, which indicates that participants could have been more resourceful than average. Due to long distances and the low population density in rural Norway, all invited to the study lived in or near urban or semi-urban areas.

We could expect cancer symptoms to be common in the population, with approximately 15 per cent of the population at any time having experienced cancer symptoms.[25] Women with symptoms in-between screening rounds could be classified in three groups: women who had an interval cancer diagnosis, women who found a benign lump, and women who delayed seeking medical advice until their next screening round. Only the first group were subject to this study, and more research on symptom interpretation among screening participants is warranted.

Implications

Confidence in mammography programmes influences the interpretation of breast cancer symptoms. Awareness of symptoms other than lumps must be improved. Though information leaflets provide information about interval breast cancer, women might not read leaflets

thoroughly. Additional verbal information during examinations could be one solution. Previous experiences of vague symptoms being set aside could lead women to neglect their own bodily sensations and prefer technology to give answers to their health status. Health professionals must take care not to define women as hypochondriacs when presenting vague symptoms but advise all individuals to present potential symptoms of cancer immediately.

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Table 1 Description of women who participated in study

Reaction time	**Detected though other medical examinations**	**1-2 days**	**Within 2 weeks**	**Less than 2 months**	**Approx 6 months**	
Age						Mean=59.4
50-54	0	2	0	1	0	3 (11,5 %)
55-59	1	5	3	1	1	11 (42,3 %)
60-64	0	3	3	2	0	8 (30,8 %)
65-69	1	1	0	1	1	4 (15,4 %)
Sum	**2 (7,7 %)**	**11 (42,3 %)**	**6 (23,0 %)**	**5 (19,2 %)**	**2 (7,7 %)**	**Total N=26**

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Ethics approval: The study was approved by the Regional committee for medical research ethics (REK midt) and informed consent was given by all participants.

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- Women who participate in mammography screening may delay acting upon breast cancer symptoms if they trust screening results to be correct.
- We asked women with interval breast cancer how they had reacted to detecting symptoms of breast cancer in-between screening rounds.

Key Messages

- Despite the last mammography screening being negative, most of the interviewed women interpreted lumps as breast cancer symptoms and sought medical advice rapidly. Some women defined themselves as delayers despite seeking medical advice less than three months after symptom presentation.
- Only a few women who detected symptoms of breast cancer in-between screening rounds delayed seeking medical advice due to a recent negative screening result in the mammography screening programme.
- Other symptoms than lumps were only acknowledged as cancer symptoms in retrospect. Screening seems a missed opportunity to inform women better about breast cancer symptoms.

Strengths and limitations

This qualitative interview study is unique in studying the experiences of women with interval cancer and how they related their experiences with breast cancer to mammography screening. A limitation to the current study is that it is based on women's retrospective reports. Self-selection in responding to the invitation present a selection bias; women with advanced cancer might not have participated in the study, and participants may have been more resourceful than average.

ABSTRACT

Objectives To explore how women with negative mammography screening results, but who were later diagnosed with interval breast cancer, reacted when they observed breast symptoms that could indicate malignancy in-between screening rounds.

Design Semi-structured individual interviews with women who have been diagnosed with breast cancer during mammography screening intervals.

Setting Two breast diagnostic units covering two counties in Norway.

Participants 26 women diagnosed with interval breast cancer.

Results Women with a screening negative result react in two ways when experiencing a possible symptom of breast cancer. Among 24 women with a self-detected palpable lesion, 14 sought medical advice immediately. Their argument was to dispose of potential cancer as soon as possible. Ten women delayed seeking medical advice, explaining their delay as a result of practical difficulties such as holidays, uncertainty about the symptom, and previous experiences of health care services' ability to handle diffuse symptoms. Also, a recent negative mammography scan led some women to assume that the palpable lesion was benign and wait for the next screening round.

Conclusion Participating in mammography screening may contribute to a postponed reaction to breast cancer symptoms, although most women acted rapidly when detecting a palpable breast lesion. Furthermore, screening participation does not necessarily increase awareness of breast cancer symptoms.

Keywords: Breast cancer, interval cancer, oncology, mammography, screening.

INTRODUCTION

Mammography screening aims to provide a pre-symptomatic diagnosis of breast cancer. Nevertheless, interval cancer, which is cancer detected between screening rounds, comprises 28 per cent of cancers among screened women in Europe.[1] Survival rates for interval cancers have improved during recent decades [2], and it is controversial whether true interval cancers have less favourable prognosis than screening detected cancers or breast cancers diagnosed outside a screening programme.[3-5] Rayson et al found poorer survival in true interval breast cancer compared to screen-detected cancers. The findings of adverse prognostic factors like higher grade and stage, receptor negativity and high mitotic index in true interval cancers might contribute to poorer survival outcome [6;7]. Diagnostic delay may also be a factor.

Diagnostic delay occurs at many stages of the cancer detection process.[8] We will here concentrate on screening participants interpretation of bodily changes, and their help-seeking. Early detection of breast cancer has been promoted throughout the 20th century, including women's responsibility to react upon a palpable breast lesion.[9-11] Nevertheless, recognition of a breast cancer symptom is not always a straightforward process. Cultural contexts influence symptom experiences and bodily signs become symptoms only after an interpretation that they are abnormal. [8;12;13] The process from the onset of bodily changes until recognition of a symptom may be the period of time accounting for the greatest proportion of patient delay.[14;15] But even then, interpreting symptoms as cancer does not automatically lead to taking action.[13;16;17]

An argument for mammography screening is that it leads to earlier breast cancer detection compared with women's self-detection. The positive effect mammography may have on the time of detection must, however, be balanced against whether patient delay could be induced by the reassurance given following a negative screening.[18] A previous qualitative study indicates that women trust mammography screening to provide true results about their breast status.[19] The question addressed in this article is whether screening participation interferes with the women's symptom interpretation and help seeking. This study explores how women with negative mammography screening results who were later diagnosed with interval breast cancer, reacted when they observed breast symptoms that could indicate malignancy in-between screening rounds.

METHODS

This was a qualitative interview study with women who had experienced interval breast cancer within the Norwegian breast cancer screening programme. This is a nationwide, public screening

programme that offers mammography biennially for all women aged 50-69. The study was approved by the Regional Committee for Medical Research; participation was based on written consent.

Recruitment

Forty women diagnosed with interval cancer at two hospitals in Central and Northern Norway were invited to the study. During the years 2006-2009, 178 interval breast cancers were diagnosed at these two hospitals. Due to long distances and the low population density in rural Norway, all invited to the study lived in or near urban or semi-urban areas. In order to have the women's stories as close to the event as possible, they were the twenty women last diagnosed with interval breast cancer at each hospital, living in or nearby one of four cities (inhabitants 9,500-150,000), counting back from six months before the study invitation was sent. A total of 26 women accepted the invitation. Due to confidentiality regulations, we have no access to information about the 14 women who did not respond to the invitation.

The interviews

Semi-structured interviews were carried out in 2009 by the first author (MS), at a hospital, a university, a hotel meeting room, or in the woman's home or workplace if requested. Following a semi-structured interview guide, the women were invited to tell their breast cancer story, including what kind of breast cancer symptoms they had reacted to. Other questions were about their views on mammography screening and reactions upon having interval breast cancer. Each interview lasted 45 to 60 minutes, and was audiotaped prior to being transcribed in verbatim. All informants have been given fictitious names to secure anonymity.

Analysis

Two researchers read all the interviews independently, and all co-authors read some of the interviews. We used a method of constant comparison, comparing themes within and between interviews. All authors discussed themes arising from the interviews. We conducted thematic analysis.[20] Data were categorized using NVivo 8.0. Within each theme we found sub-themes which were subjected to meaning interpretation.[21]

RESULTS

Participants

The 26 participating women were aged 53 to 69 years, in average 59.4. Twenty-four had discovered the symptoms of breast cancer themselves; two were detected during other medical examinations. The women were diagnosed with breast cancer between three and 23 months after their last screening mammography and were interviewed from six to 36 months after diagnosis. Based on the women's reports during the interview, all had been surgically treated, either with mastectomy or with breast conserving surgery, 21 women had undergone radiation therapy, and 14 chemotherapy (Table 1). Few women knew whether their malignant tumor represented a false negative mammography scan or a true interval cancer. Some had asked for a review of previous images, but most did not mention the possibility of false negative screening when asked about their thoughts on having breast cancer between screening rounds.

Fourteen had contacted the health care services within a week after noticing a palpable lump (Table 2). Eight had waited between two weeks and three months before seeking medical advice, and two delayed more than three months. There were no differences in type of symptom between the immediate help-seekers and those waiting for weeks or months, as all talked about having a lump. Two women retrospectively reported symptoms such as mastalgia or breast contour change, but they had not related this to breast cancer before being diagnosed. In the following we will present the women's own explanations for their timing when seeking medical advice.

Seeking medical advice immediately

Those who saw themselves as having sought medical advice promptly had all called their doctor's office or the mammography clinic at the first opportunity or at least within a week of feeling a lump.

"I detected it at eleven p.m. And there I was, with a glowing phone at eight a.m. (Laughter) Next morning, straight to the GP." (Johanne, 56)

The women who contacted their doctor immediately had no doubt about the possibility of having cancer. For them delay was no option after detecting a lump. In retrospect they had been certain that it could be a symptom of breast cancer. Thoughts about having cancer made acting upon it the rational option.

"I was very quick to get to the GP. I was certain it was cancer right away. […] I became very rational: Go to the clinic, make it go away."(Vigdis, 62)

Postponing seeking medical advice

Ten of the women had waited between two weeks and six months before seeking medical advice. Some of the women reported that they reinterpreted embodied sensations as possible cancer symptoms in retrospect, after being diagnosed. Prior to feeling a lump, they had either not noticed these symptoms or at least not interpreted them as symptoms of cancer. Each woman gave several explanations for what she retrospectively saw as her delay in help-seeking.

Uncertainty about symptom

All these women acknowledged that breast anomalies could often represent symptoms of breast cancer. However, their own bodily changes did not always stand out as definite symptoms. Being uncertain about the etiology of the breast change, it was initially interpreted as imaginary or something that could change back to normal.

> *"No you can't date it because you just sense it and consider it, and eventually it grows, so it could maybe have been a month or so. […] Yes, because it could potentially regress." (Cecilie, 67)*

Olaug (63) and Eva (57) explained their lesions due to sore skin from a tight bra or to an inflammation of some kind, sensations and observations the women later reinterpreted as possible early symptoms of cancer. They delayed seeking medical advice as the symptoms appeared too vague, for instance having an unpleasant sensation in the breast, nausea or tiredness. Their initial interpretations of their bodily sensations were framed by everyday experiences, as mentioned above. In hindsight, these bodily experiences were acknowledged as breast cancer symptoms.

Previous experiences

Postponement of help seeking also occured after a bodily sensation was identified as a potential symptom. Previous negative experiences with health care services contributed to reluctance towards seeking potentially unnecessary medical examinations. Those with multiple experiences with illness and disease were tired of being in the patient role. Prior negative encounters with health care services following diffuse symptoms resulted in a a threshold against seeking help with diffuse breast cancer symptoms.

> *"I thought it might be an inflammation because I have had joint inflammations before and maybe that could have spread. And it was sore too. And one isn't too happy to go running to the doctor either. I did that all the time when I was younger, before I was diagnosed with arthritis, and with all that pain, so I'd rather not go (laughter). I got so tired when*

they never could detect what was wrong with me and I got all kinds of medications which damaged... […] So I am glad when I feel healthy and don't have to go."(Eva, 57)

Having had frequent visits to the GP made some uneasy about being seen as whimpering. This suggests that "be a whimperer" or seeking health care services unnecessary were incoherent with their identity. Rather than be perceived as hypochondriacs, they would delay help-seeking for uncertain symptoms.

Practical reasons

There were also practical reasons given for delaying seeking medical advice. Two women had already a scheduled appointment with their GP when they detected a lump. Both waited until the appointment before bringing the lump to the doctor's attention.

"I had an appointment with the GP a few weeks after, so I waited until then. It was probably nothing anyway."(Gudrun, 60)

Noticing a lump during holidays also led to a delay in seeing the doctor. Actions after finding a lump were not solely about the lesion, but also about their social situation. Practical reasons were intertwined with other explanations such as interpreting the mass as benign or non-existent.

Mammography screening

For some of the women the essential argument for delaying was related to having participated in mammography screening. Two different time frames were important for this argument. One was about having had a negative mammography in the recent past. The other was about an upcoming mammography. Having recently had a mammography scan led some to interpret the newly discovered lump as harmless. Having trusted mammography to detect even non-palpable lumps, some of the women experienced it as strange that cancer had not been found at the screening. Petra, for instance, detected a lesion in April, but delayed acting upon it until October.

"I wonder if it [last mammography screening] wasn't in January that year. And that was probably the reason for my interpretation. Because I thought that when they hadn't seen anything then, it could not be anything now." (Petra, 66)

Being part of a screening programme thus contributed to some women's interpretation of bodily signs as not being breast cancer symptoms. One woman presented a forward-looking argument for delaying. She had started to wait for a screening invitation, but after several months with a growing tumour she called the screening unit asking for the next screening appointment.

> *"I started to wait for the [mammography] bus that used to come, but it never came. Right? It was too long to wait, because I felt this… […] Yes, because I'm usually called in. So I called the hospital and asked them when the bus was due, and they said that it would not come until later that year, and she asked me if there was something specific I had on my mind? So I told her I had pain in a breast, but that I knew it isn't any danger when it hurts. "Go see a doctor", she said. So I called my GP that day, and got an appointment the next day." (Inger, 56)*

Even when interpreting her lump as potential cancer, Inger delayed acting on it as she waited for the screening programme to act. Both women who had waited six months before seeking medical advice explained their delay with their screening participation. This suggests that some participants place too much trust in the cancer detection capabilities of the screening programme.

DISCUSSION

From this qualitative interview study we found that ten of 24 women who had been mammography screening participants put off seeking medical advice when detecting a palpable lump. True interval breast cancer could have poorer survival compared to screen-detected cancers.[6] Delaying acting on a breast cancer symptom between screening rounds could potentially decrease survival. Medically defined, diagnostic delay is waiting more than three months with a symptom before help-seeking. Though only two among these 26 women fell within this definition, eight further women who had not acted immediately considered themselves to have delayed the diagnosis. The four main reasons for waiting to seek medical advice were uncertainty about symptom interpretation, practical reasons, previous negative experiences, and being participants of mammography screening. In order to self-detect cancer, individuals must sense a symptom, acknowledge it as such, and take action to seek medical advice.[22] It has hitherto not been known whether participating in mammography screening could influence any of these processes. What was unique in the present study was that all study

participants had been participants in a mammography screening programme, and we explored whether screening participation could have contributed to a diagnostic delay.

Symptom interpretation of breast cancer may cause patient delay.[8;12-14;23;24] Palpable lumps are a well-known symptom of breast cancer that should induce seeking medical advice. All women in a Dutch study associated lumps with breast cancer.[8] However, studies vary in their conclusions about whether having a palpable lesion is associated with more or less delay than non-palpable symptoms.[16;25] In the present study, all the women referred to lumps when asked what had led to seeking medical advice. Other symptoms known to represent breast cancer, such as retraction of the nipple or skin, nipple discharge, skin discolouring or change in texture, mastalgia, a palpable lump in the axilla or a changed breast contour, had only been recognized as breast cancer symptoms after having the cancer diagnosis. For these women, participation in mammography screening might have increased awareness about self-examination for lumps but had apparently not increased knowledge of other symptoms.

Delay in seeking medical advice cannot be explained solely by lack of knowledge.[26] All the women knew that a lump could be a sign of cancer, and yet some delayed seeking medical help. Patient delay can depend on the patient's interpretation of bodily signs as related to cancer.[22] Although they knew in general that a lump could be a sign of cancer, some of the women did not immediately make that connection in their own case. As found in earlier studies, they did not expect to be ill and their current situation provided alternative explanations for their bodily experiences.[12] The present study indicates that participating in mammography screening may provide other explanations for bodily signs, since cancer had not been detected by mammography. Retrospective interpretations of bodily sensations as symptoms of breast cancer suggest that some had been reluctant to trust their own bodily sensations. In this sense mammography may contribute to medicalization, leaving women to trust medical technology over their own bodily sensations. Another interpretation is that they were too frightened by the prospect of having cancer to react to potential symptoms, in which case screening participation was not so much a contributing factor to delay as it was an available excuse to avoid contemplating cancer.

Seeing previous or upcoming mammography screening as reasons for delaying seeking medical advice about potential breast cancer suggests that too much trust in a public screening programme may contribute to delayed diagnosis. Though only a few women expressed such arguments, our study demonstrates their existence in the population. Trusting previous screens to be correct may have led to non-cancer interpretations of symptoms. Waiting for the next screening round instead of acting upon a palpable lump indicates high trust in the correctness of a biennial design.

Delay has been an essential concept throughout breast cancer history in the US.[11] Cultural studies of breast cancer have been scarce in Norway, but media campaigns against delayed diagnosis have been implemented. These women's delayed actions must be understood within such a broader cultural context. Discourses depicting breast cancer as a continuum have dominated in recent decades, making women's breasts objects of constant surveillance both by themselves and by others.[10] With a lack of clearly identified measures of primary prevention, surveillance becomes the sole option for responsible health behaviour. Although ten women in the present study claimed having delayed help-seeking, only two women delayed more than three months. Those who saw themselves as having delayed their active response had varied and complex arguments explaining their (in)actions while women who sought medical help immediately were certain they were doing the right thing.

Although the design of our study does not tell about the magnitude of the delay problem, it clearly identifies a problem which deserves closer attention. In line with conclusions from other studies [27-29], it also points in the direction of an upgrading of the importance of women's self- examinations and of further education regarding breast cancer symptoms.

Strengths and limitations

This qualitative interview study is unique in studying the experiences of women with interval cancer and how they related their experiences with breast cancer to mammography screening. Being interviewed about delaying seeking medical advice when detecting symptoms that later were diagnosed as cancer could be discomforting for those feeling guilty about delaying, leading to answers masking guilt. A limitation to the current study is that it is based on women's retrospective reports. Some had been diagnosed up to three years prior to the interview. Experiences before having cancer may not be the most important to remember after going through intensive cancer treatment, and could have been reinterpreted several times since experiencing them.

Nearly 65 per cent of those invited to the study chose to participate. All women with interval cancer within a specific period in these communities were invited, but self-selection in responding to the invitation present a selection bias. It is a limitation to the study that we cannot compare those participating with the 14 non-respondents. Serious disease might have hindered participation. Despite their cancer diagnosis, only six of the 26 respondents were fully retired. In Norway, less than 50 per cent of the population aged 55-74 were employed in 2005,[30] which indicates that participants

in the present study could have been more resourceful than women in average. If diagnostic delay is a problem among the more resourceful segments of the population, it is reasonable to think that it is also present in the population in general.

We could expect potential cancer symptoms to be common in the population, as approximately 15 per cent of the population at any time experience such symptoms.[25] Women with symptoms in-between screening rounds could be classified in three groups: women who receive an interval cancer diagnosis, women whose symptoms are diagnosed as benign, and women who delayed seeking medical advice until their next screening round. As only the first group were subjects of this study, more research on symptom interpretation among screening participants is warranted.

Implications

Confidence in mammography programmes influences the interpretation of breast cancer symptoms. Awareness of symptoms other than lumps must be improved. Though information leaflets provide information about interval breast cancer, screening participants might not read leaflets thoroughly. Additional information and reminders during mammography examinations could be one solution. Previous experiences of vague symptoms being set aside could lead women to neglect their own bodily sensations and prefer technology to give answers to their health status. In this qualitative study we have explored the women's own interpretation of help-seeking for interval breast cancer. Further studies are required as to whether their choice of actions have delayed diagnosis in medical terms, according to tumor characteristics and survival.

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Table 1 Description of treatment for breast cancer, self-reported.

Treatment	Surgery	Surgery + radiation	Surgery + radiation + chemo therapy	Surgery + chemo theraphy	
Age					

50-54	0	0	3	0	
55-59	2	3	6	0	
60-64	0	4	4	0	
65-69	2	1	0	1	
Sum	4 (15,4 %)	8 (30,8 %)	13 (50,0 %)	1 (3,8 %)	Total N=26

Table 2 Description of women who participated in study: age and help-seeking behaviour

Reaction time	Detected though other medical examinations	1-2 days	Within 2 weeks	Less than 2 months	Approx 6 months	
Age						Mean=59.4
50-54	0	2	0	1	0	3 (11,5 %)
55-59	1	5	3	1	1	11 (42,3 %)
60-64	0	3	3	2	0	8 (30,8 %)
65-69	1	1	0	1	1	4 (15,4 %)
Sum	2 (7,7 %)	11 (42,3 %)	6 (23,0 %)	5 (19,2 %)	2 (7,7 %)	Total N=26

Title page

Title: Could screening participation bias symptom interpretation? An interview study on women's interpretations of and responses to cancer symptoms between mammography screening rounds.

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Authorship-contributorship statement: MS, SF and JAS planned and designed the study. AIH contributed with recruitment together with MS. MS conducted the interviews. All authors contributed to the analysis of data and in writing the article. All authors agree on the submission of the present manuscript. MS is responsible for the overall content as guarantor.

Ethics approval: The study was approved by the Regional committee for medical research ethics (REK midt) and informed consent was given by all participants.

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Running head: Could screening participation bias symptom interpretation?

Article summary:

Article Focus

- Interval breast cancer comprises 28 per cent of cancers among screened women in Europe.
- Women who participate in mammography screening may delay acting upon breast cancer symptoms if they trust screening results to be correct.
- We asked women with interval breast cancer how they had reacted to detecting symptoms of breast cancer in-between screening rounds.

Key Messages

- **Despite the last mammography screening being negative, most of the interviewed women interpreted lumps as breast cancer symptoms and sought medical advice rapidly. Some women defined themselves as delayers despite seeking medical advice less than three months after symptom presentation.**
- Only a few women who detected symptoms of breast cancer in-between screening rounds delayed seeking medical advice due to **a recent negative screening result in the mammography screening programme.**
- **Other symptoms than lumps were only acknowledged as cancer symptoms in retrospect. Screening seems a missed opportunity to inform women better about breast cancer symptoms.**

Strengths and limitations

This qualitative interview study is unique in studying the experiences of women with interval cancer and how they related their experiences with breast cancer to mammography screening. A limitation to the current study is that it is based on women's retrospective reports. Self-selection in responding to the invitation present a selection bias; women with advanced cancer might not have participated in the study, and participants **may have been more** resourceful than average.

ABSTRACT

Objectives To explore **how women with negative mammography screening results, but who were later diagnosed with interval breast cancer, reacted when they observed breast symptoms that could indicate malignancy in-between screening rounds**.

Design Semi-structured individual interviews with women who have been diagnosed with breast cancer during mammography screening intervals.

Setting Two breast diagnostic units covering two counties in Norway.

Participants 26 women diagnosed with interval breast cancer.

Results Women with a screening negative result react in two ways when experiencing a possible symptom of breast cancer. Among 24 women with a self-detected palpable lesion, 14 sought medical advice immediately. Their argument was to dispose of potential cancer as soon as possible. Ten women delayed seeking medical advice, **explaining their delay as a result of practical difficulties such as holidays, uncertainty about the symptom, and previous experiences of health care services' ability to handle diffuse symptoms.** Also, a recent negative mammography scan led some women to assume that the palpable lesion was benign and wait for the next screening round.

Conclusion Participating in mammography screening may contribute to a postponed reaction to breast cancer symptoms, although most women acted rapidly when detecting a palpable breast lesion. Furthermore, screening participation does not necessarily increase awareness of breast cancer symptoms.

Keywords: Breast cancer, interval cancer, oncology, mammography, screening.

INTRODUCTION

Mammography screening aims to provide a pre-symptomatic diagnosis of breast cancer. Nevertheless, interval cancer, which is cancer detected between screening rounds, comprises 28 per cent of cancers among screened women in Europe.[1] Survival rates for interval cancers have improved during recent decades [2], **and it is controversial whether true interval cancers have less favourable prognosis than screening detected cancers or breast cancers diagnosed outside a screening programme.[3-5] Rayson et al found poorer survival in true interval breast cancer compared to screen-detected cancers. The findings of adverse prognostic factors like higher grade and stage, receptor negativity and high mitotic index in true interval cancers might contribute to poorer survival outcome [6;7]. Diagnostic delay may also be a factor.**

Diagnostic delay occurs at many stages of the cancer detection process.[8] We will here concentrate on **screening participants interpretation of bodily changes, and their** help-seeking. Early detection of breast cancer has been promoted throughout the 20th century, including women's responsibility to react upon a palpable breast lesion.[9-11] **Nevertheless, recognition of a breast cancer symptom is not always a straightforward process.** Cultural contexts influence symptom experiences and bodily signs become symptoms only after an interpretation that they are abnormal. [8;12;13] **The process from the onset of bodily changes until recognition of a symptom may be the period of time accounting for the greatest proportion of patient delay.[14;15] But even then, interpreting** symptoms as cancer does not automatically lead to taking action.[13;16;17]

An argument for mammography screening is that it leads to earlier breast cancer detection compared with women's self-detection. The positive effect mammography may have on the time of detection must, however, be balanced against whether patient delay could be induced by the reassurance given following a negative screening.[18] A previous qualitative study indicates that women trust mammography screening to provide true results about their breast status.[19] The question addressed in this article is whether screening participation interferes with the women's symptom interpretation and help seeking. **This study explores how women with negative mammography screening results who were later diagnosed with interval breast cancer, reacted when they observed** breast symptoms that could indicate malignancy in-between screening rounds.

METHODS

This was a qualitative interview study with women who had experienced interval breast cancer within the Norwegian breast cancer screening programme. This is a nationwide, public screening

programme that offers mammography **biennially** for all women aged 50-69. The study was approved by the Regional Committee for Medical Research; **participation was based on written consent.**

Recruitment

Forty women diagnosed with interval cancer at two hospitals in Central and Northern Norway were invited to the study. During the years 2006-2009, 178 interval breast cancers were diagnosed at these two hospitals. Due to long distances and the low population density in rural Norway, all invited to the study lived in or near urban or semi-urban areas. In order to have the women's stories as close to the event as possible, they were the twenty women last diagnosed with interval breast cancer at each hospital, living in or nearby one of four cities (inhabitants 9,500-150,000), counting back from six months before the study invitation was sent. A total of 26 women accepted the invitation. Due to confidentiality regulations, we have no access to information about the 14 women who did not respond to the invitation.

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Semi-structured interviews were carried out in 2009 by the first author (MS), at a hospital, a university, a hotel meeting room, or in the woman's home or workplace if requested. **Following a semi-structured interview guide, the women were invited to tell their breast cancer story, including what kind of breast cancer symptoms they had reacted to. Other questions were about their views on mammography screening and reactions upon having interval breast cancer.** Each interview lasted 45 to 60 minutes, and was audiotaped prior to being transcribed in verbatim. All informants have been given fictitious names to secure anonymity.

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RESULTS

Participants

The 26 participating women were aged 53 to 69 years, in average 59.4. Twenty-four had discovered the symptoms of breast cancer themselves; two were detected during other medical examinations. The women were diagnosed with breast cancer between three and 23 months after their last screening mammography and were interviewed from six to 36 months after diagnosis. **Based on the women's reports during** the interview, all had been surgically treated, either with mastectomy or with breast conserving surgery, 21 women had undergone radiation therapy, and 14 chemotherapy **(Table 1).** Few women knew whether their malignant tumor represented a false negative mammography scan or a true interval cancer. **Some had asked for a review of previous images, but most did not mention the possibility of false negative screening when asked about their thoughts on having breast cancer between screening rounds.**

Fourteen had contacted the health care services within a week after noticing a palpable lump (Table 2). Eight had waited between two weeks and three months before seeking medical advice, and two delayed more than three months. There were no differences in type of symptom between the immediate help-seekers and those waiting for weeks or months, as all talked about having a lump. Two women retrospectively reported symptoms such as mastalgia or breast contour change, but they had not related this to breast cancer before being diagnosed. In the following we will present the women's own explanations for their timing when seeking medical advice.

Seeking medical advice immediately

Those who saw themselves as having sought medical advice promptly had all called their doctor's office or the mammography clinic at the first opportunity or at least within a week of feeling a lump.

"I detected it at eleven p.m. And there I was, with a glowing phone at eight a.m. (Laughter) Next morning, straight to the GP." (Johanne, 56)

The women who contacted their doctor immediately had no doubt about the possibility of having cancer. For them delay was no option after detecting a lump. In retrospect they had been certain that it could be a symptom of breast cancer. Thoughts about having cancer made acting upon it the rational option.

"I was very quick to get to the GP. I was certain it was cancer right away. […] I became very rational: Go to the clinic, make it go away."(Vigdis, 62)

Postponing seeking medical advice

Ten of the women had waited between two weeks and six months before seeking medical advice. Some of the women reported that they reinterpreted embodied sensations as possible cancer symptoms in retrospect, after being diagnosed. Prior to feeling a lump, they had either not noticed these symptoms or at least not interpreted them as symptoms of cancer. **Each woman gave several explanations for what she retrospectively saw as her delay in help-seeking.**

Uncertainty about symptom

All these women acknowledged that breast anomalies could often represent symptoms of breast cancer. However, their own bodily changes did not always stand out as definite symptoms. Being uncertain about the etiology of the breast change, it was initially interpreted as imaginary or something that could change back to normal.

> *"No you can't date it because you just sense it and consider it, and eventually it grows, so it could maybe have been a month or so. […] Yes, because it could potentially regress." (Cecilie, 67)*

Olaug (63) and Eva (57) explained their lesions due to sore skin from a tight bra or to an inflammation of some kind, sensations and observations the women later reinterpreted as possible early symptoms of cancer. They delayed seeking medical advice as the symptoms appeared too vague, for instance having an unpleasant sensation in the breast, nausea or tiredness. **Their initial interpretations of their bodily sensations were framed by everyday experiences, as mentioned above. In hindsight, these bodily experiences were acknowledged as breast cancer symptoms.**

Previous experiences

Postponement of help seeking also occured after a bodily sensation was identified as a potential symptom. Previous negative experiences with health care services contributed to reluctance towards **seeking potentially** unnecessary medical examinations. Those with multiple experiences with illness and disease were tired of being in the patient role. Prior negative encounters with health care services following diffuse symptoms **resulted in a a threshold against** seeking help with diffuse breast cancer symptoms.

> *"I thought it might be an inflammation because I have had **joint** inflammations before and maybe that could have spread. And it was sore too. And one isn't too happy to go running to the doctor either. I did that all the time when I was younger, before I was diagnosed with arthritis, and with all that pain, so I'd rather not go (laughter). I got so tired when*

they never could detect what was wrong with me and I got all kinds of medications which damaged... […] So I am glad when I feel healthy and don't have to go."(Eva, 57)

Having had frequent visits to the GP made some uneasy about being seen as whimpering. This suggests that "be a whimperer" or seeking health care services unnecessary were incoherent with their identity. **Rather than be perceived as hypochondriacs, they would delay help-seeking for uncertain symptoms.**

Practical reasons

There were also practical reasons given for delaying seeking medical advice. Two women had already a scheduled appointment with their GP when they detected a lump. Both waited until the appointment before bringing the lump to the doctor's attention.

"I had an appointment with the GP a few weeks after, so I waited until then. It was probably nothing anyway."(Gudrun, 60)

Noticing a lump during holidays also led to a delay in seeing the doctor. Actions after finding a lump were not solely about the lesion, but also about their social situation. Practical reasons were intertwined with other explanations such as interpreting the mass as benign or non-existent.

Mammography screening

For some of the women the essential argument for delaying was related to having participated in mammography screening. Two different time frames were important for this argument. One was about having had a negative mammography in the recent past. The other was about an upcoming mammography. Having recently had a mammography scan led some to interpret the newly discovered lump as harmless. Having trusted mammography to detect even non-palpable lumps, some of the women experienced it as strange that cancer had not been found at the screening. Petra, for instance, detected a lesion in April, but delayed acting upon it until October.

"I wonder if it [last mammography screening] wasn't in January that year. And that was probably the reason for my interpretation. Because I thought that when they hadn't seen anything then, it could not be anything now." (Petra, 66)

Being part of a screening programme **thus contributed to some women's interpretation of** bodily signs as not being breast cancer symptoms. One woman presented a forward-looking argument for delaying. She had started to wait for a screening invitation, but after several months with a growing tumour she called the screening unit asking for **the next screening appointment.**

> *"I started to wait for the [mammography] bus that used to come, but it never came. Right? It was too long to wait, because I felt this… […] Yes, because I'm usually called in. So I called the hospital and asked them when the bus was due, and they said that it would not come until later that year, and she asked me if there was something specific I had on my mind? So I told her I had pain in a breast, but that I knew it isn't any danger when it hurts. "Go see a doctor", she said. So I called my GP that day, and got an appointment the next day." (Inger, 56)*

Even when interpreting her lump as potential cancer, Inger delayed acting on it as she waited for the screening programme to act. **Both women who had waited six months before seeking medical advice explained their delay with their screening participation. This suggests that some participants place too much trust in the cancer detection capabilities of the screening programme.**

DISCUSSION

From this qualitative interview study we found that ten of 24 women who had been mammography screening participants put off seeking medical advice when detecting a palpable lump. **True interval breast cancer could have poorer survival compared to screen-detected cancers.[6] Delaying acting on a breast cancer symptom between screening rounds could potentially decrease survival.** Medically defined, diagnostic delay is waiting more than three months with a symptom before help-seeking. Though only two among **these 26 women fell within this definition, eight further** women who had not acted immediately considered themselves to have delayed the diagnosis. The four main reasons for waiting to seek medical advice were uncertainty about symptom interpretation, practical reasons, previous negative experiences, and being participants of mammography screening. In order to self-detect cancer, individuals must sense a symptom, acknowledge it as such, and take action to seek medical advice.[22] It has hitherto not been known whether participating in mammography screening could influence any of these processes. What was unique in the present study was that all study

participants had been participants in a mammography screening programme, and we explored whether screening participation could have contributed to a diagnostic delay.

Symptom interpretation of breast cancer may cause patient delay.[8;12-14;23;24] Palpable lumps are a well-known symptom of breast cancer that should induce seeking medical advice. All women in a Dutch study associated lumps with breast cancer.[8] However, studies vary in their conclusions about whether having a palpable lesion is associated with more or less delay than non-palpable symptoms.[16;25] In the present study, all the women referred to lumps when asked what had led to seeking medical advice. Other **symptoms known to represent breast cancer, such as retraction of the nipple or skin, nipple discharge, skin discolouring or change in texture, mastalgia, a palpable lump in the axilla or a changed breast contour, had only been recognized as breast cancer symptoms after having the cancer diagnosis.** For these women, participation in mammography screening might have increased awareness about self-examination for lumps but had apparently not increased knowledge of other symptoms.

Delay in seeking medical advice cannot be explained solely by lack of knowledge.[26] All the women knew that a lump could be a sign of cancer, and yet some delayed seeking medical help. Patient delay can depend on the patient's interpretation of bodily signs as related to cancer.[22] Although they knew in general that a lump could be a sign of cancer, some of the women did not immediately make that connection in their own case. As found in earlier studies, they did not expect to be ill and their current situation provided alternative explanations for their bodily experiences.[12] The present study indicates that participating in mammography screening may provide other explanations for bodily signs, since cancer had not been detected by mammography. Retrospective interpretations of bodily sensations as symptoms of breast cancer suggest that some had been reluctant to trust their own bodily sensations. In this sense mammography may contribute to medicalization, leaving women to trust medical technology over their own bodily sensations. Another interpretation is that they were too frightened by the prospect of having cancer to react to potential symptoms, in which case screening participation was not so much a contributing factor to delay as it was an available excuse to avoid contemplating cancer.

Seeing previous or upcoming mammography screening as reasons for delaying seeking medical advice about potential breast cancer suggests that too much trust in a public screening programme may contribute to delayed diagnosis. Though only a few women expressed such arguments, our study **demonstrates** their existence in the population. Trusting previous screens to be correct may have led to non-cancer interpretations of symptoms. Waiting for the next screening round instead of acting upon a palpable lump indicates high trust in the correctness of a **biennial** design.

Delay has been an essential concept throughout breast cancer history in the US.[11] Cultural studies of breast cancer have been scarce in Norway, but media campaigns against delayed diagnosis have been implemented. These women's delayed actions must be understood within such a broader cultural context. **Discourses depicting breast cancer as a continuum have dominated in recent decades, making women's breasts objects of** constant surveillance both by themselves and by others.[10] **With a lack of clearly identified measures of primary prevention**, surveillance becomes the sole option for responsible health behaviour. Although ten women in the present study claimed having delayed help-seeking, only two women delayed more than three months. Those who saw themselves as having **delayed their active response** had varied and complex arguments explaining their (in)actions while women who sought medical help immediately were certain they were doing the right thing.

Although the design of our study does not tell about the magnitude of the delay problem, it clearly identifies a problem which deserves closer attention. In line with conclusions from other studies [27-29], it also points in the direction of an upgrading of the importance of women's self- examinations and of further education regarding breast cancer symptoms.

Strengths and limitations

This qualitative interview study is unique in studying the experiences of women with interval cancer and how they related their experiences with breast cancer to mammography screening. Being interviewed about delaying seeking medical advice when detecting symptoms that later were diagnosed as cancer could be discomforting for those feeling guilty about delaying, leading to answers masking guilt. A limitation to the current study is that it is based on women's retrospective reports. Some had been diagnosed up to three years prior to the interview. **Experiences before having cancer** may not be the most important to remember after going through intensive cancer treatment, and could have been reinterpreted several times since experiencing them.

Nearly 65 per cent of those invited to the study chose to participate. All women with interval cancer within a specific period in these communities were invited, but self-selection in responding to the invitation present a selection bias. **It is a limitation to the study that we cannot compare those participating with the 14 non-respondents. Serious disease might have hindered participation.** Despite their cancer diagnosis, only six of **the 26 respondents were fully retired. In Norway, less than 50 per cent of the population aged 55-74 were employed in 2005,[30] which indicates that**

participants in the present study could have been more resourceful than women in average. If diagnostic delay is a problem among the more resourceful segments of the population, it is reasonable to think that it is also present in the population in general.

We could expect potential cancer symptoms to be common in the population, as approximately 15 per cent of the population at any time experience such symptoms.[25] Women with symptoms in-between screening rounds could be classified in three groups: women who receive an interval cancer diagnosis, women **whose symptoms are diagnosed as benign,** and women who delayed seeking medical advice until their next screening round. As only the first group were subjects of this study, more research on symptom interpretation among screening participants is warranted.

Implications

Confidence in mammography programmes influences the interpretation of breast cancer symptoms. Awareness of symptoms other than lumps must be improved. Though information leaflets provide information about interval breast cancer, screening participants might not read leaflets thoroughly. Additional information and reminders during mammography examinations could be one solution. Previous experiences of vague symptoms being set aside could lead women to neglect their own bodily sensations and prefer technology to give answers to their health status. **In this qualitative study we have explored the women's own interpretation of help-seeking for interval breast cancer. Further studies are required as to whether their choice of actions have delayed diagnosis in medical terms, according to tumor characteristics and survival.**

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Table 1 Description of treatment for breast cancer, self-reported.

Treatment	**Surgery**	**Surgery + radiation**	**Surgery + radiation + chemo therapy**	**Surgery + chemo theraphy**	
Age					

50-54	0	0	3	0	
55-59	2	3	6	0	
60-64	0	4	4	0	
65-69	2	1	0	1	
Sum	4 (15,4 %)	8 (30,8 %)	13 (50,0 %)	1 (3,8 %)	**Total N=26**

Table 2 Description of women who participated in study: age and help-seeking behaviour

Reaction time	**Detected though other medical examinations**	**1-2 days**	**Within 2 weeks**	**Less than 2 months**	**Approx 6 months**	
Age						Mean=59.4
50-54	0	2	0	1	0	3 (11,5 %)
55-59	1	5	3	1	1	11 (42,3 %)
60-64	0	3	3	2	0	8 (30,8 %)
65-69	1	1	0	1	1	4 (15,4 %)
Sum	**2 (7,7 %)**	**11 (42,3 %)**	**6 (23,0 %)**	**5 (19,2 %)**	**2 (7,7 %)**	**Total N=26**

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Could screening participation bias symptom interpretation? An interview study on women's interpretations of and responses to cancer symptoms between mammography screening rounds.

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Title: Could screening participation bias symptom interpretation? An interview study on women's interpretations of and responses to cancer symptoms between mammography screening rounds.

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Running head: Could screening participation bias symptom interpretation?

Article summary:

Article Focus

- Interval breast cancer comprises 28 per cent of cancers among screened women in Europe.
- Women who participate in mammography screening may delay acting upon breast cancer symptoms if they trust screening results to be correct.
- We asked women with interval breast cancer how they had reacted to detecting symptoms of breast cancer in-between screening rounds.

Key Messages

- Despite the last mammography screening being negative, most of the interviewed women interpreted lumps as breast cancer symptoms and sought medical advice rapidly. Some women defined themselves as delayers despite seeking medical advice less than three months after symptom presentation.
- Only a few women who detected symptoms of breast cancer in-between screening rounds delayed seeking medical advice due to a recent negative screening result in the mammography screening programme.
- Other symptoms than lumps were only acknowledged as cancer symptoms in retrospect. Screening seems a missed opportunity to inform women better about breast cancer symptoms.

Strengths and limitations

This qualitative interview study is unique in studying the experiences of women with interval cancer and how they related their experiences with breast cancer to mammography screening. A limitation to the current study is that it is based on women's retrospective reports. Self-selection in responding to the invitation present a selection bias; women with advanced cancer might not have participated in the study, and participants may have been more resourceful than average.

ABSTRACT

Objectives To explore how women with negative mammography screening results, but who were later diagnosed with interval breast cancer, reacted when they observed breast symptoms that could indicate malignancy in-between screening rounds.

Design Semi-structured individual interviews with women who have been diagnosed with breast cancer during mammography screening intervals.

Setting Two breast diagnostic units covering two counties in Norway.

Participants 26 women diagnosed with interval breast cancer.

Results Women with a screening negative result react in two ways when experiencing a possible symptom of breast cancer. Among 24 women with a self-detected palpable lesion, 14 sought medical advice immediately. Their argument was to dispose of potential cancer as soon as possible. Ten women delayed seeking medical advice, explaining their delay as a result of practical difficulties such as holidays, uncertainty about the symptom, and previous experiences of health care services' ability to handle diffuse symptoms. Also, a recent negative mammography scan led some women to assume that the palpable lesion was benign and wait for the next screening round.

Conclusion Participating in mammography screening may contribute to a postponed reaction to breast cancer symptoms, although most women acted rapidly when detecting a palpable breast lesion. Furthermore, screening participation does not necessarily increase awareness of breast cancer symptoms.

Keywords: Breast cancer, interval cancer, oncology, mammography, screening.

INTRODUCTION

Mammography screening aims to provide a pre-symptomatic diagnosis of breast cancer. Nevertheless, interval cancer, which is cancer detected between screening rounds, comprises 28 per cent of cancers among screened women in Europe.[1] Survival rates for interval cancers have improved during recent decades [2], and it is controversial whether true interval cancers have less favourable prognosis than screening detected cancers or breast cancers diagnosed outside a screening programme.[3-5] Rayson et al found poorer survival in true interval breast cancer compared to screen-detected cancers. The findings of adverse prognostic factors like higher grade and stage, receptor negativity and high mitotic index in true interval cancers might contribute to poorer survival outcome. [6;7] On the other side, survival rates in the screen detected groups are biased (lead and length time bias and overdiagnosis), leading to misinterpretation of the true effectiveness of screening.[8] It should not be excluded, however, that diagnostic delay due to a recent negative mammogram may be an important factor in poorer survival rates.

Diagnostic delay occurs at many stages of the cancer detection process.[9] We will here concentrate on screening participants interpretation of bodily changes, and their help-seeking. Early detection of breast cancer has been promoted throughout the 20th century, including women's responsibility to react upon a palpable breast lesion.[10-12] Nevertheless, recognition of a breast cancer symptom is not always a straightforward process. Cultural contexts influence symptom experiences and bodily signs become symptoms only after an interpretation that they are abnormal. [9;13;14] The process from the onset of bodily changes until recognition of a symptom may be the period of time accounting for the greatest proportion of patient delay.[15;16] But even then, interpreting symptoms as cancer does not automatically lead to taking action.[14;17;18]

An argument for mammography screening is that it leads to earlier breast cancer detection compared with women's self-detection. The positive effect mammography may have on the time of detection must, however, be balanced against whether patient delay could be induced by the reassurance given following a negative screening.[19] A previous qualitative study indicates that women trust mammography screening to provide true results about their breast status.[20] The question addressed in this article is whether screening participation interferes with the women's symptom interpretation and help seeking. This study explores how women with negative mammography screening results who were later diagnosed with interval breast cancer, reacted when they observed breast symptoms that could indicate malignancy in-between screening rounds.

METHODS

This was a qualitative interview study with women who had experienced interval breast cancer within the Norwegian breast cancer screening programme. This is a nationwide, public screening programme that offers mammography biennially for all women aged 50-69. The study was approved by the Regional Committee for Medical Research; participation was based on written consent.

Recruitment

Forty women diagnosed with interval cancer at two hospitals in Central and Northern Norway were invited to the study. During the years 2006-2009, 178 interval breast cancers were diagnosed at these two hospitals. Due to long distances and the low population density in rural Norway, all invited to the study lived in or near urban or semi-urban areas. In order to have the women's stories as close to the event as possible, they were the twenty women last diagnosed with interval breast cancer at each hospital, living in or nearby one of four cities (inhabitants 9,500-150,000), counting back from six months before the study invitation was sent. A total of 26 women accepted the invitation. Due to confidentiality regulations, we have no access to information about the 14 women who did not respond to the invitation.

The interviews

Semi-structured interviews were carried out in 2009 by the first author (MS), at a hospital, a university, a hotel meeting room, or in the woman's home or workplace if requested. Following a semi-structured interview guide, the women were invited to tell their breast cancer story, including what kind of breast cancer symptoms they had reacted to. Other questions were about their views on mammography screening and reactions upon having interval breast cancer. Each interview lasted 45 to 60 minutes, and was audiotaped prior to being transcribed in verbatim. All informants have been given fictitious names to secure anonymity.

Analysis

Two researchers read all the interviews independently, and all co-authors read some of the interviews. We used a method of constant comparison, comparing themes within and between interviews. All authors discussed themes arising from the interviews. We conducted thematic analysis.[21] Data were categorized using NVivo 8.0. Within each theme we found sub-themes which were subjected to meaning interpretation.[22]

RESULTS

Participants

The 26 participating women were aged 53 to 69 years, in average 59.4. Twenty-four had discovered the symptoms of breast cancer themselves; two were detected during other medical examinations. The women were diagnosed with breast cancer between three and 23 months after their last screening mammography and were interviewed from six to 36 months after diagnosis. Based on the women's reports during the interview, all had been surgically treated, either with mastectomy or with breast conserving surgery, 21 women had undergone radiation therapy, and 14 chemotherapy (Table 1). Few women knew whether their malignant tumor represented a false negative mammography scan or a true interval cancer. Some had asked for a review of previous images, but most did not mention the possibility of false negative screening when asked about their thoughts on having breast cancer between screening rounds.

Fourteen had contacted the health care services within a week after noticing a palpable lump (Table 2). Eight had waited between two weeks and three months before seeking medical advice, and two delayed more than three months. There were no differences in type of symptom between the immediate help-seekers and those waiting for weeks or months, as all talked about having a lump. Two women retrospectively reported symptoms such as mastalgia or breast contour change, but they had not related this to breast cancer before being diagnosed. In the following we will present the women's own explanations for their timing when seeking medical advice.

Seeking medical advice immediately

Those who saw themselves as having sought medical advice promptly had all called their doctor's office or the mammography clinic at the first opportunity or at least within a week of feeling a lump.

"I detected it at eleven p.m. And there I was, with a glowing phone at eight a.m. (Laughter) Next morning, straight to the GP." (Johanne, 56)

The women who contacted their doctor immediately had no doubt about the possibility of having cancer. For them delay was no option after detecting a lump. In retrospect they had been certain that it could be a symptom of breast cancer. Thoughts about having cancer made acting upon it the rational option.

"I was very quick to get to the GP. I was certain it was cancer right away. […] I became very rational: Go to the clinic, make it go away."(Vigdis, 62)

Postponing seeking medical advice

Ten of the women had waited between two weeks and six months before seeking medical advice. Some of the women reported that they reinterpreted embodied sensations as possible cancer symptoms in retrospect, after being diagnosed. Prior to feeling a lump, they had either not noticed these symptoms or at least not interpreted them as symptoms of cancer. Each woman gave several explanations for what she retrospectively saw as her delay in help-seeking.

Uncertainty about symptom

All these women acknowledged that breast anomalies could often represent symptoms of breast cancer. However, their own bodily changes did not always stand out as definite symptoms. Being uncertain about the etiology of the breast change, it was initially interpreted as imaginary or something that could change back to normal.

> *"No you can't date it because you just sense it and consider it, and eventually it grows, so it could maybe have been a month or so. […] Yes, because it could potentially regress." (Cecilie, 67)*

Olaug (63) and Eva (57) explained their lesions due to sore skin from a tight bra or to an inflammation of some kind, sensations and observations the women later reinterpreted as possible early symptoms of cancer. They delayed seeking medical advice as the symptoms appeared too vague, for instance having an unpleasant sensation in the breast, nausea or tiredness. Their initial interpretations of their bodily sensations were framed by everyday experiences, as mentioned above. In hindsight, these bodily experiences were acknowledged as breast cancer symptoms.

Previous experiences

Postponement of help seeking also occured after a bodily sensation was identified as a potential symptom. Previous negative experiences with health care services contributed to reluctance towards seeking potentially unnecessary medical examinations. Those with multiple experiences with illness and disease were tired of being in the patient role. Prior negative encounters with health care

services following diffuse symptoms resulted in a a threshold against seeking help with diffuse breast cancer symptoms.

> *"I thought it might be an inflammation because I have had joint inflammations before and maybe that could have spread. And it was sore too. And one isn't too happy to go running to the doctor either. I did that all the time when I was younger, before I was diagnosed with arthritis, and with all that pain, so I'd rather not go (laughter). I got so tired when they never could detect what was wrong with me and I got all kinds of medications which damaged... […] So I am glad when I feel healthy and don't have to go."(Eva, 57)*

Having had frequent visits to the GP made some uneasy about being seen as whimpering. This suggests that "be a whimperer" or seeking health care services unnecessary were incoherent with their identity. Rather than be perceived as hypochondriacs, they would delay help-seeking for uncertain symptoms.

Practical reasons

There were also practical reasons given for delaying seeking medical advice. Two women had already a scheduled appointment with their GP when they detected a lump. Both waited until the appointment before bringing the lump to the doctor's attention.

> *"I had an appointment with the GP a few weeks after, so I waited until then. It was probably nothing anyway."(Gudrun, 60)*

Noticing a lump during holidays also led to a delay in seeing the doctor. Actions after finding a lump were not solely about the lesion, but also about their social situation. Practical reasons were intertwined with other explanations such as interpreting the mass as benign or non-existent.

Mammography screening

For some of the women the essential argument for delaying was related to having participated in mammography screening. Two different time frames were important for this argument. One was about having had a negative mammography in the recent past. The other was about an upcoming mammography. Having recently had a mammography scan led some to interpret the newly discovered lump as harmless. Having trusted mammography to detect even non-palpable lumps,

some of the women experienced it as strange that cancer had not been found at the screening. Petra, for instance, detected a lesion in April, but delayed acting upon it until October.

> *"I wonder if it [last mammography screening] wasn't in January that year. And that was probably the reason for my interpretation. Because I thought that when they hadn't seen anything then, it could not be anything now." (Petra, 66)*

Being part of a screening programme thus contributed to some women's interpretation of bodily signs as not being breast cancer symptoms. One woman presented a forward-looking argument for delaying. She had started to wait for a screening invitation, but after several months with a growing tumour she called the screening unit asking for the next screening appointment.

> *"I started to wait for the [mammography] bus that used to come, but it never came. Right? It was too long to wait, because I felt this… […] Yes, because I'm usually called in. So I called the hospital and asked them when the bus was due, and they said that it would not come until later that year, and she asked me if there was something specific I had on my mind? So I told her I had pain in a breast, but that I knew it isn't any danger when it hurts. "Go see a doctor", she said. So I called my GP that day, and got an appointment the next day." (Inger, 56)*

Even when interpreting her lump as potential cancer, Inger delayed acting on it as she waited for the screening programme to act. Both women who had waited six months before seeking medical advice explained their delay with their screening participation. This suggests that some participants place too much trust in the cancer detection capabilities of the screening programme.

DISCUSSION

From this qualitative interview study we found that ten of 24 women who had been mammography screening participants put off seeking medical advice when detecting a palpable lump. True interval breast cancer has poorer survival compared to screen-detected cancers. [6;8] Delaying acting on a breast cancer symptom between screening rounds could potentially decrease survival. Medically defined, diagnostic delay is waiting more than three months with a symptom before help-seeking.

Though only two among these 26 women fell within this definition, eight further women who had not acted immediately considered themselves to have delayed the diagnosis. The four main reasons for waiting to seek medical advice were uncertainty about symptom interpretation, practical reasons, previous negative experiences, and being participants of mammography screening. In order to self-detect cancer, individuals must sense a symptom, acknowledge it as such, and take action to seek medical advice.[23] It has hitherto not been known whether participating in mammography screening could influence any of these processes. What was unique in the present study was that all study participants had been participants in a mammography screening programme, and we explored whether screening participation could have contributed to a diagnostic delay.

Symptom interpretation of breast cancer may cause patient delay.[9;13-15;24;25] Palpable lumps are a well-known symptom of breast cancer that should induce seeking medical advice. All women in a Dutch study associated lumps with breast cancer.[9] However, studies vary in their conclusions about whether having a palpable lesion is associated with more or less delay than non-palpable symptoms.[17;26] In the present study, all the women referred to lumps when asked what had led to seeking medical advice. Other symptoms known to represent breast cancer, such as retraction of the nipple or skin, nipple discharge, skin discolouring or change in texture, mastalgia, a palpable lump in the axilla or a changed breast contour, had only been recognized as breast cancer symptoms after having the cancer diagnosis. For these women, participation in mammography screening might have increased awareness about self-examination for lumps but had apparently not increased knowledge of other symptoms.

Delay in seeking medical advice cannot be explained solely by lack of knowledge.[27] All the women knew that a lump could be a sign of cancer, and yet some delayed seeking medical help. Patient delay can depend on the patient's interpretation of bodily signs as related to cancer.[23] Although they knew in general that a lump could be a sign of cancer, some of the women did not immediately make that connection in their own case. As found in earlier studies, they did not expect to be ill and their current situation provided alternative explanations for their bodily experiences.[13] The present study indicates that participating in mammography screening may provide other explanations for bodily signs, since cancer had not been detected by mammography. Retrospective interpretations of bodily sensations as symptoms of breast cancer suggest that some had been reluctant to trust their own bodily sensations. In this sense mammography may contribute to medicalization, leaving women to trust medical technology over their own bodily sensations. Another interpretation is that they were too frightened by the prospect of having cancer to react to potential symptoms, in which case screening participation was not so much a contributing factor to delay as it was an available excuse to avoid contemplating cancer.

Seeing previous or upcoming mammography screening as reasons for delaying seeking medical advice about potential breast cancer suggests that too much trust in a public screening programme may contribute to delayed diagnosis. Though only a few women expressed such arguments, our study demonstrates their existence in the population. Trusting previous screens to be correct may have led to non-cancer interpretations of symptoms. Waiting for the next screening round instead of acting upon a palpable lump indicates high trust in the correctness of a biennial design.

Delay has been an essential concept throughout breast cancer history in the US.[12] Cultural studies of breast cancer have been scarce in Norway, but media campaigns against delayed diagnosis have been implemented. These women's delayed actions must be understood within such a broader cultural context. Discourses depicting breast cancer as a continuum have dominated in recent decades, making women's breasts objects of constant surveillance both by themselves and by others.[11] With a lack of clearly identified measures of primary prevention, surveillance becomes the sole option for responsible health behaviour. Although ten women in the present study claimed having delayed help-seeking, only two women delayed more than three months. Those who saw themselves as having delayed their active response had varied and complex arguments explaining their (in)actions while women who sought medical help immediately were certain they were doing the right thing.

Although the design of our study does not tell about the magnitude of the delay problem, it clearly identifies a problem which deserves closer attention. In line with conclusions from other studies [28-30], it also points in the direction of an upgrading of the importance of women's self- examinations and of further education regarding breast cancer symptoms.

Strengths and limitations

This qualitative interview study is unique in studying the experiences of women with interval cancer and how they related their experiences with breast cancer to mammography screening. Being interviewed about delaying seeking medical advice when detecting symptoms that later were diagnosed as cancer could be discomforting for those feeling guilty about delaying, leading to answers masking guilt. A limitation to the current study is that it is based on women's retrospective reports. Some had been diagnosed up to three years prior to the interview. Experiences before having cancer may not be the most important to remember after going through intensive cancer treatment, and could have been reinterpreted several times since experiencing them.

Nearly 65 per cent of those invited to the study chose to participate. All women with interval cancer within a specific period in these communities were invited, but self-selection in responding to the invitation present a selection bias. It is a limitation to the study that we cannot compare those participating with the 14 non-respondents. Serious disease might have hindered participation. Despite their cancer diagnosis, only six of the 26 respondents were fully retired. In Norway, less than 50 per cent of the population aged 55-74 were employed in 2005 [31], which indicates that participants in the present study could have been more resourceful than women in average. If diagnostic delay is a problem among the more resourceful segments of the population, it is reasonable to think that it is also present in the population in general.

We could expect potential cancer symptoms to be common in the population, as approximately 15 per cent of the population at any time experience such symptoms.[25] Women with symptoms in-between screening rounds could be classified in three groups: women who receive an interval cancer diagnosis, women whose symptoms are diagnosed as benign, and women who delayed seeking medical advice until their next screening round. As only the first group were subjects of this study, more research on symptom interpretation among screening participants is warranted.

Implications

Confidence in mammography programmes influences the interpretation of breast cancer symptoms. Awareness of symptoms other than lumps must be improved. Though information leaflets provide information about interval breast cancer, screening participants might not read leaflets thoroughly. Additional information and reminders during mammography examinations could be one solution. Previous experiences of vague symptoms being set aside could lead women to neglect their own bodily sensations and prefer technology to give answers to their health status. In this qualitative study we have explored the women's own interpretation of help-seeking for interval breast cancer. Further studies are required as to whether their choice of actions have delayed diagnosis in medical terms, according to tumor characteristics and survival.

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Table 1 Description of treatment for breast cancer, self-reported.

Treatment	**Surgery**	**Surgery + radiation**	**Surgery + chemo theraphy**	**Surgery + radiation + chemo therapy**	
Age					
50-54	0	0	0	3	
55-59	2	3	0	6	
60-64	0	4	0	4	
65-69	2	1	1	0	
Sum	4 (15,4 %)	8 (30,8 %)	1 (3,8 %)	13 (50,0 %)	**Total N=26**

Table 2 Description of women who participated in study: age and help-seeking behaviour

Reaction time	**Detected though other medical examinations**	**1-2 days**	**Within 2 weeks**	**Less than 2 months**	**Approx 6 months**	
Age						Mean=59.4
50-54	0	2	0	1	0	3 (11,5 %)
55-59	1	5	3	1	1	11 (42,3 %)
60-64	0	3	3	2	0	8 (30,8 %)
65-69	1	1	0	1	1	4 (15,4 %)
Sum	**2 (7,7 %)**	**11 (42,3 %)**	**6 (23,0 %)**	**5 (19,2 %)**	**2 (7,7 %)**	**Total N=26**

Title page

Title: Could screening participation bias symptom interpretation? An interview study on women's interpretations of and responses to cancer symptoms between mammography screening rounds.

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Running head: Could screening participation bias symptom interpretation?

Article summary:

Article Focus

- Interval breast cancer comprises 28 per cent of cancers among screened women in Europe.
- Women who participate in mammography screening may delay acting upon breast cancer symptoms if they trust screening results to be correct.
- We asked women with interval breast cancer how they had reacted to detecting symptoms of breast cancer in-between screening rounds.

Key Messages

- Despite the last mammography screening being negative, most of the interviewed women interpreted lumps as breast cancer symptoms and sought medical advice rapidly. Some women defined themselves as delayers despite seeking medical advice less than three months after symptom presentation.
- Only a few women who detected symptoms of breast cancer in-between screening rounds delayed seeking medical advice due to a recent negative screening result in the mammography screening programme.
- Other symptoms than lumps were only acknowledged as cancer symptoms in retrospect. Screening seems a missed opportunity to inform women better about breast cancer symptoms.

Strengths and limitations

This qualitative interview study is unique in studying the experiences of women with interval cancer and how they related their experiences with breast cancer to mammography screening. A limitation to the current study is that it is based on women's retrospective reports. Self-selection in responding to the invitation present a selection bias; women with advanced cancer might not have participated in the study, and participants may have been more resourceful than average.

ABSTRACT

Objectives To explore how women with negative mammography screening results, but who were later diagnosed with interval breast cancer, reacted when they observed breast symptoms that could indicate malignancy in-between screening rounds.

Design Semi-structured individual interviews with women who have been diagnosed with breast cancer during mammography screening intervals.

Setting Two breast diagnostic units covering two counties in Norway.

Participants 26 women diagnosed with interval breast cancer.

Results Women with a screening negative result react in two ways when experiencing a possible symptom of breast cancer. Among 24 women with a self-detected palpable lesion, 14 sought medical advice immediately. Their argument was to dispose of potential cancer as soon as possible. Ten women delayed seeking medical advice, explaining their delay as a result of practical difficulties such as holidays, uncertainty about the symptom, and previous experiences of health care services' ability to handle diffuse symptoms. Also, a recent negative mammography scan led some women to assume that the palpable lesion was benign and wait for the next screening round.

Conclusion Participating in mammography screening may contribute to a postponed reaction to breast cancer symptoms, although most women acted rapidly when detecting a palpable breast lesion. Furthermore, screening participation does not necessarily increase awareness of breast cancer symptoms.

Keywords: Breast cancer, interval cancer, oncology, mammography, screening.

INTRODUCTION

Mammography screening aims to provide a pre-symptomatic diagnosis of breast cancer. Nevertheless, interval cancer, which is cancer detected between screening rounds, comprises 28 per cent of cancers among screened women in Europe.[1] Survival rates for interval cancers have improved during recent decades [2], and it is controversial whether true interval cancers have less favourable prognosis than screening detected cancers or breast cancers diagnosed outside a screening programme.[3-5] Rayson et al found poorer survival in true interval breast cancer compared to screen-detected cancers. The findings of adverse prognostic factors like higher grade and stage, receptor negativity and high mitotic index in true interval cancers might contribute to poorer survival outcome. [6;7] **On the other side, survival rates in the screen detected groups are biased (lead and length time bias and overdiagnosis), leading to misinterpretation of the true effectiveness of screening.[8]** It should not be excluded, however, that diagnostic delay due to a recent negative mammogram may be an important factor in poorer survival rates.

Diagnostic delay occurs at many stages of the cancer detection process.[9] We will here concentrate on screening participants interpretation of bodily changes, and their help-seeking. Early detection of breast cancer has been promoted throughout the 20th century, including women's responsibility to react upon a palpable breast lesion.[10-12] Nevertheless, recognition of a breast cancer symptom is not always a straightforward process. Cultural contexts influence symptom experiences and bodily signs become symptoms only after an interpretation that they are abnormal. [9;13;14] The process from the onset of bodily changes until recognition of a symptom may be the period of time accounting for the greatest proportion of patient delay.[15;16] But even then, interpreting symptoms as cancer does not automatically lead to taking action.[14;17;18]

An argument for mammography screening is that it leads to earlier breast cancer detection compared with women's self-detection. The positive effect mammography may have on the time of detection must, however, be balanced against whether patient delay could be induced by the reassurance given following a negative screening.[19] A previous qualitative study indicates that women trust mammography screening to provide true results about their breast status.[20] The question addressed in this article is whether screening participation interferes with the women's symptom interpretation and help seeking. This study explores how women with negative mammography screening results who were later diagnosed with interval breast cancer, reacted when they observed breast symptoms that could indicate malignancy in-between screening rounds.

METHODS

This was a qualitative interview study with women who had experienced interval breast cancer within the Norwegian breast cancer screening programme. This is a nationwide, public screening programme that offers mammography biennially for all women aged 50-69. The study was approved by the Regional Committee for Medical Research; participation was based on written consent.

Recruitment

Forty women diagnosed with interval cancer at two hospitals in Central and Northern Norway were invited to the study. During the years 2006-2009, 178 interval breast cancers were diagnosed at these two hospitals. Due to long distances and the low population density in rural Norway, all invited to the study lived in or near urban or semi-urban areas. In order to have the women's stories as close to the event as possible, they were the twenty women last diagnosed with interval breast cancer at each hospital, living in or nearby one of four cities (inhabitants 9,500-150,000), counting back from six months before the study invitation was sent. A total of 26 women accepted the invitation. Due to confidentiality regulations, we have no access to information about the 14 women who did not respond to the invitation.

The interviews

Semi-structured interviews were carried out in 2009 by the first author (MS), at a hospital, a university, a hotel meeting room, or in the woman's home or workplace if requested. Following a semi-structured interview guide, the women were invited to tell their breast cancer story, including what kind of breast cancer symptoms they had reacted to. Other questions were about their views on mammography screening and reactions upon having interval breast cancer. Each interview lasted 45 to 60 minutes, and was audiotaped prior to being transcribed in verbatim. All informants have been given fictitious names to secure anonymity.

Analysis

Two researchers read all the interviews independently, and all co-authors read some of the interviews. We used a method of constant comparison, comparing themes within and between interviews. All authors discussed themes arising from the interviews. We conducted thematic analysis.[21] Data were categorized using NVivo 8.0. Within each theme we found sub-themes which were subjected to meaning interpretation.[22]

RESULTS

Participants

The 26 participating women were aged 53 to 69 years, in average 59.4. Twenty-four had discovered the symptoms of breast cancer themselves; two were detected during other medical examinations. The women were diagnosed with breast cancer between three and 23 months after their last screening mammography and were interviewed from six to 36 months after diagnosis. Based on the women's reports during the interview, all had been surgically treated, either with mastectomy or with breast conserving surgery, 21 women had undergone radiation therapy, and 14 chemotherapy (Table 1). Few women knew whether their malignant tumor represented a false negative mammography scan or a true interval cancer. Some had asked for a review of previous images, but most did not mention the possibility of false negative screening when asked about their thoughts on having breast cancer between screening rounds.

Fourteen had contacted the health care services within a week after noticing a palpable lump (Table 2). Eight had waited between two weeks and three months before seeking medical advice, and two delayed more than three months. There were no differences in type of symptom between the immediate help-seekers and those waiting for weeks or months, as all talked about having a lump. Two women retrospectively reported symptoms such as mastalgia or breast contour change, but they had not related this to breast cancer before being diagnosed. In the following we will present the women's own explanations for their timing when seeking medical advice.

Seeking medical advice immediately

Those who saw themselves as having sought medical advice promptly had all called their doctor's office or the mammography clinic at the first opportunity or at least within a week of feeling a lump.

"I detected it at eleven p.m. And there I was, with a glowing phone at eight a.m. (Laughter) Next morning, straight to the GP." (Johanne, 56)

The women who contacted their doctor immediately had no doubt about the possibility of having cancer. For them delay was no option after detecting a lump. In retrospect they had been certain that it could be a symptom of breast cancer. Thoughts about having cancer made acting upon it the rational option.

"I was very quick to get to the GP. I was certain it was cancer right away. […] I became very rational: Go to the clinic, make it go away."(Vigdis, 62)

Postponing seeking medical advice

Ten of the women had waited between two weeks and six months before seeking medical advice. Some of the women reported that they reinterpreted embodied sensations as possible cancer symptoms in retrospect, after being diagnosed. Prior to feeling a lump, they had either not noticed these symptoms or at least not interpreted them as symptoms of cancer. Each woman gave several explanations for what she retrospectively saw as her delay in help-seeking.

Uncertainty about symptom

All these women acknowledged that breast anomalies could often represent symptoms of breast cancer. However, their own bodily changes did not always stand out as definite symptoms. Being uncertain about the etiology of the breast change, it was initially interpreted as imaginary or something that could change back to normal.

> *"No you can't date it because you just sense it and consider it, and eventually it grows, so it could maybe have been a month or so. […] Yes, because it could potentially regress." (Cecilie, 67)*

Olaug (63) and Eva (57) explained their lesions due to sore skin from a tight bra or to an inflammation of some kind, sensations and observations the women later reinterpreted as possible early symptoms of cancer. They delayed seeking medical advice as the symptoms appeared too vague, for instance having an unpleasant sensation in the breast, nausea or tiredness. Their initial interpretations of their bodily sensations were framed by everyday experiences, as mentioned above. In hindsight, these bodily experiences were acknowledged as breast cancer symptoms.

Previous experiences

Postponement of help seeking also occured after a bodily sensation was identified as a potential symptom. Previous negative experiences with health care services contributed to reluctance towards seeking potentially unnecessary medical examinations. Those with multiple experiences with illness and disease were tired of being in the patient role. Prior negative encounters with health care

services following diffuse symptoms resulted in a a threshold against seeking help with diffuse breast cancer symptoms.

> *"I thought it might be an inflammation because I have had joint inflammations before and maybe that could have spread. And it was sore too. And one isn't too happy to go running to the doctor either. I did that all the time when I was younger, before I was diagnosed with arthritis, and with all that pain, so I'd rather not go (laughter). I got so tired when they never could detect what was wrong with me and I got all kinds of medications which damaged... […] So I am glad when I feel healthy and don't have to go."(Eva, 57)*

Having had frequent visits to the GP made some uneasy about being seen as whimpering. This suggests that "be a whimperer" or seeking health care services unnecessary were incoherent with their identity. Rather than be perceived as hypochondriacs, they would delay help-seeking for uncertain symptoms.

Practical reasons

There were also practical reasons given for delaying seeking medical advice. Two women had already a scheduled appointment with their GP when they detected a lump. Both waited until the appointment before bringing the lump to the doctor's attention.

> *"I had an appointment with the GP a few weeks after, so I waited until then. It was probably nothing anyway."(Gudrun, 60)*

Noticing a lump during holidays also led to a delay in seeing the doctor. Actions after finding a lump were not solely about the lesion, but also about their social situation. Practical reasons were intertwined with other explanations such as interpreting the mass as benign or non-existent.

Mammography screening

For some of the women the essential argument for delaying was related to having participated in mammography screening. Two different time frames were important for this argument. One was about having had a negative mammography in the recent past. The other was about an upcoming mammography. Having recently had a mammography scan led some to interpret the newly discovered lump as harmless. Having trusted mammography to detect even non-palpable lumps,

some of the women experienced it as strange that cancer had not been found at the screening. Petra, for instance, detected a lesion in April, but delayed acting upon it until October.

> *"I wonder if it [last mammography screening] wasn't in January that year. And that was probably the reason for my interpretation. Because I thought that when they hadn't seen anything then, it could not be anything now." (Petra, 66)*

Being part of a screening programme thus contributed to some women's interpretation of bodily signs as not being breast cancer symptoms. One woman presented a forward-looking argument for delaying. She had started to wait for a screening invitation, but after several months with a growing tumour she called the screening unit asking for the next screening appointment.

> *"I started to wait for the [mammography] bus that used to come, but it never came. Right? It was too long to wait, because I felt this… […] Yes, because I'm usually called in. So I called the hospital and asked them when the bus was due, and they said that it would not come until later that year, and she asked me if there was something specific I had on my mind? So I told her I had pain in a breast, but that I knew it isn't any danger when it hurts. "Go see a doctor", she said. So I called my GP that day, and got an appointment the next day." (Inger, 56)*

Even when interpreting her lump as potential cancer, Inger delayed acting on it as she waited for the screening programme to act. Both women who had waited six months before seeking medical advice explained their delay with their screening participation. This suggests that some participants place too much trust in the cancer detection capabilities of the screening programme.

DISCUSSION

From this qualitative interview study we found that ten of 24 women who had been mammography screening participants put off seeking medical advice when detecting a palpable lump. **True interval breast cancer has poorer survival compared to screen-detected cancers.** [6;8] Delaying acting on a breast cancer symptom between screening rounds could potentially decrease survival. Medically defined, diagnostic delay is waiting more than three months with a symptom before help-seeking.

Though only two among these 26 women fell within this definition, eight further women who had not acted immediately considered themselves to have delayed the diagnosis. The four main reasons for waiting to seek medical advice were uncertainty about symptom interpretation, practical reasons, previous negative experiences, and being participants of mammography screening. In order to self-detect cancer, individuals must sense a symptom, acknowledge it as such, and take action to seek medical advice.[23] It has hitherto not been known whether participating in mammography screening could influence any of these processes. What was unique in the present study was that all study participants had been participants in a mammography screening programme, and we explored whether screening participation could have contributed to a diagnostic delay.

Symptom interpretation of breast cancer may cause patient delay.[9;13-15;24;25] Palpable lumps are a well-known symptom of breast cancer that should induce seeking medical advice. All women in a Dutch study associated lumps with breast cancer.[9] However, studies vary in their conclusions about whether having a palpable lesion is associated with more or less delay than non-palpable symptoms.[17;26] In the present study, all the women referred to lumps when asked what had led to seeking medical advice. Other symptoms known to represent breast cancer, such as retraction of the nipple or skin, nipple discharge, skin discolouring or change in texture, mastalgia, a palpable lump in the axilla or a changed breast contour, had only been recognized as breast cancer symptoms after having the cancer diagnosis. For these women, participation in mammography screening might have increased awareness about self-examination for lumps but had apparently not increased knowledge of other symptoms.

Delay in seeking medical advice cannot be explained solely by lack of knowledge.[27] All the women knew that a lump could be a sign of cancer, and yet some delayed seeking medical help. Patient delay can depend on the patient's interpretation of bodily signs as related to cancer.[23] Although they knew in general that a lump could be a sign of cancer, some of the women did not immediately make that connection in their own case. As found in earlier studies, they did not expect to be ill and their current situation provided alternative explanations for their bodily experiences.[13] The present study indicates that participating in mammography screening may provide other explanations for bodily signs, since cancer had not been detected by mammography. Retrospective interpretations of bodily sensations as symptoms of breast cancer suggest that some had been reluctant to trust their own bodily sensations. In this sense mammography may contribute to medicalization, leaving women to trust medical technology over their own bodily sensations. Another interpretation is that they were too frightened by the prospect of having cancer to react to potential symptoms, in which case screening participation was not so much a contributing factor to delay as it was an available excuse to avoid contemplating cancer.

Seeing previous or upcoming mammography screening as reasons for delaying seeking medical advice about potential breast cancer suggests that too much trust in a public screening programme may contribute to delayed diagnosis. Though only a few women expressed such arguments, our study demonstrates their existence in the population. Trusting previous screens to be correct may have led to non-cancer interpretations of symptoms. Waiting for the next screening round instead of acting upon a palpable lump indicates high trust in the correctness of a biennial design.

Delay has been an essential concept throughout breast cancer history in the US.[12] Cultural studies of breast cancer have been scarce in Norway, but media campaigns against delayed diagnosis have been implemented. These women's delayed actions must be understood within such a broader cultural context. Discourses depicting breast cancer as a continuum have dominated in recent decades, making women's breasts objects of constant surveillance both by themselves and by others.[11] With a lack of clearly identified measures of primary prevention, surveillance becomes the sole option for responsible health behaviour. Although ten women in the present study claimed having delayed help-seeking, only two women delayed more than three months. Those who saw themselves as having delayed their active response had varied and complex arguments explaining their (in)actions while women who sought medical help immediately were certain they were doing the right thing.

Although the design of our study does not tell about the magnitude of the delay problem, it clearly identifies a problem which deserves closer attention. In line with conclusions from other studies [28-30], it also points in the direction of an upgrading of the importance of women's self- examinations and of further education regarding breast cancer symptoms.

Strengths and limitations

This qualitative interview study is unique in studying the experiences of women with interval cancer and how they related their experiences with breast cancer to mammography screening. Being interviewed about delaying seeking medical advice when detecting symptoms that later were diagnosed as cancer could be discomforting for those feeling guilty about delaying, leading to answers masking guilt. A limitation to the current study is that it is based on women's retrospective reports. Some had been diagnosed up to three years prior to the interview. Experiences before having cancer may not be the most important to remember after going through intensive cancer treatment, and could have been reinterpreted several times since experiencing them.

Nearly 65 per cent of those invited to the study chose to participate. All women with interval cancer within a specific period in these communities were invited, but self-selection in responding to the invitation present a selection bias. It is a limitation to the study that we cannot compare those participating with the 14 non-respondents. Serious disease might have hindered participation. Despite their cancer diagnosis, only six of the 26 respondents were fully retired. In Norway, less than 50 per cent of the population aged 55-74 were employed in 2005 [31], which indicates that participants in the present study could have been more resourceful than women in average. If diagnostic delay is a problem among the more resourceful segments of the population, it is reasonable to think that it is also present in the population in general.

We could expect potential cancer symptoms to be common in the population, as approximately 15 per cent of the population at any time experience such symptoms.[25] Women with symptoms in-between screening rounds could be classified in three groups: women who receive an interval cancer diagnosis, women whose symptoms are diagnosed as benign, and women who delayed seeking medical advice until their next screening round. As only the first group were subjects of this study, more research on symptom interpretation among screening participants is warranted.

Implications

Confidence in mammography programmes influences the interpretation of breast cancer symptoms. Awareness of symptoms other than lumps must be improved. Though information leaflets provide information about interval breast cancer, screening participants might not read leaflets thoroughly. Additional information and reminders during mammography examinations could be one solution. Previous experiences of vague symptoms being set aside could lead women to neglect their own bodily sensations and prefer technology to give answers to their health status. In this qualitative study we have explored the women's own interpretation of help-seeking for interval breast cancer. Further studies are required as to whether their choice of actions have delayed diagnosis in medical terms, according to tumor characteristics and survival.

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Table 1 Description of treatment for breast cancer, self-reported.

Treatment	**Surgery**	**Surgery + radiation**	**Surgery + chemo theraphy**	**Surgery + radiation + chemo therapy**	
Age					
50-54	0	0	0	**3**	
55-59	2	3	0	**6**	
60-64	0	4	0	**4**	
65-69	2	1	1	**0**	
Sum	4 (15,4 %)	8 (30,8 %)	1 (3,8 %)	**13 (50,0 %)**	**Total N=26**

Table 2 Description of women who participated in study: age and help-seeking behaviour

Reaction time	**Detected though other medical examinations**	**1-2 days**	**Within 2 weeks**	**Less than 2 months**	**Approx 6 months**	
Age						Mean=59.4
50-54	0	2	0	1	0	3 (11,5 %)
55-59	1	5	3	1	1	11 (42,3 %)
60-64	0	3	3	2	0	8 (30,8 %)
65-69	1	1	0	1	1	4 (15,4 %)
Sum	**2 (7,7 %)**	**11 (42,3 %)**	**6 (23,0 %)**	**5 (19,2 %)**	**2 (7,7 %)**	**Total N=26**