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Balancing risks: attitudes, motivations, and intentions about attending for mammography during the COVID-19 pandemic. Qualitative study.

Pia Kirkegaard^a, Adrian Edwards^{a,b}, Berit Andersen^{a,c}

^aDepartment of Public Health Programmes, Randers Regional Hospital, Randers, Denmark

^bDivision of Population Medicine, Cardiff University, Cardiff, UK

^cDepartment of Clinical Medicine, Aarhus University, Aarhus, Denmark.

Corresponding author: Pia Kirkegaard, Department of Public Health Programmes, Randers Regional Hospital, Skovlyvej 15, DK-8930 Randers NØ, Denmark. Email: piakik@rm.dk

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Abstract

Aim: to explore attitudes, motivations, and intentions about attending for mammography among women who cancelled or postponed breast cancer screening which had remained open in Denmark during the COVID-19 pandemic.

Method: A telephone interview study was conducted at the end of April 2020. A qualitative, phenomenological approach was chosen to identify themes and concepts, and a semi-structured interview guide was developed. The analysis was structured according to constructs from the Theory of Planned Behaviour including attitudes to breast cancer screening; norms and motivations to comply with breast cancer screening; perceived control; and anticipated regret.

Result: Interviews with 33 women aged 50-69 (mean 62 years) were performed. The women felt that screening was of secondary importance during the pandemic's height, and they felt low perceived control over transportation to the screening clinic and over the screening situation itself where social distances were impossible. They perceived messages from the authorities as conflicting regarding the request for social distancing and lack of recommendations about using face masks at the screening clinic.

Conclusion: Women who postponed or cancelled breast cancer screening during the COVID-19 pandemic felt that public recommendations appeared contradictory. Uncertainty about the 'new norm(al)' of COVID-19 made them stay home although the screening clinics remained open. The findings point to the importance of addressing perceived inconsistency between recommendations from the World Health Organization (WHO) and national management of the WHO recommendations, and to secure univocal information from the authorities about recommended use of healthcare services in a time of crisis.

Background

Almost all countries worldwide made substantial changes to daily life as the World Health Organization (WHO) declared the COVID-19 a “pandemic” in March 2020¹. Public health recommendations from WHO included self-isolation even with minor symptoms; frequent hand washing; a social distance of at least 1 meter/3 feet; and avoiding crowded places². In many countries, healthcare systems were forced to reallocate resources from detection and treatment of other diseases to combat the threat of COVID-19. The pandemic has already affected symptomatic cancer detection and treatment, but the full consequences of this 'pausing' on cancer detection remain to be seen^{3, 4}.

Most Western countries have well-established population-based breast cancer screening programmes to diagnose asymptomatic breast cancer cases at an early stage⁵, but several countries paused their screening programmes either regionally or nationally during the COVID-19 pandemic, e.g. in UK, Germany, France, Italy, Spain, Portugal, Switzerland, Belgium, the Netherlands, Slovenia, Norway, Sweden, USA, Canada, Brazil, Peru, Japan, and India. In Denmark, however, the population-based breast cancer screening programme remained open but the number of women who stayed away, postponed or cancelled their mammography screening increased⁶.

The decision to participate in mammography at any time is made in the light of several influences on personal attitudes, beliefs, perceived risks and benefits, opportunities to participate, intentions and barriers⁷⁻¹³. These influences are likely to have changed in nature or prominence during the height of COVID-19 with its additional risks, including attending at healthcare facilities, affecting decisions about participation. People invited to screening are likely to have made trade-offs between their usual appraisal of risks and benefits of cancer screening and those presented by the immediate pandemic.

Aim

The aim of this study was to explore attitudes, motivations, and intentions about attending for mammography among women in the Danish population-based breast

cancer screening programme who cancelled or postponed mammography during and due to the COVID-19 pandemic.

Methods

Setting:

The study took place in Central Denmark Region which is the second largest region in Denmark with 1.3 million residents (23% of the total population in Denmark). The administration of all population-based cancer screening programmes (breast cancer, cervical cancer, and colorectal cancer) in this region is centralized to a single department that handles all requests by telephone and email regarding the cancer screening programmes and sends out invitations to screening¹⁴. All women in Denmark aged 50-69 are invited to biennial breast cancer screening through secure digital email including a pre-booked mammography appointment at the screening clinic closest to their home. The mammography is performed by specially trained screening assistants. Screening participation and follow-up are free of charge. The Danish breast cancer screening programme has an 83% participation rate¹⁵.

Due to the COVID-19 pandemic, a national lockdown of specific commercial and public services was announced on the 11th of March 2020¹⁶, and some non-urgent detection, prevention, treatment and rehabilitation in the healthcare system were postponed to ensure capacity and to reduce contagion among healthcare professionals and patients using healthcare facilities¹⁷. By the end of April 2020, 8,000 people in Denmark had tested positive (137.9 per 100,000), and 430 had died with COVID-19 (7.4 per 100,000).

Design and participants:

A qualitative, phenomenological approach was chosen to identify themes and concepts derived from an exploration of women's accounts about reasons for postponing or cancelling their appointment for breast cancer screening during the COVID-19 pandemic and their attitudes, motivations, beliefs and intentions to be screened later. The approach

was constructivist with an emphasis on phenomenology to explore how the women made sense of their experiences in the specific context¹⁸. The study was designed as a telephone interview study with women who cancelled or postponed their pre-booked appointment for breast cancer screening at the end of April 2020. Women were recruited when they called the central breast cancer screening department in Central Denmark Region. The telephones were busy during the weeks of COVID-19, but when possible the secretarial staff asked the women to state the main reason for cancelling or postponing. Women who stated COVID-19 as the main reason were asked to participate. If they agreed, they were called back by a researcher (PK) within two working days.

Data collection:

A semi-structured interview guide was developed (Table 1)¹⁹. The questions were refined in the first four interviews and slightly changed to include more open-ended questions and time for intended silence and supportive verbal feedback to compensate for lack of visual body language during the telephone interview. The four final main questions were: Could you tell me about your thoughts and considerations about breast cancer screening when you decided to postpone or cancel your appointment for a screening mammogram? What are your general thoughts about breast cancer and breast cancer screening? What are your general thoughts about COVID-19? When and why do you (not) intend to get screened later? The telephone interviews were audio-recorded and transcribed verbatim by a secretary and validated by the first author (PK).

Data analysis:

The transcripts were independently searched for patterns by two researchers (BA and PK) and presented for discussion with second author (AE) to establish preliminary themes, raise analytic insights and discuss an appropriate theoretical approach to explore and develop the analysis. It was decided to apply constructs from the Theory of Planned Behaviour including attitudes to breast cancer screening; norms and motivations to comply with breast cancer screening; perceived control; and anticipated regret²⁰⁻²².

Ethics:

According to EU's General Data Protection Regulation (article 30), the project was listed on the register for research projects in Central Denmark Region (journal number 1-16-02-212-20). The study did not require ethical approval in accordance with Danish legislation²³. Consent was obtained orally twice, i.e. when the women called the screening unit to postpone/cancel their pre-booked screening mammography, and when the researcher called back to obtain permission to conduct an audio-recorded telephone interview. The participating women were informed that their interview data would be pseudonymised and they could withdraw their consent at any time before study publication.

Results

During the study period, the secretarial staff asked 167 women if postponing or cancelling of mammography was either COVID-19 related or for another reason, and in 42 calls, women stated COVID-19 as the main reason for cancelling or postponing mammography. Of the 42 women, six did not wish to participate in the study and three could not be reached.

Interviews with 33 women aged 50-69 (mean 62 years) were performed (mean 18 minutes per interview). Eleven women intended to be screened within one month, 13 intended to be screened in three to four months, four intended to be screened in five to six months, and five intended to wait for an invitation with a pre-booked appointment in two years (i.e. they cancelled this screening round). Nobody intended to be screened in two months because it would coincide with the summer holidays.

Attitudes to breast cancer screening: "It just needs to be done and that's it"

Attitudes included responses to the idea of screening, beliefs about outcomes, and values associated with it. All women stated that they were generally in favour of breast cancer

screening and had participated regularly although many experienced some discomfort and unease:

ID25: it's a little strenuous, but come on. You deal with it, and it's only every second year or every third year?

ID27: Some of the ladies (the screening assistants) are a bit tough, and it can be a little sensitive but that's okay with me. It just needs to be done and that's it.

Some women expressed that screening has low priority in a time of crisis. They reported that they had no symptoms of breast cancer or they did not feel at risk of breast cancer, and hence they did not feel it important to get screened right now:

ID 19: I didn't suspect anything abnormal so screening is just a 'nice to have' that can be postponed, so I thought I'd postpone it until society slowly reopens and you can stop worrying so much.

ID27: I have no problems or urgent sensations or feelings or experiences that indicate that I need to get screened right now.

Knowledge about other women who had benefitted from breast cancer screening influenced and confirmed their positive attitudes to screening, but they argued that right now, screening was of secondary importance:

ID 07: I know that I have several friends who had a breast cancer detected in screening because the cancer was hidden so deeply that they couldn't feel it. But I believe that during this period, it can wait.

ID 14: I truly want that examination. I don't like postponing such a thing because I've heard of people who postponed it, thinking 'we can do it later'. It's the corona right now and then I thought 'one month, there is not much harm in that'.

ID 16: I thought it was better that the doctors spend their energy on patients who are really sick with corona, instead of filming me.

Perceived Norms: "I cannot make any sense of it right now".

Perceived norms include beliefs about what other people do (descriptive norm) and beliefs about what they think one should do (subjective norm), and motivation to participate or not. In this context it relates to norms about 'community spirit' (conveyed by the government and the health authorities) and how the women interpreted it. The women cited the public recommendations from the government and the health authorities regarding distance and hygiene as the main motivations for postponing or cancelling their mammogram. The healthcare staff in Danish screening clinics did not wear face masks at this time of the pandemic but followed recommendations from the Danish Health Authority, including increased hygiene. Some women were sceptical about the fact that they (the patients) were expected to keep a distance from loved ones and suffer emotional deprivation, but at the screening clinic no personal protective equipment was worn by staff even though a physical distance of one to two meters was impossible:

ID 29: When I have been told to keep a distance of two meters to other people and I'm recommended not to see my grandchildren and urged to take care of myself because I'm over 65 years old, I think it is wrong that I'm told that they (the healthcare professionals) are not wearing any personal protective equipment when I call the mammography department to ask what I'm expected to bring. I know that you are standing very, very close to the person taking a mammogram, because they have to make sure that the breast is placed correctly, and you are almost rubbing your noses on each other.

Some stressed that it felt wrong to use the healthcare system for elective health matters during the pandemic, assuming that other people might think it wrong to use healthcare services not directly related to detection or treatment of COVID-19:

ID 14: It might sound a bit stupid but it feels like it's a bit more 'okay' to accept the healthcare offers when society reopens a bit.

At the time of the interview, some legal restrictions (temporary closure of e.g. shops, restaurants) were about to lessen and this added to the feeling of conflicting norms:

ID33: Once you should keep a distance of two meters and then all of a sudden you can go to a hairdresser and to a dentist where you are very close to each other, right. I cannot make any sense of it right now.

Perceived control: "I would have shown up if they had worn face masks"

Perceived control includes one's perceived amount of control over a certain behaviour (in this case screening participation) and perceptions of the degree to which environmental factors such as other people's behaviour make it easy or difficult to perform the behaviour.

Most of the women expressed that the main reason for postponing or cancelling this screening round was low perceived control regarding the trip to the screening clinic and the screening situation. They were motivated to stay home because of uncertainty about governmental recommendations and fear of other people's lack of intention or ability to maintain social distance and hygiene. At this point, there were no governmental recommendations about wearing face masks in public. For women without a car or someone to drive them to the screening clinic, the thought of being compelled to use public transportation dissuaded them from attending screening. Transportation by bus was perceived as an uncontrollable situation where the risk of COVID-19 contagion was high or unknown:

ID 16: I think I'd rather skip it (screening) than use public transportation where there is a higher risk of getting the other thing.

ID12: It's the public transportation, I'm worried about (...) I know the buses are running and everything, but I just don't want to take the bus at the moment.

Some women stated that the screening clinic itself was a place where contagion could get out of control. Two cities in the western part of Central Denmark Region (Holstebro and

Herning) had been termed 'hotspots' in the media and were mentioned regularly, although for most women, contact with the healthcare system in this time of uncertainty was preferably avoided.

ID31: I heard that many many people in Holstebro and on Herning hospital have been infected, so I just didn't dare go there.

ID18: I'd rather not get in contact with the healthcare system here in Holstebro, not just because it's Holstebro but in general.

Some women pointed out that mammography participation itself was associated with a perceived risk of getting infected with COVID-19, and over which they had no control:

ID7: I don't think it would be a problem to get there, but there may be many people waiting in the waiting facilities. However, that's not the real problem. The real problem is the examination itself. If it were just an x-ray, it would be okay because the distance is big but when you get a mammography, someone has to stand close to you to place your breast where it is supposed to be.

ID29: I would have shown up if they had worn face masks, even though nobody knows for sure that face masks work, but it would have worked for me because I would have shown up.

Although population-based cancer screening was exempted from the lockdown, a strategy of 'watchful waiting' was applied by many women who said they awaited the daily numbers of hospitalised patients and patients who had died with COVID-19 to make a decision.

ID 09: I'll wait until I believe it's safe. The death number has to go down to one or zero or something like that. I need to see that something is changing, also regarding the number of hospitalised. I have to trust that number.

ID 14: I considered it thoroughly and reasoned that I might as well watch and wait to see the numbers drop, to see they get lower and lower, to see if it gets better with the numbers.

Other women directly weighed up the risk of contagion with COVID-19 against the risk of having an undetected breast cancer directly:

ID 7: I think you should weigh the pros and cons carefully. Whether you want the corona virus and all it may imply regarding respiratory distress and cough and illness, or you want the other thing which may be nothing. I think that's the balancing of pros and cons that every individual should make. That's what I've done myself.

ID 29: But I believe that the risk of getting COVID-19 and not be cured may be at least in principle as high as getting breast cancer if you are not examined in time. You just don't know. It's a bit like playing the lottery, right?

Anticipated regret: "I'd never be able to forgive myself if they got infected"

Regret is a cognitive-based emotion that occurs when one imagines that the present situation could have been better if one had behaved differently. Anticipated regret occurs before an imagined behaviour (in this context getting screened and possibly exposed to COVID-19 contagion). For some, the risk of becoming a healthy carrier who could infect others at random informed their decision to postpone screening:

ID 12: I don't want to expose anybody to it or put them at risk right here and right now. That's why I've decided to postpone the appointment.

Some women had vulnerable family members and felt they would fail in their obligations if they put them at risk.

ID 19: My mom has diabetes so I wasn't particularly keen on posing a risk of contagion on her. I'd like to visit them with a clean conscience and I know that I'd never be able to forgive myself if they got infected and the fault was mine.

Others said they just wanted to stay away from society to avoid contagion because they were vulnerable themselves.

ID 31: I've put myself in a voluntary quarantine at home. I don't go out much because I have chronic obstructive pulmonary disease and only 28% of my lung capacity left, so I just don't dare going out.

The three areas of influences to postpone breast cancer screening overlapped for most women, and taking care of oneself and others was for all participants a direct reference to requests about exercising community spirit which was rehearsed several times by different authorities.

Discussion

Main findings

Intentions to get screened for breast cancer in the shadow of the COVID-19 pandemic were influenced by 1) the attitude(s) that screening was generally important but it was of secondary importance right now; 2) a sense of clashing norms and conflicting messages from the health authorities about the correct way to exercise 'community spirit'; 3) low perceived control over transportation to the screening clinic and the screening situation itself, and 4) anticipated regret about exposing themselves or others to COVID-19 contagion before, during or after being screened for breast cancer.

Strengths and limitations

Although face-to-face interviewing is often the preferred method for qualitative data collection about experiences, owing to the possibility of informal talk and non-verbal communication to facilitate a trustful setting²⁴, this was not feasible due to the risk of COVID-19 contagion.

The women seemed keen to discuss their attitudes, motivations and intentions to be screened but the structure of a telephone conversation may have made the interview more focused and less sensitive to unanticipated data compared with a face-to-face interview.

Data collection took place during the pandemic which is considered a strength of the study. We were able to explore attitudes, motivations and intentions during the rapidly evolving events, and by using the constructs from a well-established theoretical model, future research about the impact of a pandemic on use of healthcare services can use the findings for comparison over time and in different contexts.

Interpretation of results

A previous study showed that half of Danish women participating in breast cancer screening felt 'obliged' to participate to a 'great' or to 'some' extent (36.2 and 12.9 % respectively)²⁵. The participants in our study had balanced the risk of having an undetected breast cancer against the risk of getting COVID-19, but still including thoughts about 'obligation' towards society, loved ones, and oneself. They anticipated regret if they contracted the virus and/or infected others after screening participation. These influential feelings apparently conflicted with perceived and prior obligations to participate in cancer screening.

Despite the fact that the Danish general practitioners offered 'virtual' consulting by phone or video from the beginning of the COVID-19 pandemic, 36% of Danes wanted to avoid 'burdening' the healthcare system and had decided to postpone a healthcare visit despite having pain or symptoms of disease other than COVID-19²⁶. This underscores that uncertainty about 'new norms' during the pandemic was a key motivation to stay home. This uncertainty was exacerbated when recommendations from the Danish government and authorities differed from announcements from WHO which advocated face masks in some situations in public. The Danish government and health authorities did not recommend face masks in public at this point, citing inconsistent evidence about their effects. The contradictory recommendation about keeping a social distance and participating in breast cancer screening standing very close to a screening assistant without a face mask, seemed crucial for women who explicitly stated that they would attend for mammography if the screening assistants had worn face masks.

Access to a private vehicle is already known to influence participation in breast cancer screening²⁷, and during a pandemic the influence of not having access to a vehicle on non-participation may be exacerbated due to the fear of inability to keep a social distance, further increasing inequality in breast cancer screening for some groups. Furthermore, the government had requested citizens to avoid public transportation during rush hour, and to limit use of public transportation at all. For women without access to a private vehicle, going to a screening clinic seemed to contradict these recommendations. Perceived inconsistencies, reluctance, and public disagreement among experts have previously shown to be associated with lack of adherence to recommendations²⁸⁻³⁰, and recommendations for screening participation need to avoid such inconsistency, be adjusted to accommodate people's personal contexts and barriers, and explain clearly what people can do to manage their risks.

Conclusions

The study showed that women who postponed or cancelled breast cancer screening due to the COVID-19 pandemic were motivated to participate, except in a time of extreme uncertainty where public recommendations appeared contradictory. Balancing risk of getting COVID-19 against risk of having an undetected breast cancer drew on deliberations about responsibility – community spirit – to avoid contagion with COVID-19, and uncertainty about the 'new norm(al)' of COVID-19. Clear information and recommendations from the government and authorities are pivotal in women's decision-making about screening participation. Information needs to include what is being done to manage risks and recommendations about what people can do to manage risks themselves, such as the use of face masks at the screening clinic.

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Declaration of conflicting interests

The authors declare that there is no conflict of interest.

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