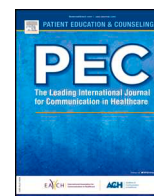




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Practice theoretical approach on the reasons why target group women refrain from taking breast cancer screening

Kadi Lubi^{a,b,*}, Vita Savicka^b, Marilyn Koor^a, Irma Nool^c, Mare Tupits^c, Silja Mets-Oja^a^a Tallinn Health Care College, Health Education Center, Kännu 67, 13418 Tallinn, Estonia^b Department of Communication Studies, Riga Stradins University, 16 Dzirciema iela, Rīga LV-1007, Latvia^c Tallinn Health Care College, Chair of Nursing, Kännu 67, 13418 Tallinn, Estonia

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ABSTRACT

Objective: Breast cancer is the most common cancer in women. Despite the availability of effective breast cancer screening programmes, there are only six countries in the European Union reaching the recommended target rate of 70% screened. In addition to the individual reasons for refraining from breast cancer screening, this research aims to follow earlier suggestions to use a practice theoretical approach.

Methods: The study sites were Estonia and Latvia, where 9 and 12 semi-structured interviews were conducted, respectively. Convenience and snowball sampling methods were used. The research was approved by ethics committees in both countries. The interviews passed textual analysis and coding.

Results: The findings revealed that there are three major types of reasons – habitual, practical, and emotional – that influence the formation of the final decision to participate in breast cancer screening.

Conclusion: The implementation of an individualistic approach is not sufficient to bring along desired health behaviour. All groups of reasons, individual and societal context are involved in the decision formation. Thus, structurally provided approaches and messages should be re-conceptualised and re-designed accordingly.

Practice implications: Future screening related campaigns and public health education should address the concerns derived from different types of reasons for refraining from screening.

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1. Introduction

Breast cancer (BC) is the most frequent cancer type for women in the world [1], and breast cancer remains the most common cause of cancer deaths in Estonia [2] and Latvia [3]. Yet, only six European countries, namely Finland, Ireland, the Netherlands, Norway, Slovenia, and the United Kingdom (UK), have reached the recommended target rate of 70% participation in breast cancer screening (BCS) programmes [4]. In three of these countries (Finland, UK and Netherlands), BCS programmes were initiated in late 1980s [5]. Additionally, it has been shown that more successful in reaching 70% threshold were countries which reached participation rate >70% already by 2004 or the first year after introduction of the

programme [6], which has been the case for all of these countries. Breast cancer screening participation rates were 56% in Estonia and 44% in Latvia in 2017 [7,8], although BCS programmes have functioned since 2002 and 2009, respectively [4].

Previous research investigating the reasons why women refrain from BCS in Latvia has taken place in small scale, unpublished projects. In Estonia, the last study, which investigated the reasons for BCS non-participation, was published in 2007 [9]. In previous research it was found that there are 5 main categories of reasons why women do not participate in BCS, namely – recent participation during BCS, not receiving the invitation to BCS, having no complaints, practical reasons (e.g. duties related to the work and lack of time to participate), and fear of the diagnosis [9]. In a qualitative thematic literature review, also, five themes surrounding BCS have been identified: fear, pain and discomfort, waiting, the physical environment of BCS, and staff interactions [10]. A Swedish study claimed there are two categories of reasons why women may refrain from BCS – i.e. individual needs, which do not adapt to the mammography screening process, and the absence of active promotion [11]. Women's immediate networks (e.g. family and close friends)

* Corresponding author at: Tallinn Health Care College, Health Education Center, Kännu 67, 13418 Tallinn, Estonia.

E-mail addresses: kadi.lubi@ttk.ee, kadi.lubi@rsu.lv (K. Lubi), vita.savicka@rsu.lv (V. Savicka), marilyn@online.ee (M. Koor), irma.nool@ttk.ee (I. Nool), mare.tupits@ttk.ee (M. Tupits), silja.mets-oja@ttk.ee (S. Mets-Oja).

are important and influential in determining whether a woman participates in BCS or not [12].

Although the reasons women refrain from BCS have been widely investigated globally, the issue needs re-examination due to changing environments and technical opportunities. An additional dimension that this research aims to add is the use of social practice theory. Practice is a “routinized type of behaviour” consisting of several elements [13]. Changes in social practices are related to external changes. Practices are always intertwined with each other, hence forming practice-bundles [14], i.e. when aiming for a social change, there are always several factors to consider. Different authors [15–17] have raised the discussion of practice in the area of health and illness. Cohn [15] stated that focusing only on individual-related aspects of health decision limits understanding the influences related to the power and sociality. As he suggests, there is a need for reconceptualizing health decision in terms of health practices rather than health behaviours. Similarly, Kelly and Barker highlight that social practice theory should be integrated more with other theoretical (especially with behavioural, psychological) concepts for the development of new public health interventions [16]. As they conclude,

“the next step is to consider the extent to which automatic and reflective processes are at work. It involves identifying the elements in the practices, the infrastructures, the meanings and the competencies exhibited by the people doing the behaviour and determining where the links between these things might be disconnected” [16].

Earlier research has questioned whether individual choices are, indeed, individual or shaped from the top down [18], as the matter of individual choice is dependent on a social context an individual lives in and, therefore, the focus of a public health campaign should be wider than just the individual [17]. It has also been shown that in the case of chronic illnesses, the existing lifestyle and practices of an individual might influence the process of adapting to illness, and the ways existing practices are adjusted to or new illness-related practices are adopted [19]. Thus, considering everything above, this research aims to expand the social practice approach to the area of preventive medicine, namely the area of breast cancer screening in order to examine more structural rather than individualistic approaches to health choices. This will be done by analysing the reasons why women refrain from breast cancer screening programmes by identifying whether and how the elements of practices and practice-bundles might influence their decisions.

2. Methods

This research was conducted as a qualitative research. In both countries, semi-structured in-depth interviews were performed between March 2019 and May 2020. Due to the sensitivity of the topic, the participants for in-depth interviews were found by using convenience and snow-ball sampling methods and recruitment was conducted via different sources. In Estonia, participants were recruited via phone (mainly primary source for convenience sample) and/or Facebook account (mainly primary source for snowball sampling). In Latvia, participant were recruited via help of union health centres who provided information about women who had not participated during BCS (both processes approved by local ethics committees and in line with local legislation). After oral consent, the aims of the research were introduced, and written consent was signed.

The research was approved by the Research Ethics Committee of the National Institute for Health Development (approval no. 2650, March 5th, 2019) and by the Research Ethics Committee of Riga Stradins University (approval Nr.6-1/01/4) The study is in line with

the requirements of Declaration of Helsinki and both EU and local data protection legislation.

2.1. Data collection

The study sites were Estonia and Latvia, former Soviet Union countries that have gone through rapid societal and (health) political developments [20]. The historical background might be important to keep in mind also in terms of medicine; the Soviet medical system focused mainly on curative care [20], while the concepts of patient-centeredness, individual responsibility, and decision-making were introduced only years after the new political system was established (i.e. within the last 10–15 years). The inclusion criteria for the conducted qualitative research were gender (women), age (between 50 and 69), and non-participation during breast cancer screening during last two calls despite receiving an invitation to breast cancer screening. In Estonia, nine women were interviewed; in Latvia, twelve women were interviewed. The first and the third author conducted interviews in Estonia, and the second author conducted interviews in Latvia. The final number of participants was sufficient to reach data saturation. According to Corbin and Strauss, saturation is not only the lack of new concepts but also the development of concepts, also the point “when all major categories are fully developed, show variation, and are integrated” [21]. Although initially related to grounded theory, data saturation is used in the context of interviews and within an inductive approach, “saturation suggests the extent to which “new” codes or themes are identified within the data” [22] In terms of present research, data saturation was considered based on the appearance of same themes as well in relation to themes across participants’ stories. Data analysis started immediately after the first interview and was an ongoing process to evaluate collected data. Therefore, it was possible to estimate when the saturation was achieved, and it was acceptable to stop data collection.

For the semi-structured interviews, we prepared an interview schedule, which was divided into thematic sections: general self-perceptions and self-evaluations about health status and habitual ways to visit the doctors or contact with the representatives of health system, knowledge and awareness about breast cancer, knowledge and awareness about the breast cancer screening programme, and reasons for non-participation during breast cancer screening. Semi-structured interviews allowed to deviate from the strict schedule and follow interesting thematic topics that participants brought in after the start with the established set of questions [23]. The interviews were performed individually. The duration of interviews varied between 20 and 60 min. All interviews were audio-recorded and transcribed verbatim. After transcription, all audio-files were deleted. All interviews were given a code containing the study code (BCS), the interview’s number, the age of the respondent, and a country code (EE or LV). The usage of age in coding is relevant due to the wide age range of the target group – it is likely that several personal and living arrangements differ in a manner that are important to take into consideration in the interpretation of the findings. However, revealing the age of respondents will secure still the anonymity of the respondents in the context of the research as other personal identifiers are not used. Although at the beginning of the interview participants were asked about their educational level and type of location, this information (with slight exceptions) is not widely explored in the analysis as the type of research limits the generalisability or connectivity of these background factors with the findings.

2.2. Data analysis

For data analysis, an inductive approach with the elements of grounded theory (e.g. substantive coding) and the themes from

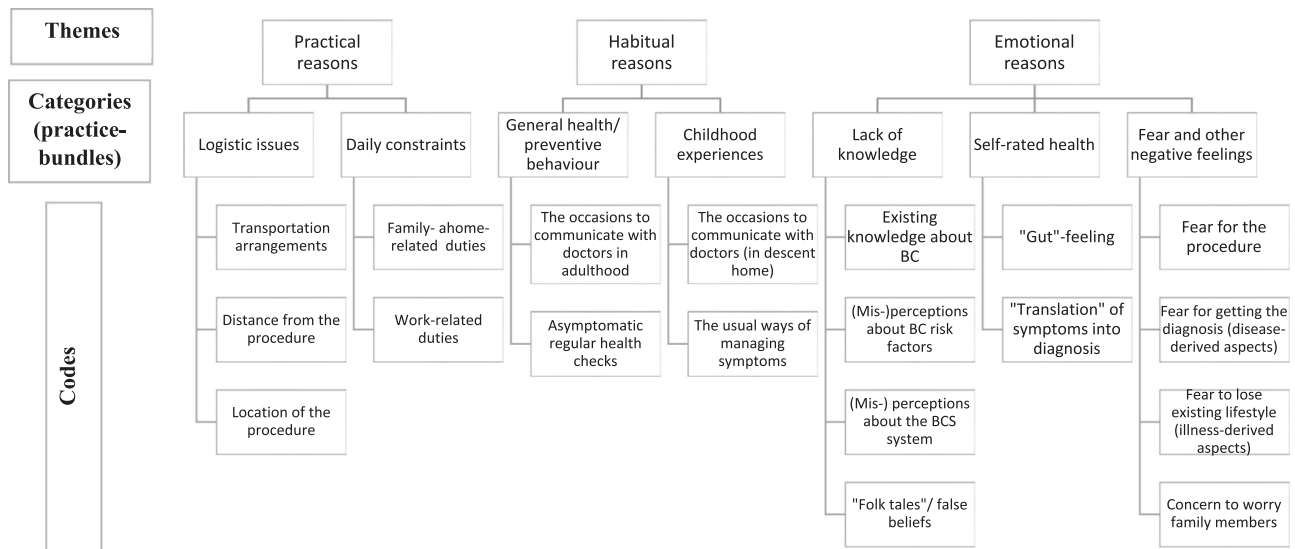


Fig. 1. The development of codes, categories, and themes. *Illness and disease are defined according to the widely recognised approach where disease represents the biological and illness the social condition [24].

interview agenda were used. The development of codes, categories and themes is shown on Fig. 1 (the concepts of disease and illness according to Eisenberg [24]). Interviews passed repeated reading by first three authors and initial coding was performed. After initial coding, research team gathered to agree on codes and categories derived from substantive codes, followed by the secondary reading of the texts and double-checking of the codes and categories. The research revealed several items (i.e. individual and/or single reasons as well as cultural-collective reasons) which contribute to the formation of practice-bundles that may hinder the decision to participate. The sub-categories that were revealed were temporal (i.e. different influential periods in participants' lives that influence the formation of the decision, such as childhood) and spatial (restrictions of physical space and time to attend). After finalisation of the development of categories which were translated into the logic of practice-bundle, the team met to agree on final themes, double-check the analysis and to ensure mutual agreement and the objectivity of the analysis. Final sub-categories were united into three main themes [25], which are seen on Fig. 1 and explained in the next section. Based on the focus and aim of the research, authors considered described research approach to be appropriate.

3. Results

The overview of participants' background is seen on Table 1. Background information involves the age and education level of the participants as well as the location where they live divided between big city/country or county centres (in the context of Estonia and Latvia, big city is considered in case of more than 100,000 inhabitants resulting in 2–3 cities in both of the countries). The analysis revealed three main areas of reasons for refrainment from breast cancer screening: habitual, practical, and emotional (Fig. 1).

3.1. "The power of habits" – influences derived from the ways participants are used to contact physicians

The habitual patterns of communication with the medical system seemed to significantly influence the ways how study participants perceived the activity related to the screening programme. Often, these habits had been acquired from childhood and were strengthened during adulthood:

Things that we take with us from our childhood are very important. Attitudes, habits etc. Also, first experiences with doctors, the development of trust, getting help, and feeling saved – all of this leaves its mark (BCS_5_61_EE).

Several participants highlighted a rather low level of contact with health care professionals – especially physicians in their parental homes – which was related to a high level of respect towards doctors and thus, "easy" health problems were not reasons to bother doctors:

The doctor was the last one. The doctor was (called) when a person was totally ill. You never went to a doctor just in case. That may be there is some use of it (BCS_6_65_EE).

These examples indicate the relevance of the practice theoretical approach, which reveals at least partly potential reasons why people might have difficulties connecting screening (i.e. go without symptoms) with a "must go" situation. Rather, as the respondent expresses, "just in case" visits were excluded.

Table 1
Background characteristics of participants.

Code	Country/Location	Age	Education level
BCS_1_50_EE	Estonia/County centre	50	Vocational education
BCS_2_55_EE	Estonia/Big City/capital	55	Secondary school
BCS_3_54_EE	Estonia/County centre	54	Higher education
BCS_4_58_EE	Estonia/County centre	58	Secondary school
BCS_5_61_EE	Estonia/County centre	61	Secondary school
BCS_6_65_EE	Estonia/County centre	65	Higher education
BCS_7_53_EE	Estonia/Big City/capital	53	Higher education
BCS_8_54_EE	Estonia/Big City/capital	54	Higher education
BCS_9_53_EE	Estonia/Big City/capital	53	Secondary school
BCS_1_67_LV	Latvia/Big City/capital	67	Higher education
BCS_2_52_LV	Latvia/Big City/capital	52	Higher education
BCS_3_50_LV	Latvia/Country centre	50	Secondary school
BCS_4_52_LV	Latvia/Country centre	52	Higher education
BCS_5_57_LV	Latvia/Country centre	57	Secondary school
BCS_6_55_LV	Latvia/Big City/capital	55	Higher education
BCS_7_54_LV	Latvia/Country centre	54	Higher education
BCS_8_60_LV	Latvia/Big City/capital	60	Secondary school
BCS_9_63_LV	Latvia/Country centre	63	Secondary school
BCS_10_51_LV	Latvia/Country centre	51	Higher education
BCS_11_70_LV	Latvia/Country centre	70	Basic education
BCS_11_70_LV	Latvia/Country centre	70	Basic education
BCS_12_69_LV	Latvia/Big City/capital	69	Secondary school

There were also participants who refused to acknowledge that childhood experiences would influence current behaviours, however unconscious choices indicate similar connections in claiming that “Can’t remember that my parents would have visit doctors too studiously. Has it influenced my behaviour? Definitely no /.../ But I hardly go to doctors, really” (BCS_1_50_EE).

One problem highlighted in the area of practical aspects – outlined other issues related to doctors, which are not substantially new, but stress the role of physicians and health communication even further:

/.../ if a doctor told me specifically that it was necessary to do it, in human language, they (women) would rather do so.” (BCS_2_52_LV).

It is possible that the issue with the “lack of human language” is bigger in study sites as the concept of patient-centeredness and the role of the patient-provider relationship are rather new in Latvia and Estonia compared to other Western countries. However, this issue is an important reminder for all professionals communicating health about the relevance of being understood as it can be literally a matter of life and death.

Also, the (unconscious) perceptions and habits of doctors, themselves, might become important as several respondents highlighted that their general practitioners might hinder their decision:

/.../ GP said it should not be done unnecessarily because it is also irradiation. (BCS_3_50_LV).

The last excerpts indicate that the decision to undergo BCS is scarcely an individual decision and the usage of the practice theoretical approach, instead of the individualistic behavioural approach, might be justifiable in the implementation of adjustments and changes in health behaviours.

3.2. Practical aspects preventing the participation during BCS

Daily arrangements and obligations were considered as practical aspects for deciding not to go undergo BCS. For example, a general rush on daily operating was highlighted:

Just the speed in daily life is so high ...so, when there are no problems /.../ you just forget about it (BCS_2_55_EE).

As the excerpt indicates, the daily schedule may be also intertwined with the habitual way of operating outlined in a previous section. Daily schedule, in combination with a lack of symptoms/problems and a habit not to take preventive actions, may lead to the “low priority” perception of BCS. Purely practical reasons are also related to the physical accessibility of the service, and it was highlighted by the participants that getting to the procedure at the closest centre will take so much time that “the whole day will pass” (BCS_1_69_LV). The physical access issues indicate that the practical organisation of screening might inadequately address personal needs. The issue is widely discussed in extant literature and indicates the need to address the issue further. Another practical aspect to prevent participation was finding suitable time, also that phones where to sign up are difficult to reach:

The procedure itself is not nasty, but what is nasty is that you have to find time during working day, then I often have to leave work /.../ I mean it is not good that you have to go /.../ (BCS_8_54_EE).

Although it is often stated that health is the most important value to a person, practical obstacles might still hinder the good will to do the right things, especially in case of professionals, where temporal and spatial aspects matter and are important in terms of fulfilling work duties.

Different respondents highlighted different life occasions that might occur. For instance, one physician-participant mentioned that

once she was so preoccupied with her dying patient that “(her) own health was not the matter of (her) interest” at that time. The importance of this notion is noteworthy as it stresses one important misunderstanding often acquired – non-participation during screening programmes is rarely only a matter of low awareness and lack of knowledge, thus indicating the importance of present research to consider the role of practices rather than behaviours in developing final participation decisions.

An important practical aspect to consider was related to health insurance. In Estonia, screening is enabled for those who have state health insurance (until the age of 64, it generally means also employment status). Thus, this was one of the practical concerns (although it actually indicates a low level of awareness about the system) related to BCS for Estonian participants:

So, when I will get to know that I have this (the cancer), where I will go then? I do not have health insurance, but I have to treat myself. Can’t become newly employed and immediately take sick leave, people are not so unscrupulous to do so (BCS_5_61_EE).

In Latvian women, this theme did not arise, which might indicate its lower relevance in this context.

A low level of awareness about the screening system, in general, was also revealed in the lack of knowledge in the case of missed opportunities:

I missed my opportunity last year. I do not know – am I still the target group, may I go this year? Probably not.../.../ or should I pay by myself now (BCS_8_54_EE)?

These examples indicate the need for raising awareness not only about the procedure itself, but also about related practical organisational aspects. However, as the findings indicate, education level might predict better general knowledge about BC and NCS, but it does not result in real-life actions.

3.3. Emotional reasons for non-participation

In this research, we aggregated different beliefs, fears, and cognitive reactions under the category of emotional aspects. The research revealed that the cognitive perception about one’s health status might play an important role in decision making. These perceptions were named “inner knowledge” or “gut feeling,” and participants counted on those largely:

I kind of trust and feel my body, I trust the feeling if everything is okay or not. If someone else feels she has to go, then she may go (to screening) (BCS_1_50_EE).

It is interesting this “feeling and sensing my body” was not characteristic only to participants with a non-medical background. Participants, also, with professionally medical backgrounds highlighted the role of a “gut feeling”.

As the findings revealed and confirmed, people are also eager to acquire and retain false-beliefs and folktale, at least in case these match their personal experiences and situations:

Well, my son has told me that I have small breasts, otherwise (in case of cancer) at least one would have bigger size (BCS_9_53_EE).

These examples reveal that beliefs, together with the “gut feeling,” strengthen and justify the decision not to participate in the screening. They also manifest potential misperceptions about the disease and the role of “important others” in supporting self-affirmation.

A special group of emotional reasons are related to different kind of fears, especially with those related to the painful procedure of mammography and this information was similar among women in both countries:

I have information that this procedure is also traumatic and not very healthy (BCS_4_52_LV).

As said, several respondents in both countries highlighted that “everybody has come and said that it is so painful,” indicating that women use others’ experience as the relevant source of information without additional processing of the information.

In addition to the fear against physical pain, it also may be that women are afraid to get emotionally hurt:

I don't want to know /.../ I love the life around me /.../ On the day when I'll have the call that there is something, everything will end for me./.../ I am keen on my life and hold it with all my nails without allowing anything to disrupt me /.../ I live in a happy bubble /.../ will not allow any other colours into the bubble (BCS_6_65_EE).

This example illustrates how people create, themselves, strategies to manage their own emotional well-being and how all potential disruptions will be removed at very early stages by ignoring potentially problematic activities. It was nicely summarised by one Latvian respondent in highlighting that, “I don't want bad information, I'm afraid, of course the diagnosis” (BCS_5_57_LV). Among different reasons, this aspect might be one of the most difficult and challenging ones to handle as the philosophy of screening is just the opposite – to find the problems. Another issue is that majority of the campaigns might have unconsciously be frightening rather than encouraging in stressing the potentially bigger problems in the future. Therefore, the chosen strategy is to “put it all as far as possible and forget” (BCS_2_52_LV).

As seen from the excerpts, the “folk tales” or others’ experiences – although individual and not extendable to each person – are powerful in creating perceptions. These are also aspects that have been scarcely addressed; thus, contributing to the decision-making process. Therefore, future campaigns should address these concerns in order to minimise or redesign the perceptions.

4. Discussion and conclusions

4.1. Discussion

The findings confirm what earlier theoretical approaches [15,16] have suggested – the reason behind actual health-related decision-making is not only an individual behavioural act. The final decision is a complex phenomenon, which forms from a combination of several factors, including both individually formed (e.g. habitual and emotional) and externally formed reasons. The general system and organisation of the screening programme do not consider practical arrangements and potential difficulties that women might have in order to participate. Thus, the findings indicate that in order to reach the target of 70% of participants, it is not enough to focus on the pure health behavioural act. As the formation of the decision is dependent on so many different aspects – including non-individual – the whole system of screening communication needs re-conceptualisation and re-design. It is important to note two aspects regarding practices: 1. practices do not equate with individual behaviours and in the formation of the decision, the context(s) plays an important role, and; 2. practices are reproduced and transformed [17]. The contexts may involve present (practical) context as well as habitual context that has formed existing perceptions and attitudes.

The habitual reasons to refrain from the screening procedure were often related to the ways participants were taught to, and used to, communicate with physicians. This finding highlights the cultural and societal aspect of the decision formation and expressed health practice, indicating that the acquirement of (health) practices is starts with childhood and continues in an ongoing process during the lifespan. In terms of communicative public health actions that call to an individual action, these campaigns (including the message)

should not address only the direct target group. Health communication campaigns should acknowledge that the development of health decision practices starts from home and should continue during different stages of life (including formal education at school) to reach to the “end-point” preventive medicine aims to. Based on the claim that practices do not equate to individual behaviours, the research highlighted important findings – the habitual reactions (derived from the childhood or earlier different professional practices) of current physicians might influence the formation of the decision to participate in screening. This aspect, in combination with expressed (health) communication, might be relevant to consider in planning awareness campaigns. As the findings revealed, the understandings of participants with medical background were not in correlation with their expected expert knowledge, but still rather dependent on different reason groups outlined in this research.

As the findings revealed, there is still room for improvements in the organisation of the screening, and although it is impossible to consider individual needs, the accessibility of the service could be improved in terms of temporal and spatial conditions. Although emotional reasons indicate the biggest lack of awareness regarding the screening, it would be oversimplistic to state that raising awareness would solve the issue. As the context is relevant, also here the daily context (including peers to live and communicate with) is important in forming the opinion.

Some limitations to this study should be acknowledged. Interview as a research method is a social occasion and revealed information might be dependent on particular interviewer. Thus, the fact that three different people interviewed participants might have unintentionally influenced the information that participants disclosed. Besides the aspect of different researchers, also the aspect of different countries and languages might have a slight impact on data collection (including different recruitment approaches) and interpretation. However, authors believe that despite these limitations, the general value of the findings and new knowledge remains, and the research provides useful insights on the issue.

4.2. Conclusions

Different types of reasons, e.g. habitual, practical, and emotional, influence the final formation of the decision to participate in BCS. As it has been shown previously, it is not efficient to use only approaches focusing on the individual responsibility and the role of individual action [15–17,19]. The contexts in which people live their daily life and make health-related decisions must support health practices, including related decisions, actions etc. Therefore, public health campaigns and education should consider and address the structural influences in addition to the existing individualistic approaches.

4.3. Practical implications

Public health messages designed for screening participation and public health education should address the concerns derived from different types of reasons for refraining from screening. There is need for physicians to revise explicit health communicative messages. In (re-)designing screening arrangements there is need to pay attention to practical aspects, such as access to screenings (e.g. appointment arrangement) but also exceptional cases to participate in between the regular time.

Ethical approval

We confirm all patient info/identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot identified through the details of the story.

CRedit authorship contribution statement

All authors have contributed to the design and conceptualization of the research and development of the methodology. Kadi Lubi, Vita Savicka, Marilyn Koor have additionally contributed to: Conducting the interviews; Initial analysis of the interviews; Writing of the original draft of the paper. Irma Nool, Mare Tupits, Silja Mets-Oja have additionally contributed to: Double check of data analysis; Heavy commenting and feedback on the manuscript.

Declaration of Competing Interest

The authors have no conflicts of interest relevant to this article to disclose.

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