

Factors Affecting Women's Participation in Breast Cancer Screening in Turkey

Duygu Luleci^{1*}, Bulent Kilic²

Abstract

Background: Breast cancer is the most frequent cancer type in Turkey and the rest of the world. Regular mammography screening leads to a significant decrease in breast cancer mortality rates. The aim of this study is to analyze the factors that affect Turkish women's participation in screening. **Methods:** This qualitative research design is grounded in a phenomenological approach. Fifteen women were selected using a purposive sampling method and participated in in-depth interviews. Interview data was analyzed using thematic content analysis. **Results:** The breast has a special meaning for participants which is heavily associated with femininity. Breast cancer causes fear because of its potential to undermine women's sense of femininity. Women's knowledge about the screening services and the mammography procedure is insufficient with only one third of women obtaining information about screening from healthcare workers. Individual and social factors that affect women's participation in screening are women's roles in the family, knowledge and awareness of breast cancer and screening, fear of cancer, anxiety about getting a mammogram, need for spouse-family support, and concerns for privacy. Organizational factors that affect participation are accessibility of breast cancer screening services, guidance given by and communication with healthcare professionals. **Conclusion:** Women should be better informed about breast cancer and screening services by healthcare professionals. Accessibility of mammography screening should be increased by expanding mobile services. National and institutional policies should be implemented to overcome women's anxiety and socio-cultural barriers to increase participation in screening.

Keywords: Breast cancer- women- mammography screening- qualitative research

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Introduction

The incidence rate of female breast cancer in Turkey is 46/100000. One in every four cancers in women is breast cancer, and 42% of breast cancer cases are in the 15-49 age group (Turkish Ministry of Health, 2019).

Community-based and standardized mammography screening can reduce breast cancer mortality by 25% in the 50-69 age group and by 40% in the 40-69 age group (WHO, 2008). Cancer Early Diagnosis, Screening and Education Centers (KETEM) were established in early 2000's in Turkey to carry out community-based screening programs for cancers which WHO recommends being screened. Cancer screening services are provided free of charge. According to the National Standards of Breast Cancer Screening Program In Turkey, women aged 40-69 should be screened by mammogram every two years.

Personal and environmental factors such as education, awareness, income, transportation, cultural characteristics, migration, marital status, and family relationships (Azami et al., 2015; Kawar, 2013; Donnelly et al., 2015) were found to be associated with participation in breast cancer

screening in studies from different countries. In many studies, it was reported that the rate of screening with mammography was low in general population. Even in high-risk groups, awareness and participation in screening was found to be low (Mulmi et al., 2020).

The rate of women who regularly undergo breast cancer screening by mammogram is low in Turkey. It has been determined that various factors such as level of education, monthly income, social security, marital status, and newspaper reading are associated with women's participation in mammography screening (Demir Yildirim and Ozaydin, 2014; Erkal Aksoy et al., 2015). Women get most of their information about breast cancer from television rather than from health professionals, and lack of knowledge is an important reason for not participating in screening (Demir Yildirim and Ozaydin, 2014).

There is a limited number of studies examining Turkish women's attitudes towards breast cancer screening with a qualitative approach. This study aims to determine the knowledge, emotions, and behaviors of women in Turkey associated with breast cancer screening by mammogram, and the factors affecting participation.

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Materials and Methods

The hypotheses of the study were that the organization of health services was not effective in increasing participation in breast screening programs, and gender and emotional issues decreased participation in breast cancer screening programs. The expected causality framework of the research consists of the fact that the breast screening programs cannot reach the desired targets due to the fact that women are not adequately informed about the screening program, and the fear they experience and gender pressure are not taken into account.

This qualitative research design is grounded in a phenomenological approach. The study was carried out in a university hospital in Izmir. The city, located in the west of Turkey, is the country's third largest metropolitan city and receives heavy immigration from Eastern Turkey.

Data Collection and Analysis

Data were collected through in-depth interviews method. Among women aged 40-69 years without breast malignancy for whom mammography screening was recommended, and who applied to the general surgery or radiology units for screening, 15 women were selected through purposive sampling. Care was taken to recruit a heterogeneous group of participants in terms of education, economic status, and age of the women to be interviewed. There were women who were having a mammogram for the first time and had had it before. The participants were random individuals who has applied to get screened at the hospital and there wasn't an established relationship between the researchers and the participants before the interviews. Data collection took place between February and April 2016, and new women were interviewed until both researchers were convinced that the data saturation was reached.

Both researchers are medical doctors and public health specialists and were working in Department of Public Health at Dokuz Eylul University Faculty of Medicine at the time the research was conducted. In-depth interviews were made by the lead researcher (female). The lead researcher had an interest in qualitative studies and women's health. She attended several training courses on qualitative study design and analysis. The second researcher has also more than 10 years of experience in qualitative studies area. Interviews were made face to face in a private room in the hospital with only the lead researcher and participant present. Participants were informed about the researchers' backgrounds and the aim of the study before the interviews. None of the individuals refused to participate in the study. Demographic information was collected with a questionnaire. Semi-structured topic guides which were prepared by the researchers were used in the interviews. A pilot interview was made before the study began. The interviews lasted between 30-50 minutes. With the permission of the participants, audio recordings were made and transcribed by the lead researcher. The voice files and transcribed data were kept. One of the interviews was not recorded as the participant did not want to be recorded, and notes were taken instead. Field notes were taken during the interviews. The transcripts could not be returned to

participants for feedback and no repeat interviews were carried out. The transcribed interviews were analyzed by two researchers separately to prevent the researcher's characteristics influence the study. The data was analyzed and coded manually by both researchers using thematic content analysis. No software was used. The main codes which emerged from the codes were considered as factors affecting the participation in mammography screening, and themes were created from the codes. COREQ (COnsolidated criteria for REporting Qualitative research) checklist was used for the manuscript.

Ethics Committee approval was obtained from Dokuz Eylul University Ethics Committee, Izmir, Turkey (No: 2015/27-34). The lead researcher informed the participants about the study's aims and methods. A written informed consent was obtained at the beginning of each interview.

Results

The median age of the women was 44 years (40-65). 13 (86.7%) women were married and 12 (80.0%) had at least one child. 8 (53.3%) were university graduates, 3 (20.0%) were high school graduates and 4 (26.7%) were primary school graduates. 5 (33.3%) of the women were housewives, 2 (13.3%) were retired, 1 (6.7%) was unemployed and the rest of the participants were working women. All women had social health insurance. 9 (60.0%) of the women described their financial status as average. At the time of the study, 7 (46.7%) of the women was getting a mammogram for the first time. The sociodemographic characteristics of the women are presented in Table 1.

There was consistency between the data presented and the findings. Factors affecting participation in the screening were classified into two themes: "individual and social factors" and "organizational and structural factors" (Table 2). These codes are also presented as a coding tree (Figure 1).

Individual and Social Factors

When women thought of "breast cancer", immediate associations mentioned included the terms "chemotherapy", "a woman with hair loss", "breast removal", "flat body", "sutures", "absent eyebrows", "pale face", and "desperate eyes".

"I think of a woman with a bald head, a woman who has turned into a man." P8

The breast had a special meaning for the women interviewed, and was considered aesthetically important.

"You are a woman after all. Your breast will be taken, it will be flat, it's a sad thing. I am not sick at the moment, but even the thought hurts." P2

During the interviews, half of the women stated that they were afraid of breast cancer, while a few stated that they were not afraid because they had regular screenings.

Womens' roles in the family were the most frequently mentioned barrier to participation in screening.

"I serve three men. My husband, son, and grandson. And they don't want to lack service. In other words, the moment the men are missing out on service, all hell breaks out at home. But I have to take time for myself." P15

It was also frequently stated that family support is

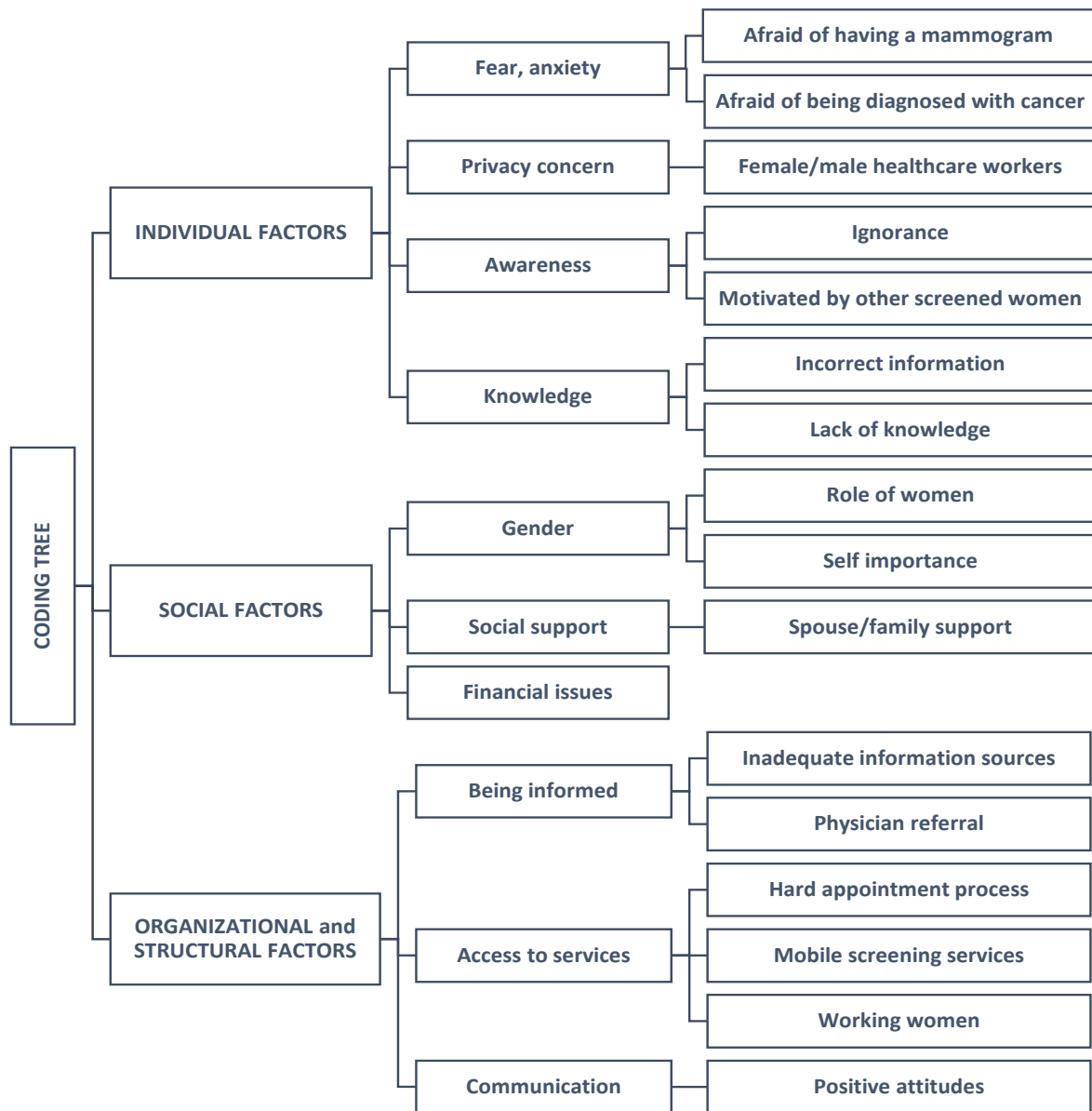


Figure 1. Coding Tree

very important because diagnosis and treatment are likely to negatively affect women in psychological terms. In addition, women were concerned that their relationships with their husbands may be negatively affected.

“Her husband should be with her, she needs to have support in everything. My friend, for example, her husband left her completely alone.” P2

“Her sex life is definitely affected.” P8

Other factors that prevented participation in screening included: the reluctance to apply to a health institution without any signs of illness, having no family history of breast cancer, fear of being diagnosed with cancer, neglectfulness, and not feeling comfortable with male healthcare professionals.

“You will go, you will wait in line in the hospital, something bad will come up and you will be upset...” P4

“Because we don’t care and everyone thinks nothing bad will happen to them.” P5

“It’s comforting to see women (healthcare workers). Everyone there is like you, they can understand you and empathize.” P2

Half of the women said that they had no knowledge of the procedure before they came for the screening. They stated that they were worried due to privacy concerns, and potential pain and suffering before the mammography procedure. Hearing from others that the procedure is painful was a frequently mentioned reason for not having mammograms.

“After all, you’re going to show your private body parts to someone you don’t know. And that pressing thing, they’re pushing too much, they’re hurting a lot, it was my worry. When people experience something they don’t know, they have some fears. I felt like that.” P10

It is remarkable that most of the women emphasized the importance of early diagnosis considering the relative lack of knowledge about breast cancer. Although women with lower education levels were less informed about breast cancer, there was no participant who knew exactly the age range and frequency recommended for breast cancer screening. Two-thirds of women have never heard of KETEMs and did not know that KETEMs offer free screening. Only three of the women had mammograms

Table 1. Sociodemographic Characteristics of the Participants

Mammography Status	Participant No	Age	Marital Status	No of Children	Education	Financial Status	Job, Working Status
Getting Mammogram for the First Time	P1	40	Single	0	Primary School	Good	Caregiver
	P2	40	Married	2	University	Bad	Teacher (Unemployed)
	P3	40	Married	2	University	Average	Civil Servant
	P4	41	Married	1	University	Good	Engineer
	P5	41	Divorced	1	University	Average	Nurse
	P6	45	Married	2	University	Average	Secretary
	P7	51	Married	2	Primary School	Average	Housewife
	P8	43	Married	1	University	Good	Academic
Had Mammogram Before	P9	43	Married	2	High School	Average	Housewife
	P10	44	Married	2	High School	Average	Caregiver
	P11	48	Married	4	High School	Average	Housewife
	P12	61	Married	0	Primary School	Average	Housewife
	P13	61	Married	0	Primary School	Average	Housewife
	P14	62	Married	3	University	Good	Teacher (Retired)
	P15	65	Married	2	University	Good	Teacher (Retired)

Table 2. Themes and Codes Derived from Women's Experiences of Factors Affecting the Participation in Screening

THEMES	MAIN CODES	CODES (n=15 women)
Individual and Social Factors	Fear, Anxiety	Family relations might be affected negatively (9) Afraid of being diagnosed with cancer (6) Afraid of mammography process (5) Afraid of going to the health centers (4) Cancer-related TV programs are scary (4)
	Gender	Sociocultural role of women (9) Women's self-importance (6)
	Need for Social Support	Spouse/family support motivates participation (7) Lack of spousal support is an obstacle to participation (4)
	Privacy Concern	Avoiding male healthcare worker (7) Preferring female healthcare worker (4)
	Knowledge	Lack of knowledge about the age range and frequency (15) Not consulting a doctor without any signs of illness (8) Not having heard of KETEM (8) Lack of knowledge about the mammography procedure (6)
	Awareness	Ignorance (10) Disregard (8) Neglectfulness (6) It is motivating to have people around who have been screened (3)
	Economical Factors	Poverty (4)
Organizational and Structural Factors	Being Informed	No information about screening by family physician (14) Need to be informed about cancer screening and procedure (7) Inadequate information source as TV (5) Physician referral motivates participation in screening (4) Being informed by KETEM staff is important (1)
	Accessibility of Services	Making appointments and receiving results are not easy (9) Not being able to have a day off from workplace (8) Easy access to screening centers is important (7) Inadequate mobile screening services (4) Family physicians should be involved in screening program (4)
	Communication with Healthcare Workers	Positive attitude of the healthcare worker is motivating (7) Being informed about the procedure is comforting (4)

at KETEM before.

While four women stated that economic problems may prevent participation in screening, the others didn't consider this as a barrier to participation.

Organizational and Structural Factors

Lack of information about the cancer screening centers was an important barrier to participation.

"To be honest, I didn't know. I keep asking where can I go, where can I go? Then when my friend came here, I asked her where did you go? What did you do, tell me about the process? I said ok, then I came, too." P2

Few of the women were informed about breast cancer screening by healthcare professionals. One woman was informed by a family physician, one was informed by KETEM, and three were informed by health professionals from other institutions. The source of information for the majority was television programs and the internet. Some women stated that they did not watch TV broadcasts on breast cancer because they found the topic too scary.

Participants stated that a referral by a physician motivated them to participate in screening. They attached great importance to screening services being easily accessible and highly reliable in terms of quality. Women also suggested mobile screening and education services to towns and villages, putting in place mobile screening services, being directly invited to screening, and for information being provided by female health workers and via mobile phone messages.

The overall attitudes and facial expressions of mammography technicians were emphasised as important factors. Women felt more comfortable when the technician kept them informed about the procedure before and during the mammography process.

"You already came there with a fear of what the result would be. And when you see a serious facial expression in front of you, all your motivation drops. For example, here in the screening, the technician said, -here is the part that will hurt, there is very little left, such things are relaxing. I think a smiling face is everything." P10

Women complained that they couldn't get an appointment quickly, that the results were late, and that they had to return to the center many times to complete the procedures. Older women and women who worked had more difficulties with this. Women who worked outside the home found it difficult to repeatedly take leave from the workplace.

"You have to take a day off. You need to leave your child to someone, you need to arrange everything for one day. You set this up and when you go there you only make an appointment. You have to create the same conditions again for the examination. When you think about this, you can give up." P2

"The problem for working women is that we cannot easily take leave from the workplace. That's why we can't get our check-ups done regularly. I had a hard time even coming here. Since there is no apparent disease, we can be subjected to criticism in terms of what's wrong, why are you leaving?" P4

Discussion

Although some of the women here had regular screening due to fear of breast cancer, fear prevented more women from obtaining information and participating in screening. In many studies, fear of breast cancer was found to be a barrier and in some both a barrier and a facilitator for participation in screening (Azaiza and Cohen, 2008; Azami-Aghdash et al., 2015; Marmarà et al., 2018).

When participants of our study thought of "breast cancer", images associated with fear and anxiety came to their minds. Women are afraid of cancer treatment resulting in breast removal and hair loss, and postpone screening the fear of being diagnosed with cancer (Kawar, 2013). Since the female breast is accepted as a core part of female sexual identity in society, its loss means "loss of femininity" for women. Another reason for the fear lied in the concern that a woman's relationship with her husband would be negatively affected. Fear of being rejected by the spouse and breaking up the family creates a feeling of insecurity in women and negatively affects participation in screening (Safizadeh et al., 2018).

Women in this study attached great importance to family and spousal support in overcoming sociocultural and economic barriers to participation in screening. Spousal-family support also facilitate participation in screening among Iranian women (Khazae-pool et al., 2014; Farhadifar et al., 2015) It is unsurprising that women particularly emphasize requiring spousal and family support to enable them to take care of their health in cultures where the needs of the family tend to be put before women's needs.

Some women interviewed expressed privacy concerns and wanted mammograms to be done by women healthcare workers. This chimes with other research highlighting various cultural contexts which mediate women's hesitancy to talk to male healthcare professionals about breast health or to expose their breasts (Kawar, 2013, Khazae-pool et al., 2014; Haddock et al., 2020; Woof et al., 2020) This hesitancy has been explained by patriarchal social structures, the fear of stigma or religious reasons (Kissal and Beser, 2011; Kawar, 2013).

Although women frequently emphasize the importance of early diagnosis, they postpone participation in screening. Reasons given for this included not wanting to request an appointment from a health institution, not consulting a doctor without complaints, and neglectfulness. The fact that, in the absence of symptoms, women postpone screening even though they know that they may be too late when symptoms appear (Khazae-pool et al., 2014; Woof et al., 2020), shows that informing about the benefits of early diagnosis itself is not sufficient for establishing a screening culture in the society.

It is noteworthy that women in this research had insufficient knowledge about the mammography procedure, the recommended age range and frequency of screening, where the screening is performed, and the existence of KETEMs. Only one third of our participants received information about cancer screening from healthcare professionals, even though all of them had a clear need for accurate information from competent

sources. Hence, there is an urgent need to expand the education services of KETEMs so that more women are reached.

Women demanded that information be conveyed to them in mobile phone messages and by means of providing education in villages and neighborhoods. Direct referral by a physician was identified as an important motivator for women in Turkey to participate in mammography screening (Ozmen et al., 2016). Since almost the entire population in Turkey is registered with family health centers, there are obvious opportunities to inform all women about breast cancer screening. However, in Turkey, family health centers providing primary care services are based in urban areas. Their mobile service is limited and they mainly provide therapeutic services (Cevik and Kilic, 2018). It may be possible to meet the mobile education service needs of women by including family health center staff in the cancer control program and increasing their mobile services provision. A cancer screening camp which was organized in a rural area of India was reported to be a successful model of cancer screening in low resource settings (MD Abu and Arun, 2020). The camps where individuals were informed, screened for common cancers, and referred to health centers if found suspicious, could be modified in accordance with Turkey's conditions and implemented in rural areas.

Requirements for easy access to screening centers and mobile screening services were frequently mentioned by participants. Similarly, in a study conducted in Brazil, it was found that mobile screening units were more accessible than fixed units, and that the proportion of women who attended for their first mammogram was higher (Costa Vieira et al., 2015). In order to facilitate access to the service in Turkey, the number of fixed KETEMs has been increased reaching 178 in 2019 (Turkish Ministry of Health, 2021), but mobile screening services are still limited. Mobile screening services provided by KETEMs should be expanded.

Participants stated that it was comforting to be greeted with a smiling face by the mammography worker and to be kept informed about the procedure throughout. In an interventional study, women were informed about the screening program and the mammography procedure for five minutes by trained nurses, and they were given the opportunity to express their concerns and questions for five minutes after the procedure. It was determined that the probability of experiencing high anxiety before mammography decreased by 60% with this 10-minute intervention (Fernández-Feito et al., 2015). Positive communication with healthcare professionals motivates women to participate in screening (Kissal and Beser, 2011), and negative experiences from past screenings and bad behavior are mentioned to be barriers (Azami-Aghdash, 2015). Training the screening personnel in terms of comforting practices and positive communication will reduce the anxiety level of women and increase their participation in screening.

Women with moderate breast cancer fear have been found to have a higher rate of accessing mammography screening than those with low and high fears (Norouznia, 2014). Hence, information about screening should

not frighten women too much but still enable them to understand the seriousness of the issue and importance of participating in the screening health professionals may be best placed to achieve the critical balance required here. In order to increase participation in screening, KETEM and family health center staff should be given special training on breast cancer screening and communication with women. Evidence-based guidelines for physician education and culturally tailored materials to address communication barriers and physician comfort might increase the success of screening facilities (Wu et al., 2020). In addition to physicians, nurses are also health professionals who are knowledgeable about breast cancer and screening practices (Zongo et al., 2017), and should have an important role in screening.

The difficulty of getting an appointment and receiving results was identified as an important barrier to participation. The working women in our study stated that they found it difficult to participate in the screening due to the long and difficult appointment process and the inability to get permission from their workplaces. Similar to our results, studies reveal that waiting long to get an appointment and long working hours are important barriers to participation in screening (Azami-Aghdash, 2015). The difficulty in getting an appointment particularly hinders the participation of older women (Kissal and Beser, 2011). The screening process should be simplified, especially for older women and working women, and policies should be developed so that employees can more easily take leave for health screenings.

Not being able to participate in the screening due to economic barriers was among the less frequently mentioned reasons in our study. There are, however, many studies that have found a relationship between low income and nonparticipation in screening (Donneely et al., 2015; Ghahramanian et al., 2016; Azami-Aghdash et al., 2015; Marmarà et al., 2018). Although the free provision of mammography screening services in public health institutions in Turkey suggests that economic problems are less likely to prevent participation in screening, individuals' knowledge, awareness, and access to screening services may be affected by economic hardship. Since our study was conducted in an urban area, we may not have been able to determine potential economic barriers experienced in rural areas.

The most important limitation of the study is that we were only able to interview women who came to the university for screening. Since the Ministry did not give permission to meet with women who apply to KETEMs, we were not able to involve them. Our study also did not include women who have never had any screening and don't plan to have any in the future. Therefore, the feelings and thoughts of those two groups could not be determined. The study was conducted in an urban area in Izmir, and there may be differences in the experiences of women living in rural areas.

In conclusion, we determined that the factors affecting the Turkish women's participation in breast cancer screening can be divided into two main groups as "*individual and social factors*" and "*organizational and structural factors*". "*Individual and social factors*"

such as women's fears, the lack of social support from families, not being able to get leave from the workplace, and sociocultural factors like gender will be more easily overcome by increasing the breast cancer screening knowledge and awareness of both women and the general population. National and institutional breast cancer screening policies in Turkey should be revised considering sociocultural characteristics. Overcoming issues about "organizational and structural factors" will be possible with a more organized and more widespread screening program. The family medicine system plays a key role in regularly informing women about breast cancer and screening services and directing them to screening. Hence, their active participation in the screening program should be ensured. In order to increase accessibility, the services provided in KETEMs should be made available to a wider population including the women in rural area by expanding mobile screening services, and simplifying appointment and result procedures, particularly for working women and older women. Finally, communication training should be given to all health workers involved in screening.

Author Contribution Statement

Both authors contributed to this study and approved the final version of the manuscript. Design: DL, BK. Data analysis: DL, BK. Interviews: DL. Manuscript: DL, BK.

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Ethical Considerations

Ethics Committee approval was obtained from Dokuz Eylul University Ethics Committee, İzmir, Turkey (No: 2015/27-34). The lead researcher informed the participants about the researchers' background, and the study's aims and methods. Informed consent was obtained at the beginning of each interview. There were no other individuals during the interviews besides the researcher and the participant. The participants' identities were kept confidential.

This study is a part of the lead researcher's approved thesis in public health speciality and the second author is the thesis supervisor. The voice files and transcribed data used in this study were kept by the researchers and are available.

Statement Conflict of Interest

The authors declare no conflicts of interest.

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