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Araştırma / Research Article

Mammography screening journeys: An action research study

Mamografi taraması yolculuğu: Bir eylem araştırması

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ABSTRACT

Objective: To observe the mammographies of women targeted by the national breast cancer mammography screening guidelines to identify process-based barriers to compliance. **Materials and Methods:** This study was conducted between December of 2018 and May of 2020. Recruitment was done during a larger study that recruited 12 focus groups of 87 women between the ages of 40-69 living in Istanbul. Observation of mammography scheduling, screening, and reporting processes was done using action research, an approach that allows the researcher to fully interact with, and advocate for, study subjects to stimulate empowerment and change. A form developed by the Susan G. Komen® Breast Cancer Foundation was used to guide and document observations. **Results**: Mammographies for ten women aged 40-57 at ten distinct public, foundation, and private facilities in Istanbul were observed. Scheduling duration ranged from two to seven minutes. The earliest available appointments ranged from the same day to 20 days later. The largest barrier to access was a prerequisite examination and referral. Signed consent forms were required at four facilities. Screening duration, including wait times, ranged from eight to 100 minutes. Out-of-pocket costs ranged from $US 0-58. Wait times for results ranged from 15 minutes to 33 days. Report formats were electronic at five facilities; others provided paper reports with compact discs. **Conclusion:** This study looked at mammography screenings through the experiences of ten women targeted by national breast cancer prevention guidelines. Opportunities for improvement were identified at facility, national, and policy levels in the areas of privacy, consent, referrals, and reporting.

Key Words:
Mammography, Cancer Screening, Breast Cancer, Action Research

Anahtar Kelimeler:
Mamografi, Kanser Tarama, Meme Kanseri, Eylem Araştırma

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ÖZ

Amaç: Ulusal meme kanseri mamografi tarama rehberinde hedeflenen kadınların mamografilerini, uyum sürecine yönelik engelleri belirlemek amacıyla gözlemlemek. **Gereç ve Yöntem:** Bu çalışma Aralık 2018 ile Mayıs 2020 arasında gerçekleştirildi. İstanbul'da yaşayan 40-69 yaşları arasında olan 87 kadınların katıldığı 12 odak grubunda yürütülen çalışmadan rekrutman yapıldı. Randevu alma, tarama ve sonuç raporlama süreçlerinin gözlenmesi, eylem araştırması ile yapıldı. Bu yaklaşım ile, katılımcılara güçlenmelerini ve değişimlerini teşvik etmek için, araştırmacı, çalışma süresinde etkileşim içinde olabilir ve savunma yapabilir. Gözlemlere rehberlik etmek ve dokümante etmek için Susan G. Komen® Meme Kanseri Vakfı tarafından geliştirilen bir form kullanıldı. **Bulgular**: İstanbul'da farklı kamu, vakıf ve özel kuruluşlarda 40-57 yaşları arasındaki on kadının mamografileri gözlendi. Randevu alma süresi iki ila yedi dakika arasında sürdü. İlk müsait randevular aynı günden 20 gün sonrasına kadar değişti. Erişime en büyük engel, muayene ve sevk önkoşulları olarak gözlendi. Dört tesiste imzalanmış onam formları istendi. Bekleme süreleri dahil tarama süresi sekiz ile 100 dakika arasında değişmekteydi. Cepten ödemeler 0-58 US$ arasındaydı. Sonuçların bekleme süreleri 15 dakika ile 33 gün arasında değişiyordu. Rapor formatları beş tesiste elektronikti; diğerleri ise kompakt disklerle kağıt raporlar halindeydi. **Sonuç**: Bu çalışma, ulusal meme kanseri tarama rehberi tarafından hedeflenen on kadının mamografi taramasına gözlemledi. Gizlilik, rıza, sevk ve raporlama konularında kurum, ulusal ve politika düzeylerinde iyileştirme fırsatları belirlendi.

INTRODUCTION

Around the world, more than 2 million women are diagnosed with, and more than 500,000 women die from breast cancer annually making it the most common type of cancer seen among women and the most common cancer overall in 76% of the world's countries. In Turkey, 22,345 women were diagnosed with, and 5,542 women died from breast cancer in 2018 (1, 2). It is estimated that the incidence rate will grow by more than 60% by 2040 which, adjusting for projected population growth in the year 2040, will result in over 35,000 breast cancer diagnoses and the deaths of over 8,500 women in Turkey (3, 4).

Diagnosing breast cancer in the early stages can offer women more options for treatment and an increased

chance of survival. There are ongoing scientific debates regarding harm vs. benefit analysis (5), limitations (6), and age/frequency guidelines of mammographies (7). In addition, new technologies like artificial intelligence and genetics are under development that may prove to be more effective than mammographies in early state diagnosis of breast cancer. At present, the World Health Organization (WHO) maintains that mammography is still the most effective method for population-based screening of breast cancer today (8) and national and international health authorities continue to recommend mammography screening as an important tool in reducing the burden of disease (9-12).

The Turkish Ministry of Health's Breast Cancer Screening Program National Standards state that women between the ages of 40 and 69 should receive biannual mammography screenings (13). The Ministry of Health (MoH) assigns all Turkish citizens to a nearby family physician. The standards state that family physicians should identify eligible women assigned to their panels and invite them to designated facilities for free mammography screenings (13). These free mammography screenings are available at 68% of the 1,423 public general hospitals in Turkey (2). They can be obtained at Early Diagnosis Cancer Screening & Training Centers known as KETEMs. As of 2019, there are 218 KETEMs and 36 mobile cancer screening centers for a total of 254 centers in all 81 provinces in Turkey (13).

Despite the availability of free, nationwide mammography screening services, the 2016 screening rate for Turkish women between the aged 40 to 69 during the prior two years has been found in different studies to be between 30 and 40% compared to the EU25 average of 58% (13-15). Numerous studies have shed light on Turkish women's awareness, health beliefs, fear levels, and perceptions indicating that awareness levels are higher than compliance rates (16-20). This study was designed to understand the actual experiences of women aged 40 to 69 as they schedule and complete mammographies in Istanbul using action research, a form of research that allows the researcher to step out of the role of observer and fully interact with and advocate for study subjects to stimulate empowerment and change (21-23).

MATERIALS & METHODS

The study was conducted between December of 2018 and May of 2020 as part of a larger qualitative study conducting 12 focus groups attended by 84 women between the ages of 40-69 living in Istanbul. The focus group participants were selected using a snowball sampling technique by recruiting existing groups of women that meet regularly such as neighborhood women's groups, hobby/sports clubs, and religious groups. None of the 84 women participating in the focus groups recalled receiving a mammography screening invitation from their designated family physician. Using the principles of action research, women participating in the focus groups who had not had a mammography screening in the prior two years were encouraged by the researcher to make mammography appointments. Assistance was given to 15 women to make mammography appointments at the facilities of their choice. Due to scheduling difficulties and, in one case, a mammography machine breakdown, the researcher was able to accompany and observe the mammography screenings of ten women. Participating women provided two separate written consent forms for the focus group and for the observation that were approved by the Marmara University Health Sciences Institute Ethics Committee.

Written approval was obtained to use a qualitative data toolkit observation form developed by the Susan G. Komen® Breast Cancer Foundation to guide and document each observation (24).

Out-of-pocket costs were incurred in Turkish Lira and converted to the approximate value in U.S. dollars using the average exchange rate for 2019.

RESULTS

Mammography screenings were observed at ten facilities in Istanbul. The facilities selected by the participating women are presented in Table 1 by type and number of observations.

Table 1. Facilities Observed for Mammography Screening

Type of Facility	No. of Observations
MoH KETEM	2
MoH Hospital	2
Foundation University General Hospital	1
Private General Hospital	4
Private Imaging Center	1
Total	10

Participating women ranged in age from 40 to 57. Half of the women had never had a mammography before, while the other half reported prior experience. Half of the women had family histories with breast cancer. Education levels ranged from elementary school to doctorate level. Table 2 displays each participant's choice of facility, age, prior experience with mammographies, family history of breast cancer, and education level.

Mammography appointment

Participants spent 2-7 minutes to make mammography appointments. The earliest available appointments ranged from later the same day to 20 days later. Prior

Table 2. Participant Demographics

1	KETEM 1	54	First time	None	University
2	KETEM 2	56	First time	Mother	Middle School
3	MoH Hospital 1	49	One prior screening 5 years earlier	None	Middle School
4	MoH Hospital 2	40	One prior screening 3 years earlier	None	High School
5	Private Hospital 1	49	First time	Mother	High School
6	Private Hospital 2	41	First time	Maternal aunt	PhD
7	Private Hospital 3	43	First time	Maternal grandmother	Elementary School
8	Private Hospital 4	45	Two prior screenings 2 and 4 years earlier	Sister	High School
9	Foundation Hospital	57	Four prior screenings every 2-3 years	None	Middle School
10	Private Imaging Center	46	One prior screening 4 years earlier	None	Masters Degree

exams and referrals from general surgery specialists were required at 60% of the facilities.

Appointments at the MoH Hospitals (n=2) were made through the online centralized booking system and call center. The women were required to first make appointments with general surgeons to get a referral for mammography testing. One woman was told by her gynecologist that only general surgery specialists have the authority to refer a patient for mammography testing. Following the general surgery examinations, the women were able to schedule mammography appointments.

Appointments at the MoH KETEM facilities (n=2) were made by telephone. KETEM telephone numbers and addresses were located online (13). Upon dialing the given numbers, the women were presented with a series of options that did not include mammography/cancer screening, so the women went through the switchboard to request the correct department which asked for their age, name, and telephone numbers.

The appointment at the foundation hospital (n=1) was made by telephone but also required a prior general surgery appointment. The mammography was completed on the same day as the general surgery exam without an additional appointment.

Appointments were made at private hospitals by telephone (n=4). Prior general surgery exams and referrals were required at three of the four hospitals. In all cases, mammography screenings were conducted on the same day as the general surgery appointment.

The appointment at the private stand-alone imaging center (n=1) was made by telephone and given for later the same day.

Durations for making and securing appointments are provided in Table 3.

Transportation: All of the selected facilities were accessible by more than one form of public transportation. Three participants drove themselves to the appointment, two were driven by their husbands, one walked, and the other four used public transportation (bus, minibus, and metro). For those who drove, parking was free at all MoH facilities. Two of the private hospitals charged parking fees of US$2. None of the women reported that transportation was a barrier to accessing service.

Table 3. Time to make appointments and earliest available appointment by facility

Facility	Time to make an appointment (minutes)	Earliest available appointment (days)
KETEM 1	2	1
KETEM 2	3	20
MoH Hospital 1	7	2
MoH Hospital 2	7	1
Private Hospital 1	6	Same day
Private Hospital 2	5	6
Private Hospital 3	2	4
Private Hospital 4	5	1
Foundation Hospital	5	1
Private Imaging Center	2	Same day

Cost: All of the women were enrolled in the public National Health Insurance (SGK) program. Private facilities that participate in the SGK program may charge patients out-of-pocket (OOP) for any difference between the program's reimbursement rate and the facilities established rate. Two women also had additional private health insurance policies that can be used alone or with the SGK depending on the policy.

All services at the MoH run KETEMs and general hospitals are free of charge. The foundation hospital participates in the SGK and the OOP cost for the general surgery appointment was the equivalent of approximately US$15 (the regular price without applying SGK would have been $30). The OOP cost for the mammography was approximately US$42 (full price would have been US$145. Private Hospital OOP costs ranged from zero in the case of private health insurance to approximately US$175 with no insurance applied. There was no OOP cost at the private imaging center with private health insurance, but the regular price was quoted at US$150. None of the women reported that cost was a barrier to accessing service. Those who selected

private organizations with OOP charges reported that they chose private facilities because they believed that the quality and speed of care was better than public facility care.

Registration: KETEM facility registration was done at the main desk upon entering the facility and required a national ID card. Participants were then directed to the mammography screening room. Registration at MoH general hospitals is not required by patients who made appointments through the centralized booking system and went directly to the mammography screening room where they presented their names and national ID numbers.

Registration at the private and foundation hospitals and the private imaging center required first going to the registration desk where national ID cards and applicable private insurance cards were presented. SGK and private insurance status were confirmed and approved online. Applicable OOP costs were requested and paid upfront. Participants were then directed to the mammography screening room.

Privacy: Participants were called into the screening room by name at all ten facilities, but none reported perceiving this as a violation of their privacy. All but one of the facilities offered a dressing area where participants could disrobe in privacy. These areas ranged from a corner with a privacy panel at the KETEMs, to a separate room with a lockable door, mirror, hangers, and seating at the imaging center. A cloth robe was offered at the private imaging center. Boxes of disposable robes were seen at both KETEMs, but neither facility offered one to the patients. Only one of the private hospitals offered a robe.

Technicians at eight of the facilities locked the outside door to the mammography screening room. At four of the facilities, there were knocks on the door during the screening and the participants reacted by covering their chests with their arms, but the doors remained locked in all instances. At one of the private hospitals, the door remained unlocked, but a curtain was drawn between the screening area and the door. The participant reported feeling uneasy that someone could come in at any moment. One KETEM facility's mammography controls were located outside of the screening room in the intake and waiting area. A window was located in the wall above the control panel that could be seen by other patients having pre-test interviews or waiting. The participant did not notice the window during the screening process, but one of the other patients mentioned it as she was leaving the screening room. The general response was "we are all women anyway."

The radiology technician at the second KETEM was male. The participant reported that although it was not a deterrent to completing the screening, she would have preferred a female technician and asked the technician if any females were available. The technician reported that the other technician was on leave for an undetermined length of time and that some women left the facility because they felt uncomfortable undressing in front of him. Technicians at the other nine facilities were female.

Mammography Screening Intake: KETEM facility technicians completed an online record of basic pre-test questions including age, symptoms, last menstruation date, family history, prior screenings, and results. No consent forms were presented for signature. MoH hospital technicians completed a paper form with basic pre-test questions. No consent forms were presented for signature. Private and foundation hospital technicians completed paper pre-test questionnaires. Four of the six facilities presented consent forms for signature. One of the private hospital technicians told the participant that she would have to reschedule the screening because she was menstruating and it would cause too much pain. The screening continued when the patient insisted she could bear the pain. Only the KETEM radiology technicians asked about and encouraged routine self-breast examinations.

Mammograpy Screening: Radiology technicians put on new disposable gloves at the beginning of the screening at all ten facilities. The duration of the actual mammography screening was standard at five minutes for nine of the ten observations with digital mammography machines. One private hospital advertised digital mammographies, but had an analog machine that required minimal additional time to change cartridges. The addition of wait times led to more significant variance among facilities as shown in Table 4. The longest mammography screening duration of an hour and 40 minutes was at the private hospital with the lowest OOP cost.

Table 4. Mammography Screening Durations and Out-of-Pocket Costs by Facility

Facility	Duration of Mammography Screening including Wait time (minutes)	Out-of-Pocket Cost Paid (equivalent value in US$)
KETEM 1	8	$0
KETEM 2	13	$0
MoH Hospital 1	27	$0
MoH Hospital 2	45	$0
Private Hospital 1	18	$47
Private Hospital 2	25	$24
Private Hospital 3	26	$58
Private Hospital 4	100	$0
Foundation Hospital	31	$15
Private Imaging Center	25	$0

Atmosphere: Participants at all ten facilities reported that they found the staff members to be friendly and respectful. None of the participants reported feeling anxious about the screening. All participants reported that they felt informed by staff members and comfortable to ask questions if they had them. Participants at the KETEMs and one of the MoH hospitals reported pleasant surprise because they expected public facilities to be crowded and have less considerate staff.

Mammography Screening Results: The duration of time between mammography screenings and radiology reports becoming available ranged from 15 minutes to 33 days. For reports that were available on the same day (n=4), the wait time ranged from 15 minutes to 3.5 hours. Two reports were available the following day. The longest duration was 33 days. The delay was related to an end of year renewal of the MoH KETEM contracting for centralized radiology reporting services which led to a backlog of six weeks according to KETEM staff explanations provided to the participant when she called to inquire about her results. MoH hospitals' results are available through the national electronic health record (EHR) system, e-nabiz. MoH KETEM results are available through an MoH website using a code number provided at the time of screening. Private hospitals released paper reports with an accompanying CD. The private stand-alone imaging center sent a digital report to the participant's phone via text message within 15 minutes (before the patient had left the facility). Radiology technicians at eight of the facilities provided participants with information as to when and how they would obtain their screening results. KETEM technicians gave participants a small card with a case number and the website that they could access to obtain their reports. Two technicians at an MoH hospital and a private hospital neglected to provide any information until prompted by the participant. A summary of the wait times and reporting formats for each facility is shown in Table 5.

Table 5. Wait times for Mammography Results and Reporting Formats by Facility

Facility	Wait time for Results	Format of Results
MoH KETEM 1	4 days	Electronic- MoH Cancer website
MoH KETEM 2	33 days	
MoH Hospital 1	13 days	Electronic- EHR e-nabiz
MoH Hospital 2	7 days	
Private Hospital 1	1,5 hours	Paper report + CD
Private Hospital 2	2 days	
Private Hospital 3	2 days	
Private Hospital 4	3 hours	
Foundation Hospital	3.5 hours	
Private Imaging Center	15 minutes	Electronic- text message

DISCUSSION AND CONCLUSION

Although mammogram screenings are available free of charge, four of the ten participants elected to pay out-of-pocket for services because they expected public facilities to be crowded and less patient-focused. The experiences of the two participants that went to MoH hospitals confirmed these perceptions as they experienced longer wait-times than four out of the five private facilities, but the wait times at one private and one foundation hospital were longer. Participants at the KETEMs reported feeling surprised by how positive the screening process was for them.

Screenings are recommended for healthy women between the ages of 40 and 69 with or without symptoms and regardless of family history (25). From a policy perspective, requiring an examination and referral from a general surgery specialist to get a mammography screening is a significant barrier to access. Women who see their obstetrics-gynecology specialists regularly are unable to get referrals and must schedule an additional examination with a general surgery specialist. In Turkey, less than 18% of general surgeons are women (26), which may present an additional barrier for women who feel uncomfortable going to a male general surgeon for a clinical breast examination. Prerequisite physician visits present barriers in terms of time and effort. Ideally, preventative health screenings should be accessible to patients directly without a referral. In the event that a referral policy is non-negotiable, obstetrics and gynecology specialists should be granted the authority to provide mammography referrals. This may have the added benefit of increasing cervical cancer screening rates. To achieve the national cancer screening goal of 70%, this barrier to care should be reconsidered at both public and private facilities.

Participants at all ten facilities reported general satisfaction with the mammography screening process and said they planned to continue getting them regularly every two years. However, mammography screening rooms should be considered from a patient perspective to ensure that women feel safe during the screening process. Privacy violating aspects such as unlocked doors, flimsy curtains, two-way mirrors, and lack of robes should be changed at the facility level. Also, informed consent should be a standard requirement for any diagnostic test involving radiation. The informed consent process may offer the additional benefit of increasing patients' knowledge about breast cancer and mammographies.

All ten participants reported feeling anxiety and fear while waiting for their mammography results. The stand-alone imaging center was able to provide results

within 15 minutes after the screening, but this level of service requires dedicated radiologists and small patient numbers. It is an unrealistic goal for hospitals. KETEM screenings are sent to a national centralized system for contracted radiology services resulting in a duration of four days at one facility and 33 days at the other due to recontracting delays. Contracting requirements may be reviewed to minimize reporting durations. The MoH's new telehealth initiative may be expanded to address the need for faster radiology reporting. While MoH facilities offer electronic reports, private and foundation hospitals offered only paper reports and CDs. All four of these hospitals offer electronic laboratory reporting but haven't extended their online services to include radiology reporting. Offering electronic results would have been more convenient for the participants at private and foundation hospitals who waited for hours or were told to come back the next day.

The largest limitation of this study is the sample size. The time needed to observe mammography screenings is considerable and the human resources available to this non-funded doctoral research study were limited. A larger study encompassing more facilities would provide a more comprehensive understanding of patient experiences. A second potential limitation is researcher bias, however, the action research approach used in this study allows the researcher to advocate and empower participants. Seven participants thanked the researcher for accompanying and guiding them during their screening and reported that the researchers' questions were informative and helpful.

This study allowed the researchers to experience mammography screenings through the eyes of ten women targeted by national breast cancer prevention guidelines. Opportunities for improvement were identified at facility, national, and policy levels in the areas of privacy, consent, referrals, and reporting.

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