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I trust doctors and midwives: exploring breast cancer literacy among women referring to the health centers in Iran

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Abstract

Background Breast cancer (BC) is the most common cancer in women worldwide. Early diagnosis of BC could considerably improve outcomes. Since health literacy could influence preventive behaviors and women's ability to make decisions about breast care, therefore, this study aimed to explore breast cancer literacy in women.

Methods This qualitative study was conducted in Iran using the directed content analysis. Data were collected through face-to-face interviews with a purposeful sample of women from April 2021 to June 2022 and continued until saturation was reached. Interviews were analyzed using the initial matrix developed based on the European health literacy framework.

Results In all twelve women were interviewed. During data analysis, 612 primary codes grouped into four dimension of health literacy (access, understanding, appraise, and apply) of three health domain (health care, disease prevention, and health promotion). Many believed that it was difficult to access accurate information about BC. They used various sources to obtain information. The participants addressed some facilitators and barriers in understanding the information and for information appraisal they mentioned seeking help from health professionals. Through the acquired cognitive skills, the participants took some steps to apply BC information. Also, having information about BC and the involvement of relatives with cancer were indicated as triggers for decision-making on breast care, while poor financial conditions, not having enough information, fear, shame, and embarrassment, were pointed out as inhibiting factors.

Conclusions The findings suggest that barriers in access, and understanding of information on breast cancer exist among women. The findings also suggest that women's decision-making and preventive behaviors on breast care are much dependent on social and cultural factors.

Keywords Health literacy, Breast cancer, Qualitative study, Iran

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Background

Breast cancer is the most common cancer in women around the world [1]. According to GLOBOCAN 2022 estimates, the incidence and mortality of cancer in Asia is 49.2% and 56.1%, respectively [2]. With an increase by 5% per year in Asia and other developing countries, in the near future it will be a major health problem with a significant burden on health care systems in middle-income countries such as Iran [3]. In Iran, breast cancer is the most common cancer among women (first in term of incidence and fifth in terms of mortality). This incidence rate was 34.5 per 100,000 women according to the report in the latest published report of Iran's national cancer registration program. However, the incidence and mortality rate of breast cancer in the country has increased significantly according to other reports from different regions of Iran [4].

Approaches to reduce the global burden of cancer include two major strategies: screening and early diagnosis and active preventive intervention [5]. Breast cancer screening methods, which include mammography, clinical breast examination (CBE) and breast self-examination (BSE), are less common in Iran and there is no a systematic screening strategy. Mammography in Iran is not affordable [6]. Although CBE is a low-cost method with wider implementation capability that does not require equipment [7], it is not performed in all health centers in Iran [8]. The results of studies in Iran indicate that almost 60% of women do not know how to perform BSE or do not have the necessary skills to perform it [6]. It is believed that BSE can increase women's awareness, empowerment and responsibility for their health [9]. The absence of screening methods in Iran is due to limited financial resources, infrastructure and existence of other health priorities. Therefore, according to the existing conditions, the implementation of the screening plan at the national level in Iran and other similar countries is far from reach. Until a well-functioning screening plan is reached, the burden of breast cancer may be reduced by increasing women's awareness and, as a result, early diagnosis at its early stages [10].

In health care, the need for self-management has increased, and people are expected to assume new roles in searching for information, understanding rules and responsibilities, and making correct decisions about themselves and their families [11]. Given the many skills that are necessary to obtain health information and receive appropriate health services, health literacy is considered as the intersection of education, culture, experience, environment and other factors [12]. Health literacy is related to literacy and includes people's knowledge, motivation, and capacity to access information, understand, evaluate, and use health information to evaluate and make daily decisions on medical care,

disease prevention, health promotion and maintaining or improving the quality of life throughout life [13]. Each component of health literacy or a combination of components may affect a person's ability to make a decision about performing a cancer screening test [14].

Health literacy could be affected by a number of factors and sociocultural factors may play an important role in influencing health-seeking behaviour [15]. It is also important to evaluate contextual factors because people with low health literacy may face barriers at the individual, interpersonal, social, and organizational levels that affect their ability to access health care and support services. In addition, it was shown that health literacy might be a contributing factor to increased breast cancer knowledge, perception, and screening behaviors. As suggested improving health literacy may empower women; thus, they can have an active role in improving their health [16–18]. In this regard, investigating the concept of breast cancer literacy in Iranian society, which has its own set of values, norms and conditions, deserves further exploration and requires qualitative research. Therefore, the present qualitative study was conducted to explore breast cancer literacy in Iran aimed to gain insight into the role of health literacy components in explaining women's health behaviours regarding breast cancer.

Methods

Design

This study was a qualitative study employing content analysis with a deductive approach [19, 20]. The intention for selection the current approach was due to the fact that we interested to explore the experiences of healthy women on breast cancer and how they dealt with such an important concern among women.

Philosophical stance of the study

The current study was based on deductive (directed) approach. This approach starts from a theory or a conceptual model (general) and ends with observations (particulars). Thus as will be explained later the data analysis was based on such a philosophical stance.

Conceptual framework

The conceptual framework and the definition of health literacy derived from the Sorensen et al. as follows:

"Health literacy is linked to literacy and entails the motivation, knowledge and competencies to access, understand, appraise and apply health information in order to make judgements and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life throughout the course of life" [13].

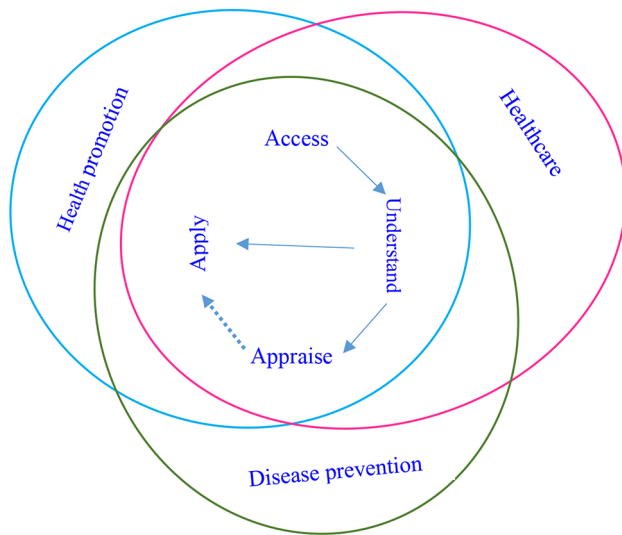


Fig. 1 Four dimensions of health literacy in three health domains. Understanding might either directly lead to apply or it might indirectly lead to apply after health information appraisal (appraise always did not lead to apply)

Table 1 Demographic information of the participants

Participant	Age (years)	Occupation	Level of education	Field of study
1	28	Student and teacher	PHD	Physics
2	28	Teacher	B.A	Public Administration
3	32	Student	M.A	Power
4	21	Student	M.A	Laws
5	26	Self-employed (clothing boutique)	Diploma	Humanities
6	30	Housewife	M.A	Financial Management
7	38	Student	PHD	Biology
8	43	Housewife	B.A	Accounting
9	32	Housewife	High school	Humanities
10	51	Housewife	Primary school	Primary school
11	46	Tailor	Associate degree	Technical and Vocational
12	39	Faculty member	M.A	Mathematics

As such health literacy is a multidimensional concept and consists of various components. In addition to considering the key components of health literacy, this conceptual model also identifies system-level factors that influence an individual’s level of health literacy, as well as pathways that link health literacy to health outcomes [13]. The essential components of this model is a matrix that places health literacy constructs in the three fields of health care, disease prevention, and health promotion (Fig. 1).

Table 2 Interview guide based on HLS-EU conceptual model

	Questions
Health care	<ul style="list-style-type: none"> • Do you have the ability to access to information about breast cancer and its treatment? • Assuming you get the information, do you see yourself as capable of understanding it? • Do you have the ability to check the accuracy of the obtained information? • Based on the information obtained, will you be able to make the necessary decision to take appropriate action?
Disease prevention	<ul style="list-style-type: none"> • Do you have the ability to access to information about breast cancer risk factors? • Assuming you get the information, do you see yourself as capable of understanding it? • Do you have the ability to check the accuracy of the obtained information? • Based on the information obtained, will you be able to make the necessary decision to take appropriate action?
Health promotion	<ul style="list-style-type: none"> • Are you able to access to information about appropriate activities for breast health such as exercise, healthy food and nutrition? • Assuming you get the information, do you see yourself as capable of understanding it? • Do you have the ability to check the accuracy of the obtained information? • Based on the information obtained, will you be able to make the necessary decision to take appropriate action?

Participants and setting

The study was conducted in Tehran and Rasht, two metropolitan in the central and the north of Iran. The participants were 12 women attending health centres for their routine care. Inclusion criteria were being age over 18, willingness to share their experiences, have at least reading and writing literacy, and not having studied medical and health sciences. Purposive sampling was done with maximum variation in terms of age, education and socioeconomic status (Table 1). Except one women who refused to participate in the study due to reluctance to talk about cancer, all women accepted our invitation to participate in the study.

Data collection

The research team designed a guide for a semi-structured interview in order to conduct the interviews based on the definition of health literacy presented above. The interview questions are shown in Table 2. Face-to-face semi-structured interviews were conducted from April 2021 to June 2022. Participants’ experiences were further investigated during the interview using probing questions. All the interviews were conducted by the first author (S R a female midwife, trained in qualitative studies, PhD candidate in Reproductive health) at the time and place (home, workplace and health centre) desired by the participants. Each interview lasted 17–48 min (average 35 min)

according to the participants' wishes. All interviews were audio recorded with the consent of the participants. After the interview, the participants received a gift as a token of appreciation for their participation in this study. The analysis was performed after each interview. The interviews continued until a new code was not discovered and saturation was reached.

Data analysis

For data analysis, deductive (directed) qualitative content was used. We analysed the data based on the proposed algorithm of Hsieh and Shannon [20] and the DQICA (a tool for the directed qualitative content analysis) [21]. As such the interviews were transcribed word by word immediately after each interview, and by analysing the text of the interviews with the help of MaxQDA, concrete examples of breast cancer literacy were identified and coded. Then, codes were placed in predefined matrix. In fact, by classifying the extracted codes. The data analysis process was also supervised and approved by co-authors and external peers experienced in qualitative research. The process of coding and assigning codes to the key concepts of health literacy was audited, controlled and reviewed many times in the process of data collection and analysis by the research team. Given that the concepts of health literacy in many instances had the same and overlapping features, we attempted to eliminate the overlapping cases as required. Finally, four dimensions of health literacy in three health domains, was formed.

Rigour

Guba and Lincoln criteria were used to confirm the reliability of the study [22]. The study results, which is based on the detailed analysis of the opinions of the participants, form the basis of validity. Reliability was maintained through prolonged interaction with the data, member checking, and sampling with maximum diversity. For prolong interaction with the data the main investigators reviewed the interviews for several times to provide accurate unit of meanings and the condense codes. For member checking, a brief report of the results along with the transcripts of the interviews were provided to the participants to confirm the consistency of their experiences with our findings. In order to increase the transferability of the findings, the main investigator recorded all stages of the current research describing the characteristics of the participants, the methodology, the sampling method, and the time and place of data collection.

Results

Participants

A total of 12 women participated in the study. The mean age of participants was 34.5 years ranging from 21 to 51

years. The level of education varied from elementary literacy to university degrees. Four participants had a history of breast cancer in their first and second degree families, and three had a family history of other cancers such as thyroid, stomach, and uterus (Table 1).

Overall findings

During data analysis, 612 primary codes were generated and grouped into twelve main predetermined categories as shown in Fig. 1. In the following sections we report more detailed results to explore the breast cancer literacy (access, understanding, appraise, and apply).

Access

Participants expressed different views on access to information on breast cancer. Most notably many of women believed that access to accurate information on breast cancer was difficult but nevertheless they indicated that they usually used Internet or asked their care physicians in order to find information on breast cancer including risk factors, methods of screening, signs and diagnosis, treatment and sexual activity if someone develops breast cancer.

A participant said that:

I usually use Internet to seek information about breast cancer. (Pt 2, aged 28).

Participants stated that they used different sources including family members, Internet, health professionals, and media to access information on breast cancer. A participant said that:

I have permanent access to information on breast cancer since my sister, is a midwife, and ask my questions from her when needed. (Pt 7, aged 38).

Also, women stated that the ease of access to Internet plays a significant role in her access to breast cancer information. She said that:

I can easily get breast information because the internet is easily available to me. (Pt 3, aged 32).

Women stated different reasons for seeking information on breast cancer. For instance, a women said:

Breast cancer has increased so much and currently one of my relatives is suffering from the disease. This made me keen to search and get information about it. (Pt 5, aged 26).

However, women pointed out that at present although access to information on breast cancer is relatively easy,

assessing the source credibility remain difficult expect on occasions that they receive information from trusted physicians or TV programs.

The participants also stated there are various factors that make it difficult to obtain breast cancer information including traditional structure of Iranian families and religious beliefs. A participant said that:

There is limited programs on TV. Usually, programs are not opening the topic explicitly since they are only allowed to discuss general things. (Pt 4, aged 21).

Understanding

A mixed feeling was found with regard to understanding the information on breast cancer. While a number of women said that they understand the information they obtained or received, a number of women experienced difficulties in understanding the information. Those who indicated they understood the information was due to the fact that the information was presented in a simple way without technical language and included some pictures. However, those who did not understand the information or had problems said that it was very technical and complex.

A women said:

I enjoyed reading an Internet article. It was very simple and pictures (Pt 1, aged 28).

In contrast a woman said:

I do not know how they write this information about breast cancer. Are they writing these for medical students or for us.

The women said that giving practical and objective training has a positive effect on their learning. Women said:

The midwife taught me the breast examination very well, in a practical way. (Pt 14, aged 32).

The participants stated that in order to facilitate the understanding of breast cancer information, it is helpful to consider some factors in providing information. They stated that providing information along with the image plays an important role in their understanding of the topic. A participant stated:

The abnormal breast symptoms shown with the picture had a great impact on my understanding. (Pt 7, aged 38)

Appraise

Participants stated that although information about breast cancer is relatively easy to obtain, it needs to be checked for accuracy via different approaches. A number of women mentioned that they are confident in the information obtained from the care physicians, while a number of women stated that for the correctness of the information they usually compare information from different sources. A participant stated:

Whatever it is, the midwife and doctor's information is correct, I trust them. (Pt 7, aged 38).

Another participant noted that:

I usually compare the information from different sources including the Internet to see if it is correct. (Pt.1, aged 28)

Most participants reported that when they obtain information from Internet or untrusted sources, they examine the accuracy by asking from health professionals including midwives or doctors. A participant stated:

I consult with my doctor when I get information about breast cancer from the Internet or from any other sources. (Pt 13, aged 43).

Apply

The participants did not report difficulty to access health-care system, but they did not go to the care physicians for clinical breast examination or mammography. Women felt that because they do not have abnormal symptoms or family history of breast cancer, they do not need to go to the care physicians. A participant stated that:

I have not visited a specialist for an examination until now because I don't have any abnormal symptoms in my breast. (Pt 3, aged 32)

In addition, participants expressed cancer fear, shame and embarrassment, not having enough information, not being insured, and the high cost and pain of mammography as barriers for preventive behaviors regarding breast cast cancer. A participant stated:

Mammography is really expensive so I did not attend to perform yet. (Pt 13, aged 43).

another participant said:

I don't do an examination or I didn't visit doctor for an examination. The truth is, I don't have the enough information. (Pt 6, aged 30).

One participant added an explanation as to why she did not go to the care physicians for breast examination. She indicated that there was a cultural barrier since being single makes it difficult to visit a male doctor. She said that:

I am a single girl; it is very strange for my family to visit a male doctor for breast examination. (Pt 1, aged 28)

The participants mentioned the role of some facilitating factors to apply preventive measures needed for breast care. These factors included the knowledge of the hereditary nature of cancer and effectiveness of early detection of breast cancer. One of the participants said:

My father died sometimes ago due to cancer. Cancer may have a hereditary origin. So, I took action sooner. (Pt 13, aged 43)

Only one woman stated that she took measures such as eating less fat and more vegetables, and exercise to reduce her risk of breast cancer and improve her health. she said that:

Both myself and my husband started exercising because it prevents many cancers, such as breast cancer and we eating less fat and more vegetables. (Pt 15, aged 51)

Discussion

This study was conducted aiming to investigate breast cancer literacy in women. In general, the results showed that women knew the importance of early diagnosis in its successful treatment, but they had little information about breast cancer screening, and almost all women only sought specialized care when they had abnormal symptoms.

Searching about breast cancer for conditions in which a person does not feel any symptoms or problems is not common among women in Iran. The importance of knowing about breast health is important for early cancer diagnosis and has a positive effect on survival [23]. The result of the study showed that health information literacy and awareness of breast cancer had a positive and significant correlation [24]. There is a positive relationship between improving health literacy and early detection of breast cancer [25].

The source of information mentioned in this study was the media (television, and the Internet), health

professionals and family members. Health information about breast cancer in low-income countries is obtained from mass media, health workers, and the public. Many people including health workers of society, volunteers, religious leaders, civil leaders and medical professionals can provide such messages [26].

The high prevalence of cancer and the involvement of family members was a factor that encouraged women to obtain information. Family history affects people's perception of cancer risk and makes them feel more at risk than breast cancer [27]. A person's perceived risk of breast cancer increases the motivation to search and scan information using mass media [28].

The inhibitors of obtaining information were embarrassment to talk about breast cancer with family, relatives or friends. Cultural barriers, gender roles, stigma, and fear of losing social status may also affect seeking behaviours for breast cancer information, BSE and other preventive measures [29].

The results of the present study showed that increasing the understanding of breast cancer information using strategies such as using simple language without technical and medical terminology, using pictures, providing practical and objective training, providing educational content in written forms, training people according to their literacy level, repeating educational content, using short sentences in training and asking questions is possible and facilitated. People need access to information about cancer prevention and care that is easy to understand and linguistically appropriate. Providing clear and applicable health information supports prevention efforts. It is a recognized strategy for clearly communicating health information, both spoken and written, and addressing the health literacy needs of all patients [30].

The skills to appraise the obtained information are vital for making informed decisions about breast cancer. The results of the present study showed that by comparing and matching information from several sources it is possible to evaluate the correctness of information on breast cancer and breast care. Also, women considered the information received from health professionals to be valid. Providing training on evaluating information sources may be a useful strategy to promote women's health literacy about breast cancer.

The effectiveness of early detection of breast cancer was found to be a facilitator for breast cancer decision-making. Awareness of the benefits and harms of screening, attitude towards the importance of cancer screening; and using decision aids to improve knowledge and guide decision making influences decisions about screening [31]. Studies have shown that more knowledge about breast cancer and screenings has a positive correlation with higher screening rate [32]. Having health knowledge is a predisposing factor that affects a person's health

behaviour [33]. The effectiveness of cancer screening programs depends on their adherence. By improving the level of health literacy, this adherence can be increased [34].

Barriers to breast care included shame and embarrassment, the perception that for instance that mammography is painful, high cost, fear of cancer, and lack of information about breast cancer. A study showed that gender barriers (physician gender), cultural barriers (shame), social barriers (loss of position among family/friends) and environmental barriers (lack of financial and geographic access to care and lack of fluency in the language of the host country) had a negative impact on the performance of Muslim women in relation to CBE [35]. Health care policies should address the specific barriers that indigenous women face to improve their participation in early detection and early help seeking for breast symptom care [36].

In the present study, the protective behaviours that promote breast health included avoiding inappropriate diet and regular exercise. Given that one of the most important predisposing factors for cancer are carcinogens and lifestyle (poor eating habits and physical inactivity), primary prevention including changes in lifestyle, avoiding risk factors and screening are recommended [37].

Strengths and limitations

The strengths of this study included collecting data from women in two urban areas of Iran lending support to transferability of our results to other similar contexts. Another strength of the present study is that our study has provided valuable insights into the understanding of barriers to breast screening and its facilitators, which can increase the likelihood of breast cancer screening by examining and addressing such barriers and implementing necessary strategies. This study had limitations. First, the study relied on participants' verbal reports, which has the potential to lead to recall bias and over- or under-reporting of socially acceptable and unacceptable behaviours. Secondly, the maximum variation approach was only based on the sociodemographic aspects and we did not include the clinical aspects. Those attending health care service related to cancer may have a different and richer insights on BC literacy.

Conclusion

Breast cancer literacy is a multidimensional concept with an interconnected nature. The initial requisite of the concept is the need to improve women's skills to access and understand information related to breast cancer. Women indicated that understanding breast cancer information could be facilitated by different strategies including the provision of pictorial information and avoiding technical terms in available sources. The concept is completed

by the individual ability of women to consciously apply information to take appropriate action for breast care. The findings suggest that inhibitors and facilitators of breast care can be used for the formulation of strategies aimed to increase breast cancer literacy.

Abbreviations

BSE	Breast self-examination
CBE	Clinical breast examination
HLS-EU	European health literacy survey

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Author contributions

All authors contributed to conceptualization and methodology. SR collected the data and drafted the manuscript. ML supervised the study and contributed to all aspects of the study. FA was the study advisor and contributed to the conduct of the study and the formal analysis of the data. AM jointly supervised the study, critically reviewed the paper, and provided the final manuscript. All authors have read and approved the final manuscript.

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Data availability

Data and materials are available on request to the corresponding authors.

Declarations

Ethic approval and consent to participate

This study has been approved by the Ethics Committee of Tarbiat Modares University, Tehran, Iran (code: IR.MODARES.REC.1399.056). The participants received explanations about the objectives of the study and the fact that participation is voluntary. All those who agreed to participate in the study gave written informed consent before conducting the interviews. They were assured that only the researcher and co-authors would have access to the raw interview data. Confidentiality was maintained by assigning unique identification codes to the participants in the dataset, and only the researcher was familiar with the unique coding identifier. In this way, data security was guaranteed. All methods were carried out in accordance with the Helsinki Declaration.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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