# RESEARCH ARTICLE

# Delayed Presentation of Self-discovered Breast Cancer Symptoms in Iranian Women: A Qualitative Study

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## Abstract

<u>Background</u>: Delayed presentation of symptomatic breast cancer is a public health issue in Iran, making a major contribution to low survival. Despite the importance of this problem, current knowledge is insufficient to inform interventions to shorten patient delay. The aim of this study was to explore factors influencing patient delay in Iranian women with self-discovered breast cancer symptom. <u>Materials and Methods</u>: This qualitative study was conducted during 2012-2013. Purposeful sampling was used to recruit 20 Iranian women with self-discovered symptoms of breast cancer who attended the Cancer Institute of Tehran University of Medical Sciences, Tehran, Iran. Data were collected through semi-structured in-depth audiotaped interviews, which were transcribed and analyzed using conventional content analysis with MAXqda software version 10. <u>Findings</u>: Content analysis of the data revealed four main themes related to the delay in seeking medical help including: 1) attributing symptoms to the benign conditions; 2) conditional health behavior; 3) inhibiting emotional expression; and 4) barriers to access to health care systems. <u>Conclusions</u>: These results suggest that patient delay is influenced by complex and multiple factors. Effective intervention to reduce patient delay for breast cancer should be developed by focusing on improvement of women's medical knowledge, managing patients' emotional expression and reform of the referral system.

Keywords: Breast cancer - delay - Iran

## Introduction

Breast cancer is the most common cancer in women worldwide (Ott et al., 2010). According to the World Health Organization report, annually 1.38 million women are diagnosed with breast cancer; almost 50% of breast cancer cases and 58% of deaths occur in less developed countries (World Health Organization, 2014). Breast cancer also is the most common cancer in Iranian women (Noroozi and Tahmasebi, 2011) and its incidence rate doubled during three past decades (Babu et al., 2011). Increasing population and life expectancy along with tendency to adopt western lifestyle has turned breast cancer into a growing public health concern in many developing countries (Benson and Jatoi, 2012).

The World Health Organization has proposed early detection of breast cancer as an important strategy for disease control through early awareness and diagnosis of breast cancer sign and symptoms in symptomatic women and mammography screening in asymptomatic population. (World health organization, 2014). However particularly in low-and middle-income countries, a high proportion of breast cancers is diagnosed in late stages (Shulman et al., 2010, Tfayli et al., 2010).

Delayed diagnosis may occur in different stages of diagnostic cancer journey. Conventional definitions of delay are usually focused on the patient or medical service providers. Patient delay refers to the period from initial detection of signs by the patient to the first medical consultation (Unger-Saldana and Infante-Castaneda, 2011). In breast cancer this period is often considered 3 months (Facione, 1993) and is associated with poor prognosis (Ramirez et al., 1999). In a study by Harirchi et al. (2005), a significant number of Iranian women with advanced breast cancers (42.5%) delayed in medical consultation by more than 3 months (Harirchi et al., 2005). According studies that conducted in Asian countries, late presentation is a public problem in rejoins i.e., Iran (Rastad et al., 2012), Singapore (Chang et al., 2011), Malaysia (Norsa'adah et al., 2012; Yusuf et al., 2013) and Taiwan (Lu et al., 2010).

Preventing delay in diagnosis and treatment of

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various types of cancer has been considered by cancer researchers worldwide since early 1930s (Facione, 1993) and has led to numerous studies with different approaches. A Systematic Review indicated that older age, low educational level and family history of cancer influence breast cancer late presentation in Middle East countries (Alhurishi et al., 2011). A meta-ethnographic synthesis also showed that individuals who attributed their symptoms to a non- serious symptom are more likely to delay seeking medical help than those who interpreted their symptom as a cancer symptom (Smith et al., 2005). Lam et al. (2009), in a qualitative study with the aim to investigate help seeking patterns in Chinese women with self-discovered breast cancer symptoms, showed that non-matching symptom nature with women's expectations and knowledge of breast cancer symptoms associated with patient delay (Lam et al., 2009). Anderson et al. (1995), also reported that symptom disclosure to others provoked help seeking process and embracement about symptoms led to delayed help seeking.

However, review studies stress that existing knowledge is inadequate to develop delay mitigation strategies (Ramirez et al., 1999). Culture, gender, experiences, teachings, and beliefs can affect individual's perception and feelings of symptoms (Teel et al., 1997). Therefore people's perception and how they respond to symptoms in different communities, requires further studies (Petrie and Weinman, 2003).

Given increasing prevalence of breast cancer in the past decades in Iran, high incidence of delay and lack of sufficient information about help-seeking behaviors in Iranian women, the researcher decided to conduct an in-depth qualitative study to explore influencing factors of patient delay by Iranian women with self-discovered breast cancer symptom. Qualitative studies can provide an in-depth understanding of health behaviors and underlying factors that influence patient delay. The present qualitative study attempted to furnish researchers, policy makers, and health service providers with key factors affecting delayed presentation rooting from contextual factors in Iranian women.

## Materials and Methods

As part of a more extensive research, the present study was conducted with a qualitative approach using content analysis method. The study was performed in Cancer Institute that is situated in the Imam Khomeini Medical Center of Tehran University of Medical Sciences with 210 active beds. This centre is a governmental referral center that offers specialized cancer care for patients who are either physician or self-referred from all regions of Iran.

To achieve objectives of the study, purposive sampling was carried out from women who presented to the breast clinic of Imam Khomeini Cancer Institute. Data saturation directed sampling and twenty Iranian women with self-detected symptoms of breast cancer entered to the study across June 2012 and January 2013.

Participants underwent semi-structured in-depth interviews, lasting 40-90 minutes, about their experiences from detection of symptoms to the time they visited a

doctor. Interviews began with a few open and general exploratory questions about how women detected and subsequently dealt with their symptoms. The initial questions were followed by probing questions to extract further and clearer explanations. In some cases, data from informed relatives of women were also used. Interviews were completely recorded and transcribed. The participants provided written informed consent.

Data were analyzed concurrently using qualitative content analysis with MAXqda software version 10. First, the text of each interview was carefully read to catch an overall sense of the data. Then meaning units including all statements containing relevant concepts to subject of the study were selected and labeled with a code. Conceptual analysis was carried out in the course of study by constant comparison and comparing created codes in terms of similarities and differences. Concurrently abstraction was performed at different level and codes, subthemes and themes were created (Graneheim and Lundman, 2004).

Trustworthiness of data was achieved through establishing good relationship and prolonged engagement with participants, agreement of research team on interview method and coding process, in-depth description of findings, and use of external review by an expert qualitative in relation to study process and findings.

To observe ethical considerations, research project was approved by the Ethics Committee of the university, and agreement of hospital authorities was obtained. Then, participants were briefed about objectives of the study, recording interviews, confidentiality of data, optional participation, and withdrawal at any stage of study, and written consents were obtained.

## Results

The participants were aged 26-71 years. Two had a family history of BC. Sixteen women presented with

**Table 1. Characteristics of the Study Participants**

| Variable | | Participants (n=20) |
|---|---|---|
| Education level | Illiterate & Primary school | 6 |
| | Secondary school | 3 |
| | Diploma | 8 |
| | Bachelor | 3 |
| Employment status | Unemployed | 17 |
| | Employed | 3 |
| Marital status | Married | 18 |
| | Single | 2 |
| Age | ≤35 years | 6 |
| | 36-45 years | 5 |
| | 46-55 years | 5 |
| | 56- 71 years | 4 |
| Nature of symptom | Breast Lump | 16 |
| | other symptoms* | 4 |
| Diagnosis: | Breast cancer | 12 |
| | Benign | 6 |
| | Without diagnosis | 21 |
| Family history of breast cancer | | |
| | Negative | 2 |
| | Positive | 18 |

*Other symptoms include breast pain, bloody nipple discharge, inverted nipple, hand edema, peau d'orange skin, fever, weakness and fatigue

a breast lump and twelve had BC diagnosis (Table 1). Analysis of data led to exposure of four themes including attributing symptoms to benign diseases, conditional health behaviors, inhibiting emotional expressions and barriers to access to health care systems. Below, each is explained in detail:

*Attributing symptoms to benign diseases*

Immediately after detecting abnormal symptoms, patients attached different labels to the disease, including benign and malignant options. Delaying women were more likely to perceive their symptom as a benign or trivial condition. Women interpreted symptoms according to the nature of symptoms, matching symptoms with their knowledge about symptoms of breast cancer, risk assessment of the disease, and social messages. Absence of pain and distressing signs, inadequate knowledge, receiving reassurance messages and not considering the risk of breast cancer led to delayed care.

Absence of pain and distressing signs: In most participants, painless lump was attributed to a normal or trivial situation such as breastfeeding, hormonal changes, trauma, fatty mass, or menopausal changes, which led to delayed presentation, conversely lump accompanied with pain was attributed to a serious disease needing follow up. A participant stated:

*"It didn't hurt, so I thought it was nothing. Perhaps it's a fatty lump, nothing special. When it hurt badly and was irritating, I thought I should go to the doctors to see what it was."* (P11, 64 yr., BC).

Symptoms such as edema of the arm, malaise, fatigue, and fever were attributed to general diseases or adjacent organs. Attributing symptoms to adjacent organs were associated with delayed presentation. In this respect, one of the participants, despite detecting a large lump and progressive changes asserted:

*"It's nearly two years since I found it in my breast, but I didn't care much. Didn't think it was important. I had no pain. But since my arm was swelling, I went to the doctor, and he said it was sensitivity to bleach"*. (P3, 43 yr., BC)

Inadequate knowledge: Women's knowledge and experience about symptoms and risk factors of breast diseases influenced their understanding about nature of the symptom and subsequent action. Participants' specific information about breast cancer was insufficient. Some women considered their insufficient specific cancer knowledge one of the reasons for delayed presentation. One of the participants with three months delayed presentation, said:

*"I didn't know this lump can take my life. I didn't know at all that I had to see a doctor. If you had knowledge or experience then I'd go earlier."* (P1, 35 yr., BC)

Conversely another participant with a postgraduate degree in nutrition described pain and breast lump in mid-menstrual cycle as abnormal according to her own knowledge about normal cyclic breast changes and visited a doctor two days after discovering a symptom. In this respect she said:

*"This month, I had some heaviness and discomfort in my right breast before my period. I thought it could be due to the period, and didn't doubt it, as I know there may be*

changes before menstruation. But almost after two weeks, I touched a lump. I was scared, that's why. It was different. Why should there be pain and discomfort in mid-cycle?"* (P18, 39 yr., benign).

Not considering the risk of breast cancer: Family history of breast cancer influenced help seeking behaviors. Because of no history of cancer in family or among friends and acquaintances, some participants thought it unlikely to get breast cancer themselves. One of the participants argued:

*"I didn't think about this disease at all, because I had no problem, I was healthy. No one in the family had it either."* (P1, 35 yr., BC).

Conversely, those with a history of cancer in a family member, experienced a disturbing concern about likelihood of having breast cancer, and hastened their presentations. A participant with a family history of cancer that presented only one day after a bloody discharge from breast said:

*"Because of family history, and since I had seen my aunt, especially in her last days, it affected me a lot. I always feared having cancer. Yesterday, when I realized, I was scared even more."* (P 16, 47 yr., without diagnosis).

In addition, personal belief that the disease is common also affected people's behavior. Those that believed prevalence of disease in the community was on the increase, considered the risk more seriously.

Receiving reassurance messages: Disclosing the discovered symptoms with other people was applied by participants to cope with their problems. In most cases, consultation helped participants to realize seriousness of the situation, and making decision to seek medical help. A participant described her daughter's motivational role in seeking treatment said:

*"My daughter insisted that I visit a breast doctor, so I did, and then I went to doctor."* (P3, 43 yr., BC).

However, in some women consultation was associated with getting misinformation that there is no need to take action. Receiving reassurance messages led to trivialize the situation and delayed presentation. One of the participants said:

*"It took two to three months. Anyone I spoke to said it was nothing; don't worry. So I was like that "* (P14, 48 yr., BC).

*Health style: conditional health behaviors*

For some participants, health behaviors were conditional on various conditions. These people predominantly delayed presentation because of other priorities in their lives, such as priority to self-medication, occupational and family commitments, or presentation depending upon suitable finances.

Priority to self-therapy: Prior health style seriously affected recent women's health behaviors. Those women who were sensitive to other their heath changes, they were also sensitive to the present breast symptom as a diversion in their health. This perspective prompted women to seek help as soon as possible irrespective of other priorities or problems. A participant said:

*"Some people realize their problems after 4 years. I was very sensitive. Not for my-self, but for my family.*

*Everybody has to look after oneself, so as not to become frail.*" (P2, 59yr., BC).

However although the majority of our participant trusted to the conventional medicine, some women tested self-medication to deal with the symptoms before medical help seeking. Daughter of one of the participants who had delayed presentation by 3 months, described mother's health behaviors as follows:

"*She generally believes that one should cure oneself with proper diets, rather than visiting a doctor. It was for this belief that she didn't take her disease seriously.*" (P3, 43 yr., BC).

Priority to work or daily commitments: Some participants introduced their professional/family responsibilities as a barrier for not seeking medical help. One of the participants stated:

"*I never thought to go to a doctor to see what it was. I was so busy with work; my children, my husband, guests, cooking, I have to attend to all of them.*" (P3, 43 yr., BC).

Presenting on the condition of affordability: One of the participants with more than one year's delay considered her presentation, conditional on appropriate finances, and argued:

"*Well, I go to the doctors if I have money. My husband insists that I go, but without money, it's difficult.*" (P11, 64yr., BC).

*Inhibiting emotional expressions*

Women experienced emotional expressions such as fear, denial, depression, anxiety, and occasionally optimistic thinking, with different reasons and intensity. Emotional expressions had complex effects on seeking medical care.

Fear and denial: Fear of cancer, prompted presentation in some patients and delayed it in others. In some participants, fear of facing diagnosis of cancer made them hesitant toward action for definitive diagnosis. A participant stated:

"*God forbid, I was scared that they may say it is cancer, when the pain got worse. So I went doctor*". (P7, 37 yr., benign).

Conversely, a participant that had presented with the first opportunity said:

"*I constantly cried, I worried it might be cancer, and dangerous.*" (P5, 35 yr., BC).

The story of a participant was a good example of denial. This participant that presented with several months delay and clear symptoms of cancer revealed her secret concern and said:

"*I talked to my sisters and kids; I said I was sure it's nothing, sympathized with myself. All doctors say that it is (cancer), but I say it isn't. God willing, it just a lump of fat.*" (P8, 71 yr., BC).

Optimistic perspective: Patients that did not experience negative emotions in facing symptoms, due to optimistic perspective, delayed in presentation. These women understood optimistic thinking as "*avoiding negative thinking*" and "*avoiding magnification*". Optimistic perspective in facing symptoms exhibited as delayed presentation. One of the participants described:

"*I never thought it negative at all. I never thought about it negatively. I'm an optimist. I never considered this aspect at all.*" (P1, 35yr., BC).

Another participant considered paying attention to symptoms as a kind of exaggeration, and argued:

"*I believe that you shouldn't exaggerate things*" (P14, 48 yr., BC).

Embarrassment of breast examination: Embarrassment to perform diagnostic procedures by a male doctor was reported by a number of patients, but only in one patient led to delayed presentation. A participant said:

"*I was embarrassed; I was too shy to ask to be examined.*" (P20, 31 yr., benign).

*Barriers to access to health care systems*

Despite deciding to seek medical help, some women delayed visiting a doctor because of indecision about choosing a specialist, and systemic barriers.

Indecision about choosing a specialist: The majority of participants chose a specialists in private or public hospitals and only one patient with breast abscess consult to a general practitioner because of lack of a specialist in her rural residence. Specialty of a doctor was selected according to the type of symptom. Most of women with breast lump, consulted a gynecologist first rather than presenting their symptoms to a surgeon or general physician. Some other, according to information obtained from informed people, chose a surgeon or an oncologist. Indecision about specialty of doctors was challenging for some patients. A participant said:

"*Nearly a year ago, I had a burning sensation in my breast, I thought it could be related to the heart. I didn't know which specialist I had to go to. So I went to a gynecologist.*"(P6, 31yr., BC).

Systemic barriers: Presenting with a non- breast symptom led to diagnostic delay as a cause of both patient and provider delay. Two patients with non-breast complaints, including arm edema (despite detecting a considerable lump), consulted internal and orthopedic specialists. These specialists did not perform general clinical examination, did not request proper diagnostic test and failure to refer the patient to a specialist center.

"*It is nearly two years since it was found in my breast. My arm was swollen. I went to a doctor, and he said it was allergy to bleach. I went again, and again it was not diagnosed.*" (P3, 43 yr., BC).

Lack of a medical referral system, patient's indecision about choosing the specialty and some problems associated with systemic factors, including official holidays, irregular presence of doctors, and prolonged admission time to public medical centers were barriers to some patients' timely access to the doctor. Due to official New Year's holidays, one of the patients had 12 days delayed presentation.

"*It was on the 2nd or 3rd day of new year holidays that I noticed the problem. It was holiday, and it was on the 14th that I began pursuing my problem*", (P5, 35 yr., BC)

Another participant considered irregular presence of doctors and prolonged admission time to public medical centers effective in her delayed presentation, and said:

"*Every time I went to the hospital, doctors weren't there, or didn't have time. There was a female breast*

*specialist doctor. Every time I went she wasn't there, or I was late, and she was only in hospital on Mondays. These delayed me*." (P6, 31yr., BC).

## Discussion

According to the results, delayed presentation was influenced by complex interaction of different personal, cultural-social, and structural aspects. Ignoring painless breast lumps, limited information, inhibiting emotional expressions, receiving reassurance messages, insensitivity to health, considering it unlikely to get breast cancer, and systemic barriers in access to services, were common narratives in the story of majority of patients with delayed presentation.

The present study showed that delaying women tended to attribute their symptoms (especially painless lumps) to normal and benign causes. This finding supported by other similar studies. For example according to a study by Nosarti et al. (2000), conducted with a quantitative approach on 692 patients in a London clinic, attributing breast symptom to less serious conditions was reported the most common reason for delayed presentation (Nosarti et al., 2000). Studies conducted with a qualitative approach also confirm our findings that attributing symptoms to normal changes or trivial are associated with patient's delay. Conversely, those symptoms that attributed to cancer often lead to action (Nosarti et al., 2000, de Nooijer et al., 2001, Unger-Saldana and Infante-Castaneda, 2011).

Furthermore, the present study showed that appearance of pain was a strong trigger to action, and absence of pain was a reason for delay in receiving care. This finding has been similarly supported by other qualitative studies conducted in Mexican (Unger-Saldana and Infante-Castaneda, 2011), Malaysian (Taib et al., 2011), and Ethiopian (Dye et al., 2012) women. Lam et al. (2009), discussed that painful lumps are taken more seriously than painless lumps because they are indicative of two concurrent problems: lump as specific sign of cancer, and pain as non-specific indicator of a variety of diseases (Lam et al., 2009).

Burgess et al. (2001), suggested that understanding seriousness of symptom is influenced by the nature of symptoms and matching its nature with patient's knowledge and experience of cancer symptoms (Burgess et al., 2001). The present study results, in line with quantitative studies (Heidari et al., 2008, Babu et al., 2011) are indicative of inadequate knowledge of Iranian women about screening methods, symptoms and risk factors of breast cancer. Thus, increasing women's knowledge is an undeniable necessity in design of patients' delay mitigation strategies.

Indeed according to the present study, patient's attention to non-breast symptoms such as arm edema and fever prolonged the process of seeking care. In a study by Anderson et al. (2001), on people with various symptoms of cancer, well-known symptoms of cancer such as lumps were associated with haste, and non-specific symptoms, like change in intestine function or weight loss, were associated with delay in receiving care (Andersen et al., 1995). In a study by Burgess et al. (2001), women

presenting with non-lump breast symptoms had greater delay than women with lump (Burgess et al., 2001).

According to the present study, emotional expressions such as denial, lack of concern and optimism about the nature of symptoms led to patient delay and fear of cancer in some participants led to early presentation, and in some others, led to delay. The role of denial in delayed presentation has been confirmed in various studies. Fear and worry about diagnosis and its consequences in facing symptoms have been reported as a common experience in facing with breast symptoms (O'Mahony and Hegarty 2009, Unger-Saldana and Infante-Castaneda 2011). The effect of different type of fears on health seeking behaviors is complicated. This finding points to the need for attention to different emotional expressions of women by medical service providers in patients' education and consultation opportunities.

The present study in line with some other studies (Lam et al., 2009), found that competing priority such as work and family commitment can act as barriers to seek medical help in some participants. It seems, in people that maintaining health is understood as necessary for playing other daily roles, personal responsibilities cannot act as a barrier to seeking medical help.

In the present study, timely access to doctor in most cases happened with no challenge. Although the majority of participants chose specialists and in some times, they experienced challenges in choosing a specialist. Presenting with non-breast symptom was accompanied with both patient and provider delay. It seems this finding stresses the gap due to absence of a referral system by general practitioners in Iran. People are themselves responsible for identifying the specialty and choosing their doctor. Doctors, also based on patient's complaints, search for related disease according to their own specialty. Thus, it appears, in cases that patient's main problem is neglected due to the lack of patient's knowledge, doctors specialty does not allow detection of symptom that was ignored by patients. Arndt et al. (2001), also confirmed the relationship between provider delay and referral with non-breast symptoms of patients with breast cancer in Germany.

Some participants were faced with such problems as private doctors' offices or public clinics being closed during New Year's holidays, prolonged admission time, and irregular presence of doctors. Lam et al. (2009), identified lack of knowledge about service providing centers, long distance, and financial problems as reasons for delay in Chinese women. Unger-Saldana and Infante-Castaneda (2011), also considered patients' admission procedure and referral system as a cause for patients' fatigue and frailty to pursue treatment in Mexican women (Unger-Saldana and Infante-Castaneda, 2011).

Finally, according to the present study results, conclusion can be drawn that several factors at personal, social and systemic levels influence patients' delayed presentation. Identifying these factors is useful in order to develop delay mitigation strategies. According to the results, it seems interventions through informing the public in the media by focusing on enhancing knowledge and reforming public beliefs about breast cancer, introducing

*Zohreh Khakbazan et al*

specialist breast cancer clinics, emphasis on promising results of timely treatment, and reforming medical service system, especially development of a uniform referral system of specialist services, have an extensive capacity in reducing patients' delayed presentation.

The small number of sample size, was the main limitations of this study that seems it is inevitable in a study with qualitative approach. Considering maximum variation based on the type of breast symptoms, patient age, and duration of patient delay was applied to overcome this limitation. These results can be tested in studies with quantitative approach and larger sample size.

## Acknowledgements

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