

RESEARCH ARTICLE

Causes of Delay in Seeking Treatment in Patients with Breast Cancer in Iran: a Qualitative Content Analysis Study

Hadis Rastad¹, Narges Khanjani^{1,2*}, Behjat Kalantari Khandani³

Abstract

Background: In the Middle East, including Iran, breast cancer is the most frequent malignancy among women. Without treatment, a malignant breast tumor advances in stage, diminishing a woman's chances of survival. In this study we aimed to gain insight into the causes of delay in seeking treatment in patients with breast cancer. **Methods:** The participants in this qualitative, content analysis study were 10 women in whom a diagnosis of breast cancer in the stages of II b, III or IIV had been made. They were selected from patients of a major oncology clinic in Kerman, Iran. Data were collected by means of semi-structured interviews that lasted between 20 to 30 minutes. Sampling was discontinued when data saturation was achieved. Content analysis was conducted by classifying the data into themes and sub-themes. **Results:** The results of our study revealed several factors that interfered with patients' professional consultation seeking and prompt treatment. These factors included; lack of knowledge, fear of being diagnosed with cancer, not seeing oneself at risk, mental preoccupation and wrong diagnosis by physicians. **Conclusions:** This study suggests that women and even physicians need further information about breast cancer symptoms. Women need encouragement to seek medical advice when they encounter suspicious symptoms. Additionally, women may benefit from awareness of the pros of early detection and reassurance about the improvements in the success of breast cancer treatment.

Keywords: Breast cancer - symptoms - delay - Kerman - Iran

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Introduction

World statistics show that breast cancer is the most prevalent female malignancy (Harirchi et al., 2005). In Iran, breast cancer is the most frequent malignancy among women (Harirchi et al., 2005), and led to a mortality of 3.3 per 100,000 among females in 2004-2005 (Mousavi et al., 2009).

In case of delayed treatment, a malignant breast tumor advances in stage, diminishing a woman's chances of survival (Facione, 1993). Delayed presentation of breast cancer also has a significant economic impact, in view of the fact that it is far less expensive to treat patients with early-stage disease. Consequently, an understanding of the factors influencing delay in treatment is important for policymakers to develop strategies to shorten delays (Yau et al., 2010). Patient delay in help-seeking refers to the period between an individual's first awareness of a sign or symptom of disease and initial medical consultation (Bish et al., 2005). There is strong evidence that delayed presentation of symptomatic breast cancer is associated with lower chances of survival (Richards et al., 1999).

Patients with total delays of 3-6 months have considerably worse survival than those with delays of less than 3 month (Richards et al., 1999). A systematic review reported that in at least a third of all patients, the time between first symptom and treatment is longer than 3 months, and in about a quarter this time is longer than 6 months (Richards et al., 1999). The review also showed that more than 50% of patients visit a family physician within 1 month of developing symptoms, but 20-30% delay more than 3 months. Family physicians refer most cases of breast cancer to hospitals directly after the first consultation, but a small percentage of patients (6-16%) experience longer delays (>3 months) at this step of the process (Richards et al., 1999).

In order to develop effective new strategies to shorten delays before presentation of breast cancer we require an understanding of the factors that influence these delays. Determining the factors which contribute to delays in seeking treatment has been the continued focus of cancer researchers throughout the world (Mor et al., 1990) and a variety of socio-demographic, clinical and psychosocial factors have been examined in relation to patients' delay

¹Department of Epidemiology and Statistics, Faculty of Public Health, ³Department of Oncology, Shahid Bahonar Hospital, School of Medicine, Kerman Medical University, Kerman, Iran, ²Honorary Research Fellow, Monash Centre for Occupational and Environmental Health, School of Public Health and Preventive Medicine, Monash University, Melbourne, Australia *For correspondence: n_khanjani@kmu.ac.ir

in seeking treatment. According to a systematic literature review published in 1999 and subsequent research, there is strong evidence of a relationship between older age and patient delay (Ramirez et al., 1999, Arndt et al., 2002). This systematic review found less strength of evidence for socioeconomic status and ethnicity and more strength of evidence that marital status was unrelated to patient delay (Ramirez et al., 1999).

So far there is very little data about causes of delay in breast cancer patients in Iran. Therefore, a qualitative research was undertaken to deeply explore the beliefs and attitudes associated with delay in medical help-seeking in Iranian breast cancer patients.

Materials and Methods

The participants were selected from breast cancer patients of a major oncology clinic in Kerman, Iran who were diagnosed with breast cancer in stage II b, III or IIV. The entry criteria for this study were delay in seeking treatment for at least 3 months after detecting a suspicious symptom. This entry criteria were selected by recent evidence which suggests delay greater than 3 months between onset and diagnosis may be detrimental to survival (Richards et al., 1999). Participant enrollment continued until data saturation was achieved.

Data were collected by means of semi-structured, open-ended questions in interviews. Interviews were conducted at the oncology clinic when the patients came for their follow up visits and lasted between 20 to 30 minutes. They were conducted by a female interviewer who was not involved in the clinical management of the patients. Respondents were encouraged to talk freely in relation to obstacles that prevented them from seeking prompt consultation. The interview questions were piloted and refined before the study. Before starting the interview, participants consented to participate in the study and their voice being recorded. The entire interviews were recorded on tape and transcribed. The interviews sought to gather a history from participants, about their experience from symptom discovery to diagnosis and treatment. Participant’s thoughts and feelings about symptom discovery were also investigated, as well as their behavior in reaction to the symptom and who they sought advice from, including close friends, family, and health professionals. The resulting interview elicited a narrative of each participant’s disease from symptom discovery to treatment. Participants were assured anonymity in the writing up of study findings. After interviewing 10 participants data saturation was achieved.

Data were coded and analyzed using a thematic approach where the experiences and beliefs that participants expressed were interpreted for key themes. Data relating to each of the codes were then read several times, looking for similarities and dissimilarities in women’s views and experiences. The relationship between codes was then assessed prior to key concepts were developed. At last, the main concepts extracted were discussed with the individual participants and their comments were sought to increase the confirmability of the findings.

Results

The participants’ average age was 47 years and most of them were married. The participant characteristics are presented in Table I. The main themes extracted from the data were.

Information deficiency

False interpretation of the initial symptom was a prevalent and common issue expressed as a main reason for delay in seeking treatment by the participants. Participants spoke about not knowing the initial symptom they discovered might be a sign of breast cancer. For example, they confessed that they did not know that inward retraction of the nipple, an axillary mass, a painless mass, etc could be an early sign of breast cancer. “My breast had no problem at all! Just a little hard lump under my arm ...” “I went to take a bath, ... the brown areola was pulled in and a large piece ... of this side of my breast was very hard... because it didn’t have any pain, I did not think that it was serious.” Also due to lack of knowledge, some patients did not seek professional advice on time and wasted time by engaging in false believes. “It was a lump that became sore, and then blood and fluid came out of it... there is an ancient saying that a wound which opens up, heals by itself, little by little.” “... I showed my breast [with an inverted nipple] to the neighbors and they said it’s the wind ... there is no problem ...eat fenugreek and you will get better...” Some of the participants said that because of information deficiency about its necessity they did not do breast cancer screening examinations such as breast self examination, but most of them did not do it because they did not know how to perform the examination. “We live in a village. No one had told us [that we must perform the examinations]. No one knew [that we must perform examinations]. The local health center did not tell us either.” In this study, a few participants referred to this subject that being previously familiar with breast cancer patients could have increase their knowledge and awareness, and they would become more alert, take the matter more seriously and seek treatment earlier. “I never had seen anyone with this problem...if it was so, maybe I would come sooner.” “I knew nothing [about breast cancer]... since we did not have it in our family.”

Wrong diagnosis by the doctor

Another subject which was expressed by the women who participated in this study as a cause of delay in their treatment was related to wrong diagnosis by doctors and

Table 1. Some Characteristics of the Participants.

Personal Characteristics	Number	
Marital status:	Married/cohabiting	8
	Single/separated/widowed	2
Job status:	Employed	3
	Housekeeper	6
	Retired	1
Education:	Illiterate	3
	Elementary/secondary	2
	High school	2
	Academic	3

the assurance which they received from non-oncologists that these symptoms are not serious. "I visited an internist, he touched it [the lump] and said it's nothing, it's probably a fat mass ...I was comforted by his saying..." "I visited an endocrinologist in ... [a city name, deleted]. He gave me antibiotics for a few months but it didn't get better."

Fear of cancer

Some of the participants confessed that because of their fear about being diagnosed with cancer they postponed their medical consultation. Seems like, they felt safer not to know they have cancer, even if they suspected it.

"I was very scared. The neighbor's wife died of breast cancer in two months." "I didn't tell anyone. I didn't want to think about it. I was scared. Since, my sister died due to breast cancer two years ago, my sister's death scared me." Some participants said that they were scared because they thought cancer did not have any cure and they had received wrong information about cancer. "A midwife scared me; she said that cancer does not have a cure ... give hope to women... even if it is malignant don't scare them, tell them there is a cure."

Not seeing oneself at risk

Some patients referred to this issue that despite of knowing about the importance of breast cancer screening examination for detecting early signs of breast cancer and even having sufficient information about how to do it, still they did not perform it and they mentioned that not thinking that this disease may happen to them, was the cause. "I knew ... , but I did not examine myself .This time, because I had sharp, sudden pain, I paid attention to it. I thought that it [cancer] could occur to others but I didn't think it would occur to me".

Family and career commitments

Among the common subjects mentioned by the women, which they felt was responsible for their delay was family engagement and career commitments, which were classified as a higher priority by them. These dilemmas included the problems of other family members and also problems with their own career. Some women said they knew that the present signs could be serious; however they thought that visiting a doctor and the subsequent workup will take too much time, and they'll have to sacrifice their family responsibilities and job commitments. Meanwhile as a mother, wife, sister or daughter, for some of the participants it seemed like solving other people's problems was more important than their own. "I liked to do my work. I told myself that I will retire soon, until then my children will grow up. I was scared that my therapy would take a long time and I'll face problems ..." "I was scared that if I visit a doctor, I may need an operation. My children were too young and I was working..."

Discussion

The aim of this research was to gain insight into the causes of delay in seeking treatment in patients with breast cancer in Iran. The results of our study suggest a number of factors that seem to influence the delay between

detecting possible cancer symptoms and seeking medical consultation.

Lack of knowledge was one of the relevant factors in the process of symptom detection and seeking treatment. In this study most participants did not know they need to have monthly examinations. Therefore, although they noticed some changes by the time they visited a physician, their disease had progressed to higher stages. The results of the interviews showed that nearly all of patients were unfamiliar with cancer symptoms and in most cases symptoms were interpreted incorrectly. Increasing knowledge about correct interpretation of symptoms for early detection of cancer may lead to a shorter time between symptom detection and seeking medical attention. Hence, more information should be given to women about the symptoms of breast cancer and how to react upon the detection of cancer symptoms. Education must also put emphasis on the various and neglected symptoms that may be evidence for the existence of cancer. Lack of knowledge about breast cancer symptoms has also been reported to influence women's judgment regarding whether to delay an evaluation for a self- discovered breast cancer symptom in other studies (Harirchi et al., 2005, Facione et al., 2002) .

Although increasing knowledge of symptoms is one factor in reducing delay, emotional reasons for delay, such as fear, or not knowing that anyone could be at risk should also be taken into account in educational programs. Hope giving information about treatment and survival chances and anticipating the feelings of fear might reduce fear and stimulate women to seek help sooner. In addition, stimulating people to talk about detecting symptoms and gaining courage to seek prompt medical consultation may also lead to less delay. Other research has also mentioned fear as a factor which makes patients become reluctance to seek help, however in a different cultural context and due to different reasons. For example, African and Afro-Caribbean patients with breast cancer feared they might end up having a mastectomy and were concerned about their fertility and ability to keep their sexual partners (Littlewood and Elias, 2000). In other studies other patients with breast cancer talked about their fears of treatment and they did not mention the effect it might have on their sexuality (Burgess et al., 2001). In this study among women who recognize the symptoms, in spite of believing the symptom could be cancer, some women delayed seeing a doctor because they feared the consequences of therapeutic intervention. It seems like the patient was convinced that cancer cannot be cured or necessitates invasive treatments. This sort of coping with fear can be explained by Leventhal's danger control theory (Leventhal and Cameron, 1987), which states that being aware of a danger (a cancer symptom) and the existence of an effective remedy (consulting a GP) will lead to acceptance of the remedy. These fears had often been influenced by horrific past experiences of cancer in family or friends. Recent health education in relation to cancer tells us how to identify cancer symptoms but provides little information about the consequences of a cancer diagnosis. There may be some profit in reassuring women of the positive effects of early treatment on prognosis, and that total breast surgery is not always necessary, if breast

cancer is diagnosed early enough, and that there have been advances in the management of the side-effects of chemotherapy.

Therefore, education should be more focused to promote true beliefs and attitudes in relation to breast cancer and its treatments in the general population. Similar findings appear in the breast cancer screening literature which suggests that attenders for screening have more faith in the health care system than non-attenders, perceiving positive, rather than negative, consequences as the possible outcome of screening (Sutton et al., 1994). Fear of hospitals, operations, and medical tests has also been recognized as a main barrier to help seeking in non cancer patients (Gardner et al., 1999).

Our findings showed that patients delay was due to fear, for instance fear of being told that the diagnosis is cancer. Therefore one reaction could be that discovered symptoms are ignored or overlooked. This mechanism used for coping with fear, or avoidance, is the result of a patient's focus on controlling and alleviating her feelings instead of considering the danger. This process has been explained by Leventhal as fear control (Harirchi et al., 2005) which is a short term effort to reduce unpleasant affects. It should be noted that there is huge variety in the nature of fear and that its effect on delay also varies. Noticeably, the influence of fear on help-seeking behavior is still ambiguous and requires further research (Facione, 1993).

In our study a number of women who delayed did not prioritize their health over competing demands. There is evidence that those who seek consultation quickly have lives that are less busy and stress-filled (Burgess et al., 2000). The breast cancer screening literature also finds that difficulties related to family or work are a common reason that women give for not attending breast screening (French et al., 1982).

The results of this qualitative study offer a number of clear hypotheses to be tested in large scale quantitative studies, such as the hypotheses that help seeking is influenced by symptom interpretation and beliefs about the consequences of cancer treatments and people not seeing themselves at risk. If confirmed, these findings recommend implications for the education of the general population and perhaps as well for the primary health care teams.

Although some symptoms are supposed to be detected by conscious actions, for example a lump or swelling by breast self examination (BSE), our results show that these symptoms were in fact frequently detected by chance and for instance, none of the participants with breast cancer knew they were supposed to do monthly breast self examination and their lump or other symptom was detected by chance in most cases. The majority of the interviewed breast cancer patients said they didn't practice BSE, the rest of them pointed out that they did not always follow the instructions consistently. A study from Kerman, Iran, also showed that the knowledge and attitude of Iranian women about breast cancer screening and the signs of breast cancer is not enough (Khanjani et al., 2012).

An assurance from naïve doctors that these symptoms are not serious caused delays in follow-up in some of

our patients. Perhaps it can be said that this subject on one hand is an indicator of medical negligence, which may be due to negligence about a doctor's ethical and professional responsibilities or because of insufficient medical education in our medical schools. But on the other hand, it indicates this false belief among patients that doctors do not make mistakes in their practice and even after their signs deteriorated they did not visit their doctors again. Pack and Gallo (Pack and Gallo, 1938) reported that approximately 15%, of their cancer patients had received "poor advice" from their physicians. The "poor advice" took the shape of misdiagnosis or false reassurance that the lesion was benign, and resulted in treatment delays, often to the point where the cancers were termed "not survivable." However we did not find a similar study done in Iran to confirm this finding.

Eventually, this study suggests that not only women but also doctors need further information about the different types of breast cancer and their symptoms to assist early diagnosis, along with encouraging women to seek medical advice if a symptom is ambiguous. In addition, women may profit from greater awareness of the benefits of early detection and reassurance about the recent medical improvements in the quality of breast cancer care..

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