RESEARCH ARTICLE

Exploratory Study of Factors Affecting Continuity of Cancer Care: Iranian Women's Perceptions

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Abstract

> Background: Today, breast cancer is increasing in nearly all societies. Currently, cancers are the third leading cause of death in Iran after cardiovascular diseases and accidents. Of the cancers, breast cancer is spreading particularly rapidly among Iranian women. Negative effects of discontinuation of care on patient survival have been well documented. Inhibiting or facilitating factors affecting continuity of care at different stages of the patient care continuum should be identified. Materials and Methods: The current study implemented a qualitative method that provided tools to examine factors in detail. This study was conducted on 22 women, undergoing surgery and chemotherapy after being diagnosed with breast cancer. Content analysis was the technique adopted. Results: The effective factors in continuity of care from the patients' perception, based on the participant statements, were classified into three categories of evaluation of symptoms, psychological reactions, and care triggers with several subcategories. Conclusions: According to the outcomes of the current study, it can be noted that, the patient experiences can be brought into use by health-care professionals and assist them in providing patient sand their families with adequate consulting services. It can also provide an opportunity for making interventions tailored to the community culture, and closer adherence of patients to the prescribed treatments.

Keywords: Breast cancer - patient care - continuity - factors - Iranian females

Introduction

Today, breast cancer, as a social problem, is growing in all societies (Klaeson et al., 2011). The reported incidence rate for breast cancer by the studies undertaken all over the world has been approximately% 12.5; put another way, almost one out of every 8 women is at the risk of developing cancer in her lifetime (Brunicardi et al., 2010). A young age group and late stage at presentation was similarly reported in developing countries such as Pakistan, Iran, Nigeria and Mexico(Abdullah 2004). Currently, cancers after cardiovascular diseases and accidents are the third leading cause of death in Iran (Naghavi et al., 2007). Of the cancers, the breast cancer is spreading rapidly among Iranian women (Mousavi et al., 2007). Breast Cancer with the incidence rate of 22.6 per cent is the most common cancer in Iranian women, and 81% of its surgical treatments are in the form of mastectomy (Fazel et al., 2008). Breast cancer is the most common cancer occurring among women and the leading cause of site-specific cancer death in women aged between 20 and 59 (Harirchi et al., 2011).

There is no nationwide, population-based, breast screening mammography program in Iran. Due to lack of screening tests, most of patients seek for treatment in more advanced stages of the disease (Brunicardi et al., 2010). Annually, over 1,100 new cases of cancer in Ardabil province is recorded (Mousavi et al., 2007).

In case of delayed treatment, a malignant breast tumor advances in stage, diminishing a woman's chances of survival (Facione., 1993; Bish et al., 2005; Azaiza F, Cohen M, 2008). The five-year survival rate for breast cancer in this province is 51 % (Fouladi et al., 2011).

Patients with breast cancer based on the severity of the disease, receive various treatments including surgery, radiation therapy and chemotherapy (Lynn et al.,2006). The negative effect of discontinuation of care on patients' survival has been well detected (Bairati et al.,2006, Facione et al 2002). The ultimate goal of health care is the improvement of the consequences of the disease, therefore in order to develop effective new strategies to shorten delays we require an understanding of the factors that influence these delays, and affect on continuity of care at different stages of patient care. An understanding of the factors influencing delay is important for policymakers to develop strategies to shorten delays (Yau et al., 2010). Therefore, in the present study, effort was made to investigate and recognize these factors according to patients' perception and to employ them in designing interventions in the health-care services' center.

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Materials and Methods

The purpose of this study was to understand the factors affecting continuity of care from diagnosis to treatment in patients with breast cancer. Regarding the fact that the quantitative research methods fail to respond to questions concerning the background and motivation, howness and whyness of individuals' behavior, the current study implemented a qualitative method that provides tools to examine these factors and yields deep information on them. Content analysis was the technique adopted in this study.

According to documents filed in the province's cancer record center, the women with definite diagnosis of breast cancer were chosen. Then, to arrange interviews with them, they were contacted. Consent was obtained from those who participated in the study.

This study was conducted on 22 women, undergone surgery and chemotherapy after being diagnosed with breast cancer. The duration of each interview was 2 hours. To facilitate the process of data collection, interviews were conducted at a time and place that was convenient for the participants. The data collection instruments included a questionnaire related to demographic data and a semi-structured questionnaire.

In as much as interviews are the most common technique for collecting data in qualitative studies, and using open-ended questions in interviews provides the participants with opportunity for detailed description of their feelings about the intended phenomenon, semi-structured interviews were used for collecting data. Hence, a number of general and open-ended questions was phrased that could assist the researcher in maintaining the flow of the interview. To respect the rights of the participants, before interview, the research methodology was explained to them, and to build trust, effort was made to establish good rapport with them. Information about how the disease was detected in patients, what type of treatments they had received, and the factors that affected facilitating or constraining these treatments was gathered. Taking the participants' responses into consideration, when necessary, the form of questions was modified and follow-up questions were asked, the interview proceeded in a way that in-depth information was obtained. Interviews were recorded by an audio recorder, and immediately after the interviews the participants responses were transcribed word by word.

Analysis and coding of each interview took place prior to the next one, and the flow of next interview was determined by the data obtained during the previous interview. Coding process included identifying 1- the existence of an event or something that affected the movement of patients for receiving care, 2- the type of the event affecting the care continuum (either accelerating or constraining) 3- the point of care continuum where the intended event's effect stands.

Research ethics

By keeping the participants' information confidential and acknowledging their right to withdraw from the study at any time they wish, the ethics of research was tried to be observed. Also, all the interviewees were assured that the interviews were transcribed only by the researcher and no information about their identity would be disclosed. Hereupon, a code was assigned for each participant.

Results

The average age of women under study was 55.5, ranging from 33 to 71. The mean duration that the participants suffered from the disease was 2.5 years. Of the participants, 8 patients were illiterate, 7 women had only received elementary education, 4 women had got secondary or high school education, and 3 patients had academic education. In terms of marital status, 17 of them were married, 4 were singles and one was widowed.

Regarding the number of children, 5 patients had 0- 2 children, 5 women had 3-4 children, and 2 patients had 5 or more children, and one person was infertile.

The effective factors in continuity of care from the patients' perception, based on the participants' statements, were classified into three categories of evaluation of symptoms, psychological reactions, and care continuum catalysts with several subcategories.

Evaluation of symptoms

The patients' evaluation of disease symptoms was one of the key themes affecting the care continuum before diagnosis. Lack of pain, ignoring the existence of masses, specific cultural or traditional beliefs about the causes of breast lumps and enlargement of one of the breasts were factors that played role in making the patient not to visit a doctor timely.

Psychological reactions

This theme, comprising two sub-categories of denial and fear and concerns over care from diagnosis to treatment of the disease, can affect the patients.

Denial

The participants' statements indicated that denial and refusal, feeling guilty, and soul-searching had effect upon the patient's decision making for diagnosis and treatment of the disease. These psychological reactions in the individuals manifest themselves in the behavioral form such as consulting with numerous doctors, non-acceptance of biopsy results, spending a lot of time and money to remove their doubt about disease and reject the probability of medical laboratory or doctor's error in diagnosing the disease.

Fears and concerns

In this subcategory, there are several factors that cause fear among patients and result in lack of continuity in patient care including.

Concern over decreasing marriage chance after surgery: the most frequent point made by single patients that indicated their serious concern, was their feeling anxious about impossibility/low chance of getting married after undergoing mastectomy and losing their breast.

The patient's solicitude for her family members in the case of her death during surgery: another factor

pointed out by the patients was their concern over the effect of disease, the type of surgery and the death risk while undergoing surgery or chemotherapy on the family members.

Concern over the impact of illness or side effects of treatment on marital relationships: the vexing problem for the patients was their fear of their husband's probable petulance and behavior's change after the surgery, mainly mastectomy. *"One of our neighbors did surgery. Her breast was removed. And her husband's behavior changed. He kind of became bad-tempered and impatient with her. Seeing that, I was afraid of being misbehaved by my husband".*

Fear of others becoming informed: the change of people's attitude to the patient, due to the disease and the changes resulting from treatments, was another factor affecting the continuity of care, which was mentioned by the patients. *"I did not want anyone, because of the cancer and not having breast, to see me as an object of pity. This issue had made me preoccupied and didn't let me decide wisely."*

Fear of appearance change: another reason behind non-acceptance of treatment in patients was related to the fear from change in their appearance. As a piece of evidence, when the case was lobectomy, it took shorter while the patients acceded to undergo surgery and continue care, compared with the total mastectomy cases. As well, when the patients were informed about the possibility of restoring their first physical appearance, by undergoing aesthetic surgery; they admitted to receive treatments readily. Besides the feasibility of performing surgery with minimal complications and change in the physical appearance was a contributing factor for the continuation of treatment in most patients.

Metastasis and concerns about side effects of treatment: the patients' negative attitude toward usefulness of chemotherapy, metastasis following therapy, non-recovery of patients after getting various treatments were also factors for unwillingness of patients to continue receiving care.

Care triggers

This theme with subcategories of family support, spiritual beliefs, observing the disease in close persons, and motivation for restoring health affected care continuum.

Family support: fear, as the main intervening factor in patients taking medical cares, can be controlled by supportive family network, particularly husband, children, friends and medical staff. Consequently, accelerate the care in the patients. Supportive actions basically involve emotional support and, in the later stages, financial and informational supports from family. *"To tell the truth, when learned about my cancer, I tried to control myself, because I have three sons that are fond of me. They boosted my morale. My sons and my husband didn't let me, even for a moment, feel sadness for having to do surgery. I was going to have surgery by the next week, during that week I had my husband continuous support, he convinced me to do the surgery. He told: if you get surgery, you can regain your health. I don't want you die, just for having a breast. I want you to stay alive".*

Spiritual beliefs: another effective factor inferred from the statements of a number of patients was related to having strong religious beliefs. The statements indicated the positive effect of such beliefs on patient's admitting the disease in the diagnosis stage and continuing care. To believe that each man coming to this world will pass away someday, and to attribute the incidence of the disease to the divine fate were examples of these beliefs. *"I said to myself, it is a fate that God has determined for me and the cure is surgery, so I have to face it. This is my fate"* (P18).

To believe in the fundamental principle that incidence of the disease is upon God's will and is part of the destiny determined by God for them: *"I tried not to get too upset, and said to myself: it is the divine fate. Because frankly I'm a religious person myself, and think it is a sin to get grief-stricken."*

Observing the disease in the close relatives: disease in close relatives, friends or neighbors and observing illness and death in the family can serve an important and effective role in diagnosis and treatment. To observe directly the side effects of breast cancer and the late surgical treatment in close persons can develop sensitivity of the patients and their families, and make them take immediate action for diagnosis and treatment. *"It was not more than 5 days after my sister did surgery for her breast cancer that I found the lump in my breast. I and my father went to a doctor immediately. She suggested me getting surgery. I felt sad but I didn't want, like my sister, to let my disease progress"* (P8).

"I was upset that I had to get surgery, but I didn't want, like our neighbor, to die of breast cancer."

Motivation for restoring health: desire to regain health in a number of patients was another factor in the continuity of care. *"As the doctor said to me that I had cancer, and my breast must be removed, I was only thinking about doing surgery. And since I'm very obsessive about my health, I even begged the doctor to perform surgery and remove my breast as soon as possible. because I was very concerned".*

Discussion

To postpone receiving care in breast cancer cases is one of the common problems. The obtained results from the present study revealed that the erroneous interpretations of the early symptoms and not placing importance on symptoms of the disease are major factors leading to primary delay in receiving care. The deferral in this stage is due to wrong decision making and evaluative processes on the disease by the patient herself and her family. This finding complies with the Anderson's model (1995).

The study has shown that delay in diagnose and treatment of breast cancer can be attributed to the social and cultural perception of disease .The negative socio cultural perception of breast cancer is the reason for the delay in this study. The results of this study in this area are consistent with the findings of Abdullah study (2004).

The results showed that most of the participants did not properly evaluate early symptoms and this makes the patients not consult with a doctor in time. The results of this study are consistent with the findings of Burgess's study (2011) and Harirchi (2005) in this area. Considering symptoms to be harmless was the most important reason for delaying consultation for more than half of the patients (Harirchi 2005).

Proper evaluation of the symptoms can contribute to the initial diagnosis of the disease and prevent patients

from being diagnosed with the disease in its advanced stages. This study presents a finding which is in line with that in the Ashing et al study (2004), indicating that late referral of patients to use care services is one of the major causes of concern. Due to the diagnosis of the disease in the early stages, the possibility of undergoing invasive surgery for the patients, as well as metastasis reduces; thereby increasing the survival rate in patients. It has been shown that the early diagnosis of the disease and recognizing the most appropriate treatment for the disease can lower the mortality rate in high-income countries (Stanley et al., 2011).

Designing and implementation of training, counseling and supportive programs can be helpful in this regard. The broad educational programs at the community level and the change of public perceptions of symptoms can bring about acceleration of care and prevention of delay. It is important to develop culturally sensitive health communication programs and policies, especially in limited-resource countries.

Taking into account that the mean age of cancer incidence in Ardabil province is a decade lower than that in developed countries (Fouladi et al., 2012), concern over the impact of mastectomy on married women's sexual relationships and reduction of marriage chance in single women was found as other effective factors in the postponement of receiving care. The outcomes of the present study on this issue is compatible to the results of the Kklaeson's study in which younger women diagnosed with breast cancer had more sexual problems than patients with a higher mean of age (2011).

The early diagnosis of the disease can decrease the risk of undergoing invasive surgery such as total mastectomy, and consequently it can reduce the patients concern over physical change in their appearance, metastasis, others' becoming informed about their illnesses, and being misbehaved with their spouse due to lack of breast.

Another source of patients' concern found in in this study was related to the disease relapse which was in agreement with the findings of Ashing (2003).

Similar to the findings of a study conducted by Stanley et al (2011), fear of others' becoming informed, was identified as another factor in discontinuity of care.

The patient's solicitude for her family members' loneliness in the case of her death during surgery or due to the disease relapse was another identified factor which corresponded to the Connell (2006) and Ashing's (2004) findings.

Fears and concerns affect the willingness of patients to make use of diagnostic and medical services, and influence the patients' survival rate in turn. The five -year survival rate is 51% in Ardabil (Fouladi et al., 2011).

Since the incidence age of breast cancer for the Iranian women is a decade lower than those in developed countries, and the diagnosis of disease mostly takes place in the advanced stages of the disease in the studied population, the risk of requiring invasive surgery increases, as a result (Fouladi et al, 2011). This factor itself arouses higher degree of concern in the community under study and affects the continuity of care in turn. The results of the previous studies have also shown a greater degree

of concern over marital/sexual relationship change in the patients who had undergone mastectomy, which affects the process of consenting for mastectomy in the patients (Fouladi et al., 2013).

All of the above mentioned factors cause the postponement of care and reduce the 5-year survival rate to 51% in these patients (Fouladi et al., 2011).

Another source of concern for women was pertinent to changes in their physical appearance due to surgery, specifically total mastectomy. Changing women's identity as a consequence of this type of treatment causes fear in the patients, since having breast for women is synonymous with their gender and sexual identity. Therefore, lack of it can lead to disorder in women's gender identity and entail problems in their sexual relationship with the opposite gender.

As other communities, existence of breast performs an influential role in giving Iranian women the female identity. Thus, being diagnosed with breast cancer threatens both the patients' life and her female identity. And this can be considered as a barrier to continuity of care in women (Fouladi et al., 2013).

As the results indicated the existence of social support to overcome these fears, especially from husband, children and relatives is extremely valuable and increases patients' motivation for fighting the disease. The obtained results in this regard are concordant with the prior studies' findings (Landmark et al., 2002; Arman et al., 2003; Ashing et al., 2004; Nausheen and Kamal., 2007).

In as much as the concerns over and fears of effective factors in care continuum entail survival rate decrease and death rate increase in patients; their social effects also can promote the idea that breast cancer is synonymous with death and lower the public willingness to participate in screening programs in the society. Furthermore, it can create a vicious cycle in the society, where the mortality rate of patients is high and their survival rate is low. Therefore, it seems necessary to reduce these fears, as much as possible, by taking training, counseling and supportive actions to accelerate the care in the society.

The results highlighted that contrary to fears, concerns, beliefs, and unawareness which prohibit the early diagnosis and treatment of the disease, there are factors that can speed up the care and maintain the continuity of it. Identifying and emphasizing these variables and awakening patients to them can accelerate the care continuum, and improve the quality of care in patients.

In our study, women with a family history of breast cancer were less likely to delay in seeking medical care. This sounds reasonable as the perceived risk might have led to more immediate actions upon discovery of a mass. The obtained results in this regard are concordant with the prior study' findings (Harrirchi et al., 2005).

The study undertaken by Avci et al (2009) has shown that the patients' religious background, and support from family and medical team, as well as doctors' advice are effective factors in making the patients enter the treatment and tackle the crisis (Harun et al, 2013; Avci et al., 2009; Kreps, 2008).

Encouraging women to seek help early for a breast cancer symptom by focusing on risk factors for delay

(such as knowledge of symptoms, appropriate attribution of symptoms, disclosure to another and attitudes to help seeking) has the potential to significantly improve survival from breast cancer.

According to the outcomes of the current study, it can be noted that, the patients' experiences can be brought into use by health-care professionals and assist them in providing patient and their families with adequate consulting service. It can also provide an opportunity for making interventions tailored to the community's culture, and the closer adherence of patients to the prescribed treatments.

It should be mentioned that considering the patients' preferences and values in care programs and designing interventions suited to these preferences can result in achieving high quality care of patients.

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