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Ali A. Moqaddas Shiraz University, moqadas.ali@gmail.com

Fatemeh Adjdari Shiraz University

Akbar Aghajanian Fayetteville State University, aaghajanian@uncfsu.edu

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A Preliminary Study of Perception and Coping Mechanism of Breast Cancer Patients in an

Iranian City Ali A. Moqaddas Shiraz University Shiraz Iran moqadas.ali@gmail.com Fatemeh Adjdari Shiraz University Shiraz, Iran Akbar Aghajanian Department of Sociology Fayetteville State University

Fayetteville, NC 28301 aaghajanian@uncfsu.edu

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Abstract

The life expectancy of women in Iran has increased in the last quarter of the 20th century. On the other hand obesity has increased during the first decade of the 21th century for both adult males and females but particularly for females. These trends are contemporary with a growing incidence of breast cancer among women in urban areas. Casual observation has shown that organized and systematic coping support and mechanism for women with breast cancer disease has expanded much less than the treatment technology, leaving surviving women in ambiguity and fear of unknown. The analysis of qualitative data from a preliminary study of women in one city confirms the limited support for coping with the disease and the aftermath of the technology based treatments. Except for a few educated women, the majority of the subject studied in this research saw their situation as catastrophic and ambiguous. They relied on their religious belief and family support to cope with their situation, but had limited success due to their lack of knowledge about the natural order of the disease and consequences of treatment. While there is need for more comprehensive studies of coping strategies using representative sample of breast cancer patients across rural and urban areas of Iran, the findings from the present study calls for organized and systematic community based support system to help women faced with this disease, to cope.

Background

Breast cancer is the most frequently occurring form of cancer worldwide among women, and the second highest cause of cancer deaths (Parkin, et al., 2005). In Iran, the crude annual incidence rate of breast cancer is estimated at 120 per 100,000 women (Hashemzadeh, et al, 2012; Mousavi et al., 2012). However, the incidence of cancer is increasing 4 per 1000 population (Marjani & Kabir, 2009; Mokarian, 2011). It is estimated that under conservative assumptions, the number of new case of breast cancer in Iran will be more than 15,000 in 2030 (Fatemeh, et al, 2012a; Harirchi, et al, 2004). There increasing obesity among middle class urban women is likely to contribute to the increased incidence of breast cancer. But there is no systematic data about this and other risk factors. Like in many other countries socioeconomic disparities in cancer are observed in Iran and breast cancer has had the highest level of socioeconomic disparities (Rasaf, et al, 2012a; 2012b). A number of studies based on regional registry have shown that the average age of breast cancer in Iran is about 10 years younger than the average age of breast cancer in Western countries (Harirchi , et al, 2011Nafisi, et al, 2012; Sadjadi, et al, 2009).

Research on biomedical and social behavioral aspect of breast cancer among Iranian women accelerated in Iran during the 1990s. The support of government for establishment of regional and provincial registries helped with improvement of the availability of data for measuring the trends and variation in the incidence rate and mortality rate of breast cancer. These epidemiological studies have shown that breast cancer hits at younger ages than conventionally seen in other countries; the incidence rates is increasing; and in most cases when diagnosed, the cancer is in stages two and higher (Eivazi-Ziaei, et la, 2011; Ghiasvand, et al, 2011). In addition, knowledge about cancer and cancer prevention among the population at risk is very low (Fatemeh, et al, 2012; Khanjani, Noori, & Rostami, 2012; Khalili & Shahnazi, 2010;).

While there has been some research published on biomedical risk factors of breast cancer in Iran, social and behavioral aspect of breast cancer and its consequences has been less studied (Ahmadian, et al 2012; Ahmadian, 2010; Lotfi & Shobairi, 2008). Such studies have been emerging in the first decade of 21th century with the existence of a more visible population of female breast cancer patients and the attention of medical establishments to the social and psychological need of the patients going under a variety of treatment and the side effects of these treatments. As a result study of the quality of life of the breast cancer patients has been focused more recently (Bastani, et al, 2012). Furthermore, a limited literature on coping and lifeadjustment of the breast cancer patients has emerged (Hadi, Asadollahi & Talei, 2009; Sharif, 2010) which needs to be expanded based on the Iranian cultural-social environment.

A major factor in the coping strategy and success in coping is the perception of the patients in relation to the situation that has emerged for her as a breast cancer patient. This issue is very important in the context of the situation of the Iranian women who not only are the victim of breast cancer at young ages, but have limited knowledge of the risk of breast cancer and the prevention strategies. Research on understanding the perception of breast cancer and how this perception is related to the copying strategies of the Iranian patients is very limited. The present preliminary study focuses on filling the gap in this literature.

Methodology

Drawing on ground theory, this study utilized qualitative data collected from 23 female breast cancer patients. The target population for the study was breast cancer patients at different stage of treatment visiting oncology specialists in private or public outpatient clinics or outpatient clinic in hospitals in the city of Shiraz in southern Iran. The city of Shiraz has a population of more than a million and since 1960s has grown to become a major center for health and medical education services in the southern region. Patients from rural and urban areas in the region come to Shiraz to access high level treatment for cancer and other degenerative diseases in several large medical centers and many outpatient specialists' offices.

The study protocol was approved by the Research Committee of College of Social Sciences at Shiraz University. For the purpose of recruitment, trained university senior students visited the collaborative oncology establishments and introduced themselves to the breast cancer patients. The students explained the purpose of the study to the patients and the persons who accompanied them and invited the patient to join the study. The interviewers made sure to clarify that the study does not have anything to do with the treatment they are receiving at the establishment. If the patients agreed to join the study, an appointment was setup for the in-depth interview. The volunteering patients were given the choice of interview at their home or in a private corner in the oncology establishment. At the time of interview they were reminded again that their participation is voluntary and will help the improvement of the knowledge about cancer treatment. They may strop at any time during the interview and do not continue. The interviews took on the average about one and half hours. In a few cases a second visit was needed to continue the interview. During the interviews some patients were very nervous. Some expressed themselves with cry. Some were happy. Among those visited at homes, some were very neat and some had very sloppy home environment.

Findings

Characteristics of the Sample

Out of the 26 recruited patients, 23 completed the interviews and provided data for the study. Three of the original participants did not continue due to personal reasons. The average age of the participating patients was 48.6 and out of the 23 patients, six were 40 years and younger. Almost half of the subjects were diagnosed within the last two years. The majority of them were married. The average number of education for the subjects was nine year and only three were illiterate. Ten out of 23 had some paid employment status. They were either retired or they were currently not working due to their treatment. Both education and work status data suggest that our sample shows a higher level of education and work participation as compared to the general population of middle age and older women in Shiraz. Five of the subjects were from out of Shiraz and the came to Shiraz to access care that did not exist in their home town.

Perception of the Event

Out of the 23 patients 15 had total mastectomy, five had Lumpectomy, and the rest were under chemotherapy. Hence all subject had some pain, deformation, inflammation or itching and other physical impact of the breast cancer and hence they were faced with some painful event that they perceived differently. The event seemed to have higher density for subjects who were exasperated by other circumstances such as economic issues particularly related to the cost of treatment. Another exasperating factor was marginality due to being in a different and a large town for those patients who came from rural and small towns to Shiraz. Similarly the situation was aggravating for those who had other cancer symptoms in addition to the breast cancer.

For those subjects that mentioned they have had relatives with breast cancer, the situation was more aggravating if their relatives had low survival and harsh experience. On the other hand, they saw their situation more hopeful, if their relatives had survived long after diagnosis. The subjects who were divorced, separated or single had a more aggravating perception as compared

to those with nuclear and extended family network and support. The cancer event was less aggravating for those subjects with more knowledge of cancer development as compared to those with less solid knowledge about cancer.

Three situational perspectives emerged from the axial coding of the interviews. These were: catastrophe, uncertainty, and natural. The catastrophic perspective viewed cancer and its related pains as a "difficult situation or revenge" in response to bad behavior. Cancer is also seen a catastrophe due to God will for testing the followers. For example, Giti, a 62 year old subject with total mastectomy says, "we have engaged in bad ills..it is important to die when all the sins are forgiven by God". Parvin, a 56 years old subject perceives her situation like this, "I think perhaps God wanted me to slow down in work …… God gave me this paint to understand myself better".

The subjects with uncertain perspective expressed wonder as why they got into this situation; they do not see any explanation. Sara a 59 year old subject has a retard child who is institutionalized and has modest economic circumstances. She expresses her uncertainty of the cancer event like this, "I had enough difficulties, so I did not think I will be also struck by cancer". Fati, a 45 year old patient who was divorced at a very early age, expressed her uncertainty of her situation by focusing on fate. "When I learned that I had cancer, I got stressed and cried... I thought I am faced with a bad fate". Shamsi, 65 year old widow, says, "Nobody in my family had cancer and I did not think that this disease catch me". Leylla, 54 years old and divorced showed her uncertainty by evil eyes. "I have had some continuous bad events. I believe I have been affected by evil eyes".

The natural perspective is linked to knowledge of cancer and cancer development with regard to life-style issues and heredity and other scientific explanation. Sanaz, a 48 years old

subject expressed this perspective by saying, "Cancer is like other diseases that demand treatment; the treatment has improved; facilities are more available now; the probability of cure and survival has improved". Nikoo, a 39 years old subject expresses her natural explanation by saying, "I realize that in every second many of the cells change". Nikoo has college education and has been working as a teacher. Educational level and professional working status are associated with perception of breast cancer as something that can happen to all women *Coping Mechanisms*

The coding revealed three coping approaches. These were religious and faith, nepotism, and medical instrumentation. The religious coping was based on strong faith in God and what God wishes was. Miracles and serendipity were considered very important. One's death was considered as another life and the expectation of better things after the life in this world. The nepotism coping focused on how family members particularly husbands and sons can be helpful and supportive in these situations. The medical instrumentation coping centered in the support from experts and specialists in the field and finding more experienced well-known physicians for more advanced technology for treatment.

Classification of Perspectives and Coping Approaches

The intersection of perspectives and copying approaches found from the 23 patients expressions are presented in Table 1. The subjects who felt their condition was catastrophic relayed on religion and rituals for coping. These subjects showed very high level of coping. The women who perceived their situation as insecure focused on family relationship to cope with their problems. The subjects who considered disease a natural part of life and events that can happen to anyone, utilized instrumentation, technology and scientific progress in their coping mechanism and expressions. The lowest coping level was observed among women with catastrophic perspective who appealed to their familial relationships. The second most adjusted group of the subjects included those who had insecure perception and depended on religion for coping. For these women religion and religious practices were frequently reported as a relief from the anxiety of the consequences of the disease. The highest copying level belonged to the subjects who were familiar with breast cancer as a disease among women all around the world and knew technology and pharmaceutical solutions are available to help. These women supplemented their instrumental coping with support from family and relaying on faith. They showed a high level of confidence in treatment and technology that can lead to their improvement. On the other hand, the patients with insecure perception saw themselves in a structured situation that cannot and will not change.

(Table 1 about here)

Summary and Conclusion

The life expectancy of women in Iran has increased in the last quarter of the 20th century (Abbasi-Shavazi, et al, 2005). On the other hand obesity has increased during the first decade of the 21th century for both adult males and females but particularly for females (Baygi, et al, 2012; Hosseini-Esfahani, 2012; Maddah, 2012; Veghari, 2012). These trends are contemporary with a growing incidence of breast cancer among women in urban areas. Hence, a growing section of tertiary medicine has emerged for treatment through surgery, chemotherapy and radiation therapy. Both the disease and the treatment technology are new to Iranian women particularly those coming from rural villages and small towns to get treatment in large cities. Many of them are unaware of the trajectory of the disease and the side effects of the treatment. Yet, despite the growth in technology, very limited support exist for culturally relevant information

dissemination and coping support for women getting various treatments. The results from our preliminary research, affirms the situation described by casual observers. The majority of our subjects reported catastrophic and insecure situation about their disease and perceived it as penalty for what they have done wrong and they kept asking what they have done wrong to deserve this. Given the role of religious and family institutions in Iran, it is not surprising that the great majority of the women depended on religion and family in their coping effort. However, their lack of knowledge about the natural origin of the disease, the treatment technology, and its side effects, disturbed their coping process.

The data we presented here is limited in representation of the breast cancer population and the variables measuring a variety of socio-demographic, disease history, treatment side effects, and coping mechanisms. However, it is obvious that there is need to for developing community based support system which utilizes the religious beliefs and practices and family resources to strengthen the coping effort of the growing number of women who are faced with this disease.

Table1. The cross section of perspectives and mode of coping			
Coping	Perception of the Situation		
Mechanism	Catastrophe	insecurity	Normalized
Religiosity	High	Low	Middle
Instrumental	Middle	Middle	High
Familial	Low	High	Middle

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