

## RESEARCH ARTICLE

# Un-met Supportive Care Needs of Iranian Breast Cancer Patients

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### Abstract

**Background:** Assessment of supportive needs is the requirement to plan any supportive care program for cancer patients. There is no evidence about supportive care needs of Iranian breast cancer patients. So, the aims of present study were to investigate this question and its predictive factors. **Materials and Methods:** A descriptive-correlational study was conducted, followed by logistic regression analyses. The Supportive Care Needs Survey was completed by 136 breast cancer patients residing in Iran following their initial treatment. This assessed needs in five domains: psychological, health system and information, physical and daily living, patient care and support, and sexuality. **Results:** Patient perceived needs were highest in the health systems and information (71%), and physical and daily living (68%) domains. Logistic regression modeling revealed that younger participants have more un-met needs in all domains and those with more children reported fewer un-met needs in patient care and support domains. In addition, married women had more un-met supportive care needs related to sexuality. **Conclusions:** The high rate of un-met supportive care needs in all domains suggests that supportive care services are desperately required for breast cancer patients in Iran. Moreover, services that address informational needs and physical and daily living needs ought to be the priority, with particular attention paid to younger women. Further research is clearly needed to fully understand supportive care needs in this cultural context.

**Keywords:** Breast cancer - supportive care - supportive care needs - Iran

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### Introduction

Breast cancer is the most common cancer among women worldwide with an estimated 1.38 million women diagnosed each year; making up 23% of all new cancer cases (Jemal et al., 2011). Following treatment, many of these women struggle with significant and often chronic medical sequelae, including lymphedema, fatigue, hot flashes, and pain (Fobair et al., 2006; Brandberg et al., 2008; Schmid-Büchi et al., 2012), psychological sequelae, including anxiety, depression, uncertainty, fear of recurrence, hopelessness, and impaired body image (Northouse et al., 2002; Fobair et al., 2006; Brandberg et al., 2008; Armes et al., 2009; Schmid-Büchi et al., 2012), and social sequelae, including sexual dysfunction, marital distress and impaired daily functioning (Sammarco, 2001; Northouse et al., 2002; Avis et al., 2004; Thewes et al., 2004; Fobair et al., 2006; Armes et al., 2009; Gilbert et al., 2010). However, breast cancer patients, especially in Western Asia, frequently do not receive adequate supportive care that assists them to cope and adjust to these challenges (Ganz and Hahn, 2008; Abdullah et al.,

2013; Günüşen et al., 2013; Öztunç et al., 2013; Yusuk et al., 2013; Sait et al., 2014).

Supportive care needs can arise at any point along the breast cancer trajectory, from diagnosis, to end of treatment, and even during the palliative phase. These needs can be categorized into five main domains, including psychological, health system and information, physical and daily living, patient care and support, and sexuality (Fitch, 1994). Previous research of cancer patients in Germany and China (Lam et al., 2011), Australia (Sansón-Fisher et al., 2000; Hodgkinson et al., 2007), Europe (Armes et al., 2009; Griesser et al., 2011; Schmid-Büchi et al., 2011; Schmid-Büchi et al., 2012), North America (Whelan et al., 1997), and Japan (Okuyama et al., 2011) found the highest unmet needs to be in the psychological (Cruickshank et al., 2008; Armes et al., 2009; Crowe et al., 2009; Griesser et al., 2011; Lam et al., 2011; Okuyama et al., 2011; Schmid-Büchi et al., 2012) and information/education domains (Whelan et al., 1997; Sansón-Fisher et al., 2000; Rutten et al., 2005; Cruickshank et al., 2008; Griesser et al., 2011). Unmet supportive needs related to physical and daily living, patient care and support, and

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sexuality have also been reported, but less frequently (Akechi et al., 2011; Schmid-Büchi et al., 2011).

Differences in supportive care priorities and unmet needs between Asian and Western breast cancer patients provides evidence that culture and health system issues shape patients' desires for diverse types of support (Lam et al., 2011). Thus, investigations focusing on country specific breast cancer patients are necessary for relevant and effective health services. While a number of studies focusing on unmet supportive needs of breast cancer patients have been conducted, very little is known specifically about the unmet needs of breast cancer patients residing in Middle Eastern countries, including Iran. In Iran, breast cancer is the most frequent cancer among women (Haghighat et al., 2012), with an incidence rate of 22 in 100,000 (Mousavi et al., 2007), and incidence rates are expected to triple by 2030 (Asadzadeh Vostakolaei et al., 2013). Unfortunately, the results of some studies showed that breast cancer affects Iranian women at least one decade younger than their counterparts in developed countries and a considerable proportion of Iranian breast cancer patients were in stage II or III at diagnosis (Harirchi et al., 2004).

Investigations of supportive care needs among South East Asian breast cancer patients suggests that a large percentage have unmet needs (Akechi et al., 2011; Liao et al., 2012; Au et al., 2013; Li et al., 2013; Nakaguchi et al., 2013). Previous Iranian researchers have documented high rates of disrupted psychological functioning among breast cancer patients (Montazeri et al., 2002; Tavoli et al., 2008), and a lack of disease and treatment related information or education (Montazeri et al., 2002), but evidence of unmet supportive care needs is lacking.

Improving supportive care services for Iranian breast cancer patients will require knowledge of this population's met and unmet needs and factors that influence these needs. Identifying met and unmet supportive care needs provides the opportunity to address these needs, enhance the quality of care and promote comprehensive patient-centered care (Bonevski et al., 2000). The aim of the present study was to describe the prevalence and predictors of supportive care needs among breast cancer patients residing in Iran.

## Materials and Methods

This was a descriptive-correlational study with subsequent logistic regression. Potential participants were recruited from in-patients wards and an out-patient clinic at the Ghazi Tabatabay Hospital, which is affiliated with the Tabriz University of Medical Sciences (TUOMS), in Tabriz, Iran. All cancer patients in East Azerbaijan Province, the North Eastern province of Iran, are referred to this hospital for treatment. Potential participants were also recruited from the Breast Cancer Support Center in Tabriz, which is a non-governmental organization that provides educational programs for breast cancer patients in East Azerbaijan Province.

Breast cancer patients who received curative or palliative treatment in Ghazi Tabatabay Hospital or attended the Breast Cancer Support Center were invited

to participate. Participant inclusion criteria included being finished the initial phase of treatment (4 to 6 month after diagnosis), 18 years of age or older, aware of diagnosis for at least 3 months, mentally and physical willing and able to complete the questionnaire, and having no other major chronic disease that could affect their supportive care needs. Based on a pilot study, it was determined that a sample size of 130 participants would provide sufficient power. Finally, the data for 136 breast cancer patients was gathered.

The Regional Ethic Committee at TUOMS approved this study. Breast cancer patients who met the inclusion criteria and were admitted to in-patient wards or attending the out-patient clinic at Ghazi Tabatabay Hospital were approached, informed of the study, and invited to participate by one researcher (N.M.) from June in 2012 to September in 2012. During 3 month of data collection at this hospital, 79 breast cancer patients were invited to participate. A list of 180 eligible patients attending the Breast Cancer Support Center was obtained and 80 patients were randomly selected using a random number generator. These patients were informed of the study and invited to participate by one of the researchers (N.M.) by telephone. After patients consented to participate, a private in-person interview was conducted in private rooms in the Breast Cancer Support Center and in Ghazi hospital, wherein questionnaire data was collected.

The instrument used in this study consisted of two parts. The demographic and treatment-related participant information was gathered with a questionnaire consisting of seven items (age, marital status, children, household composition, level of education, time since diagnosis and treatments received). Treatment-related information was obtained through medical records when participants did not know what treatment they received. The supportive care needs of the participants were assessed using the short form of the Supportive Care Needs Survey (SCNS-SF34) (Bonevski et al., 2000). This questionnaire consists of 34

**Table 1. Participant Characteristics (n=136)**

		No. (%)
Age (years)	≤40	36 (26.5)
	>41	100 (73.5)
Mean (SD)		46.8 (10.1)
Time science diagnosis in years, Mean (range)		35.8 (11.2)
Children	Yes	125 (91.9)
	No	11 (8.1)
Marital status	Married	117 (86)
	Single	5 (3.7)
	Divorced /widow	14 (10.3)
Level of education	Illiterate	16 (11.8)
	Primary school	64 (47.0)
	High school diploma	39 (28.7)
	University degree	17 (12.5)
Employment status	Housewife	111 (81.6)
	Employed	25 (18.4)
Household composition	Alone	19 (14)
	Husband	21 (15.4)
	Husband and children	96 (70.6)
Received treatment*	Chemotherapy	129 (93.3)
	Radiotherapy	63 (46.3)
	Surgery	121 (88.9)
	Other	5 (3.7)

\*Participants could choose all responses that applied; SD: standard deviation

**Table 2. Most Frequent Unmet and Met Supportive Care Needs**

Rank	Item	Domain	n (%)
Most frequent unmet supportive care needs			
1.	Lack of energy/tiredness	Physical and daily living	119 (88.8)
2.	Feelings of sadness	Psychological	109 (82.0)
3.	Having access to needed professional counseling for you, family or friends	Health system/information	109 (82.0)
4.	Being informed about things you can do to help yourself to get well	Health system/information	110 (80.9)
5.	Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up	Health system/information	109 (80.7)
6.	Anxiety	Psychological	109 (80.1)
7.	Being informed whether the cancer was under control or diminishing	Health system/information	104 (76.5)
8.	Being given explanations of tests for which you would like explanations	Health system/information	101 (74.3)
Most frequent met supportive care needs			
1.	More choice about which hospital you attend	Patient care and support	56 (42.4)
2.	More choice about which cancer specialist you see	Patient care and support	60 (44.8)
3.	Fears of death and dying	Psychological	65 (49.2)
4.	Hospital staff attending promptly to your physical needs	Patient care and support	72 (54.5)
5.	Changes in your sexual relationship	Sexuality	74 (54.8)
6.	Keeping a positive outlook	Psychological	71 (55.0)
7.	Fears of cancer spreading	Psychological	78 (57.4)
8.	Feeling down or depressed	Psychological	80 (59.7)

items that investigate supportive care needs in 5 domains; physical and daily living-needs related to coping with physical symptoms and side effects of treatment and performing usual physical tasks and activities; (5 items); psychological-needs related to emotions and coping (10 items); health system and information-needs related to the treatment center and obtaining information about the disease, diagnosis, treatment, and follow-up (11 items); patient care and support-needs related to health care providers shoring sensitivity to physical and emotional needs, privacy, and choice (5 items); and sexuality-needs related to relationships (3 items). Each item asks the respondent to rate their level of need for help in the last month using a 5-point scale with the following response options: 1=no need, not applicable; 2=no need, satisfied; 3=low need; 4=moderate need; 5=high need.

Two independent English-Persian translators translated the English version of the SCN-SF34 into Persian for the purposes of this study. The questionnaire was reviewed by 12 academic staff at TUOMS for face and content validity and minor revisions made based on their feedback. The internal reliability coefficients (Cronbach Alpha) of the translated questionnaire was substantial, greater than 0.90, when piloted with 20 breast cancer patients.

The data analyses were performed using SPSS software (version 13, SPSS Inc., Chicago, IL, USA). Descriptive statistics were calculated for demographic and treatment-related variables and supportive care needs. The associations between quantitative demographic and treatment-related variables and each of the 5 domains of the SCNS-SF34 were assessed with Pearson's correlation coefficients. To explore whether any patient or treatment-related variables predicted supportive care needs, separate logistic regression analyses were conducted for each of the 5 domains of the SCNS-SF34. Mean scores were calculated for each domain, which were then dichotomized into met needs and unmet needs, similar to previous studies (Beesley et al., 2008; Griesser et al., 2011; Uchida et al., 2011). The stepwise form of logistic regression was used and a two-tailed p value <0.05 was considered statistically significant in this study.

## Results

A total of 159 eligible breast cancer patients, 79 from the hospital and 80 from the Breast Cancer Support Center, were approached. Of these, 136 consented to participate and completed study questionnaires, 66 from the Hospital (84% response rate) and 70 from the Breast Cancer Support Center (88% response rate). There were no statistically significant differences between participants and non-participants in sex, age, marital status, educational level and time since diagnosis.

Table 1 shows the demographic and treatment-related participant characteristics. The majority were older than 40 years of age, married, have at least one child, have a primary school education, live with their husband and children, and received chemotherapy.

The study participants reported unmet needs in all domains; 70.7% in health systems and information, 67.8% in physical and daily living, 62.7% in psychological, 60.5% in patient care and support and 59.1% in sexuality. The eight most frequent unmet and met supportive care needs are reported in Table 2. Five of eight of the most frequent unmet needs were in the health system and information domain. Of the 8 most frequent met needs, 3 were in the patient care and support domain and 4 were in the psychological domain.

The predictors of unmet supportive care needs are presented in Table 3. Younger participants had higher unmet needs across all domains. No other variables predicted unmet needs in the health system and information domain, the physical and daily living domain, or the psychological domain.

In the patient care and support domain, having children, along with younger age was predictive of unmet supportive care needs. In the sexuality domain, being married, along with younger age was predictive of unmet supportive needs.

## Discussion

This study is the first to investigate the supportive care needs of breast cancer patients residing in a Middle Eastern

**Table 3. Predictors of Supportive Care Needs in Iranian Breast Cancer Patients in All Domains**

	Health system and information			Physical and daily living			Psychological			Patient care and support			Sexuality		
	Score (SD)	P Uni.	P Multi.	Score(SD)	P Uni.	P Multi.	Score(SD)	P Uni.	P Multi.	Score(SD)	P Uni.	P Multi.	Score(SD)	P Uni.	P Multi.
Age (year)	r=-0.14, p=0.120	0.126	0.045	r=-0.11, p=0.210	0.016	0.049	r=-0.20, p=0.024	0.138	0.023	r=-0.03, p=0.709	0.041	0.039	r=-0.32, p=0.001	0.024	0.001
Time science diagnosis (month)	r=-0.08, p=0.389	0.545	0.575	r=-0.02, p=0.880	0.670	0.670	r=-0.14, p=0.099	0.907	0.907	r=-0.17, p=0.048	0.503	0.470	r=-0.11, p=0.213	0.983	0.983
Number of children	r=0.14, p=0.108	0.941	0.981	r=0.04, p=0.667	0.574	0.574	r=0.02, p=0.800	0.304	0.207	r=0.24, p=0.006	0.112	0.037	r=0.02, p=0.824	0.943	0.943
Marital status															
Single	34.8 (11.0)	ref	ref	17.3 (4.5)	ref	ref	27.3 (7.4)	ref	ref	16.1 (4.9)	ref	ref	4.8 (3.5)	ref	ref
Married	39.5 (9.8)	0.397	0.600	16.9 (4.3)	0.335	0.349	32.0 (8.4)	0.839	0.836	14.9 (5.5)	0.295	0.331	9.5 (3.8)	0.015	0.001
Level of education															
Illiterate	33.8 (10.7)	ref	ref	17.4 (4.9)	ref	ref	29.4 (5.1)	ref	ref	13.1 (3.2)	ref	ref	7.1 (3.7)	ref	ref
Primary school	39.1 (10.5)	0.813	0.813	17.6 (4.2)	0.819	0.878	31.7 (8.9)	0.341	0.226	15.1 (8.1)	0.329	0.428	8.7 (4.6)	0.700	0.661
High school diploma	40.0 (8.6)	0.857	0.857	16.4 (4.4)	0.144	0.287	32.6 (8.4)	0.790	0.913	15.4 (5.2)	0.978	0.924	9.4 (3.7)	0.819	0.788
University degree	40.2 (10.9)	0.857	0.857	15.5 (4.1)	0.114	0.344	29.3 (9.0)	0.694	0.546	16.4 (5.0)	0.543	0.456	10.1 (2.3)	0.419	0.408
Employment status															
Housewife	38.5 (10.2)	ref	ref	17.2 (4.5)	ref	ref	31.5 (8.4)	ref	ref	14.8 (5.4)	ref	ref	8.6 (4.2)	ref	ref
Employed	40.3 (9.8)	0.556	0.481	16.2 (3.6)	0.172	0.256	30.9 (8.9)	0.251	0.191	16.3 (5.7)	0.851	0.851	9.9 (3.1)	0.343	0.136
Household composition															
Husband	38.0 (10.0)	ref	ref	16.3 (4.5)	ref	ref	32.4 (7.1)	ref	ref	15.5 (6.2)	ref	ref	8.9 (4.3)	ref	ref
Husband and children	39.8 (9.8)	0.398	0.428	17.1 (4.3)	0.345	0.232	31.9 (8.7)	0.508	0.478	14.8 (5.4)	0.649	0.634	9.7 (3.6)	0.244	0.221
Alone	34.8 (11.0)	0.342	0.413	17.3 (4.5)	0.424	0.326	27.3 (7.4)	0.401	0.411	16.1 (4.9)	0.502	0.458	4.8 (3.5)	0.256	0.224

\*r: Pearson correlation coefficient; p: p value; SD: Standard deviation

country, and more specifically, Iran. The women in this study had high unmet supportive care needs, with unmet needs greatest in the health system and information, and physical and daily living domains. This is similar to Asian studies conducted in Taiwan (Liao et al., 2012), Japan (Nakaguchi et al., 2013) and Hong Kong (Au et al., 2013; Li et al., 2013) wherein breast cancer patients reported high rates of unmet supportive care needs, particularly in the informational domain. This contrasts with research conducted in Western countries, including Switzerland (Schmid-Büchi et al., 2012), Australia (Hodgkinson et al., 2007; McDowell et al., 2010), Germany (Lam et al., 2011), England (Armes et al., 2009; Harrison et al., 2011) and Canada (Whelan et al., 1997), wherein breast cancer patients have moderate levels of supportive care needs and unmet needs were highest in the psychological domain. Differences in supportive care needs have led others to conclude that supportive care needs are culturally dependant (Lam et al., 2011).

Previous research in the Middle East suggests there are few supportive care services and limited educational programs available to cancer patients (Bingley and Clark, 2009). In Iran, cancer patients do not receive sufficient information about their disease (Montazeri et al., 2002) and, therefore, often attempt to obtain information from unreliable resources, such as relatives or other patients (Valizadeh et al., 2012). It is unsurprising, then, that the Iranian women in the present study had high unmet information needs. These findings suggest that educational programs would likely benefit breast cancer patients and ought to be a health service priority.

The breast cancer patients in the present study reported lower psychological unmet needs than those reported in Western research (Whelan et al., 1997; Hodgkinson et al., 2007; Armes et al., 2009; Harrison et al., 2011; Lam et al., 2011; Schmid-Büchi et al., 2011). It should be noted that the women in the present study had completed their initial course of treatment and were four to six months post diagnosis. Previous Iranian researchers found that psychological stress among breast cancer patients decreases over time (Vahdaninia et al., 2010) and it is possible that psychological supportive care needs had dissipated by the time they participated in the present study. It is also possible that these women relied heavily on religion and spirituality to cope with psychological challenges, considering that Middle Eastern women have reported that religious beliefs and a strong relationship with God play an important role in coping with distress (Montazeri et al., 2005; Ben-Arye et al., 2012). Moreover, Iranian cancer patients experience high levels of posttraumatic growth related to their spirituality following treatment (Rahmani et al., 2012). It is also possible that the women in the present study had insufficient or inaccurate information about their diagnosis and prognosis. Previous researchers found that many Iranian cancer patients do not have valid information about their prognosis and they often do not fully understand the gravity of their situation (Zamanzadeh et al., 2013). Future research is needed to illuminate the psychological challenges experienced by Iranian breast cancer patients, their use of effective coping strategies, and acceptable means of providing support.

Findings of the present study suggest that Iranian breast cancer patients have very low unmet needs in the sexuality domain. However, this finding ought to be considered within the context of Iranian culture wherein sex is taboo (Farnam et al., 2008). It is, therefore, highly likely that study participants under-reported their supportive care needs related to sexual health.

In the present study, age was the main predictors for all supportive care domains, with younger breast cancer patients having more unmet needs. This is similar to previous research, wherein younger women had greater needs related to the psychological (McDowell et al., 2010; Griesser et al., 2011; Schmid-Büchi et al., 2011), informational (Sanson-Fisher et al., 2000; Salminen et al., 2004), physical and daily living (Griesser et al., 2011), and sexual domains (Fridfinnsdottir, 1997; Sanson-Fisher et al., 2000; Akechi et al., 2011; Griesser et al., 2011). Breast cancer patients with children in the present study had fewer unmet needs, possibly because children are likely a positive source of support, and the more children and woman has, the greater the availability of social support. The present study also suggests that married women have more unmet sexuality needs, and is consistent with some previous studies (Beesley et al., 2008; Akechi et al., 2011; Schmid-Büchi et al., 2012).

These results have important clinical and research implications. The high rate of unmet supportive care needs in all domains suggests that supportive care services are desperately needed for breast cancer patients in Iran. Moreover, services that address informational needs and physical and daily living needs ought to be the priority, with particular attention paid to younger women. The development and implementation of educational and self-care programs tailored to the needs of breast cancer patients could potentially lead to comprehensive, patient-centered care. Further research is clearly needed to more fully understand the supportive care needs of Middle Eastern and Iranian cancer patients, with particular focus on different times along the cancer trajectory. In addition, qualitative research that provides in-depth knowledge of Iranian patients' needs, particularly related to issues associated with cultural stigma, such as sexual health, would provide important insight.

As with all research, there are limitations of this study that limit the generalizability of findings. First, this study was conducted in one medical center, and even though this is the main referral center for North Western Iran, this does not cover all of Iran. Second, only breast cancer patient who finished the initial course of treatment participated and so their supportive care needs are representative of this point in the cancer trajectory and not necessarily applicable to the time just following diagnoses, during treatment, or long-term. Third, the findings related to sexual health supportive care needs ought to be interpreted with caution, considering the taboo associated with sexual issues in Iran.

In conclusion, this study highlights that Iranian breast cancer patients have many unmet needs in all domains of supportive care needs, especially in health systems and information and physical and daily living domains. These findings indicated that programs and services to address

the supportive care needs are urgently needed. Moreover, further research in Iran, as well as other Middle Eastern countries, would shed further light on the supportive care needs of patients in this cultural context.

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