

## Supportive Care Needs of Iranian Cancer Patients

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### ABSTRACT

**Background:** A supportive needs assessment is an essential component of any care program. There is no research evidence regarding the supportive care needs of cancer patients in Iran or other Middle Eastern countries.

**Aims:** The aim of this study was to determine the supportive care needs of Iranian cancer patients.

**Materials and Methods:** This descriptive study was conducted in a referral medical center in the northwest of Iran. A total of 274 cancer patients completed the Supportive Care Needs Survey (SCNS-59). Descriptive statistics were used for data analysis.

**Results:** In 18 items of the SCNS, more than 50% of the participants reported that their needs were unmet. Most frequently, unmet needs were related to the health system, information, physical, and daily living domains, and most met needs were related to sexuality, patient care, and support domains.

**Conclusions:** Iranian cancer patients experience many unmet needs and there is an urgent need for establishing additional supportive care services in Iran.

**Key words:** Cancer, Supportive care, Supportive care needs, Supportive care needs survey

### INTRODUCTION

In spite of the recent advancement in the treatment of several types of neoplastic disease, the prognosis of many cancers is still relatively poor.<sup>[1]</sup> As a result, the diagnosis of cancer may be experienced as a stressful event that negatively impacts many aspects of a patient's life.<sup>[2]</sup>

Cancer patients often experience many problems including negative physical symptoms, social isolation, spiritual suffering, and often psychological distress.<sup>[3,4]</sup> This underpins the need for a wide range of robust

supportive care services.<sup>[2,5]</sup> Supportive care may be defined as those services designed to help patients, their families, and caregivers with their experiences during the diagnosis, treatment, follow-up, and palliative stages of the cancer journey.<sup>[6]</sup> Nowadays, providing supportive care is considered to be of equal significance to diagnosis and to treat cancer.<sup>[7]</sup> The first step in planning any supportive care services for cancer patients is identifying their supportive care needs.<sup>[1,6,8]</sup>

While several studies have investigated the supportive care needs of cancer patients worldwide, most are conducted in Western countries.<sup>[6,9-16]</sup> Few studies have investigated the supportive care needs of cancer patients in non-Western setting.<sup>[17-21]</sup> While results of studies in non-Western countries reported that cancer patients have many unmet supportive needs, there remains several nuances between studies in the West and non-Western countries.<sup>[17-21]</sup>

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Supportive care needs are a culture-dependent concept. Therefore, in order to develop an effective supportive care program, cultural issues must be considered.<sup>[19]</sup> In an extensive review of the literature, we identified no previous studies that have investigated the supportive care needs of cancer patients in Iran or any other Middle Eastern countries. Therefore, this study aims to determine the supportive care needs of cancer patients in Iran.

## MATERIALS AND METHODS

This study was conducted in a tertiary hospital in the East Azerbaijan Province (EAP), Iran. This hospital is an educational center affiliated to Tabriz University of Medical Sciences (TUOMS) and is a referral center for subspecial cancer treatment in EAP.

A total of 310 eligible cancer patients were invited to participate in the study from April to September in 2012. Eligibility criteria included: 18 years or above; having a definite diagnosis of any type of cancer; physically or mentally able to participate in the study; and be aware of exact diagnosis for at least 3 months. Twenty patients did not agree to participate upon the invitation and 16 participants failed to complete the questionnaire adequately, therefore were excluded from the study. A total of 274 cancer patients participated in the study (participation rate = 88%).

Participants completed an instrument consisting of two parts. The first part assessed basic demographic and disease-related characteristics of participants. Information on medical treatments was obtained from the patients' health records. The second part consisted of a Supportive Care Needs Survey (SCNS). The long form of SCNS was used to investigate the supportive care needs of cancer patients.<sup>[22]</sup> This scale contains 59 items addressing five domains of needs: Psychological (22 items), health system and information (15 items), physical and daily living (7 items), patients care and support (8 items), sexuality (3 items), and no specific items (4 items). Patients reported their supportive care needs in each item based on 5-point Likert scale (1 = not applicable or no need, 2 = satisfied, 3 = low need, 4 = moderate need, 5 = high need). To determine the supportive care needs, a 5-point Likert scale was dichotomized to unmet need (if the response was moderate need or high need) or no need (if the response was not applicable, satisfied, or low need). This scoring system has been widely used in previous research.<sup>[23,24]</sup>

Two independent English-Persian translators translated the English version of the Supportive Care Needs (SCN)-SF59

into Persian. The questionnaire was reviewed by 10 academic staff at TUOMS for face and content validity and minor revisions made based on their comments. The internal reliability coefficients (Cronbach Alpha) of the translated questionnaire were substantial, greater than 0.90, when piloted with 25 cancer patients.

The researchers recruited participants from inpatient wards and outpatient clinics of the hospital. Participants were provided with study information and the questionnaires to complete. If participants were unable to complete the questionnaires due to poor reading and writing comprehension, researchers assisted them via a short interview.

Previous research has highlighted that many cancer patients in Iran may not know the exact diagnosis of their disease<sup>[25,26]</sup> and only limited information is disclosed to cancer patients. Therefore, an important clinical concern in this study was to ascertain the participant's own awareness of their diagnosis of cancer.<sup>[27]</sup> In order to ascertain this and prevent unwanted disclosure, this information was obtained from the patients caregivers and/or health care professionals and then checked with the patients via a short private interview. This procedure was approved by the local Ethics Committee. This study was approved by Regional Ethics Committee at TUOMS. All participants were informed of the study aims and objectives. Written consent was obtained.

Data analysis was performed using the Statistical Package for the Social Sciences (SPSS) software (version 13, SPSS Inc, Chicago, Illinois). Descriptive statistics including frequency, percentage, mean, and standard deviation were used to analyze the demographic characteristics, cancer-related information, and unmet and met supportive care needs of participants.

## RESULTS

Demographic and disease-related characteristics of participants are reported in Table 1. Most of the participants were female (56%), married (76%), educated at primary level (33%), house worker (45%), and living with their partner and children (62%). The mean age of the patients was 42 years and the mean of the time passed since diagnosis was 24 months.

The data analysis shows that in 18 items of SCNS, more than 50% of the participants reported that their supportive care needs were not satisfied [Table 2]. This demonstrates that the participants have many unmet supportive care needs. From

these 18 items, 8 items were in health system and information domain; 5 items were in psychological domain; 2 items were in physical and daily living domain; 2 items were in no specific items; 1 item was in patient care and support domain. In health system and information, three of the most unmet needs were “to have one member of hospital staff with whom you can talk about all aspects of your condition,” “to be informed about cancer that is under control or diminishing,” and “to be informed about things you can do to help yourself get well.” These results highlight that the patients have many unmet needs especially in the information domain. Within the psychological domain, two most unmet needs were for “change in usual routine and lifestyle” and “concern about the worries of those close to you.” This means that the patients were not distressed about the outcomes of the disease and worried about the changes in the routines of their disease and their families. The most frequent unmet needs were “not being able to do the things you used to” that is related to physical and daily living domain. In patient care and support domain, only one item was reported as unsatisfied by more than half of participants and was “waiting a long time for clinic appointment.”

The score of the participants in five domains of SCNS based on 100 score is reported in Table 3. As evident in this table,

in four domains (health system and information, physical and daily living, psychological, and patients care and support), the participants gain score more than 50 that indicate that most of the participants have many unmet needs; and only in sexuality domain, the score is less than 50. The most unmet needs were for health system and information (59.70), physical and daily living (65.92), psychological (59.70), patients care and support (57.71), and sexuality (49.39) domains.

The 10 most frequent met needs of the participants are reported in Table 4. More than 70% of the participants reported that they have no needs in these items. As shown in this table, the first six met needs are related to aspects

**Table 1: Demographic and disease-related characteristics of participants**

Variable	Number (%)
Sex	
Male	121 (44.2)
Female	153 (55.8)
Marital status	
Single	51 (18.6)
Married	209 (76.3)
Divorce	14 (5.1)
Educational level	
Illiterate	69 (25.4)
Primary	89 (32.7)
Diploma	83 (30.5)
University degree	33 (11.4)
Job*	
Employee	103 (38.6)
House worker	121 (45.3)
Unemployed	33 (16.1)
Living situation*	
Living alone	22 (8.1)
With partner	32 (11.8)
With partner and children	168 (61.8)
With parents	50 (18.3)
Age in years, mean (SD)	41.8 (15.1)
Time since diagnosis in month, mean (SD)	24.1 (28.8)

SD, Standard deviation; \*some patients did not respond to these items

**Table 2: Most frequent unmet supportive care needs of participants**

Items	Domain	Number (%)
Not being able to do the things you used to	P and D	199 (73.4)
To have one member of hospital staff with whom you can talk about all aspects of your condition	H and I	194 (71.6)
To be informed about cancer that is under control or diminishing	H and I	192 (70.8)
To be informed about things you can do to help yourself get well	H and I	179 (66.8)
Lack of energy/tiredness	P and D	176 (65.2)
Concern about financial situation	N	172 (63)
To be given information about aspects of managing your illness and side effects at home	H and I	169 (62.1)
To be informed about your test results as soon as possible	H and I	163 (60.4)
Change in usual routine and lifestyle	P	160 (60.2)
Concern about getting to and from the hospital	N	163 (59.9)
Concern about the worries of those close to you	P	160 (59.7)
To be adequately informed about the benefits and side effects of treatments before you chose to have them	H and I	161 (58.8)
Worry that the result of treatment are beyond your control	P	156 (57.4)
Making the most of your time	P	153 (56.3)
Waiting a long time for clinic appointment	P and S	147 (54.6)
To be given explanations of those tests for which you would like explanations	H and I	146 (53.3)
Feeling down or depressed	P	145 (53.1)
To be given written information about the important aspects of your care	H and I	136 (50.2)

P, Psychological; H and I, Health system and information; P and D, Physical and daily living; P and S, Patients care and support; N, No specific items

**Table 3: The score of participants in each domains on Supportive Care Needs Survey**

Items	Mean•	SD•
Psychological	59.70	16.80
Health system and information	70.89	16.22
Physical and daily living	65.92	18.18
Patients care and support	57.71	15.32
Sexuality	49.39	28.01

•The scores is based on 100 score; SD, Standard deviation

of psychological domain; two items were in the domain of physical and daily living; one item was in the patient care and support domain; and one item was in health system and information domain. Interestingly, three of these items that are related to physical and daily living (2 items) and health system and information (1 items) domains were not related because in our health system, patients have a little choice about them.

## DISCUSSION

To our knowledge, this is the first study that has investigated the supportive care needs of cancer patients in Iran and other Middle Eastern countries. The results demonstrate that Iranian cancer patients have many unmet supportive care needs, especially in the domains of health system, information, physical, and daily livings. More than half of the participants reported unmet supportive care needs in 18 items of SCNS.

In an extensive review of the literature, few studies reported that cancer patients have low needs;<sup>[10,19]</sup> and most studies highlight that cancer patients in both non-Western<sup>[17-21]</sup> and Western countries<sup>[9,14,28]</sup> have many supportive care needs. No studies identified reported such high levels of needs as reported by the participants of our study.

The results of our study demonstrate that 8 out of 18 most frequent unmet supportive care needs of cancer patients are related to health system and information domain. Some previous studies in Iran confirm this finding and show that cancer patients in Iran do not receive desired information about the many aspects of their condition.<sup>[25,26]</sup> This finding is to some degree different with previous studies conducted in the Western countries that reported health system, and

information domain is the second or third domain that cancer patients' needs are not met.<sup>[6,9,13,29-33]</sup> In contrast, the results of some studies in the southwest of Asia showed that the needs from health care and information domain are between the most frequent unmet supportive care needs of cancer patients.<sup>[17,20,21,34]</sup> Similarly, the result of a comparative study showed that Hong Kong breast cancer patients rated health system and information needs as the most frequent unmet supportive care needs and German women consider needs from physical and daily living and psychological needs as the most frequent unmet supportive care they experienced.<sup>[19]</sup> Therefore, this finding supports that the supportive care needs are a culture-dependent issue.<sup>[19]</sup>

The results of our study also indicated that psychological needs are the third category of unmet supportive care needs of Iranian cancer patients after needs from health system and information and physical and daily living domains. This finding is consistent with the results of other studies in non-Western countries.<sup>[17,20,21,34]</sup> It should be noted that previous Iranian studies reported that many of the Iranian cancer patients were not aware of the prognosis of their diseases<sup>[27,35]</sup> and consider cancer as a curable disease.<sup>[36]</sup> So, it may be concluded that the nondisclosure of cancer prognosis for most of the Iranian cancer patients may result in a situation that Iranian cancer patients reported, lower levels of psychological supportive care needs.

The results of this study have important clinical implications. The results demonstrate that cancer patients in Iran have many supportive care needs in different domains. There are few established supportive care programs for cancer patients in Iran. Our results highlight that there is urgency for such programs to be developed. Most unmet supportive care needs cancer patients in Iran are from the perspective of the health system and information and physical and daily living domains. Therefore, educating cancer patients and meeting their physical needs should be considered as a fundamental part of the supportive care programs.

There are limitations to our study. This study was conducted in one medical center in Iran; and even though this is the main referral center for one large province in the northwest of Iran, it does not include all areas of Iran. The findings related to sexual health supportive care needs ought to be interpreted with caution, considering the taboo associated with sexual issues in Iran. There are needs for further studies that investigate the supportive care needs of different cultures in the Middle East; using other data collection methods including private interviews may increase the validity of results in sexual domain of supportive care needs.

**Table 4: Most frequently met supportive needs of participants**

Item	Domains	Met needs, n (%)
Feeling bored and/or useless	P	181 (70.2)
Accepting changes in your appearance	P	207 (76.7)
Keeping a positive outlook	P	202 (75.1)
Making the most of your time	P	212 (77.4)
Feelings about death and dying	P	188 (70.4)
Finding meaning in this experience	P	203 (74.4)
To be given choices about when you go in for tests or treatment	H and I	217 (80.1)
More choice about which hospital you attend	P and D	200 (73.3)
More choice about which cancer specialist you see	P and D	195 (71.9)
To be given information about sexual relationship	P and S	189 (70.4)

P, Psychological; H and I, Health system and information; P and D, Physical and daily living; P and S, Patients care and support; N, No specific items

## CONCLUSION

This study highlights that Iranian cancer patients have many unmet needs in all domains of supportive care needs. These findings indicated that programs and services to address the supportive care needs are urgently needed. Future research in Iran would shed light on the supportive care needs of patients in this cultural context.

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