



Unmet needs in Iranian cancer patients

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Abstract

Background: The identification and management of unmet needs is an essential component of health care for the growing cancer patient population. Information about the prevalence of unmet need can help medical service planning/redesigning. Therefore, this study aimed to identify unmet needs in Iranian patients suffering from cancer.

Methods: This cross-sectional correlational study was conducted on 650 cancer patients admitted to the major medical centers in Mashhad and Neyshabur by census sampling. The data was gathered by the Survivor Unmet Needs Survey (SUNS). Data were analyzed using ANOVA, t-test and Pearson correlation.

Results: Most of participants were female (56%, n=263) and Mashhad resident (67.1%, n=436). The most common cancers were colorectal (17.8 %, n=116), stomach (13.6%, n=88) and lung (9.4%, n=62), respectively. The highest unmet needs score belonged to work and financial needs (2.46 ± 0.91), and the least was the emotional domain (1.92 ± 0.90). Among demographic factors, a significant relationship was found between resident places ($p < 0.001$), and cancer type ($p < 0.0001$).

Conclusion: This is the first study addressing the unmet needs of cancer patients in Iran. It reveals that cancer patients had a relative high number of unmet needs; this shows the necessity of including these factors in the routine assessment of all cancer patients and planning treatment interventions based on their individual's need.

Keywords: Cancer, Patient, Iran

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Introduction

Cancer is the second death cause in the world and the third one in Iran (1). Eight million people died in 2005 and mortality rate will increase to 11.5 million people in 2030 (2). It is estimated 70000 new cases happen annually in Iran and the cancer incidence will be twofold in the next 2 decades by increasing the life expectancy and more elderly people population (3).

Living with cancer, for many, has become a reality, with all the psychological and physical consequences and needs that this may elicit. Living "well" with cancer and associated treatment is fundamental to a person's well-being and quality of life, and care should, wherever possible, fit the

needs of individual cancer patients and their families (4).

Effective, high-quality cancer care is now viewed as involving more than just the anti-cancer therapy, and increasingly, cancer service providers are required to address patients' supportive care needs (5).

The term supportive care needs is an umbrella term which covers the physical, informational, emotional, practical, social, and spiritual needs of an individual with cancer. Unmet supportive care needs are those needs which lack the level of service or support, and an individual perceives they are necessary to achieve optimal well-being (6).

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↑What is "already known" in this topic:

The highest unmet needs' score belonged to the domain of psychological needs and health and information. Identifying and addressing the unmet needs of patients are important because they are found to be significantly associated with quality of life.

→What this article adds:

The work and financial concerns' domain was the greatest unmet needs in Iranian cancer patients and that patients with a lower level of economic status, living in rural residents, younger patients and colorectal cancer patients were more likely to report significantly higher unmet needs.

Identifying and addressing the unmet needs of patients are important because they are found to be significantly associated with both psychological distress and poor quality of life (QoL) (7), which may in turn negatively affect the health care system by increasing health care utilization and costs(4,8).

As more people survive, more attentions are drawn to support the needs of cancer patients in the transition period between the end of treatment and survivorship and improve their QoL. In fact, cancer patients unmet needs is highest in the post-treatment phase in comparison with other phases in the cancer continuum (5, 9).

Studies have been reported that the prevalence of unmet needs among cancer survivors varied from 30% to 50% (5). However, most of them focus on the needs of cancer patients on the diagnosis and treatment phases and studies which examined their needs immediate after treatment is lacking (4, 9, 10).

Also, few studies reported only the unmet needs among cancer survivors in general (11,12) ,without considering cancer's type, but these evidence of influencing factors on unmet needs may not be able to apply to specific cancer types (13).

The increased attention on measure development and description of unmet needs suggests that it is important to establish how these needs can be ameliorated (14). So, unmet need measures help to provide an indicator of an individual's judgment regarding the significance of the need in relation to their psychosocial well-being (15).

Despite, the importance of assessing cancer population and determining their needs; no study has been conducted to fulfill this objective in Iran. Therefore, this study was done to identify the unmet needs of cancer patients in the east centers of cancer treatment of country.

Methods

Design and sample

This cross-sectional study was conducted between February to June 2014 and 2015. This study was conducted on 650 cancer patients admitted to Omid hospital in Mashhad and 22 Bahman hospital in Neyshabur. Inclusion criteria were: enough consciousness to answer the questions, having a definite diagnosed cancer by oncologist, aged between 18 and 70 years old, no evidence of psychosis, dementia, or suicidal behavior, developed cancer more than 6 months.

Instrument

For gathering data two self-report questionnaires were used: a socio-demographic and clinical characteristics questionnaire which was a researcher's made form, and the Survivor Unmet Needs Survey (SUNS) (16).

Socio-demographic and clinical characteristics

The following data were collected through participants' self-reports: age, gender, marital status, education, employment status, monthly income, travelling time from home to hospital, and family history of cancer. Similarly, the following clinical data were collected from the participant's medical record: time since diagnosis, stage of the

disease, the number of cancer treatment received, comorbidity, and family history of cancer.

Survivor Unmet Needs Survey (SUNS)

The SUNS is an 89-item survey with 5 domains including information (8 items), work and financial concerns (11 items), access and continuity of health care (22 items), coping and relational needs (15 items), and emotional needs (33 items). Scores for each SUNS question ranges from 0 (no unmet need) to 4 (very high unmet need). Respondents were asked to recall their unmet needs in the past month. In order to give respondents an option to identify areas which they needed to assistance with, "No unmet need" was also included as a response option in the survey. Each individual domain scores was between 0-260 and the mean scores can range is 0-4, higher scores indicate the more need of a person to receive supportive care and treatment services.

This is a comprehensive scale that has worldwide high acceptability, item test-retest reliability and internal consistency (Cronbach's alpha 0.990), face, content and construct validity" with a combined total of 64.4% variance across the 5 domains (16), but already has not been used in Iran. Therefore, the validity and reliability of it were investigated by researchers. Its face and content validity were assessed by 12 faculty members of Nursing and Midwifery school of Tehran and Shahid Beheshti University of Medical Sciences. The internal consistency of each subscale was good (Cronbach's alpha scores ranged from 0.82 to 0.95) and total alpha Cronbach was calculated 0.95 to examine its reliability.

Procedure

This is a cross-sectional correlational study. Convenience method was used for sampling the outpatient and inpatient cancer patients with inclusion criteria and admitted to Omid hospital of Mashhad and 22 Bahman hospital of Neyshabur. The purpose of the study was explained to them, and all signed the informed consent. Then questionnaires were fulfilled by samples or co-researcher for illiterate ones.

Data analysis

For analyzing data, descriptive statistics such as measures of central tendency and index of dispersion, tables and graphs; and inferential statistics including one-way ANOVA, t-test, and linear regression model were used. All statistical analyses were performed using SPSS version 16. All tests were two-sided, with a confidence level of 0.05.

Ethical considerations

This research was approved by the ethics committee of Tehran University of Medical Sciences and Neyshabur University of Medical Sciences. All possible ethical issues addressed as explained above and the participants signed a written informed consent.

Results

Participants' demographic and clinical characteristics

The demographic and clinical characteristics of 650 participants are displayed in Table 1 and Table 2. The five most common cancer types include colorectal (17.8%, n=116), stomach (13.6%, n=88), lung (9.4%, n=62), breast (9.2%, n=60), and leukemia (7.8%, n=50), respectively.

Prevalence of unmet needs

The top 10 unmet needs that were rated as moderate to high are shown in Table 3. Among the 10 highest needs, 4 items were related to the work and financial and 4 items were related to the access and continuity of health care, and the remaining two items were in the domain of the information needs. Regarding to the items, the most common unmet needs were 'Having to take a pension or disability allowance' (52.6%) followed by 'Worry about earning money' (41.7%), 'Dealing with fears about cancer spreading' (38.5%), 'Adapting to living on a pension or disability allowance' (33.1%), and 'Having access to can-

cer services at night and on weekends' (28.9%).

Unmet Needs according to domains

Table 4 shows the mean differences of unmet needs according to different domains. The highest unmet needs score belonged to the domain of concern about work and financial needs with an average of (2.46±0.91), and the other unmet needs belonged to the domains of information needs (2.38±0.91), needs for access and continuity of health care (2.16±0.98), coping and sharing needs (1.94±0.94), and emotional needs (1.92±0.90), respectively.

Total Unmet Needs Score and patient characteristics

Data analysis revealed that patients with a lower level of economic status were more likely to report significantly higher unmet needs ($p<0.001$). There was a significant difference between cancer's type and the unmet needs

Table 1. Patient's characteristics

Characteristic	Category	N (%)
Age (years)	30≤	104(16.1)
	31-59	399(61.4)
	60≥	146(22.5)
Sex	Female	363(56)
	Male	287(44)
Marital status	Married	537(82.5)
	Single	113(17.6)
	Literate	220(33.8)
Education	Secondary school	260(39.9)
	High school	115(17.7)
	University	55(8.4)
Job	employed	105(16.2)
	Unemployed	439(67.5)
	Retired	104(16.3)
Economic status	High	76(11.7)
	Middle	215(33)
	Low	359(55.3)

Table 2. Characteristics of illness and treatment

Characteristic	Category	N (%)
Cancer diagnosis	Colorectal	116(17.8)
	Stomach	88(13.6)
	Lung	62(9.4)
	Breast	60(9.2)
	Leukemia	50(7.8)
	Lymphoma	46(7.2)
Type of treatment	Other	228(35)
	Chemotherapy	166(25.6)
	Radiotherapy	12(1.8)
	Surgery	33(5)
Time since diagnosis (months)	combination of the above	439(68.6)
	12 <	379(58.4)
	12 ≥	271(41.6)

Table 3. Top 10 unmet needs by percentage rating with moderate or high need

Unmet needs item	% of sample reporting needs	Needs domain
Having to take a pension or disability allowance	52.6	work and financial needs
Worry about earning money	41.7	work and financial needs
Dealing with fears about cancer spreading	38.5	information needs
Adapting to living on a pension or disability allowance	33.1	work and financial needs
Having access to cancer services at night and on weekends	28.9	access and continuity of health care needs
Getting appointments with specialists quickly enough (oncologist, surgeon, etc.)	27.5	access and continuity of health care needs
Having access to cancer services close to my home	26.7	access and continuity of health care needs
Finding what type of financial assistance is available and how to obtain it	18.3	work and financial needs
Finding out what is involved in follow-up care	17.9	access and continuity of health care needs
Dealing with feelings of worry (anxiety) between follow-ups	15.7	information needs

Table 4. Mean score on the Survivors Unmet Needs Survey (SUNS) in each category

SUNS domain of unmet need	Mean±SD
Information	2.38±0.91
Financial concerns	2.46±0.91
Access and continuity of care	2.16±0.98
Relationships	1.94±0.94
Emotional health	1.92±0.90

($p < 0.001$), the unmet needs in prostate cancer was the lowest (56.00 ± 0.00) and in colorectal cancers the highest (141.16 ± 32.66). Also, residential area (rural or urban), and educational level had a significant relationship with unmet needs (both p -values were less than 0.001). The rural residents had a higher level of unmet needs (2.1 ± 0.65) rather than urban residents (1.95 ± 0.69). And the correlation between education and unmet needs was indirect; the more education level, the lower unmet needs ($r = -0.2$). The results also showed that significant indirect correlations were between the scores of unmet needs and patient age ($r = -0.10$, $p = 0/04$). Other characteristics had no significant relationship ($p > 0.05$).

Discussion

This is the first study addressing the unmet needs of cancer patients in Iran and the first comprehensive one investigating all types of cancers. It revealed that cancer patients had relatively high number of unmet needs (2.04 ± 0.68) in multiple domains including work and financial (2.46 ± 0.91), information (2.38 ± 0.91), access and continuity of care (2.19 ± 0.98), relationships (1.94 ± 0.94) and emotional (1.92 ± 0.90), respectively. The high incidence of unmet needs among cancer patients is shown the necessity of including these factors in the routine assessment of all cancer patients. No similar study was found to examine all types of cancers in one study.

Work and financial concerns had the highest prevalence of unmet needs in our study, and the information is the second one that is different from previous studies; as shown previously the health and information domain is the most common unmet needs. For example, So et al. (2014) have demonstrated health and information had the highest frequency among unmet needs domain and the second one belonged to work and financial concerns (17). Olson et al. (2014) had the same findings, and in a context of rural and urban samples, the most common unmet needs had been information (18). In another study Edib et al. (2016) illustrated psychological domain is the most mentioned needs, followed by physical, patient care needs, health information and the lowest was sexuality domain (19). Schmid-Buchi et al. (2013) have found psychological needs, healthcare system, information, physical, and daily activities are the highest needs, and the least ones included sexual needs and support (20). McDowell et al. (2010) and Boyes et al. (2012) also mentioned the psychological needs as the most common unmet needs among cancer patients (13, 21).

The reason of the difference between our study and others may be due to the high treatment expenditure, especially their drugs, in Iran and low insurance coverage of it.

There was no relationship between unmet needs and

some of the patient characteristics including gender, cancer stage, duration of disease and marital status; but an indirect correlation was found between age and unmet needs ($p < 0.004$, $r = -0.10$). Also, economic status, resident area, and education level had a significant relationship with unmet needs ($p < 0.001$).

The significant indirect correlation in our study between age and unmet needs shows as the patients' age increased their unmet needs decreased, which is the same as Jorgensen et al. (2012) findings (22). Jorgensen et al. (2012) illustrated elder patients reported lower unmet needs, unlike younger patients. But, Sanders et al. (2010) in their study on patients with lung cancer found no relationship between age and unmet needs; this may be due to their limited age range (23).

Our study found no relationship between gender and unmet needs ($p > 0.05$), which is consistent with Sanders et al. (2010) and Bredart et al. (2013) (23, 24); but differs from Boyes et al. (2012) (21). Boyes et al. (2012) showed female patients had higher supportive care needs.

Our results showed there is a significant relationship between resident area and the unmet needs ($p < 0.004$), which is inconsistent with the results of Ream et al. (2008) (25). Ream et al. conducted a study on prostate cancer patients and found no relationship between the resident area and the unmet needs of patients. However, Olson et al. (2014) examined the effect of resident area on unmet needs incidence and revealed rural patients had more unmet needs in all domains (18), similar to our study, which is the result of lack of access to specialist and equipped medical centers.

Park et al. (2012) found significant relationships between education level, economic status and unmet needs (7). Our study, also, confirmed their results and showed a significant relationship between education, economic status and unmet needs ($p < 0.001$, $p < 0.001$, respectively). High cancer treatment expenditure results in a lack of accessibility of all patients to necessary treatments, underuse of effective drugs and consequently lower health status and finally upper reported needs in low-income patients.

Since perceiving experiences, perceptions and unmet needs of cancer patients can help healthcare system to prioritize their medical and nursing care and improve patients' treatment, care and communication, determining the unmet needs of cancer patients seems necessary. Planning interventions based on each individual's needs results in improvement of the quality of life of cancer patients. If the quality of life increases, the patient tries more for her/his disease self-management and self-control which all ends to health level enhancement.

Conclusion

The results showed that the work and financial concerns domain was the greatest unmet needs of cancer patients, which can be provided by improve social workers' role in the hospital, introduction patients to charities and community health centers, also supportive projects such as the expansion of insurance coverage for cancer patients may be able to reduce their financial concerns and alleviate the suffering caused by the complications of the disease and

help to solve their problems effectively.

Information needs can be considered by more educational classes regarding patients' disease and educational level, preparing booklets due to patients' educational priorities, introducing patients with same disease and longer duration to each other, and introducing validate internet and library resources.

Limitation

As it was a comprehensive study on all cancer types, we had limitation to compare our results with similar studies which all was done on a specific type of cancer.

Another limitation was a significant number of illiterate patients in our study. Obviously, this population needed to read the questionnaire by the researcher and in this case understanding and responding to the questions was more difficult than in literate persons and might reduce the accuracy of responses. However, it is a global problem in all researches and producing special questionnaire for illiterate samples may be helpful.

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Conflict of Interests

The authors declare that they have no competing interests.

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