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Chapter

Unmet Supportive Care Needs of General Cancer

Ezaddin Kamal Mahmod and Saadia Ahmed Khuder

Abstract

Purpose Aside from their oncology condition, cancer patients often experience many ancillary problems, including negative physical symptoms, social isolation, spiritual suffering, and often psychological distress. Supportive care services can be defined as 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. In an extensive review of the literature, we identified no previous studies that have investigated the SCNs of cancer patients in Iraq or any other Middle Eastern countries. Therefore, this study aims to determine the SCNs of cancer patients in Iraq. Methods The present cross-sectional study and data was conducted in Rezgary teaching and Nankaly Oncology Hospital in the Kurdistan Federal Region of Iraq. A total of 300 eligible cancer patients were invited to participate in the study from February to August, 2018. 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 being aware of exact diagnosis for at least three months. Results In 15 items of the SCNs, more than 60% of the participants reported that their needs were unmet. Most frequently, unmet needs were related to health system and information, physical and daily living, psychological, and patient care and support domains, and most met needs were related to physical and daily activity domains. Conclusions Kurdish cancer patients had many unmet needs and there is a need for establishing additional supportive care services and educational programs to increase quality of life in Kurdistan Region- Iraq.

Keywords: unmet, cancer patient, supportive care needs, Kurdistan region

1. Introduction

Cancer is the second leading cause of death worldwide, with an estimated global health burden of 193.6 million disability-adjusted life years. This presents a particular challenge for developing nations, which face additional challenges in delivering complex cancer treatments [1]. As a result, the diagnosis of cancer may be experienced as a stressful event that negatively impacts many aspects of patients' lives [2].

After the Iraqi regime change in 2003, rapid changes occurred in the lifestyles of Kurdish people that affected patterns and rates of cancer trends in Kurdistan. Additionally, the population suffers from the cumulative impacts of three vicious wars in Iraq, including targeted genocide against the Kurds and the use of chemical weapons, creating long-term environmental pollution and increasing cancer incidence, aside from their immediate casualties, with especially high rates of

hematological malignancies. Tentative published data evidences the increasing cancer prevalence in Kurdistan, [3–6] but related phenomena and care needs have not been explored in detail. This study presents new and more accurate data on the patterns of cancers in Kurdistan and the care needs of cancer patients.

Aside from their oncological condition, spiritual suffering, social isolation, and negative physical and psychological symptoms are among many other problems that cancer patients may experience [7, 8]. Due to this, a variety of supportive care services is needed and has to be reinforced [2, 9]. Such services can be directed to support patients, their families, and caregivers during different stages of the cancer journey, such as at the initial post-diagnosis phase, the duration of treatment and follow-up, and even end of life care [6]. Currently, offering supportive care services is regarded to be of equal importance to the diagnosis and treatment of cancer itself, and it involves more holistic healthcare provision compared to the biomedical approach that dominates mainstream oncology treatment [10]. The first step in planning any supportive care services for cancer patients is identifying their supportive care needs (SCNs) [1, 11, 12].

While several studies have investigated the SCNs of cancer patients worldwide, most were conducted in Western countries [11, 13–20]. Few studies have investigated the SCNs of cancer patients in non-Western settings, but pioneering research indicates that cancer patients in the latter have many unmet supportive needs, albeit there are numerous methodological issues and diverse findings between studies in Western and non-Western countries [21–25].

Unmet needs are defined as "the requirement for some desirable, necessary or useful action to be taken or some resource to be provided in order for the person to attain optimal well-being" [26, 27]. A systematic review by Harrison et al. [28] concluded that unmet needs were frequently reported in relation to activities of daily living, psychological and psychosocial issues, the need for information, and physical concerns. Similar findings were reported by Fiszer et al. [29].

SCNs are a "culture-dependent" notion. Thus, cultural issues must be taken into consideration when developing an effective supportive care program [23]. After an extensive literature review, no previous studies found to investigate the SCNs of cancer patients in Iraq or in any other Middle Eastern countries. Hence, this study aimed to determine the SCNs of cancer patients in Iraq.

2. Materials and methods

This study was conducted in Rezgary Teaching Hospital and Nankaly Oncology Hospital in the Kurdistan Federal Region of Iraq. Both hospitals are educational centers affiliated with Hawler Medical University, a referral center for sub-special cancer treatment.

A total of 300 eligible cancer patients were invited to participate in the study from February to August, 2018. Participant eligibility criteria included being aged 18 years or above; having a definite diagnosis of any type of cancer; being physically or mentally able to participate in the study; and being aware of exact diagnosis for at least three months.

Participants completed a questionnaire comprising two parts. Participants' basic socio-demographic and disease-related characteristics were assessed in the first part. In addition, information regarding medical treatments was obtained from the participants' health records. The second part consisted of an SCNs Survey (SCNS), used to examine the SCNs of cancer patients; it is derived from previous studies [30]. The SCNS comprises 48 items addressing five domains of needs:

- H&I: health system and information (15 items).
- NS: non-specific items (4 items).
- P&D: physical and daily living (7 items).
- P&S: patient care and support (8 items).
- Psycho: psychological (11 items).
- Sex: sexuality (3 items).

Each item was based on a five-point Likert scale (1 = not applicable or no need, 2 = satisfied, 3 = low need, 4 = moderate need, 5 = high need). To determine the SCN score, the five-point Likert scale was dichotomized to unmet need (for moderate need or high need) or no need (for not applicable, satisfied, or low need). Previous researches have used this scoring system widely [23, 24].

The English version of the SCN SF48 was translated into Kurdish by two independent English-Kurdish translators. Eight academic staff at Hawler Medical University (HMU) College of Nursing reviewed the questionnaire to ensure face and content validity. Based on their comments, minor amendments were made. The internal reliability coefficients (Cronbach's alpha values) of the translated questionnaire were substantial (greater than 0.90) when piloted with 25 cancer patients.

The participants were recruited from inpatient wards of both studied hospitals. Participants were provided with information about the study and the questionnaire to fill in. If participants were incapable to complete the questionnaire due to literacy problems, the researchers assisted them to complete it with a short interview.

Many cancer patients in Iraq may not know the exact diagnosis of their disease, and only limited information is disclosed to them, as highlighted in previous research. Consequently, an important clinical concern in this study was to determine participants' own awareness of their diagnosis of cancer [3–6]. In order to identify this and prevent unwanted revelations, this information was obtained from the patients' caregivers and/or healthcare professionals and then checked with the patients through a short private interview. This procedure was approved by the Regional Ethics Committee at HMU College of Nursing. All participants were informed of the study aims and objectives, and informed consent was obtained. Participants were told that participation was entirely voluntary, and their decision would not affect their care or statutory rights. They were also assured of data anonymity and their right to withdraw from the study at any time.

Data analysis was performed using SPSS version 22 (SPSS Inc., Chicago, Illinois). Analyzing the demographic characteristics, cancer-related information, and unmet and met SCNs of participants was undertaken using descriptive statistics (frequency, percentage, mean, and standard deviation).

3. Results

Participants' demographic and cancer-related features are reported in **Table 1**. Most of the participants were female (66.7%), married (84.7%), educated at primary level (19.7%), employed as independent workers (65.7%), and living in urban areas (54.7%). More than half of them were aged above 48 years old. The particular cancer

No.	Variable	Categories	N	%
1	Age group	18–27 years	26	8.7
		28–37 years	35	11.7
		38–47 years	58	19.3
		48–57 years	76	25.3
		58–67 years	72	24.0
		68–77 years	28	9.3
		78–87 years	5	1.7
2	Gender	Male	100	33.3
		Female	200	66.7
3	Living situation	Urban	164	54.7
		Rural	136	45.3
4	Marital status	Married	254	84.7
		Single	43	14.3
		Widowed	1	0.3
		Divorced	2	0.7
5	Education status	Illiterate	129	43.0
		Read and write	37	12.3
		Primary school	59	19.7
		High school graduate	50	16.7
		College and postgraduate	25	8.3
6	Occupational status	Student	12	4.0
		Employed	51	17.0
		Unemployed	21	7.0
		Independent worker	197	65.7
		Retired	19	6.3
7	Cancer origin	Breast cancer	120	40.0
		Colon cancer	28	9.3
		Leukemia	11	3.6
		Myeloma	1	0.3
		Non-Hodgkin's lymphoma	6	2.0
		Ovarian cancer	23	7.7
		Pancreatic cancer	4	1.3
		Prostate cancer	10	3.3
		Lung cancer	34	11.3
		Rectal cancer	2	0.7
		Uterine cancer	2	0.7
		Other	60	20.0
8	Type of treatment	Hormonal therapy	54	18.0
		Chemotherapy	253	84.3
		Radiotherapy	86	28.7
		Surgical removal of cancer	134	44.7
		Immunotherapy	104	34.7
		Bone marrow treatment	45	15.0

Table 1.
Participant demographic and disease-related characteristics.

diagnosis, treatment received, and the taking of treatment were noted; over 40% of the 120 patients participating in this study had been diagnosed with breast cancer, and their treatment was primarily chemotherapy and/or radiation therapy. Most of them attended treatment and were receiving chemotherapy.

The data analysis shows that in 13 items of SCNS, more than 65% of the participants reported that their SCNs were not satisfied (**Table 2**). This demonstrates that the participants have many unmet SCNs. In terms of domain, 6 of these 13 items concerned H&I; 3 were Psycho; 2 were in NS; and 1 each was in P&D and the P&S domains. In H&I, three 3 of the most unmet needs were "Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home," "Being informed about your test results as soon as feasible," and "Being adequately informed about the benefits and side-effects of treatments before you choose to have them." These results highlight that the patients have many unmet needs, especially in the information domain. Within the Psycho domain, the 3 most unmet needs were for "Concerns about the worries of those close to you," "Anxiety," and "Concerns about the ability of those close to you to cope with caring for you." This means that the patients were distressed about the outcomes of the disease or worried about the changes in the routines of their disease and their families. The most frequent unmet needs were "Concerns about your financial situation" and "Concerns about getting to and from the hospital," which were related to the non-specific domain. In the P&S domain, only one item was reported as highly unsatisfactory by more than 83% of participants, which was "Lack of energy and tiredness."

Participants' mean scores in the SCNS domains are illustrated in **Table 3**. In four domains (Psycho, H&I, P&D, and P&S), the participants gained scores of more than 10, which indicates that most of the participants had many unmet needs. However, only the sexuality domain had a score of less than 10. The most unmet needs were for the domains of H&I (36.42), P&D (35.56), Psycho (28.4), P&S (14.27), sexuality (7.76) and non-specific (6.07).

Items	Domain	No.	%
Lack of energy and tiredness	P&D	251	83.7
Concerns about the worries of those close to you	Psycho	249	83
Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	H&I	249	83.0
Being informed about your test results as soon as feasible	H&I	244	81.3
Being adequately informed about the benefits and side-effects of treatments before you choose to have them	H&I	241	80.3
Concerns about the ability of those close to you to cope with caring for you	Psycho	232	77.3
Being informed about cancer which is under control or diminishing	H&I	231	77.0
Being informed about things you can do to help yourself get well	H&I	224	74.7
Having access to professional counseling (e.g., psychologist, social worker, counselor, nurse specialist) if you/your family/friends need it	H&I	223	74.3
Concerns about your financial situation	NS	211	70.3
Concerns about getting to and from the hospital	NS	209	69.7
Anxiety	Psycho	202	67.3
Family or friends being allowed with you in hospital whenever you want	P&S	197	65.7

Table 2.
Top 15 unmet SCNs of cancer patients.

Domain	Mean	Std. Deviation
Health system and information	36.42	8.15
Non-specific	6.07	2.11
Patient care and support	14.27	4.68
Physical and daily activity	35.56	9.50
Psychological	28.4	7.98
Sexuality	7.72	3.36

Table 3.
The score of participants in each domain on SCNs survey.

Items	Domain	No.	(%)
Itching	P&D	253	84.3
Being treated like a person, not just another case	H&I	252	84
Keeping a positive outlook	Psycho	233	77.7
Nausea and vomiting	P&D	219	73.0
Swelling of arms, legs, or abdomen	P&D	217	72.3
Being treated in a hospital or clinic that is as physically pleasant as possible	H&I	204	68
Learning to feel in control of your situation	Psycho	203	67.7
Having one member of hospital staff with whom you can talk about all aspects of your condition, treatment, and follow-up	H&I	198	66
Feelings about death and dying	Psycho	195	65
Prickling or numb sensation	P&D	185	61.7

Table 4.
Top 10 most frequently met needs of participants.

The 10 most frequently met needs of 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, in terms of the studied domains, 4 of the commonly met needs related to aspects of physical and daily activity; and 3 each related to the H&I domain. Interestingly, 4 of these items are related to P&D (3 items) and H&I mean no need to help in physically and patients have equal rights to being treatment and follow-up.

4. Discussion

To our knowledge, this is the first study that has investigated the SCNs of cancer patients in the Kurdistan Federal Region, and indeed Iraq in general. The results demonstrate that Kurdish cancer patients have many unmet SCNs, especially in the domains of health system, information, P&D. Most of the participants reported unmet SCNs in 13 items of SCNs.

In an extensive review of the literature, it was found that some studies reported that cancer patients have low needs; [11, 19] but most studies highlight that cancer patients in both non-Western [17–21] and Western countries [9, 14, 31] have many SCNs. None of the analyzed studies reported such high levels of needs as reported by the participants of our study.

The results of our study demonstrate that 6 out of 15 most frequently unmet SCNs of cancer patients are related to the H&I domain. This finding is to some degree different with previous studies conducted in Western countries, which reported the H&I domain to be the second or third domain in which cancer patients' needs are unmet [6, 9, 13, 32–36]. Conversely, the findings of other studies conducted in Southwest Asia indicated that H&I domain needs are among the most frequent unmet SCNs of cancer patients [17, 20, 21, 34]. Likewise, a comparative study revealed that Hong Kong breast cancer patients ranked H&I needs as the most frequent unmet SCNs, while German women consider needs from P&D and Psycho needs to be the most frequently unmet supportive care they experienced [19]. Therefore, this finding supports that SCNs are a culture-dependent issue [19]. Additionally, survivors' needs are dynamic and might change over time. A shift in perceived cancer survivors' needs from informational needs to Psycho needs has been found by researchers, partly attributable to improvements in information delivery over the years [37]. Further research is required to ascertain whether the predominance of H&I needs in the Kurdistan region can be justified by reasons like changing expectations for information provision due to ease of access to internet-based information, or an institutional deficit instigated by other possible reasons, such as lacking clinical resources or insufficient staff education. No additional evidence could be established on the prevalence of cancer patients' informational needs, and whether these needs have changed over time or been influenced by contemporary changes in information seeking practices.

The results of our study also indicated that Psycho needs are the second category of unmet SCNs of Kurdish cancer patients, after H&I needs. This finding is consistent with the results of other studies in non-Western countries [17, 20, 21, 37]. It should be noted that Kurdish cancer patients are often unaware of the prognosis of their diseases, and consider cancer to be a conventional, curable disease. Consequently, it can be inferred that the nondisclosure of cancer prognosis for most Kurdish cancer patients may explain the unusually low level of Psycho SCNs found among Kurdish cancer patients.

The results of this study have important clinical implications, particularly in demonstrating that cancer patients in the Kurdistan Region of Iraq have many SCNs in different domains. Few established supportive care programs are available for patients with cancer in Iraq, and our findings underline that there is an urgent need for such programs to be established. Most unmet SCNs cancer patients in Iraq are from the perspective of the domains of H&I and P&D. Thus, educating cancer patients and meeting their H&I and Psycho needs should be considered as a fundamental part of supportive care programs.

There are limitations to our study. This study was conducted in two oncology centers in the Kurdistan Region of Iraq; even though the setting comprises the main referral center for a large province in northern of Iraq, it does not include all areas of Iraq. The findings related to non-specific SCNs ought to be interpreted with caution, considering the taboo associated with sexual issues in Iraq and Kurdish culture. Further studies are necessary that investigate the SCNs of different cultures in the Middle East. Using other data collection methods, including private interviews, may increase the validity of results in the sexual domain of SCNs.

5. Conclusion

This study highlights that Kurdish cancer patients have many unmet needs in all domains of SCNs. These findings indicate that programs and services to address the SCNs are urgently needed. Future research in Iraq should shed light on the

particular SCNs of patients in cultural contexts, to help tailor more comprehensive and holistic care, particularly for cancer patients, in order to improve the quality of healthcare services provided.

Ethical considerations

The research project was approved by the Ethics Committee of Hawler Medical University, College of Nursing (Project No. 3, approval date: 2016/03/16).

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Author details

Ezaddin Kamal Mahmod* and Saadia Ahmed Khuder
Hawler Medical University, College of Nursing and Midwifery,
Erbil City, Kurdistan Region, Iraq

*Address all correspondence to: ezaddinbotany@yahoo.com

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