

# Unmet Supportive Care Needs of General Cancer in Kurdistan Region- Iraq

Ezaddin Kamal Mahmod<sup>1</sup>, Saadia Ahmed Khuder<sup>2</sup>

<sup>1</sup> Assist. Lecturer; <sup>2</sup> Prof. Dr., College of Nursing and Midwifery, Hawler Medical University, Erbil, Kurdistan Region- Iraq

## Abstract

**Background:** Cancer is a class of diseases or disorders characterized by uncontrolled division of cells.

**Objective:** The study aims to to determine the SCNs of cancer patients in Iraq.

**Methodology:** 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.

**Key words:** Cancer patient, Supportive Care Needs, Kurdistan region.

## Introduction

Cancer is the second leading cause of death worldwide, with an estimated global health burden of 193.6 million disability-adjusted life years.<sup>1</sup> As a result, the diagnosis of cancer may be experienced as a stressful event that negatively impacts many aspects of patients' lives.<sup>2</sup> Rapid changes occurred in the lifestyles of Kurdish people that affected patterns and rates of cancer trends in Kurdistan. Additionally the populations suffer 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<sup>3, 4-6</sup> Aside from their oncology condition, cancer patients often experience many ancillary problems, including negative physical symptoms, social isolation, spiritual suffering, and often psychological distress.<sup>7, 8</sup> This underpins the need for a wide range of robust supportive care services.<sup>2, 9</sup> 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.<sup>6</sup> Nowadays, providing supportive care is considered to be of equal significance to diagnosis and treatment of cancer, and it involves more holistic healthcare provision compared to the biomedical approach that dominates

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### Corresponding Author:

**Ezaddin Kamal Mahmod**, College of Nursing and Midwifery, Hawler Medical University, Erbil, Kurdistan region- Iraq;  
E-mail: Ezaddinbotany@yahoo.com

mainstream oncology treatment.<sup>11</sup> The first step in planning any supportive care services for cancer patients is identifying their supportive care needs (SCNs).<sup>10, 12</sup>

SCNs 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 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.

## Materials and Method

This study was conducted in Rezgary teaching and Nankaly Oncology Hospital in the Kurdistan Federal Region of Iraq. Both hospitals are educational centers affiliated to 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. 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.

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 SCNs Survey (SCNS). The long form of SCNS was

used to investigate the SCNs of cancer patients; it is diverted from previous studies.<sup>20</sup> This scale contains 48 items addressing five domains of needs: psychological (11 items), health system and information (15 items), physical and daily living (7 items), patient care and support (8 items), sexuality (3 items), and no specific items (4 items). Patients reported their SCNs in each item 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 SCNs, the five 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>19</sup>

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

Data analysis was performed using SPSS version 22 (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 SCNs of participants.

## Results

**Table 1. Top 15 unmet SCNs of cancer patients**

Items	Domain	Number	(%)
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

**Cont... Table 1. Top 15 unmet SCNs of cancer patients**

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

Participants mean scores in the SCNS domains are reported in Table 2. As shown in this table, in four domains (health system and information, physical and daily living, psychological, and patient care and support), the participants gained scores of more than 10, indicating that most of the participants have many unmet needs; only the sexuality domain had a score of less than 10.

**Table 2. The score of participants in each domain on SCNs survey**

Domains	Mean	Std. Deviation
Psychological	28.4	7.98
Sexuality	7.72	3.36
Physical and daily activity	35.56	9.50
Health system and information	36.42	8.15
No specific	6.07	2.11
Patient care and support	14.27	4.68

The 10 most frequently met needs of participants are reported in Table 3. More than 70% of the participants reported that they have no needs in these items.

**Table 3. Top 10 most frequently met needs of participants**

Items	Domain	Number	(%)
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

**Cont... Table 3. Top 10 most frequently met needs of participants**

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

### 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, physical and daily living. 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;<sup>10, 16</sup> but most studies highlight that cancer patients in both non-Western<sup>15-18</sup> and Western countries<sup>9, 17, 14</sup> 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 health system and information domain. This finding is to some degree different with previous studies conducted in the Western countries that reported health system and information domain as the second or third domain in which cancer patients' needs are not met.<sup>6, 9, and 13</sup> In contrast, the results of some studies in Southwest Asia showed that the needs from health care and information domain are between the most frequent unmet SCNs of cancer patients.<sup>15, 17, and 18</sup> Similarly, the results of a comparative study showed that Hong Kong breast cancer patients rated health system and information needs as the most frequent unmet SCNs, while German women consider needs from physical and daily living and psychological needs to be the most frequent unmet supportive care they experienced.<sup>16</sup> Therefore, this finding supports that the SCNs are a culture-dependent issue.

The results of our study also indicated that psychological needs are the second category of unmet SCNs of Kurdish cancer patients, after needs from health system and information. This finding is consistent with the results of other studies in non-Western countries.<sup>15, 18</sup> 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 psychological SCNs found among Kurdish cancer patients.

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 no 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, which may increase the validity of results in the sexual domain of SCNs.

### 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.

**Conflicts of Interest:** there is no

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**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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