

Unmet Health Care Needs among Cancer Patients in Baghdad, National Centre for Cancer Diseases in 2018.

Mustafa Majid , Sara Shihab Ahmad , Ali Abdulmortafea ¹ Manwar Al-Naqqash ²

¹ Student at Baghdad University College of medicine.

² Oncology Specialist, Baghdad Medical City; Department Of Surgery

ABSTRACT

Background: Identifying the unmet health care needs of cancer patients represents the first step in making health care provided to these patients better. Being able to accurately estimate the extent of these unmet needs and whether there are certain factors affecting their prevalence and distribution can give helpful information to healthcare providers guiding them on how to solve these problems. This study aims to identify the unmet health care needs and find out whether there is a possible association between these unmet needs and some demographic factors such as age gender and occupation.

Patients and Methods: A cross-sectional study was conducted on 200 cancer patients in The National Centre for cancer diseases in Baghdad selected by convenient sampling. The data was collected by interviewing patients with a preformed questionnaire (SUNS questionnaire, Access and Continuity Domain). Data was analyzed by using SPSS v20.

Results: The highest prevalence of unmet needs was related to having family doctor items, while the lowest was related to having access to the patients' medical information when planning services for them. 30.34% of a sample of patients were fully satisfied with the National Center for cancer diseases and said that there are no changes needed to be done while 17.39% complained about the unavailability of therapy at the center.

Conclusion: This Study reveals that there is a low level of unmet needs among cancer patients indicating a good quality of provided care in the center with highest unmet needs for the family doctor and lowest for accessibility of health team to medical files and information.

Keywords: Cancer, Unmet Needs, Health Care

Corresponding author: Mustafa Majid Student at Baghdad University College of medicine., Baghdad, Iraq. Email : Mustafa.majid.1997@gmail.com

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INTRODUCTION

Cancer is considered the second leading cause of mortality worldwide. ⁽¹⁾ Cigarette smoking accounts for 80% of lung cancer cases in men and 50% of lung cancer cases in women worldwide. These cases alone account for more than 20% of all global cancer deaths. ⁽²⁾

Cancer was responsible for about 8.8 million deaths in 2015 and found to be the cause of nearly 1 in 6 deaths worldwide and this number is likely to increase in the future. This projected increase in cancer can be attributed to population ageing, better detection and registration, and most importantly, to increased exposure to risk factors. In Iraq, it represented the second leading cause of death among non-communicable diseases in 2016 being responsible for 11% of total deaths. ⁽³⁾

In 2018, the global cancer burden was estimated to have increased to 18.1 million new cases and 9.6 million deaths. Men have an incidence of one in 5 for developing cancer during their lifetime while in women it is one in 6 with death rate of one in every 8 men and one in every 11 women. ⁽⁴⁾ The latest Iraqi Cancer Registry revealed that among an estimated population size of 39,339,754, a total of 25,320 new cases of cancer were registered in 2018. ⁽⁵⁾

Having cancer, for many people, has become a fact that they are forced to live with, with all the emotional, social and physical consequences and needs that it brings. Living “well” while having cancer and associated treatment is fundamental to a person’s well-being and quality of life, and care should, wherever possible, fit the peculiar needs of individual cancer patients and their families. ⁽⁶⁾

However, Cancer care often lacks completeness and continuity, as patients are

frequently referred between different health care providers in different hospitals and sometimes across several geographic areas. This fragmentation of provided health care tends to affect its quality and increases patients' unmet needs. ⁽⁷⁻¹⁰⁾

Unmet health care needs are those needs - provided by health care staff; i.e. doctors, nurses, etc.- that are necessary for the person to achieve an optimal wellbeing and satisfying outcome but sometimes, he might not fully receive; either due to lack of services at his province , unskilled techniques of the medical staff or other causes. ⁽¹¹⁾

Being able to appropriately identify these unmet needs is important because they are found to be significantly associated with both psychological distress and poor quality of life ⁽¹²⁾ which may in turn negatively affect the health care system by increasing health care utilization and costs. ⁽¹⁰⁻¹³⁾

Furthermore, an accurate estimation and management of these problems would make a great impact on the quality of provided care and enhance patients' experiences within health care facilities. ⁽¹³⁾

Despite, the importance of determining these unmet needs; not many studies have been conducted to cover this objective in Iraq. This research builds upon a previous research completed by Ramezanzade Tabriz E et al done in Iran regarding the unmet needs of cancer patients to identify the "unmet health care needs" section, the problems that the patient faced during his/her visit to the hospital, take some suggestions and solutions from the patients for their problems.

Study Aims

- To identify the patients' unmet needs regarding the health care provided to them.
- To find if there is any possible association between patients' unmet needs and some demographic factors such as age, gender and employment.

MATERIALS AND METHODS

Study Design and settings

A cross sectional study was held in National Centre for cancer diseases in Baghdad, 2018 from first of July to first of August.

Population and sampling

This study included 200 patients selected by convenient sampling.

Inclusion criteria were: age above 15 years and having a definite diagnosis of cancer. Patients who were coming to center for the first time were excluded.

Data was taken from the patients themselves or their relatives in cases where patients were too tired to answer questions or were not aware of their sickness.

Data Collection

For collecting data, an interview was done with the patients using survivor unmet needs survey (SUNS),⁽¹⁴⁾ health access and continuity domain. The questionnaire includes demographics (age, sex, marital status, educational level, employment status) cancer related factors, treatment related questions and 22 items regarding health care access and continuity. Each item has a score from 0 to 4, depending on the case response.

The participants were asked to assess their unmet needs on a scale of 0 to 10 with 0 representing no unmet needs (score of 0), 1-3 low unmet need (score of 1), 4-6 moderate unmet needs (score of 2), 7-9 high unmet needs

(score of 3), and 10 very high unmet needs (score of 4)

As for patients who were not educated enough, subjective assessment was done by the researchers. These terms were appropriately explained to the patients as follows:

No unmet need (score of 0): This is not a problem for me as a result of having cancer now or in the past.

Low unmet needs (score of 1): I needed a small amount of help with this problem but was not able to get it.

Moderate unmet need (score of 2): I needed a moderate amount of help with this problem but was not able to get it.

High unmet need (score of 3): I needed a high amount of help with this problem but was not able to get it.

Very high unmet need (score of 4): I needed a very high amount of help with this problem but was not able to get it.

Statistical Analyses

Data was analyzed using descriptive statistics such as tables and inferential statistics including one-way ANOVA and T- test. All statistical analyses were performed using SPSS version 20. All tests were two-sided, with a confidence level of 0.05.

The questionnaire was translated to Arabic. Face, content validity were assessed by a 5 public health doctors in Baghdad University, College of Medicine. Internal consistency was also assessed (alpha Cronbach is 0.59). Inter-rater reliability was done using Pearson's correlation coefficient with minimum r value of 0.64 for a single item.

Ethical Considerations

The aim of the research was clarified to the patients, an informed consent was taken from them and their identity will remain anonymous.

RESULTS

Demographical factors Results

In this study, all the demographic factor are illustrated in Table (1) except for educational level status which is shown in Graph (1) 97.5% of the patients were with an accompanying member of the family when visiting the cancer center. The mean number of the households of the patients was 7.1 ± 3.77 . 3.5% of the patients or relatives interviewed participated in a support group

Disease-related factors Results

101 (51.3 %) of the patients were diagnosed in year 2018, 56 (28.4 %) in year 2017 and others in the previous years. 40 (20%) of the patients faced a recurrence, 79 (39.5%) faced a metastasis. The types of cancer are illustrated in (Table 2)

Treatment-related factors Results

44.1% of the patients go to an outpatient clinic when they need any health care service (related or not related to the chemotherapy), 49.7% to the hospital and 6.1% to a nearby medical assistance or a doctor in their family, nearby medical assistant. 96.5% of the patients have received treatments (scheduled chemotherapy) in the last month, 97% were seen by a doctor the last month. 80% of the patients had to buy part of the chemotherapy from outside the hospital, at least once due to shortage of the supplies in the center. 72.1% of the patients faced a health problem (which may be related to chemotherapy) in the past month.

The mean driving time in hours from home to hospital is 1.14 ± 2.26 SD.

45.7% of the patients had to do the follow up tests at least for once outside the hospital, 42.5% of them because of the long time needed in the center, 45% because they are unavailable in the center and 12.5% for other reasons.

Unmet needs-related items Results

The mean of the scores of the health care access continuity domain of the SUNS questionnaire is 0.99 with SD of 0.387. This score calculated for 162 participants, as the other 38 showed some missing data.

Regarding the associations:

Males (n=39) showed a score of 0.95, while the females (n=123) showed a score of 1, so the association between gender and unmet health care needs, that was calculated using t-test is insignificant with p value of 0.496.

Illiterate and those with primary education degree (n=91) had a score of 0.93, those with secondary degree (n=33) showed a score of 1.08, and participants graduated from college, institutes or have higher educational level (n=38) showed a score of 1.06. Also, Employees (n=122) showed a score of 1.01 and the other group (non-workers) showed a score of 1.01, so the association between the needs and the educational level and employment status was also insignificant using ANOVA with p-value of 0.104 and 0.412 respectively.

Those above 55 years (n=77) had a score of 1.02, those below that age (n=85) showed a score of 0.95, so the relationship between age and unmet needs, there was an insignificant relationship with $r = 0.05$ and p value of 0.53

No other significant relationships were found between unmet health care needs, Types of cancer and year of diagnosis with p- values of 0.72 and 0.81 respectively

To examine the distribution of unmet needs in the sample, we created three levels of need for each individual unmet need item: none (no unmet need), low to moderate, high to very high unmet need. The Number of patients, percentages and scores' means of unmet health care needs levels are illustrated in (Table 3).

Patients' Suggestions

In sample of 46 cases, we asked patients about their suggestions on how to make the hospital a better place. The results are shown in the (Fig. 2)

Table 1: Patients' Demographic Characteristics.

Characteristic	Category	No. of patients
Gender	Males	49 (24.5%)
	Females	151 (75.5%)
Age	<20 years	5 (2.5%)
	21-40 years	24 (12.1%)
	41-60 years	94 (47.2%)
	61-80 years	75 (37.7%)
	>80 years	1 (0.5%)
Marital Status	Married	182 (91%)
	Not married	18 (9%)
Employment Status	Not Employed	148 (74%)
	Employed	49 (24.5%)
	Students	3 (1.5%)

Figure 1 : Educational Level Status among Patients

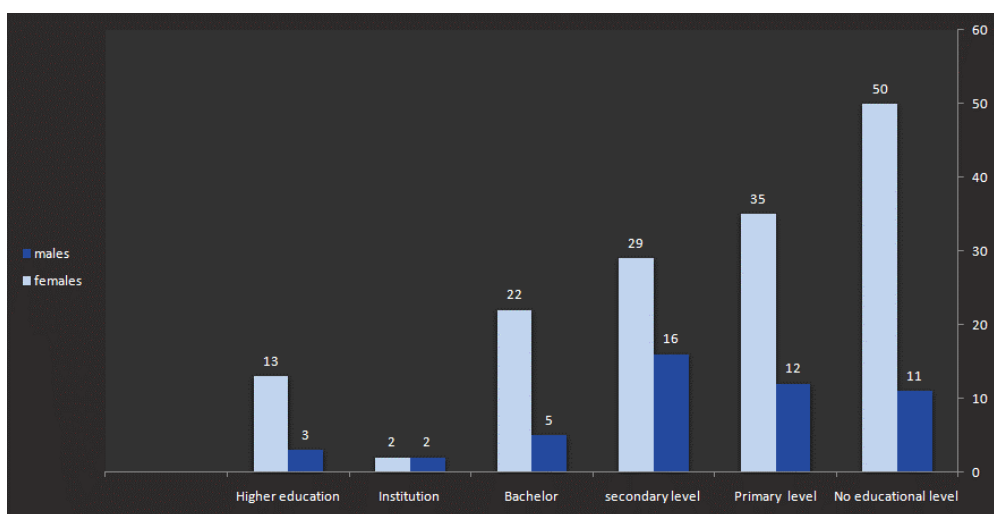


Table 2: Cancer Types in 200 Sample in National Center for Cancer Diseases, 2018

Type of cancer	No. of patients
Breast	91 (45.7%)
Lung	19 (9.5%)
Head and Neck	14 (7%)
uterine	13 (6.5%)
ovaries	13 (6.5%)
Soft tissue sarcoma	12 (6%)
colorectal	10 (5%)
Lymphoma	7 (3.5%)
Pancreatic	5 (2.5%)
Other	16 (8%)

Table 3: Number of patients, percentages and scores' means of unmet health care needs levels in national center for cancer diseases in Baghdad 2018

Unmet health needs item	No unmet need	Low to moderate unmet need	High to very high unmet need	Mean score
Making sure my family doctor could get information from specialists*	27(13.6%)	3(1.5%)	169(84.9%)	3.40 ± 1.40
Getting appointments with my family doctor quickly enough	30(15%)	3(1.5%)	167(83.5%)	3.36 ± 1.45
Making sure I had choices about which hospital or clinic I could go to*	58(29.4%)	8(4.1%)	131(66.5%)	2.63 ± 1.79
Finding information about who I should contact if I have a problem or concern*	84 (44%)	12(6.3%)	94(49.5%)	2.04 ± 1.92
Having access to cancer services close to my home*	73(36.7%)	37(18.6%)	89(44.7%)	1.92 ± 1.73
Finding out what is involved in follow up care*	76(41.1%)	53(28.6%)	56(30.3%)	1.48 ± 1.53
Feeling comfortable in the waiting room*	88(46.3%)	85(44.7%)	17(8.9%)	0.92 ± 1.10
Getting test results quickly	115(57.5%)	61(30.5%)	24(12%)	0.84 ± 1.16
Making sure I was treated in a hospital or clinic that was as physically pleasant as possible*	99(50%)	89(44.9%)	10(5.1%)	0.83 ± 1.12
Getting follow up tests quickly	135(67.5%)	46(23%)	19(9.5%)	0.64 ± 1.07
Understanding the information I was given	162(81%)	14 (7%)	24(12%)	0.56 ± 1.25
Finding information about cancer and its effects in a way I can understand	161(80.5%)	17(8.5%)	22(11%)	0.53 ± 1.16
Making sure all your health care workers had all the medical files related to my cancer care*	169(86.2%)	5(2.6%)	22(11.2%)	0.44 ± 1.15
Getting appointments with specialists quickly	161(84.7%)	12(6.3%)	17(8.9%)	0.43 ± 1.14

Unmet Health Needs among Cancer Patients in Baghdad

Enough (oncologists, surgeons, etc.)				
Making sure you were treated like a person , not just another case	166(83%)	21(10.5)	13(6.5%)	0.42 ± 1.03
Finding health care professionals who were friendly and could have a laugh with you	162(81%)	27(13.5%)	11(5.5%)	0.42 ± 0.99
Making sure the health care team understood and was aware of my feelings and emotional needs	170(85%)	19(9.5%)	11(5.5%)	0.35 ± 0.92
Having access to care from other health specialists (dieticians, physiotherapists, occupational therapists)*	182(91.2%)	0(0%)	17(8.5%)	0.34 ± 1.10
Making sure you had enough time to ask my doctor or nurse questions	175(87.5%)	12(6%)	13(6.5%)	0.32 ± 0.93
Getting the health care team to attend promptly to my physical needs	176(88%)	14(7%)	10(5%)	0.30 ± 0.86
Having access to cancer services at night and on weekends*	194(97.5%)	2(1%)	3(1.5%)	0.08 ± 0.51
Making sure health care workers had access to my medical information when planning services for me*	196(98.5%)	2(1%)	1(0.5%)	0.04 ± 0.32

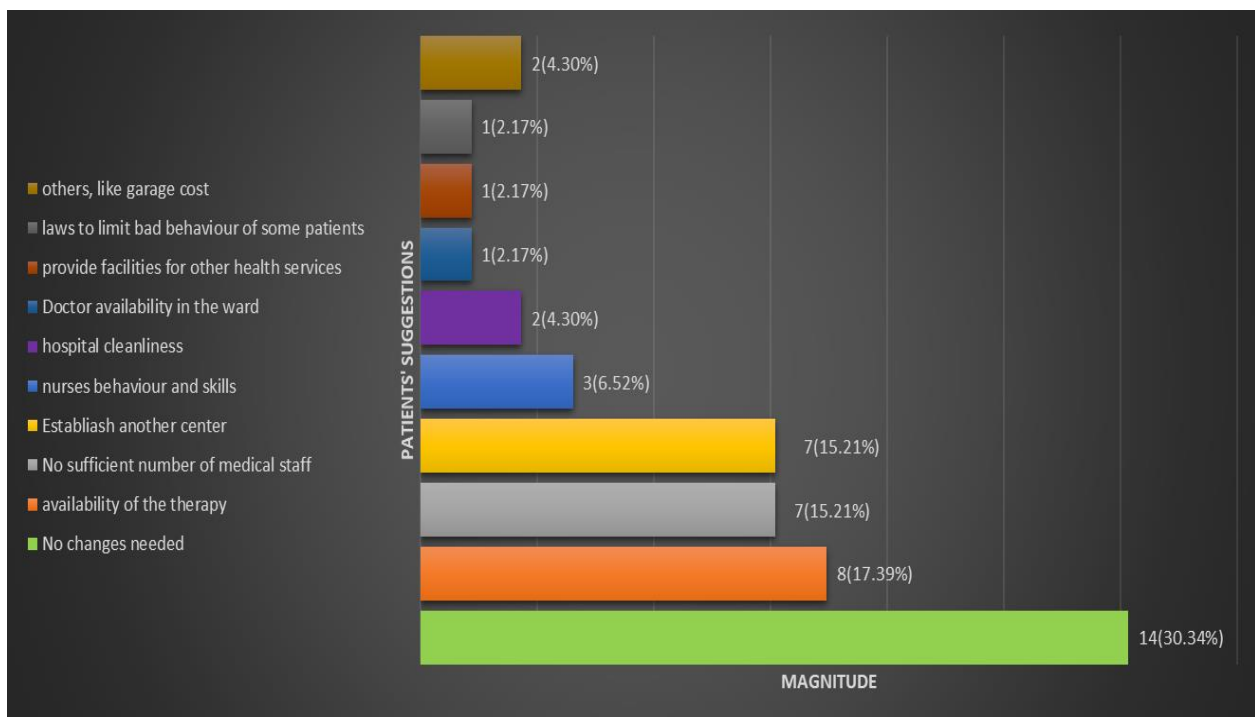


Figure 2 : Patients' Suggestions Regarding Hospital Improvement

DISCUSSION

This study discusses the unmet health care needs of cancer patients. However, there are a number of limitations that should be considered when interpreting the results. Firstly, some patients (60 out of 200) were illiterate, so their estimations of the unmet need score may not be as precise as the rest of the sample

Secondly, some of the patients were not aware of their illness or were too tired to give an answer so data was taken from their relatives who usually come with them that could be different from their own unmet needs; overestimating some and underestimating others.

Thirdly, this study involved only one center for cancer treatment and so the results we found may be different from other centers in Iraq and hence this could limit the generalizability of the results.

Lastly, since the majority of the population were females, their unmet needs may be overrepresented in this study and so larger sample size may be required in future studies.

Despite these limitations, this study is considered one of the first studies in Iraq to assess patients' unmet need. The mean score of these unmet needs indicates a low level of unmet needs. When comparing this mean to the research done in Iran of Ramezanzade Tabriz E et al. ⁽¹⁵⁾, their score was about 2.16 (which means a moderate level of unmet needs); this may points out that the care provided here is more sufficient.

As for unmet needs items, the highest prevalence of unmet needs was related to having family doctor items. Since family doctor system is usually inapplicable in our country according to a study done in Kurdistan regarding Iraqi primary care system ⁽¹⁶⁾, here we considered a family doctor as the doctor who is being visited by the patient and his family frequently for any health problem. Only

a few 15% cases had a family doctor and could get appointment with him quickly, out of those only 15% having their family doctor communicating with the specialist.

The lowest prevalence of unmet needs was related to having access to the patients' medical information when planning services for them, reflecting the excellent continuity of the follow up care.

As for having access to cancer services at night and on weekends:

The vast majority of the patients found that the hospital is open in these times, indicating good availability of the health care services.

Since about 97% of patients have been seen by the doctor and have received treatment in the last month, this indicates good follow up care and commitment on the side of the medical staff.

The majority of the patients participated in the study had enough time to ask their doctor and understood the information given to them, this means that the information given to the patients during consultation seems to be sufficient which is different from what was found by Nielsem Bohlman, Panzer and Kindig ⁽¹⁷⁾, in which patients did not find the information given to them enough. This is important since increased knowledge could facilitate communication between the clinician and the patients, thereby improving their care. ⁽¹⁷⁾

Our results showed that the association between gender and unmet health care needs is insignificant ,which is consistent with the research done in Iran by Ramezanzade Tabriz E et al ⁽¹⁵⁾ , Sanders et al and Bredart et al. ^(18,19) but is different from Boyes et al whose results showed that female patients had higher needs. ⁽²⁰⁾

Our study showed that the association between the needs and the educational level and employment status were also insignificant

which is different from Ramezanzade Tabriz E et al and Park et al. ⁽¹²⁾ who found a significant relationships between education level, economic status and unmet needs.

As for the relationship between age and unmet needs, there was an insignificant relationship that is also different from Ramezanzade Tabriz E et al ⁽¹⁶⁾ who found that there is a relationship that is indirect, that is , as the patients' age increased ;their unmet needs decreased ($r=-0.10$).

Regarding Treatment, The needed therapy is available in the national center fully reimbursed to the patients, which facilitates the accessibility to the patients. While according to Ramezanzade Tabriz E et al, ⁽¹⁵⁾ high expenditure on the treatments limits the accessibility of the patients, and higher unmet needs among low socioeconomic states are found. However, 80% of patients had to buy therapy from outside the hospital, at least once, either due to shortage of supplies or because they don't trust the quality of the therapy. Hence, some of the patients suggested the need to establish a nearby pharmacy from which they can buy the therapy in times when it is not available at the center.

CONCLUSIONS

Generally, this study showed a low level of unmet needs. The lowest was related to having access to the patients' medical information when planning services for them. The highest was about the family doctor health needs items that most of the patients did not have which if present may improve early detection and outcome of some cancer patients.

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