Evaluation of Referral System for Cancer Patients and The Information they received about Their Disease in Tertiary Hospitals in Riyadh, 2012

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Abstract

Cancer is a major health problem in both developed and developing countries. This study was designed to evaluate the referral system for cancer patients, and to assess the information which is received by cancer patients about their disease in tertiary hospitals in Riyadh, KSA. A cross sectional study was conducted on 73 cancer patients who received treatment in two tertiary hospitals in Riyadh; King Fahd Medical city and King Khalid University Hospital in March 2012. The study included any man or woman above 15 years old, who had been diagnosed with any type of cancer, and received treatment in the tertiary hospital for any time period. All the participants were recruited from the chemotherapy department and outpatient clinic. Data was collected through questionnaire interview with all patients or their relatives by the study investigator. QLQ-INFO25 questionnaire was used. There were 30 (44.8%) patients who had been referred to KFMC or KKUH, and 37 (55.2%) patients who had been admitted without referral. The main cause of referral was to confirm the diagnosis 76.7%, then to receive chemotherapy 16.7%. Time duration to the acceptance was 40% less than one week, 36% one to two weeks, 3.3% three to four weeks, 13.3% one to two months, and 6.7% more than two months. 70% of cancer patients gave their case report by hand to the tertiary hospital, 23.3% sent their case report by fax, and 3.3% sent the case report by email. 25 (83.3%) cancer patients were satisfied with the referral system of cancer patients in Saudi Arabia. The global score of the information module "QLQ-INFO25" was 67. The mean score was 31.3 (46.8) and standard deviation was 12.1. From this study, we conclude that, the referral system for cancer patients in Saudi Arabia needs to be electronic, unified in all hospitals, fair with all cancer patients, time effective, connect all tertiary hospitals and have a two way direction between secondary and tertiary hospitals. All medical facilities should provide the disease information to cancer patients by transparency and honesty. Health educators and social workers have an important role in psychological support to cancer patients.

Key words: **Referral system, information, cancer patients, Riyadh Saudi Arabia**

Introduction

Cancer is a major health problem in both developed and developing countries. According to the World Health Organization's most recent figures, the global incidence of cancer was nearly 12.7 million in 2008. Projected incidence rates are calculated at over 21.4 million by 2030. Also, in 2008 over 7.6 million people died from cancer and projected mortality rates will exceed 11 million by 2030. However, WHO reports future mortality rates could be reduced with regular screenings, timely diagnosis and early treatment of cancers (1).

In Saudi Arabia, age-standardized death rate per 100,000 for cancer patients was 79.2 in males and 66.2 in females. Cancer was estimated to account for 6% of all deaths in 2010 (2). According to the KSA National Cancer Registry, from January 1998 to December 2007 there were 69,941 Saudi nationals diagnosed with cancer. More than 50% of cases presented with advanced cancer (31% of males and 24% of females presented with distant metastasis, and regional metastases were present in 20% of males and 28% of females) (3). A comprehensive cancer control encompasses primary prevention, early detection/ screening, treatment and palliative care (4). Cost-effective interventions are available across the four broad approaches to cancer prevention and control (5, 6, 4-7). Early detection and screening for cancer and Population-based screening for common cancers are important complements to primary prevention.

Early diagnosis is essential to reduce cancer morbidity and mortality since cancer stage at diagnosis is the most important determinant of treatment options and patient survival. Early detection is based upon awareness of early signs and symptoms. In a population where the majority of the cancers are diagnosed in late stages, the establishment of an early diagnosis program is an effective strategy to reduce the proportion of advanced stages and improve survival rates for selected cancers that may be amenable to effective treatment with limited resources (e.g. cervical, breast, oral or skin cancers) (6, 4-7).

Referral system is one of the services provided to cancer patients to confirm the diagnosis and receive the appropriate treatment. Referral was defined as a process in which the treating physician at a lower level of the health service, who has inadequate skills by virtue of his qualification and/or fewer facilities to manage a clinical condition, seeks the assistance of a better equipped and/or specially trained person, with better resources at a higher level, to guide him in managing or to take over the management of a particular episode of a clinical condition in a beneficiary.(8)

In Saudi Arabia, Ministry of Health is responsible for the supervision of health care and hospitals in both the public and private sectors. The system offers universal health care coverage.(9) In Riyadh, there are 4 tertiary hospitals. They receive the cancer patients from all Saudi regions, and offer a free service. Most of cancer patients are diagnosed initially in the primary or secondary hospitals in different regions, and they are referred to the tertiary hospitals to confirm diagnosis or to receive chemotherapy, radiotherapy, or to do some special surgeries. After the case report of the cancer patient is written and sent to the tertiary hospitals, there is a special committee to study the case and get the acceptance or rejection. Each tertiary hospital has its own referral system and its own processes. So, there is no unified system that can facilitate and organize the referral system.

There is some evidence that doctors are failing to inform patients when they diagnose cancer, particularly in older patients (10, 11, 12). This is despite evidence that some patients with malignancy want to know if their illness is cancer, and others want to know as much as possible about their illness, often more than a doctor assumes they want to know (13, 14, 15, 16).

This study discusses two issues. The first one is the referral system for cancer patients in Saudi Arabia and the other issue is the information received by cancer patients about their disease.

Material and Methods

This study was conducted throughout 4 months, March-July 2012, using the information module QLQ-INFO25, by questionnaire interview method. The questionnaire consisted of 4 parts: The first part consisted of sociodemographic data; the second part was eight multiple choice questions which were qualitative variables. They included information regarding the disease, the time and place of diagnosis and type of treatment received. The third part discussed the way, time, and processes of referral system, and the opinion of the participant about the referral system. The last part was composed according to guidelines from the EORTC Quality of Life Group.

Study Design:

A cross sectional study was conducted on 73 cancer patients who received treatment in two tertiary hospitals in Riyadh to evaluate the referral system and information conveyed to patients about their disease and its treatment.

Study Population:

The study included any man or woman above 15 years old who has been diagnosed with any type of cancer and received treatment in the tertiary hospital for any time period. Only Saudis were eligible in the study.

Data Analysis:

SPSS "Statistical Package for the Social Sciences" was used for data entry and data analysis. Each questionnaire had a serial number in the cover page and each question had a serial number in the questionnaire.

Scoring of QLQ-INFO25

		Items	Range	Score	Question
Multi-item Scales	Information about the disease	4	3	12	38-41
	Information about medical tests	3	3	9	42-44
	Information about treatments	6	3	18	45-50
	Information about other services	4	3	12	51-54
Single-item Scales	Information about different places of care	1	3	3	55
	Information about things you can do to help yourself	1	3	3	56
	Satisfaction with the information received	1	3	3	57
	Written information	1	1	1	58
	Information on CD tape /video	1	1	1	59
	Wish to receive more information	1	1	1	60
	Wish you have received less information	1	1	1	61
	Overall the information has been helpful	1	3	3	62
	Global score	1	25	67	

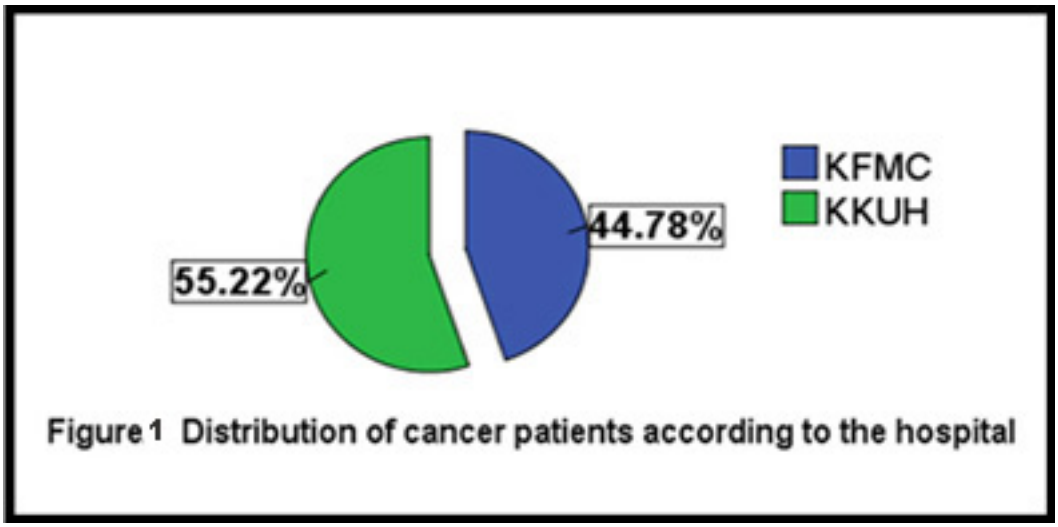

Figure 1 Distribution of cancer patients according to the hospital

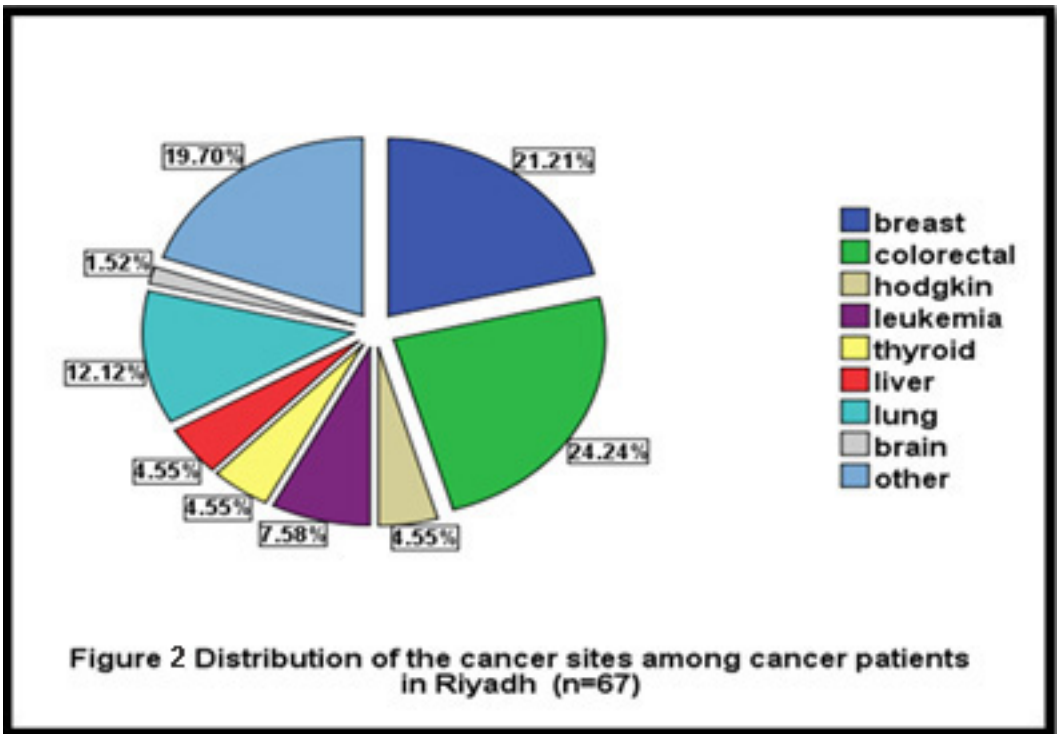

Figure 2 Distribution of the cancer sites among cancer patients in Riyadh (n=67)

Ethical issues were considered. The informed consent was clear and indicated the purpose of the study and right of the participant to withdraw at any time without any obligation to participate. No incentives or rewards were given to the participants and no obligation to participate. Participants' anonymity was assured by assigning each participant with a code number. IRB approval was obtained from King Khalid University Hospital on 18/4/2012.

Results

Sample size was 73 cancer patients; six patients were non Saudis and excluded. Of the other 67 cancer patients, 30(44.8%) were from KFMC and 37(55.2%) from KKUH. (Figure 1 - opposite page).

There were 52 (77.6%) males and 15 (22.4%) females. Educational level of participants was 17% university, 16% illiterate, 16% secondary, 10% intermediate, and 6% primary. The age was between 15 to 80 years old, mean was 50.1 and standard deviation was 16.29.

56.7% of patients have been diagnosed with cancer for less than one year, 34.3% between one to three years, and 9% for more than three years. Patients who received surgery were 57 (85.1%), patients who received chemotherapy were 32 (47.8%), and patients who received radiotherapy were 8 (11.9%). The cancer patients were 24.2% with colorectal cancer, 21.2% with breast cancer, 12.1% with lung cancer, 7.6% with leukemia, 4.5% with Hodgkins, 4.5% with thyroid, 4.5% with liver, and others were 22.3% (Figure 2).

There were 30 (44.8%) patients who had been referred to KFMC or KKUH, and 3 7(55.2%) patients who had been admitted without referral. 63.3% patients had been diagnosed for less than one year, 23% between one to two years, and 13.4% for more than two years. 63.3% had treatment at one tertiary hospital and 33.3% had two tertiary hospitals. The main cause of referral was to confirm the diagnosis 76.7%, then to receive chemotherapy, 16.7%. Time duration to the acceptance was 40% less than one week, 36% one to two weeks, 3.3% three to four weeks, 13.3% one to two months, and 6.7% more than two months. The duration between the acceptance and the first appointment was 50% less than one week in, 33.3% one to two weeks, 6.7% three to four weeks, and 10% one to two months. 70% of cancer patients gave their case report by hand to the tertiary hospital, 23.3% sent their case report by fax, and 3.3% sent the case report by email. 80% came to the tertiary hospital by car, 16.7% by free air plane service for cancer patients, and 3.3% by taxi. (Table 1 - next page)

Extent of satisfaction with referral system (Table 2 - page 31). Percent of patients who thought they were referred in a proper time was 86.7%. Percent of patients who thought the processes of referral were simple and clear was 76.7%. There were 26.7% who thought the referral processes were not unified in all tertiary hospitals, and 73.3% didn't know. There were 30% who thought their disease was affected by the delaying in the referral system. 73% didn't know if there was an electronic referral system, and 20% answered "No". In general, 25 (83.3%) cancer patients were satisfied with the referral system of cancer patients in Saudi Arabia.

The last part of the questionnaire was evaluation of the information received by cancer patients. Patients were 66, and one patient was missed. Regarding the information about disease, maximum score was 12, mean score was 6.2 (51.6%), and standard deviation was 2.4. The maximum score of the information about medical tests was 9. The mean score was 5.1(56.2%), and standard deviation was 2.3. The maximum score of the Information about treatments was 18. The mean score was 10 (56.2%) and standard deviation was 4.5. The maximum score of the Information about other services was 12. The mean score was 2.9 (24.2%) and standard deviation was 3. The global score was 67. The mean score was 31.3 (46.8) and standard deviation was 12.1. In KFMC, cancer patients who had been referred numbered 20 (66.7%), and in KKUH 10 (27%). The difference between the two hospitals was statistically significant by chi-square test. In KFMC, there was an electronic referral system and they had radiotherapy, but in KKUH there was not. In KFMC, time duration to the acceptance was 40% less than one week, and 45% one to two weeks. In KKUH, time duration to the acceptance was 40% less than one week, and 20% one to two weeks. In KFMC, 85% of cancer patients referred to KFMC were satisfied with the referral system, and 80% of cancer patients referred to KKUH were satisfied. In KKUH, 78.4% answered "not at all" and in KFMC, 41.4% answered "not at all". Regarding the information received by the cancer patient, the mean global score was 31.3. In KFMC, the mean global score was 34.8 and standard deviation was 8.95. In KKUH, the mean global score was 28.7 and standard deviation was 13.7.

Discussion

Regarding referral system, most of the studies in Saudi Arabia focus on referral between primary and secondary health care. Sample size of this study was few and not enough (73). There were 30 (44.8%) patients who had been referred to KFMC or KKUH, and 37 (55.2%) patients were not referred. The percent of patients who had not been referred to tertiary hospitals was 55.2%. Some of them had a special royal decree, or they know some workers in the hospital. Other patients were admitted through the emergency department or they were treated by their own account. The main cause of referral was to confirm the diagnosis in 76.7%. This means, 76.7% of cancer patients have confirmed their diagnosis in tertiary hospitals. On the other hand, 23.8% of cancer patients have confirmed their diagnosis in primary and secondary hospitals.

Regarding the standardization of procedures for referral system in the tertiary hospitals, 73.3% of cancer patients did not know about it and 26.7% answered there was not any standardization. There were 20% of cancer patients

Table 1: General information of referral system:

Q	Question	Items	Frequency	Percent
1	When were you referred to the tertiary hospital? "Missing 37"	<1year	19	63.3
		1-2year	7	23.3
		3-4years	2	6.7
		>5years	2	6.7
		Total	30	100.0
2	How many hospitals did you address in the referral?	1	19	63.3
		2	10	33.3
		3	0	0
		4	1	3.3
		Total	30	100.0
3	What was the main cause of the referral?	chemotherapy	5	16.7
		surgery	2	6.7
		confirm diagnosis	23	76.7
		Total	30	100.0
4	When you sent the referral form to the hospital, when did they answer?	<1week	12	40.0
		1-2week	11	36.7
		3-4weeks	1	3.3
		1-2month	4	13.3
		>2months	2	6.7
		Total	30	100.0
5	What was the time period between a hospital acceptance to the first appointment?	<1week	15	50.0
		1-2week	10	33.3
		3-4weeks	2	6.7
		1-2month	3	10.0
		Total	30	100.0
5	What is the time period between the appointments in the tertiary hospital?	1-2week	6	33.3
		3-4weeks	7	38.9
		1-2month	1	5.6
		3-4months	4	22.2
		Total	18	100.0
6	How did you send the referral form to the tertiary hospital?	fax	7	23.3
		email	1	3.3
		by hand	21	70.0
		some one	1	3.3
		Total	30	100.0
7	How do you come to the hospital usually?	car	24	80.0
		taxi	1	3.3
		air plane	5	16.7
		Total	30	100.0
8	Who is the person who escorts you?	parent/son	13	43.3
		relative	15	50.0
		other	2	6.7
		Total	30	100.0

Table 2: Participant's self-perception of referral system:

	Question	Items	Freq.	Percent
1	Have you been referred in a proper time?	Yes	26	86.7
		No	4	13.3
2	Were the processes of referral simple?	Yes	23	76.7
		No	4	13.3
		I don't know	3	10.0
3	Were the processes of referral clear?	Yes	22	73.3
		No	5	16.7
		I don't know	3	10.0
4	Were the processes of referral identical in all hospitals?	No	8	26.7
		I don't know	22	73.3
5	Did you experience difficulty when you referred?	Yes	6	20
		No	24	80
6	Was the time between the appointments suitable for you?	Yes	24	82.8
		No	2	6.9
		I don't know	3	10.3
7	Have you been affected by the delay in the referral system?	Yes	9	30.0
		No	17	56.7
		I don't know	4	13.3
8	Was there a free transportation service in the referred hospital?	Yes	1	3.3
		No	1	3.3
		I don't know	28	93.3
9	Was there an electronic referral system in the hospital?	Yes	2	6.7
		No	6	20.0
		I don't know	22	73.3
10	In general, are you satisfied with the referral system for cancer patients?	Yes	25	83.3
		No	5	16.7

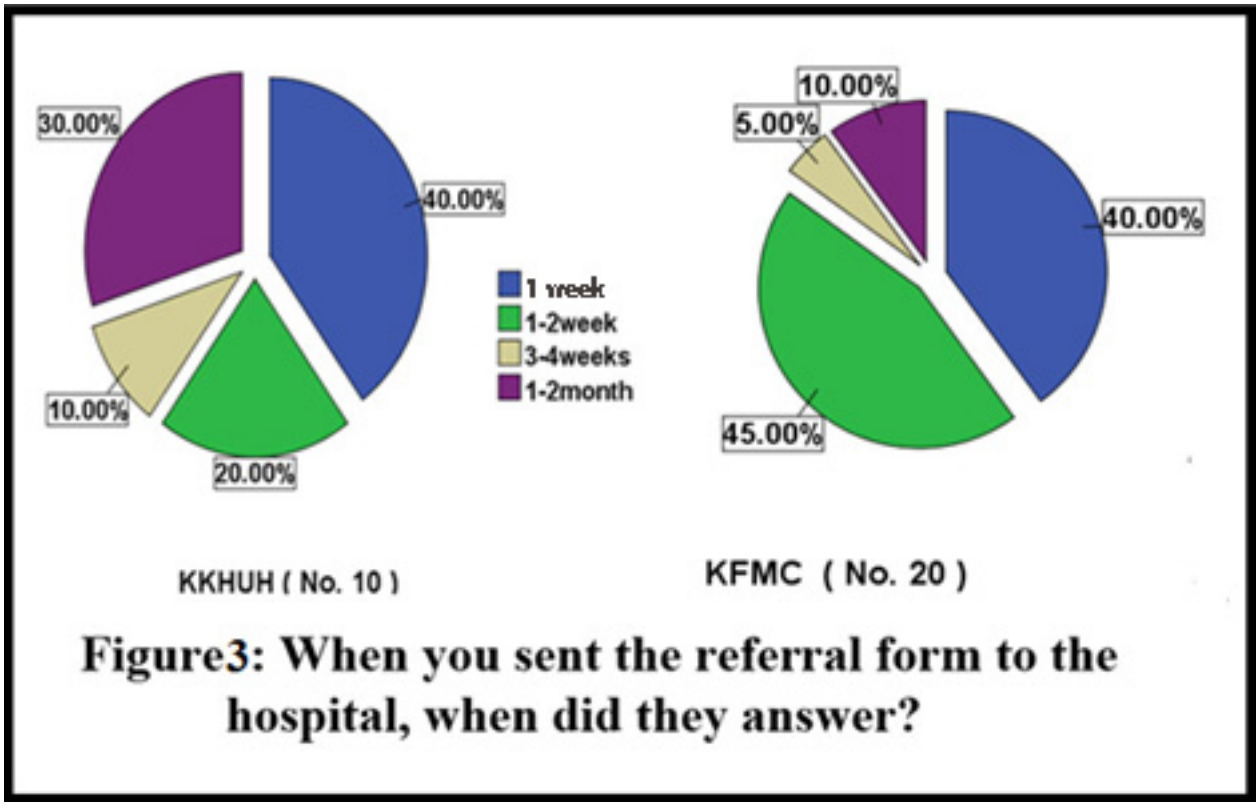

Figure3: When you sent the referral form to the hospital, when did they answer?

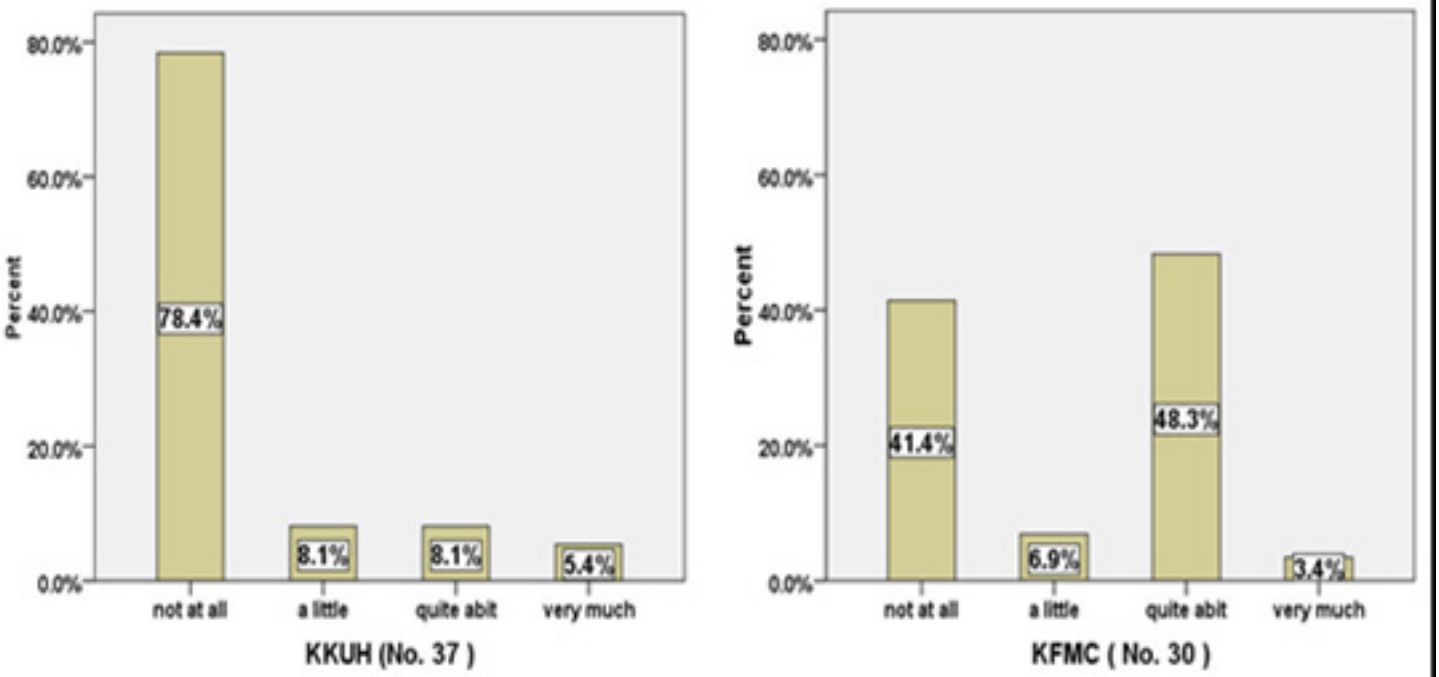

Figure 4: Distribution of information received about psychological support according to hospital

who answered there is no electronic referral system and 73.3% answered "I do not know". In fact, there was no general electronic system connecting all tertiary hospitals in Saudi Arabia. There were 16.7% of cancer patients who had a free transportation service by air plane. Ministry of Health provides the free delivery service for cancer patients who live in remote areas.

There were some limitations in the study. First, the administrative procedures of the tertiary hospitals were complex and not clear. It consumed almost more than month from the study period. The work place was not suitable to conduct the study. Second, there was scarcity of information which related to referral system. It was difficult to know the number of cancer patients who have been referred to each tertiary hospital per month or year, number of referred patients from each region, number of free beds and the capacity of each tertiary hospital, the referral time required of each cancer stage, or the referral time required of each cancer type. Third, the study period was short "four months". Fourth, recall bias was present in some situations. Fifth, sample size was not enough. Sixth, there was no central electronic referral system in Saudi Arabia.

The central electronic referral system controls referral procedures between secondary and tertiary hospitals in all Saudi regions, connects tertiary and secondary hospitals, provides statistics about referral system and produces an annual report, and communicates with patients and hospitals to facilitate the referral procedure and reduce the time. It facilitates the distribution of cancer patients to the tertiary hospitals according to region, type of cancer, age, sex, or type of treatment. It applies standardized guidelines in all tertiary hospitals without discrimination.

Conclusion and Recommendations

Referral system for cancer patients in Saudi Arabia needs to be electronic, unified, fair, time effective, and provide a two way direction between secondary and tertiary hospitals. All medical facilities should provide the disease information to cancer patients by transparency and honesty.

Central electronic cancer referral system aims to connect and coordinate between the different health care levels.

By this criteria it will be an effective referral system and it will ensure a close relationship between all levels of the health system and help to ensure people receive the best possible care closest to home.

This effective referral system will reduce the mortality & morbidity associated with this disease.

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