البحث عن المعلومات الطبية: دراسة السلوك المعلوماتي لدى مرضى السرطان في الكويت

إلهام الدوسري

ملخص: هدفت هذه الدراسة إلى الكشف عن الاحتياجات والمعلومات المبلغ عنها ذاتياً والسلوك المعلوماتي لدى مرضى السرطان في الكويت، لهذا الغرض جمعت البيانات من 400 مريض بالسرطان باستخدام الاستبانة الورقية. وأشارت النتائج إلى أن معظم مرضى السرطان بحاجة إلى تزويدهم بالمعلومات مباشرة بعد التشخيص. وأراد معظمهم تزويدهم بهذه المعلومات حول المرض ومعرفة فرص الشفاء. وبينت النتائج أن الأطباء والإنترنت هم المصادر الأكثر استخداماً من قبل مرضى السرطان في البحث عن المعلومات. وكانت الإناث ومرضى السرطان من الحاملين شهادات ما بعد البكالوريوس أكثر عرضة من المجموعات الأخرى للحصول على المعلومات من الإنترنت. وشهدت النتائج أن مرضى السرطان يواجهون صعوبات عند التماس المعلومات المتعلقة بمرضهم نظراً لعدم وجود مساعدة من مقدمي الرعاية الصحية في توفير المعلومات وتضاربها على شبكة الإنترنت. وأعرب مرضى السرطان عن الحاجة إلى خدمات مثل الثقافة الصحية وتوفير المعلومات من وزارة الصحة الكويتية على شبكة الإنترنت. إن تحديد المعلومات الصحية من خلال مرضى السرطان هو المصدر الأساسي.

المصطلحات الأساسية: المعلومات الصحية، السلوك المعلوماتي، مرضى السرطان، الكويت.

Seeking Health Information in Context: An Examination Cancer Patients' Information Seeking Behavior in Kuwait

Elham A. Aldousari[*]

Abstract: The aim of this study was to explore the self-reported information needs and information-seeking behaviour of cancer patients in Kuwait. Data were collected from 440 cancer patients using a paper-based questionnaire. Cancer patients wished to be provided with information immediately after diagnosis. Patients mostly wanted information about their disease and prognosis. Physicians and the internet were the most frequently used sources by cancer patients in seeking information. Females and Cancer patients with University degrees were more likely than other groups to obtain their information from the Internet. Cancer patients experienced difficulties when seeking information related due to the lack of help from health care providers in providing information and the inconsistency of information on the internet. Cancer patients expressed a need for services such as health education and provision of information from the Kuwaiti Ministry of Health website. Seeking health information among cancer patients is context oriented.

Key words: Health information seeking, Cancer patients, Kuwait-health.

Introduction

Cancer patients' information needs and information-seeking behaviour have become an important focus in health care research. Czaja, Manfredi & Price (2003) have found that information seeking by cancer patients is associated with their desire to be involved in clinical decision-making and treatment planning. Providing patients with the information they seek facilitates patients' participation in decision-making; it helps them to understand their condition and cope with their illness. It also provides social support (Sawyer, 2000; Kreps & Massimilia, 2002; Wenzel, Glanz & Lerman, 2002; Hiramanek & McAvoy, 2005; Shim, Hornik, 2006).

* Department of Library and Information Science, Social Sciences college, Kuwait University.

A literature review found that most research has focused on the information needs and information-seeking behaviour of patients with particular types of cancer, such as colon or breast, and that no studies have investigated this in Kuwait. This research constitutes the first study to be undertaken on this subject in Kuwait and may provide guidance and insight for others. Therefore, the present study explored the different types of information sources available in the Kuwait Cancer Control Center (KCCC) and the extent to which information sources were used by patients with different types of cancer. The study aimed to identify: the various types of information sources sought by cancer patients; difficulties in obtaining the necessary information; and patients' perceptions of improving information resources and services in Kuwait. The study aimed to examine in more depth the differences in perception among different demographic groups (Gender, Age, Educational levels and Types of cancer) of cancer patients with regard to the information need, information seeking, and improving services and resources.

Studies on Information Seeking

Most of the studies that have investigated the information needs of cancer patients have explored the methods and attitudes of patients seeking information. Cancer patients seek information from a range of sources, in a variety of formats, and for different purposes. All these sources of information have been examined to determine those most used and sought after by cancer patients, and whether they have met patient information needs. Many studies have investigated Interpersonal resources. The most common of these used by cancer patients are their health care professionals (Ruttena et al, 2005; Ankem, 2006; Cutilli, 2010). Other interpersonal resources include communication with relatives and friends (Ankem, 2006). Print resources are another source used by cancer patients but not often (Basch et al, 2004; Mayer & Grober, 2006).

The internet is also an important source of health and medical information for cancer patients (Eysenbach, 2003;Bass et al., 2006). Accessing health information on the internet has encouraged cancer patients to participate more in medical decision making (Lee, Gray & Lewis, 2010). Physicians are increasingly seeing patients bringing internet printouts to consultations (Van Rijen,de Lint, & Ottes et al., 2000; Wolffenbuttel & Van Woerkum, 2000; Murray et al, 2003).

Van Woerkum, (2003) has outlined reasons for people obtaining health information from the internet, including the feeling that that they could not obtain such information from their doctors. People obtain information from the internet to verify a medical opinion or treatment. Information acquired from the internet is used by patients to overcome their reticence in discussing personal issues.In contrast, other patients, who seek informational resources beyond their MDs, wish to be well informed about their disease and treatment,yet prefer to rely on their physicians for clinical decision-making.

Despite the existence of many information resources for cancer patients, there are certain impediments to patients seeking information. Major obstacles include difficulties in using information technology and lack of consistency of information on the internet. Accurate, authoritative, and up-to-date are important issues when cancer patients seek information (Maddock et al., 2011).

In the past 10 years, cancer has been the second leading cause of death in Kuwait after cardiovascular diseases (El-Basmy, Al-Mohannadi & Al-Awadi, 2012), with 740 cancer cases diagnosed annually in the country. Many factors are associated with the increase in cancer in Kuwait. Lack of awareness and the delayed detection of breast cancer are the most common reasons for the increasing mortality risk among women (Al-Bhrawi, 2010).Studying the information needs of cancer patients and their information-seeking behaviour is crucial in improving current health care services.

Methods

Participants

This was an exploratory study that involved a semi-structured, paper-based questionnaire. The study was conducted at KCCC,located in the Al Sabah Medical District within Shuwaikh area in the city of Kuwait, between September 2011 and July 2012.The target population included male and female patients attending the outpatient departments of KCCC with various types of cancer: breast, tracheal, bladder, prostate, uterine, ovarian, liver, pancreatic, stomach cancer, or leukaemia. KCCC is a comprehensive government facility that provides cancer care for patients aged years throughout Kuwait.

Measure

The questionnaire was developed from the previous literature review in light of the objectives of the present study. It was divided into four sections. The first section included demographic questions about respondents' gender, age, nationality, level of education, and type of cancer. The second section explored the information needs of cancer patients. The third section focused on the information-seeking behaviour of cancer patients. In the final section, the respondents were asked if they had problems in obtaining relevant information and how information resources and services in their hospital could be improved. Most of the response categories ended with 'other' category to allow the respondents to express themselves freely, which is useful in exploratory research. The questionnaire was finalized after the literature review and pilot test had been completed, and feedback from pre-testing had been used to refine the questions.

Analytical Approach

On average, there were 300 daily visits to the outpatients departments at KCCC. Five hundred questionnaires were distributed over three consecutive days in October 2011. A total of 440 were returned, giving a response rate of 88%. Statistical analysis was used to analyse the quantitative data to obtain descriptive statistics. Descriptive statistics, such as frequencies and percentages, were used to describe the categories and continuous variables and to show the number of responses. For the purpose of this study, the differences in perception among different demographic groups (Gender, Age, Education level and Types of cancer) and each item in the scale (each item x different groups) will be examined. Accordingly, Chi-square analyses will be used hereafter to examine the perception of different demographic groups on each item.

Results

Demographic Information

The majority of respondents were female (66.8%); 33.2%were male. Half the respondents (51.6%) were aged 40-59 years; 28% were aged 13-39 years; a few of the respondents (14%) were aged 60-69 years; and only 6.1% were $\geq$ 70 years. Less than half the respondents (36.8%) had a bachelor's degree, and 5.7% had a postgraduate qualification; 31.1% of the sample only finished secondary school. Less than half the respondents

(33.2%) had breast cancer, 15.7% tracheal cancer, and 9.5% leukaemia. Other cancer reported (4.8% prostate cancer, 7.3% uterine and ovarian cancer, 5% liver, panccreas and stomach and 1.8% bladder cancer).

Information Needs

Respondents were asked to rank the top five items, with 1 being the most important and 5 the least important. The rank order (0-5) of the types of information needed is listed in Table 1. Two of the 10 types of information were identified to be highly important by cancer patients, namely information about the disease (48% very important and 11.8% important vs. 21.8% not important at all, 7.3% not sure, 3.9% slightly important, and 7.3% very slightly important) and prognosis (29.1% very important and 38.2% important vs. 13% not important at all, 8.4% not sure, 8.9% slightly important, and 2.5% very slightly important). This means that the information about prognosis and the information about the disease are highly important services for cancer patients (67.3% and 59.8%, respectively). The other types of information need were perceived to be either slightly important or not important at all.

Table 1. Information needs of cancer patients

Item No.	Cancer patients (%)						
Which information is important for you?		**5**	**4**	**3**	**2**	**1**	**0**
1	Information about disease	7.3	3.9	7.3	11.8	48	21.8
2	Information about prognosis	2.5	8.9	8.4	38.2	29.1	13
3	Information about possible treatments	6.1	11.4	33.6	22.7	7.3	18.9
4	Information about side effects of chemotherapy	9.5	24.3	18.2	10.7	4.1	33.2
5	Cost of treatment plan (non-Kuwaiti)	14.3	5.5	4.8	1.6	0.7	73.2
6	Seeking second opinions	14.3	13.4	7.7	3.6	2.7	58.2
7	Effect on social life or leisure	12	12	5.9	2.7	2.3	65
8	Risk of disease for family members	16.6	11.8	8.6	3.9	5.9	53.2
9	Effect on employment or work life	12.7	7	3.6	3	1.6	72
10	Information about other topics	2.5	0.2	0.5	0.7	0	96.1

A chi-square analyses was used to examine the difference in the perception of male and female cancer patients regarding the Information need. There were significant differences in perception between male and female cancer patients regarding two types of information; The information about possible treatments ($X2 = 11.470$, $p < .05$), and Effect on employment or work life ($X2 = 21.171$, $p < .001$). However, males and females viewed the two types of information as not important at all. Males perceived the information about possible treatment as not important at all more than females (25.3% for males vs. 15.5% for females). Whereas, females perceived the information about effect on employment or work life as not important at all more than males (75.9% for females vs. 64.4% for males).

Also the findings of the analyses show that there were significant differences in perception among cancer patients of different ages regarding the information about prognosis ($X2 = 26.882$, $p < .05$), and Seeking second opinion ($X2 = 29.849$, $p < .01$).

All patients of different ages needed the information about prognosis. However, cancer patients of ages 60 to 69 highly needed this information, when compared to other age groups. On the other hand, the findings show that patients of different ages did not need the information related to Seeking second opinion. However, cancer patients of ages 40 to 59 were less likely than other age groups to need such information.

The Chi-square analyses indicated the differences in perception among cancer patients of different educational levels regarding the information need. There were significant differences in perception among the groups regarding two types of information; Information about side effects of chemotherapy ($X2 = 39.940$, $p < .05$), and Effect on employment or work life ($X2 = 52.597$, $p < .001$. However, cancer patients of different educational levels viewed the two types of information as not important at all. Cancer patients with primary educational level were less likely than other educational groups to view the Information about side effects of chemotherapy as important; whereas cancer patients with university educational level were less likely than other educational groups to view the Effect on employment or work life as important.

The Chi-square analyses indicate the differences in perception among cancer patients of different types of cancer regarding the information need.

The findings of the analyses found that, there was significant difference in perception among the groups regarding one type of information; Effect on employment or work life ($X2 = 50.116$, $p < .05$). This means that cancer patients of different types of cancer viewed the type of information selected as not important at all. Cancer patients with Bladder cancer were less likely than other groups to view the information about the effect on employment or work life as important.

Information Seeking

Time and Purpose

We focused on examining the time and purpose of providing the two types of information perceived to be highly important by cancer patients, namely information about the disease and information about prognosis.The other types of information were not examined here because they were perceived to be only slightly or not at all important.

Table 2 shows that most cancer patients who ranked information about the disease as very important (rankorder 1 or 2) needed this service immediately after diagnosis(70.1% vs. 15.2% between diagnosis and treatment, 3.8% after treatment, and 10.9% do not seek information). Also, cancer patients who ranked-order the information about the disease as important (rank-order 2) needed this service immediately after the diagnosis (63.5% vs. 25% between diagnosis and treatment, 5.8% after treatment, and 5.8% do not seek information)

Similarly, most cancer patients who ranked information about prognosis as very important (rank order 1 or 2) wanted this information immediately after diagnosis. Table 2 shows that cancer patients who ranked-order the information about prognosis as very important (rank-order 1) needed this service immediately after the diagnosis (64.8% vs. 18.8% between diagnosis and treatment, 8.6% after treatment, and 7.8% do not seek information). Also, cancer patients who ranked-order the information about prognosis as important (rank-order 2) needed this service immediately after the diagnosis (63.7% vs. 17.9% between diagnosis and treatment, 4.2% after treatment, and 14.3% do not seek information)

These results stress the importance of providing information about cancer and the prognosis immediately after the patients discover their illness.

Table 2. Time of Providing Information about Disease and Chances of Recovery to Cancer Patients

Type of information needed										
Time of providing information		**Immediately after diagnosis**		**Between diagnosis and treatment**		**After treatment**		**Do not seek information**		**Total**
		n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	
1) Information about disease	Rank-order									
	0	54	56.3	21	21.9	8	8.3	13	13.5	96
	1	148	70.1	32	15.2	8	3.8	23	10.9	211
	2	33	63.5	13	25	3	5.8	3	5.8	52
	3	23	71.9	6	18.8	2	6.3	1	3.1	32
	4	11	64.7	3	17.6	1	5.9	2	11.8	17
	5	18	56.3	8	25	5	15.6	1	3.1	32
	Total	287	65.2	83	18.9	27	6.1	43	9.8	440
2) Information about prognosis	Rank-order									
	0	36	63.2	9	15.8	5	8.8	7	12.3	57
	1	83	64.8	24	18.8	11	8.6	10	7.8	128
	2	107	63.7	30	17.9	7	4.2	24	14.3	168
	3	29	78.4	5	13.5	2	5.4	1	2.7	37
	4	25	64.1	11	28.2	2	5.1	1	2.6	39
	5	7	63.6	4	36.4	0	0	0	0	11
	Total	287	65.2	83	18.9	27	6.1	43	9.8	440

Table 3 shows the purpose of seeking information about the disease and prognosis. With regard to information about the disease, cancer patients who ranked this as very important (rank order 1) or important (rankorder 2) wanted it mainly so that they would know their prognosis, followed by knowing what was wrong with them, an understanding of the particular tests and treatments involved and their possible outcomes, so that they could care appropriately for themselves and their families, and be reassured and feel able to cope. A similar order of purposes was seen for information about prognosis.

Table 3. Purposes of Providing Information to Cancer Patients about their Disease and Chances of Recovery

Type of information needed	Purpose of providing information (%)																
		P1		P2		P3		P4		P5		P6		P7		P8	
		No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes
1) Information about disease	Rank-order																
	0	38.5	61.5	69.8	30.2	81.3	18.8	77.1	22.9	57.3	42.7	55.2	44.8	82.3	17.7	100	0
	1	34.6	65.4	60.7	39.3	67.3	32.7	74.9	25.1	73.9	26.1	58.3	41.7	87.7	12.3	99.1	.9
	2	19.2	80.8	76.9	23.1	67.3	32.7	78.8	21.2	63.5	36.5	63.5	36.5	90.4	9.6	98.1	1.9
	3	46.9	53.1	78.1	21.9	81.3	18.8	75	25	75	25	50	50	90.6	9.4	100	0
	4	29.4	70.6	82.4	17.6	76.5	23.5	82.4	17.6	76.5	23.5	70.6	29.4	82.4	17.6	100	0
	5	34.4	65.6	68.8	31.3	71.9	28.1	87.5	12.5	71.9	28.1	34.4	65.6	87.5	12.5	100	0
	Total (n)	151	289	296	144	317	123	339	101	304	136	248	192	382	58	437	3
2) Information about prognosis	Rank-order																
	0	56.1	43.9	66.7	33.3	71.9	28.1	77.2	22.8	71.9	28.1	59.6	40.4	86	14	96.5	3.5
	1	26.6	73.4	71.1	28.9	77.3	22.7	84.4	15.6	60.9	39.1	54.7	45.3	85.9	14.1	99.2	.8
	2	25	75	63.1	36.9	67.3	32.7	74.4	25.6	73.8	26.2	58.9	41.1	88.1	11.9	100	0
	3	45.9	54.1	59.5	40.5	67.6	32.4	62.2	37.8	62.2	37.8	48.6	51.4	81.1	18.9	100	0
	4	46.2	53.8	76.9	23.1	79.5	20.5	87.2	12.8	76.9	23.1	48.7	51.3	92.3	7.7	100	0
	5	72.7	27.3	81.8	18.2	72.7	27.3	45.5	54.5	72.7	27.3	72.7	27.3	81.8	18.2	100	0
	Total (n)	151	289	296	144	317	123	339	101	304	136	248	192	382	58	437	3

Note. P1 = To know the prognosis.

P2 = To understand what is wrong with me.

P3 = To understand what particular tests and treatments are involved and what their outcomes might be.

P4 = Contribute in a more informed way to discussions or decisions about my case and care.

P5 = Care appropriately for myself and my family.

P6 = To be reassured and feel able to cope.

P7 = To explain to others (for example, families, friends or employers) what is wrong with me and what treatments I might need.

P8 = Other.

Sources of Information

Table 4 indicates that cancer patients mainly obtain their information about the disease from two out of 14 sources.The most common sources were their physicians (74.8%) and the internet (46.8%).The other sources were seen as less indicated among cancer patients, and ranged from 0.9 to 19.5%.

Table 4. Sources of Information for Cancer Patients

Statement		Cancer patients (%)	
	Where do you obtain cancer related information?	No	Yes
1	Physician	25.2	74.8
2	Nurse	87.7	12.3
3	Other health care professional	87.7.	12.3
4	Friends and/or family	91.4	8.6
5	Other patients	80.9	19.1
6	Internet	53.2	46.8
7	Media (TV, radio, or videos)	80.5	19.5
8	Libraries/unspecified readings	92.5	7.5
9	Brochures and leaflets	86.1	13.9
10	Magazines and newspapers	87.5	12.5
11	Medical journals or books	84.5	15.5
12	Charitable or professional organizations	90.2	9.8
13	Health care organizations	93.2	6.8
14	Other (not specified)	99.1	0.9

The findings of the Chi-square analyses show that there were significant differences in perception between male and female cancer patients regarding the two sources of information; Other patients ($X2 = 5.224$, $p < .05$), and Internet ($X2 = 21.171$, $p < .001$). Males were less likely than females to obtain the information about the disease from other patients.; whereas, females were more likely than males to obtain the information about the disease from the internet.

The findings of the Chi-square analyses show that there were

significant differences in perception among cancer patients of different age groups regarding three sources of information; Friends and family ($X2 = 9.184$, $p < .05$), Brochures and leaflets ($X2 = 10.621$, $p < .01$), and Health care organization ($X2 = 14.156$, $p < .01$). However, patients of different age groups did not obtain these sources of information. Cancer patients of ages 70+ were less likely than other age groups to obtain the information about the disease from Friends and family. Whereas, cancer patients of ages 19 to 39 were less likely than other age groups to obtain the information about the disease from Brochures and leaflets. And cancer patients of ages 40 to 59 were less likely to obtain the information about the disease from Health care organization.

The findings of the Chi-square analyses show that there was significant difference in perception among cancer patients of different educational levels regarding source of information; Internet($X2 = 35.046$, $p < .001$). Cancer patients of different educational levels differ in obtaining sources of information. More specifically, cancer patients with Post University were more likely than other groups to obtain their information from the internet. The finding stresses the importance of the internet for cancer patients with higher education.

The findings of the Chi-square analyses show that there were significant differences in perception among cancer patients of different types of cancer regarding sources of information; other health care professional($X2 = 21.325$, $p < .01$), and other patients ($X2 = 16.928$, $p < .05$). Patients with bladder cancer were more likely than other types of cancer groups to obtain their information from other health care professionals; whereas patients with prostate cancer were less likely than other types of cancer groups to obtain their information from other patients.

Difficulties in Seeking Information

Table 5 lists the problems encountered by cancer patients when seeking information about their disease. The main difficulties were: lack of help from healthcare providers in providing information(56.8% having difficulties vs. 43.2% not having such difficulties); inconsistency of the information obtained (42.5 vs. 57.5%); lack of motivation to look for information; (33% vs. 67%); psychological impairments(31.4 vs.

68.6%); and language barriers(29.8% vs. 70.2%). All the other types of difficulty were experienced to a lesser degree by cancer patients.

Table 5. Problems Encountered by Cancer Patients When Seeking Information

Which of the following have been a problem for you when seeking information about your disease?			
Statement		**No**	**Yes**
1	Lack of motivation to look for information	67	33
2	Ageism from healthcare providers	78.9	21.1
3	Lack of help from healthcare providers in providing information.	43.2	56.8
4	Frustration/anxiety with technology	71.4	28.6
5	Psychological impairments	68.6	31.4
6	Cognitive impairments	92	8
7	Physical impairments (vision and hearing)	91.4	8.6
8	Lack of technical skills	70.7	29.3
9	Health information presented at an inappropriate level.	79.8	20.2
10	Language barriers	70.2	29.8
11	Inconsistency of information	57.5	42.5
12	Lack of credibility of the information on the Internet.	70.7	29.3
13	Other	96.4	3.6

The Chi-square analyses show the differences in perception among gender groups regarding the difficulties of information-seeking.The result indicated that there were significant differences in perception between male and female cancer patients regarding the two types of difficulties of seeking information; Physical impairment ($X2 = 5.710$, $p < .05$), and Lack of technical skills ($X2 = 5.306$, $p < .05$). The finding showed that females were less likely than males to experience difficulties related to Physical impairment, and Lack of technical skills.

The Chi-square analyses indicate the differences in perceptionamong different age groups regarding the difficulties of information-seeking.

There was a significant difference in perception among the age groups regarding one type of difficulties of seeking information, namely the Lack of credibility of the information on the internet ($X2 = 8.013$, $p < .05$). The finding showed that cancer patients of ages 70+ were less likely than other age groups to experience difficulties related to Lack of credibility of the information on the internet.

In addition, the result of Chi-square analyses shows the differences in perceptionamong cancer patients of different educational groups regarding the difficulties of information-seeking.There were significant differences in perception among the groups regarding three types of difficulties of seeking information; Lack of help from healthcare providers in providing information ($X2 = 13.348$, $p < .05$), Inconsistency of information ($X2 = 16.353$, $p < .001$), and Lack of credibility of the information on the Internet($X2 = 11.898$, $p < .05$). The finding showed that cancer patients with university level were more likely than other educational groups to experience difficulties related to lack of help from healthcare providers in providing information. Whereas cancer patients with Post University were more likely than other educational groups to experience difficulties related to inconsistency of information, and lack of credibility of the information on the Internet.

The Chi-square analyses show the differences in perceptionamong different types of cancer patients regarding the difficulties of information-seeking.There was significant difference in perception among the groups regarding one type of difficulties of seeking information; Ageism from health care providers ($X2 = 17.861$, $p < .01$). The finding showed that patients with bladder cancer were more likely than other groups to experience difficulty related to ageism from health care providers.

Improving Information Resources and Services

Table 6 shows the improvements in information resources and services suggested by cancer patients. Some services were viewed as highly important for future planning, such as health education for cancer patients(65.7% vs. 34.3%), and providing information on the Kuwaiti Ministry of Health website for internet use (55.5% vs. 44.5%). Other services were viewed as moderately important, such as:improving communication with other international cancer centres for information sharing, providing seminars to help identify further sources of informa-

tion and support; providing more resources in the hospital library, involving cancer patients in decision making about health information service planning, providing materials from physicians, and providing telephone information services.

Table 6. Suggestions from Cancer Patients for Improving Information Resources and Services

What do you think would most help to satisfy your information needs about your disease?			
Statement		**No**	**Yes**
1	Health education for patients	34.3	65.7
2	Provide more resources in the hospital library	62.3	37.7
3	Provide information on the Kuwait Ministry of Health website	44.5	55.5
4	Provide seminars to help patients identify further sources of information and support	58.6	41.4
5	Provide seminars to help patient judge the quality of information provided	71.6	28.4
6	Involve the patient in decision making about health information services planning	63	37
7	Improve communication with other international cancer centres for information sharing	55	45
8	Provide more leaflets, brochures and guidelines using different languages	74.8	25.2
9	Provide telephone information services (e.g. Cancer Information Service)	70.2	29.8
10	Counselling, support groups or services	71.6	28.4
11	Provide materials from physicians	66.4	33.6
12	Others	98	2

Discussion

Cancer patients need different types of information, but the most sought after in the present study was information about the disease and prognosis. This result corroborates the findings of previous studies

(Sawyer, 2000; Meredith et al, 1996; Piredda et al, 2008; Mistry et al, 2011). Other authors have shown that cancer patients need information about their disease, patient care, treatment planning, and side effects (Lei, Har, & Abdullah, 2011; Beckjord et al., 2008; Mistry et al., 2010).

This study found that information seeking behaviour varied by cancer type, age, gender, and education level. The result shows that females perceived information about the effect on employment or work life as not important at all more than males. Cancer patients of ages 60 to 69 highly needed information about prognosis. In addition, cancer patients with primary education level were less likely to view the information about side effects of chemotherapy as important.

Our results stressthe importance of providing information about cancer and the prognosis immediately after diagnosis.There is a lack of previous reports to support these findings, although Noh et al (2009) have found that cancer patients need information at the time of diagnosis. These results show that cancer patients seek basic information about their disease, prognosis and treatment plan, and this type of information is often raised at their first appointment after diagnosis. There is evidence in the literature to show that cancer patients need only basic information about their disease and treatment, and do not need further information at all stages of their illness (Thomas, Thornton , &Mackay, 1999; Leydon et al., 2000). That contradicts the idea of patient being involved in treatment decisions.

Our results indicate that the main purposes of cancer patients in seeking information about their disease and prognosisare related to their wish to knowwhat is wrong with them so they can find out more about their prognosis, understand the various tests and treatment, care appropriately for themselves, and be reassured and feel able to cope. Evidence from previous studies shows that cancer patients need information to improve their knowledge about their disease, treatment plan, self care, coping with their disease, reducing stress, and social support (Shim, Kelly, & Hornik, 2006; Derdiarian, 1986; Kreps & Massimilia, 2002; Ziebland et al., 2004).

Our research showed that cancer patients obtain their information from various sources but mainly from their physicians (74.8%) and the internet (46.8%). This confirms the findings of previous studies that have shown that healthcare professionals are the most used and trusted

sources of information sought by cancer patients (Steginga et al, 2002; Mills& Davidson 2002; Newnham et al., 2006; James et al., 2007). A recent study by Tautz et al, (2012)has found that cancer patients rely on family and friends and their general practitioners forinformation.We showed that the internet was another important source of information for cancer patients. This supports the findings of Mayer et al, (2007) who showed that the most frequent source of information for cancer patients was the internet (35.4%), followed by healthcare providers (19.4%). In contrast, only 10% of patients reported using the internet in the study of Mills and Davidson, (2002). This possibly reflects a change in information-seeking behaviour in recent years, and Carlsson, (2009) has found that the use of the internet by cancer patients was greater in 2008 compared to 1998.

Our results indicate that females and cancer patients with Post University were more likely than other cancer patients group to obtain information they seek form the Internet. Tortolero-Luna et al (2010) found that cancer patients with college education rely more on the Internet for accessing cancer health and cancer information.. In addition, the results show that cancer patients of ages 70+ were less likely than other patient groups to seek information from friends and family. Kowal Czyk and Draper (2012) found that older generations appear to rely on Internet sources more often than they rely on healthcare providers. Patients with bladder cancer were more likely to obtain information they need from other health care professionals.

Although there are a variety of information sources for cancer patients, they did experience a range of difficulties when trying to access information. The most common difficulties related to a lack of help from healthcare providers in providing information. There were also problems related to the inconsistency of the information. Similarly, Leng et al, (2012) have found that patients expressed dissatisfaction with the amount, reliability and comprehensibility of the available information. Our research showed that patients with bladder cancer and patients with university level were more likely to experience difficulties related to lack of help from healthcare providers.

One of the objectives of the current study was to viewpatients' ideas and suggestions to improve the health information resources and services in government hospitals in Kuwait.Cancer patients expressed a particular

need for information on the Kuwaiti Ministry of Health website. Perhaps it can be said that cancer patients needsources of information that are evidence-based and which originate from a trusted source.Al-dousari, (2009) explored the information needs and information-seeking behaviour of doctors in Kuwait government hospitals, and somewhat surprisingly found that 53% of the doctors reported that lack of patient awareness in understanding medical terms was a problem, and 89.8% of doctorsrecommended health education for patients. The interviewees revealed thatlack of awareness of some patients regarding health information issues caused patient-doctor conflict when discussing diagnoses or treatment plans. In addition, the patients sometimes sought health information from unauthorised people, such as in social gathering places (Dewaniya), which exposed the patients to inaccurate health informationand in turn, affected communication with their doctors.

Cancer patients need to be aware of the principal issues related to their disease. This can be achieved by: (1) improving health education through providing booklets, leaflets,pamphlets, handbills, and posters in hospitals and public areas; (2) giving seminars and lectures in hospitals and schools; (3) transmitting commercials and advertisements on television and radio (the most cited information source in some studies (James et al., 1999; Noh et al., 2009); (4) developing the healthcare website of the Kuwait Ministry of Health; (5) establishing an email subscription service to send free medical advice; (6) providing free general health information through newspapers.

In our literature review and current research, we found that healthcare providers were cited as the most common and trusted source of information by cancer patients. However, patients faced difficulty in obtaining information from this source. Hiramanek and McAvoy, (2005)indicated that healthcare providers need to be up-to-date with cancer information in order to help meet their patients' information needs. Priedda et al,(2008)emphasised the need to improve healthcare providers' education and practice. Cooley et al, (2011)has highlighted that cancer patients still consider doctors to be the most reliable and trusted source of information, and doctors must therefore counsel patients on where to find reliable and evidence-based resources on the internet. However, Ogah ans Wassersug, (2013) reviewed 43 noncommercial and easily found websites that offered extensive information on treatment options for prostate cancer patients. They found that most

websites were out of date.Therefore,healthcare providers must keep abreast of current information in their specialties and improve their healthinformation literacy to communicate effectively with their patients and help them to obtain the right information in the right place.

Conclusions

The study described herein was undertaken to gain a greater understanding of the information-seeking behaviour of cancer patient-sand their preferences for accessing different information sources. From the above discussion it is clear that information-seeking behaviour is not consistent for all cancer patients, and varies over time from one patient to another. By paying attention to the provision of information for cancer patients and respecting their needs, one can develop a successful strategic plan on information, thereby helping to improve healthcare for cancer patients, as well as the performance of healthcare providers.There is significant evidence from the literature that the provision of information can help cancer patients regain control over their lives and participate fully in their treatment. This study provides KCCC with evidence-based data to help them plan their services. The decision makers in the Kuwait Ministry of Health should provide a range of tools and suggestions for better healthcare and for the provision of information services.New technology opens up the possibility of doing much better.Understanding the information needs of cancer patients, together with an awareness of their preferred sources of information, will help with patient education and decision making across the care continuum.

References

Al-Bhrawi, M. (2012). Deaths from breast cancer among women in Kuwait world's highest grim stats tied to lack of awareness, delay in detection. *Arab Times*. available at http://www.arabtimesonline.com/NewsDetails/tabid/96/smid/414/ArticleID/171901/reftab/36/Default.aspx. accessed on January 7, 2010.

Al-Dousari, E. (2009). Information needs and information seeking behaviour of doctors in Kuwait government hospitals: an exploratory study. *PhD thesis*, Department of Information Sciences, Loughborough University.

Ankem, K. (2006). Factors influencing information needs among cancer patients: a meta-analysis. *Library and Information Sciences Research*, 28(1), 7-23.

Basch, E.M.,Thaler, H.T, S., & Schrag, D. (2004).Use of information resources by patients with cancer and their companions. *Cancer*, 100(11), 2476-2483.

Bass, S.B, Ruzek, S.B., Gordon, T.F., Fleisher, L., McKeown-Conn, N., & Moore, D. (2006). Relationship of internet health information use with patient behavior

and self-efficacy. Experiences of newly diagnosed cancer patients who contact the National Cancer Institute's Cancer Information Service. *Journal of Health Communication*, 11(2), 219-236.

Beckjord, E., Arora, N.K., McLaughlin, W., Oakley-Girvan, I., Hamilton, A.S, & Hesse, B.W. (2008). Health-related information needs in a large and diverse sample of adult cancer survivors: implications for cancer care. *Journal of cancer survivorship*, 2(3), 179-189.

Carlsson, M.E. (2009) Cancer patients seeking information from sources outside the health care system: change over a decade. *European Journal of Oncology Nursing*, 13, 304-305.

Cooley, D.L., Mancuso, A.M., Weiss, L.B., &Coren, J.S. (2011). Health-related Internet use among patients of Osteopathic physicians. *Journal of American Osteopath Association*, 111(8):473-82.

Cutilli, C. C. (2010). Patient education corner: seeking health information: what sources do your patients use?. *Orthopedic Nursing*, 29(3), pp.214-219.

Czaja, R. Manfredi, C., & Price, J . (2003). The determinants and consequences of information seeking among cancer patients. *Journal Health Communication*, 8:529-62.

Derdiarian, A.K.(1986). Informational needs of recently diagnosed cancer patients. *Nursing Research*, 35:276-81.

El-Basmy, A., Al-Mohannadi, S. & Al-Awadi, A. (2012). Some epidemiological measures of cancer in Kuwait: national cancer registry data from 2000-2009. *Asian Pac J Cancer Prev*. 13(7):3113-8.

Eysenbach, G. (2003). The impact of the Internet on Cancer outcomes. CA *Cancer Journal Clinic*, 53: 356-371.

Hiramanek, N. & McAvoy, B.R. (2005). Meeting the needs of patients with cancer-a GP guide to support services. *Australian Family Physician*, 34(5):365-7.

James, C., James, N., Davies, D., Harvey, P . & Tweddle, S. (1999). Preferences for different sources of information about cancer. *Patient Education and Counseling*, 37(3), 273-282.

James, N., Daniels, H., Rahman, R., McConkey, C., Derry, J., & Young, A. (2007). A study of information seeking by cancer patients and their carers. *Clinical Oncology*, 19, 356-362.

Kowalczyk, N. & Draper, L.J. (2012). Trends in patient information preferences and acquisition.*Radiol Technol*, 83(4):316-24.

Kreps, G. & Massimilia, D. (2002). Cancer communications research and health outcomes: review and challenge. *Communication Studies*, 53,318-36.

Lee, C. J., Gray, S.W, &Lewis, N. (2010). Internet use leads cancer patients to be active health care consumers. *Patient Education and Counseling*, 81(1), 723-734.

Lei, C.P., Har, Y.C, & Abdullah, K.L. (2011). Informational needs of breast cancer patients on chemotherapy: differences from nurses' perceptions. *Asian Pac J Cancer Prev*, 12, 797-802.

Leng J., Lee, T., Sarpel, U., Lau, J., Li, Y., Cheng, C., Chang, M.D. & Gany, F. (2012).

Identifying the informational and psychosocial needs of Chinese immigrant cancer patients: a focus group study. *Support Care Cancer*, 20(12): 3221-9.

Leydon, G.M., Boulton, M., Moynihan, C., Jones, A., Mossman, J <http://www.ncbi.nlm.nih.gov/pubmed?term=Mossman%20J%5BAuthor%5D&cauthor=true&cauthor_uid=10742000>., Boudioni, M., et al. (2000). Information in practice. Cancer patients' information needs and information seeking behavior: in depth interview study. *BMJ*, 320, 909-913.

Maddock, C., Camporesi, S., Lewis, I., Ahmad, K. &Sullivan R. (2011). Online information as a decision making aid for cancer patients: recommendations from the Eurocancercoms project, *Eur J Cancer*, 10(1016).

Mayer D.K., Terrin, N.C., Kreps, G.L., Menon, U., McCance, K., Parsons, S.K. & Mooney, K.H. (2007). Cancer survivors information seeking behaviors: a comparison of survivors who do and do not seek information about cancer. *Patient Education and Consulting*, 65, 342-350.

Mayer, M. & Grober, S. E. (2006). Silent voices: women with advanced (metastatic) breast cancer share their needs and preferences for information, support, and practical resources. *Living Beyond Breast Cancer (LBBC)*. Available at: hhtp://www.lbbc.org/data/news/LBBCsilentvoices.pdf. Accessed on: January 7, 2010.

Meredith C., Symonds, P., Webster, L., Lamont, D., Pyper, E., Gillis, C.R., et al. (1996). Information needs of cancer patients in the west of Scotland. *British Medical Journal*, 313:7059, 724-726.

Mills, ME & Davidson, R. (2002). Cancer Patients' sources of information: use and quality. *Psycho-Encology*, 11, 371-378.

Mistry A., Wilson, S., Priestman, T, Damery, S & Haque, M.S. (2010). How do the information needs of cancer patients differ at different stages of the cancer journey? A cross -sectional survey. *Journal of the Royal Society of Medicine Short Reports*, 1(4), 30.

Mistry M., Parkin, D. M, Ahmad, A. S. & Sasieni, P. (2011). Cancer incidence in the UK: Projections to the year 2030, *British Journal of Cancer*, 105, 1795-1803.

Murray E., Lo, B., Pollack, L., Donelan, K., Catania, J., White M, et al. (2003). The impact of health information on the internet on the physician-patient relationship: patient perceptions. *Arch Intern Med*, 18;163(14): 1727-1734.

Newnham, G.M., Burns, W.I., Snyder, R.D., Dowling, A.J., Ranieri, N.F.Gray, E.L, et al.(2006). Information from the Internet: attitudes of Australian oncology patients. *Intern Med J*. 36(11): 718-23.

Noh, H.I., Lee, J.M, Yun, Y.H, Park, S.Y, Bae, D.S, Nam, J.H, et al, (2009). Cervical cancer patient information-seeking behaviors, information needs, and information sources in South Korea. *Support Care Cancer*. 17(10): 1277-83.

Ogah, I. &Wassersug, R.J <http://www.ncbi.nlm.nih.gov/pubmed?term=Wassersug%20RJ%5BAuthor%5D&cauthor=true&cauthor_uid=23141782>. (2013). How reliable are "reputable sources" for medical information on the Internet? The case of hormonal therapy to treat prostate cancer. Urol Oncol. <http://www.ncbi.nlm.nih.gov/pubmed/23141782>, 31(8):1546-52.

Piredda, M., Rocci, L., Gualandi, R., Petitti, T., Vincenzi, B., &De Marinis, M.G. (2008). Survey on learning needs and preferred sources of information to meet these needs in Italian oncology patients receiving chemotherapy. *European Journal of Oncology Nursing*, 12,120-126.

Ruttena, L.J. Arora, N.K., Bakos, A.D., Aziz, N., & Rowland, J. (2005). Information needs and sources of information among cancer patients: a systematic review of research (1980-2003). *Patient Education and Counseling* 57, 250-261.

Sawyer, H. (2000). Meeting the information needs of cancer patients. *Professional Nurse*, 15:4,244-247.

Shim, M., Kelly, B, &Hornik, R. (2006). Cancer Information Scanning and Seeking Behavior is Associated with Knowledge, Lifestyle Choices, and Screening. *Journal of Health Communication*, 11, 157-172.

Steginga, S.K, Occhipinti, S., Gardiner, R.A., Yaxley, J., &Heathcote, P. (2002). Making decisions about treatment for localized prostate cancer. *BJU Int*., 89:255-260.

Tautz, E., Momm, F ., Hasenburg, A., & Guethlin, C. (2012). Use of complementary and alternative medicine in breast cancer patients and their experiences: A cross-sectional study. *European Journal of Cancer*, 48(17), 3133-3139.

Thomas R., Thornton, H., &Mackay, J. (1999). Patient Information materials in oncology: are they needed and do they work? *Clinical Oncology*, 11(4), 225-231.

Tortolero-luna, G., Finney Rutten, L.J., Hesse, B.W., Davis, T., Kornfeld, J., Sanchez, M., et al. (2010). Health and cancer information seeking practices and preferences in Puerto Rico: creating and evidence base for cancer communication efforts. *J Health Commun*, 15(1): 30-45.

Van Rijen, A.J.G, de Lint, M.W., & Ottes, L. (2000). *Over E-Health En Cybermedicine: Achtergrondstudie*. RVZ: Dutch.

Van Woerkum, C.M. (2003). The internet and primary care physicians: coping with different expectations. *American Journal of Clinical Nutrition*, 779(4), 1016S-1018S.

Wenzel, L. Glanz, K. & Lerman, C. (2002). Stress, coping, and health behavior. In K. Glanz, B.K. Rimer, & F.M. Lewis (Eds.), *Health behavior and health education: Theory, research, and practice,* San Fansico: Jossey-Bass, 210-239.

Wolffenbuttel, K. & Van Woerkum, C.M.J. (2000). *Gezondheidsinformatie via het internet*. (Healthy information via the internet) Wageningen, the Netherlands: Group Communication and Innovation Studies, Wageningen University, (in Dutch).

Ziebland, S., Chapple, A., Dumelow, C., Evans, J., Prinjha, S., &Rozmovits, L. (2004). How the internet affects patients' experience of cancer: a qualitative study. *BMJ*, 6, 328(7439):564.

Submitted: June 2014
Accepted: November 2015