

## RESEARCH ARTICLE

# Patients with Cancer and their Relatives Beliefs, Information Needs and Information-Seeking Behavior about Cancer and Treatment

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### Abstract

**Purpose:** To identify cancer patient and relatives beliefs, information needs, information-seeking behavior and information sources about cancer and treatment. **Methods:** This research was conducted at two hospitals of a university. Data was collected via questionnaires and the Turkish version of the Miller Behavioral Style Scale (MBSS) to assess information-seeking behavior. The sample included 82 patients and 54 relatives. **Results:** Patients were receiving treatment mostly for breast, gynecologic, lung cancer and leukemia/ lymphoma. All of them indicated that they want to be informed by a doctor about their diagnosis and treatment first. Other information sources were internet, media and nurses. The majority of the patients and half of their relatives agreed that “cancer is curable and preventable disease”. Only 2.5% of patients agreed with the statement “I don’t want to get information about disease which disturbs me”. According the data obtained from MBSS; the mean patients MBSS score ( $6.41 \pm 3.2$ ) was higher than their relatives ( $5.46 \pm 3.1$ ). Respondents with higher education and younger age indicated more information-seeking behavior. **Conclusions:** Patients and their relatives differ in some of their information-seeking behavior. Patients beliefs and their strategies for coping with their illness can constrain their wish for information and their efforts to obtain it. Healthcare professionals need to assess and be sensitive to the information-seeking behavior of cancer patients and their relatives.

**Keywords:** Cancer treatments - beliefs - information needs - information seeking behavior

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### Introduction

In spite of medical and treatment advances and increasingly researched psychological interventions, people with cancer and their relatives still face uncertainty and a sense of not being in control of their lives. Lack of accurate information about cancer and its treatment appear as matter which frequently encountered in many societies (Brokalaki et al., 2005; Papadopoulos et al., 2007). Within Turkey, cancer is perceived to be a life-threatening illness by patients and relatives, and it continues to be the most feared of diseases in spite of important developments in its treatment (Cetingoz et al., 2002; Afsaroglu et al., 2010; Gultekin et al., 2011). Consequently, cancer patients are affected by many factors and are constrained in their ability to cope with their disease effectively. Significant amongst these factors are the perceptions, beliefs, information needs and information-seeking behaviors of patients and their relatives.

Cancer is often perceived as stressful life experience that reveals information-seeking behaviors for patients and their families. Recent studies showed that the

majority of cancer patients desire as much information as possible about their disease and treatment; however, not all patients want that much information (Ankem, 2006; Adams et al 2009). The amount and timing of information desired varied in those with a blunting style (avoiding threatening information) or for those trying to maintain hope. Information seeking behavior in health is the key coping mechanism to deal with stressful situations as shock of diagnosis, emotional burdens of decisions about treatment, unpredictability of illness (Lambert et al., 2009). It is known that some people cope with the illness by seeking the information actively because it reduces the uncertainty and it increases the feeling of control. But some people can display avoiding behavior as wanting limited information or not wanting any information (Rees and Bath, 2001; Eheman et al., 2009).

Many factors can influence information needs of oncology patients such as gender, age, coping style, cultural background, socio-economic status, educational level, cancer type and stage of disease. Most cancer patients generally want as much information as possible. Younger age and female gender seem to be associated

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with the highest degree of desire in receiving relevant information (Rutten et al., 2005; Ankem, 2006a; Piredda et al., 2008).

The most frequently used and preferred information source is one-to-one personal communication with health professionals, especially with physicians and nurses, followed by communication with other people. Other frequently mentioned sources are printed materials which most patients prefer to receive in combination with verbal information. Educational level and age seem to be related to patient's preference for education sources (Rutten et al., 2005; Ankem, 2006b).

Little is known about beliefs, information needs and information-seeking behaviors in Turkish cancer patients and their relatives. It appears that the literature about Turkish cancer patients and relatives information needs and preferences is still scarce. This study was conducted to identify cancer patient and relatives' beliefs, information needs, information-seeking behaviors and information sources about cancer and treatment.

## Materials and Methods

This research was conducted at two hospitals of a university, located in Ankara and Adana, between March 2008 and May 2009. The sample consisted of 82 patients and 54 relatives. The adopted inclusion criteria were: cancer diagnosis within last 3 months and over than 18 years of age, aware of their diagnosis and volunteer to participate.

Data were collected via questionnaires prepared based on the literature (Leydon et al., 2000; Echlin and Rees, 2002; Brokalaki et al., 2005; Liu et al., 2005; McCaughan and McKenna, 2007) and Turkish version (Gençtürk, 2004) of Miller Behavioral Style Scale (MBSS) to evaluate information-seeking behavior.

Two questionnaires were prepared for patient and relatives to obtain socio-demographics (age, sex, educational level, marital status, occupation, insurance, place of living, family income, concurrent drugs and habits), cancer and treatment characteristics (type of tumor, stage, date of diagnosis, treatments and side effects), information needs and information seeking behaviors besides common beliefs on cancer were included in 48 items. The questionnaire for relatives was included same parts in 33 items.

The Miller Behavioural Style Scale (MBSS), developed by Miller (1987) to identify 'monitors' who actively seek information and 'blunters' who are disposed to distract themselves (Miller, 1987). The MBSS consists of four hypothetical threat-evoking scenarios with eight corresponding potential coping responses categorized as either monitoring or blunting. A Turkish translation of this questionnaire as well as validity and reliability has been established by Gençtürk (2004) and used to measure information seeking behaviors in breast cancer patients and their first degree relatives.

All these forms were pre-tested with 8 patients and relatives. Then, the preliminary testing responses were examined and discussed and corrections were made by researchers.

## Data analyses

Descriptive statistics (frequencies, medians, means) were applied to analyze the relationship between clinical, socio-demographic and information needs and MBSS scores. For all analyses,  $p < 0.05$  was considered significant. The open-ended questions were grouped into themes and summarized as percentages.

## Ethical considerations

This study was approved by Baskent University Institutional Review Board (Project no: KA08/75) and supported by Baskent University Research Fund. Each participant was invited to read and sign a consent form if they wished to take part in the study.

## Results

Demographic characteristics of patient and relatives were presented in Table 1. Mean age of patients was 49 and for relatives 44 years. More than half of them were women and married. Majority of the relatives were first degree relatives such as spouse (37%); son/daughter and brother/sister.

Diagnostic and treatment related characteristics can

**Table 1. Demographics Characteristics of Patients and Relative**

Demographics	Patient (n=82)		Relatives (n=54)	
	n	(%)	n	(%)
Age	(mean=44.7 ±12.08; range: 22-65) (mean=49.4±14.3; range: 20-78)			
Gender				
Female	52	63.4	29	53.7
Male	30	36.6	25	46.3
Marital Status			(n=53)	
Married	66	80.5	45	84.9
Single	12	12.6	7	13.2
Divorced	4	4.9	1	1.9
Education	(n=80)			
Primary	28	35	7	13
Secondary/High School	31	38.8	26	48.1
University	21	26.2	21	38.9
Working status	(n=75)		(n=43)	
Retired	29	38.7	19	44.2
Unemployed	31	41.3	9	20.9
Full-time	12	16	15	24.9
Part-time	3	4	-	-
Occupation	(n=74)		(n=49)	
Self-employed	27	36.5	14	28.6
Housewife	28	37.8	12	24.5
Civil servant	14	18.9	21	42.9
Worker	5	6.8	2	4.1
Income Level				
< expenditure	42	51.3	27	50
equal with expenditure	24	29.2	16	29.6
> expenditure	16	19.5	11	20.4
Place of living*				
Near to treatment center/in the same city	46	56.1		
Outside of the city/ far away from treatment center	36	43.9		
Having a relative with cancer*				
Yes	44	53.7		
No	38	46.3		

\*These questions did not asked to relatives

be seen in Table 2. Patients were receiving treatment mostly for breast, gynecologic, lung cancer and leukemia/lymphoma. Mean duration of diagnosis was 3 years and most of them were receiving chemotherapy.

When asked about whom they would prefer to receive information about disease and treatments all of them indicate that they want to be informed by doctor (Table 3). Other information sources were internet, media and nurses (Figure 1). Half of the patients were satisfied the information they received; however need more information on diseases process, treatment and side-effect management.

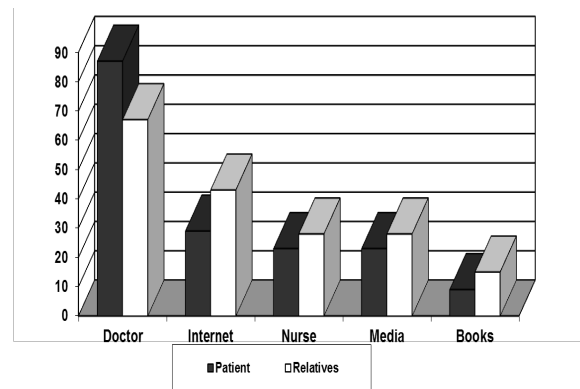
Information-seeking behavior was identified using the modified MBSS. The number of monitor responses was recorded for each respondent, and a monitor subscale was dichotomized at the median score into low monitors (those with a score under 6) and high monitors (those with a score of 6 or above). Of the respondents, 74 were classified as high monitors, and 59 were classified as low monitors. The mean patients' MBSS score ( $6.4 \pm 3.2$ ) were higher than their relatives' mean MBSS score ( $5.4 \pm 3.1$ ). Majority of patients (61.7%) were high monitors while 46.2% of their relatives were high monitors (Table 4). No significant relationship was found between monitor score and any of these characteristics; age ( $p=0.547$ ), marital status ( $p=0.737$ ) and education ( $p=0.20$ ). Respondents with higher education and younger age indicated more information-seeking behaviors.

Majority of patients and half of their relatives were agreed on "cancer is curable and preventable disease". While half of the patients were agreed "accepting the disease is difficult for me" 71% of relatives responded so. Only 2.5% of patients agreed with the statement "I don't

**Table 2. Diagnosis and Treatment Related Characteristics**

Characteristic (n=82)	n	%
<b>Cancer Diagnosis</b>		
Breast	21	25.6
GYN (Over, cervix, endometrium, uterus)	25	30.3
Leukemia/Lymphoma	15	18.4
Lung	7	8.5
Colorectal	5	6.2
Bladder Ca	2	2.4
GI (gallbladder, liver)	4	4.8
Other (Maxillar)	3	3.6
<b>Duration (mean:3.4 years; range: 3 months to 8 years)</b>		
3-6 month	15	18.3
7-12 month	25	30.5
1-2 year	15	18.3
3-4 year	19	23.2
5-8 year	8	9.7
<b>Stage (n=81)</b>		
Initial stage	28	34.6
Medium	31	38.3
Unknown	18	22.2
Advanced	4	4.9
<b>Treatment types* (n=80)**</b>		
Chemotherapy	70	86.4
Surgery	46	57.1
Radiotherapy	17	20.7
Other(antibiotics)	6	6.3

\*Multiple answers received; \*\*percentages were calculated



**Figure 1. Sources of Information They Used Regarding Disease and Treatment**

**Table 3. Information about Disease and Treatment, Sources of Information**

Information about Disease and Treatment	Patient (n=82) n (%)	Relatives (n=54) n (%)
Where/Whom do you prefer to get information first? (n=77)		
Doctor	77 100.0	*
Did you need information? (n=81)		
Yes	61 75.3	*
No	20 24.7	
If YES, When? (n=58)		
When learned the diagnosis	35 60.3	
Beginning of the treatment	12 20.7*	
You had symptom	11 19.0	
Did you receive information on diagnosis and treatment? (n=81) (n=52)		
Yes	77 95.1	41 78.8
No	4 4.9	11 21.2
Sources of information** (n=77)*** (n=52)***		
Doctor	67 87.1	36 66.7
Internet	24 29.3	23 42.6
Media	19 23.2	15 27.8
Nurse	19 23.2	15 27.8
Medical book	7 8.5	8 14.8
Friends	12 14.6	12 22.2
Another patient/relatives	11 13.4	10 18.6
Booklet	6 7.3	7 13.0
Content of the information** (n=77)*** (n=52)***		
About diseases	63 76.8	33 61.1
Treatment type and options	54 65.8	28 51.9
Side effects of the treatment	45 54.9	30 55.6
Follow up and tests	30 36.6	24 44.4
Home care	25 30.5	22 40.7
Satisfaction with the information (n=77) (n=43)		
Yes	42 54.5	21 48.8
Partly	33 42.9	17 39.5
No	2 2.6	5 11.6
Preferred methods of learning** (n=77)*** (n=52)***		
One-by-one personal conversation from health-care professionals	74 90.2	44 81.5
Given written information(leaflets, pamphlets, etc.)	27 32.9	24 44.4
By searching through medical books and literature	20 24.5	22 40.7
Meeting and talking with other patients	19 23.2	9 16.7
By seeing and doing	13 15.9	7 13.0

\*These questions did not asked to relatives; \*\*Multiple answers received; \*\*\*Percentages were calculated

**Table 4. Information-seeking Behaviors**

	Mean MBSS Score	High Monitors n %	Low monitors /Blunters n %	Total n %
Patient	$6.41 \pm 3.2$	50 61.7	31 38.3	81 100
Relatives	$5.46 \pm 3.1$	24 46.2	28 53.8	52 100

**Table 6. Subjects' Perceptions to Importance of the Support Related their Cancer Experience\***

	Patient (n=82) (mean±SD)	Patient's Relatives (n=54) (mean±SD)
Having one designated member of your treatment team with whom you can talk about all aspects of cancer, treatment and follow-up	3.6±0.7	3.7±0.6
Being informed about things you can do to help yourself get well	3.6±0.6	3.7±0.6
Being given written information about important aspects of care	3.6±0.8	3.6±0.7
Being given explanations about tests and test results	3.7±0.7	3.6±0.5
Being adequately informed about the benefits and side-effects of treatments before you have to choose them	3.6±0.8	3.7±0.6
Having access to professional counseling if you need it	3.3±1.07	3.3±0.8
Being given information about aspects of managing your illness and side effects at home	3.1±1.0	3.2±1.2
Being informed about support groups and sources in your area	2.9±1.12	3.0±0.9
The opportunity to talk to someone who understands and has been through a similar experience	2.3±1.13	2.8±1.02
Being given information about sexual problems that may be caused by your cancer or treatment	2.9±1.2	**

\*Scaled as "1 = not important" to "4 = very important", \*\*this item has not been asked

**Table 5. Subjects' Responses Related to Common Beliefs about Cancer and Treatment**

Statements	Patient (n=82)			Patient's Relatives (n=54)		
	Yes	No	Sometimes	Yes	No	Sometimes
Cancer is curable	74.7	2.5	22.8	66.7	2.0	31.4
Cancer is a preventable disease	67.1	7.6	25.3	55.8	5.8	38.5
Cancer is contagious	1.3	94.8	3.9	6.0	94.0	-
The disease which mine or relatives' is threaten me	35.4	36.7	27.8	49.0	27.5	23.5
Accepting the disease is difficult for me	48.1	40.5	11.4	71.4	16.3	12.2
I think the disease which mine or relatives' is serious than other diseases	72.2	16.5	11.4	76.9	7.7	15.4
I don't want to get information about mine or relatives' disease which is disturb/frighten me	2.5	83.5	14.0	4.0	92.0	4.0

want to get information about disease which disturbs me", whereas majority of relatives agreed (Table 5).

Subjects' perceptions to importance of the support related their cancer experiences were presented in Table 6. While respondents gave high importance for the many support items, less importance were given to the "being informed about support groups", "being given information about sexual problems" and "the opportunity to talk someone who has similar experience" (Table 6).

Majority of patients reported physical changes in their appearance, which was the most difficult to deal with as stated by one third of the subjects. Half of the subjects stated worries about future.

**Discussion**

The study highlighted common beliefs, information needs and information-seeking behaviors of cancer patients and relatives in Turkey. Results from this survey are consistent with the existing literature regarding information priorities; quantity of information desired and preferred methods of information (Rutten et al., 2005; Piredda et al., 2008; Ehemann et al., 2009). All of them indicate that they want to be informed by doctor about their diagnosis and treatment first. The great majority of respondents, far more than the average numbers in the literature, favored oncologists as the preferred source

of information. This can be explained that traditionally Turkish cancer patient information has been performed by doctors, while Turkish nurses' function as educators has been recognized only in recent years as part of their professional role. Similarly, postgraduate programs in oncology nursing have started in Turkey only a few years ago; therefore, most nurses working with cancer patients are not specialized in oncology nursing (Platin, 2010).

Majority of patients and half of their relatives were agreed on "cancer is curable and preventable disease". Previous studies from Turkey regarding public perceptions towards cancer showed conflicting results to our own. One recent survey conducted in 26 cities (n=3096) showed that the majority of respondents (93.2%) believed cancer to be a fatal disease (Gultekin et al., 2011). This is similar to the findings of another study by Cetingoz et al. (2002) who found that 87% of respondents agreed that cancer is a fatal disease. In both studies, respondents who were better educated had a better understanding and held more positive perceptions towards cancer.

When asked about their information needs while they were listed as "diagnosis and treatment process" treatment options and management of side effects; did not indicate emotional status during disease and treatment process. During long illness and therapy process patient and their relatives need to seek information about various topics. When the patient' knowledge and the experiences were increased, their information requirements get detailed. Each new situation directed patient to seek information during process. In our study, it was found that patient seek information mostly about therapy process and prognosis. So the priorities of the information needs could be change in the process. Taken together, these findings clearly show the importance of concrete information about the disease, therapy/side effects and care of the patients.

The most preferred information sources were reported as healthcare professionals, medical brochures and family and friends; least used sources were internet and support groups (Ankem, 2006b). Healthcare professionals are most used information source as found in previous studies (Cowan and Hoskins, 2007). Many factors would have an impact on patients information needs and no prescriptive/one method would be applied for all/ one method does not fit all. Therefore different method should be used based on patients' information needs and characteristics (Mills and Sullivan, 1999).

When asked about “who should be the decision taker about your treatment and choices”, more than half were responded as “together with doctor”. This result shows the changes in the “doctor knows the best” tradition in our culture however further research needed to explore.

In a study conducted by Cowan and Hoskins (2007) to determine information preferences of women with breast cancer (n=36) authors reported that more than half of the women (56%) were high monitors; suggested that individual’s personality greatly effects how they will perceive information. Rees and Bath (2000) investigated breast cancer women and their partners (n=109) communication flow; mean score of MBSS found as 9 and only one in third of the group were over then this score, therefore defined as high monitors. In a study conducted by Gençtürk (2004) in our Country first degree relatives of breast cancer patients information seeking behaviors, to identify their needs and impact of educational program, reported that mean MBSS as 7 and nearly half of them were high monitors. Individuals who are monitors actively seek information to help them through their treatment. The information they seek can be written as well as face to face support from a health care professional. Individuals who are blunters like to distance themselves from the entire event, not needing any information or support.

In this study high monitors and blunters based on MBSS were compared according to the factors such as age, gender, marital status, income, educational status the number of information resources, disease stage, place of living and information needs; found no statistical significance.

In this study reverse relationship was found between age and information seeking behavior; patient and relatives under 50 years old were more in high monitors. In consistence with this Mills and Sullivan (1999) reported that younger patients were requesting more information needs than older patients.

In this study we found no difference between information needs and the stage of the diseases. In a study by Leydon et al. (2000) it was reported that most patients information needs and the amount of information varies/ differ among patients as well as type of needs during the disease continuum. Echlin and Rees (2002) reported that men with prostate cancer have distinct information needs and information-seeking behaviors throughout their cancer journeys. Although there is considerable variation in the amount and type of information that men require, the majority of men with prostate cancer are satisfied with the information they receive. Although partners of men with prostate cancer have needs for information, these needs are often unmet (Echlin and Rees, 2002).

A number of limitations of the study must be acknowledged. This was a small-scale survey aimed to investigate learning needs of cancer patients of a single institution in order to plan an education project tailored to them. Moreover, respondents were not stratified according to tumor sites, time since diagnosis or current treatments. Thus, in order to achieve generalisable results, the study should be extended to several Oncology Centers through Turkey with a larger sample stratified for age, sex, tumor sites and time since diagnosis.

In conclusions, patient and their relatives relied heavily on their doctors for information. Patient and their relatives differ in some of their information-seeking behaviors. Cancer patients’ beliefs and their strategies for coping with their illness can constrain their wish for information and their efforts to obtain it. By this way, essential needs of parents would be identified earlier and strategies could be planned to meet these needs. Healthcare professionals need to assess and be sensitive to the common beliefs, information needs and information-seeking behaviors of cancer patients and their relatives.

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