

## Original Article

# Effect of Knowing the Diagnosis or Not on Cancer Patients' Hopelessness Levels

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### Abstract

**Objectives:** This study aims to assess the effect of knowing the diagnosis or not on hopelessness level in patients who receive cancer treatment.

**Methodology:** This study is descriptive and comparative in nature. Target population of the study is the patients who applied to the Research Hospital in 2010 and were diagnosed with cancer. Participants included patients who applied to Medical Oncology and Chemotherapy Polyclinic between September and December, who were over 18, who could communicate, and who volunteered to participate in the study.

**Results:** Beck Hopelessness Scale mean score was found  $3.93 \pm 3.89$ . An analysis of patients' Beck Hopelessness Scale mean scores were statistically higher in women, in those who do not have a job bringing income, who do not have social security, who are illiterate, and who have monthly income of 870 TL and less, also who did not believe in coping with the disease ( $p < 0.05$ ,  $p < 0.01$ ).

**Conclusions:** The present study found that the participants did not have feelings of hopelessness, and knowing or not knowing the diagnosis did not affect hope levels. Female patients and patients who had low education and income level were found to be more hopeless. More effort should be made in order to increase hope levels among cancer patients in socioeconomically disadvantaged groups.

**Key Words:** Cancer, Diagnosis, Hopelessness.

### Introduction

In addition to being a chronic and deadly disease, cancer is an important problem that causes emotional, psychological and behavioural reactions. Cancer patients could show various reactions in the process of adapting to their diseases. In this regard, it is important to identify psychological problems and the factors that affect these psychological problems in order to understand the patient, enhance his/her adaptation to the new situation, and plan an appropriate approach.

Hope, which is a positive concept, is defined as an expectation and desire which focuses on human presence, which is specific to person, and which creates dynamism for the soul. Hope, which is also perceived as a moral power, prevents feelings of hopelessness and helplessness in case of diseases. Hope has an

important place in cancer patients' adaptation to the disease and the treatment (Oz, 2004; Aslan et al., 2007).

Hopelessness, which is opposite of hope, expresses negative emotions, negative consequences, and helpless expectations. In his cognitive model, Beck defines hopelessness as negative expectations about future. Hopelessness was approved as a nursing diagnosis by NANDA in 1986 and defined as "subjective state in which an individual sees limited or no alternatives or personal choices available and is unable to mobilise energy on own behalf". By making one's life passive, hopelessness becomes a factor for depression and self-destructive behaviours (Oz, 2004). It is reported that cancer patients experience intensive anxiety and fear of death, which could be highly associated with the feelings of hopelessness; and feeling of hopelessness might

result from negative perceptions about cancer and perceiving it as a deadly disease. Cancer patients experience hopelessness due to such factors as deterioration in body image, inability to meet needs on time, inadequacy in social supports, negative beliefs about the disease, isolation due to the disease, long treatment processes, and limitations in activities.

Two different studies conducted with breast cancer patients found that the patients were not hopeless (Solak and Baser, 2003; Fadiloglu et al., 2006). Another study conducted with cancer patients and their relatives found the hopelessness levels low (Alacacioglu, 2007). In a study which aimed to assess psychosocial features of gynaecologic cancer patients, depression, hopelessness and loneliness levels were found to be high; it was reported that there was an increase in depression levels with the increase in hopelessness and loneliness levels (Dansuk et al., 2002). Similarly, a study which investigated psychiatric disorders found that the most frequently encountered diagnoses were adjustment disorder and major depressive disorder accompanied by depressive emotions; patients' feelings of hopelessness, worthlessness, and renunciation of life are reported to be important in the identification of self-destruction risk (Ateşçi et al., 2003).

Cancer patients with high hope levels tended to live longer; and the duration spent without disease was longer.

Generally, people demonstrate behaviours as if nothing would happen to them in their daily life. Yalom defines this case as a thinking disorder that contradicts with human beings' biological existence (Okyayuz, 2003). One of the cases when people clearly feel the fact that they are mortal is the moment when they face the cancer diagnosis. The statement of "deadly disease" is analysed under "breaking bad news" concept in the literature (Girgis, 1998; Ptacek, 2001). Bad news is defined as a message which has a meaning in which there is no hope or which creates a threat to the individual's physical and emotional well-being, and which has a risk of ruining one's life or decreasing choices in his/her life (Ptacek and Eberhardt, 1996).

A study conducted with cancer patients found psychiatric disorder proportions as 35% in those who knew their diagnosis, 41.4% in those who guessed the diagnosis, and 21% in those

who did not know the diagnosis. When the patients who knew their diagnosis and who guessed it were analysed in the same group, the proportion of psychiatric disorder-with a proportion of 37.7%- was significantly higher in comparison to those who did not know the diagnosis (21%) (Ateşçi et al., 2003).

Patient's right to be informed was determined by law in the Turkish Medical Deontology and Medicine Research Regulations (Ayan, 1991). Besides, the patient's right to obtain information about his/her health is clearly defined in the 15<sup>th</sup> item of the 3<sup>rd</sup> section in the Patient Rights Regulations launched in 1998 (Official gazette 01.08.1998; 23420). On the other hand, it is an ethical obligation to inform patients about the procedures to be applied and obtain their informed consent. Studies show that the proportion of not knowing cancer diagnosis ranges between 20% and 54% (Bilgin, 2008). Particularly families make an effort to keep the diagnosis secret from the patient and ask the health professionals not to tell the diagnosis to the patient. Similar behaviours are demonstrated in our region as well, and patients frequently go through the treatment process without knowing about their diagnosis.

This study aims to assess the effect of knowing the diagnosis or not on hopelessness level in patients who receive cancer treatment.

### Research Questions

Does patients' knowing their diagnosis affect their level of hope?

Do patients' socio-demographic features affect their level of hope?

Do features about the disease and treatment affect patients' level of hope?

### Methodology

This study is descriptive and comparative in nature. Target population of the study is the patients who applied to the Research Hospital in 2010 and were diagnosed with cancer. Participants included patients who applied to Medical Oncology and Chemotherapy Polyclinic between September and December, who were over 18, who could communicate, and who volunteered to participate in the study. Data were collected through face to face interviews using the Questionnaire which involved the independent variables and Beck

Hopelessness Scale which involved the dependent variable.

The 22-item questionnaire which involves the variables related to the dependent variable of the study, Hopelessness, was prepared by the researchers. Neither the questionnaire nor the interviews involved statements about cancer; it was investigated through such questions as “Do you know the name of your disease? And “Do you know what kind of a disease it is?”. In addition, patient relatives were asked “Was the patient told about his/her diagnosis? “Was s/he told only the diagnosis or was s/he informed about the disease? If the diagnosis had not been told, they were asked to explain the reason. As a result of these questions, those who knew the disease and diagnosis were grouped as “knows the diagnosis” and those who did not were grouped as “does not know the diagnosis”. The reason for not telling about the diagnosis was asked through an open-ended question; and groupings were performed in line with the statements of the patient relatives.

*Socio-demographic Features:* The open-ended question investigated age while close-ended questions investigated gender, marital status, education level, working or not, and social security. Monthly income was grouped according to a research conducted by a labour union every year in Turkey, considering the breadline and poverty limit reported. The study conducted in 2011 indicated 870 TL as breadline and 2835 TL as poverty limit (TURK-İS, 2011).

*Questions about the Disease and the Treatment Process:* Close-ended questions were used for the information related to the disease and treatment process, surgery, intervention used, searching about the disease, wanting to know about the disease and treatment, place of treatment, believing in being able to cope with the disease, compliance to the medical treatment, cancer area, and practices performed apart from the medical treatment.

**Beck Hopelessness Scale:** The 20-item self report scale was developed by Beck et al. in

1974. It aims to identify the individual's hopelessness level about future. Questions are answered as “Yes” and “No”; each question that complies with the key receives 1 point, and those that do not comply with the key receive no scores. The total score is taken as the hopelessness score. Scores range between 0 and 20. The scale has three subscales including “feelings and expectations about the future” “loss of motivation”, and “hope”. Validity and reliability of the scale was first performed by Seber in 1991, and Cronbach's alpha value was found .86. It was then retested by Durak and Plabiyikoglu in a group which included cancer patients as well. Cronbach's alpha value was found .85 in the present study. Item 1,3,7,11 and 18 belong to the “feelings and expectations about the future” factor; Item 2,4,9,12,14,16,17 and 20 indicate the “loss of motivation factor”, and Item ,6,8,10,13,15 and 19 indicate the “hope” factor. 11 items are scored 1 point if the answer is “Yes” (2,4,7,9,11,12,14,16,17,18, and 20) and 9 items are scored 1 point if the answer is “no” (Item 1,3,5,6,8,10,13,15, and 19). Higher scores indicate high hopelessness levels (Beck et al., 1974; Seber et al., 1993; Durak and Plabiyikoglu, 1994).

Data were analysed in SPSS, using descriptive statistics, Shapiro Wilk, Mann-Whitney U test and Kruskal Wallis test.

### **Ethical Considerations**

Written approval was obtained from University Research Hospital. Verbal consent was obtained from the patients who accepted to participate in the study.

### **Results**

Average age of the participants was found  $54.21 \pm 13.3$ . Of all the participants, 52.9% were male, 85.5% were married, and 52.9% graduated from primary school. Only 16.7% had job bringing income, 98.9% had social security, and 73.2% lived on the breadline. Beck Hopelessness Scale mean score was found  $3.93 \pm 3.89$  (see Table 1).

**Table.1. Patients' Socio-demographic Features and Beck Hopelessness Scale Mean Scores**

		S	%
Gender	Female	130	47.1
	Male	146	52.9
Marital Status	Married	236	85.5
	Single	14	5.1
	Widow(er)/Divorced	26	9.4
Education Level	Illiterate	79	28.6
	Primary school	146	52.9
	Secondary school	19	6.9
	High school	22	8.0
Working	Yes	46	16.7
	No	230	83.3
Social security	Yes	273	98.9
	No	3	1.1
Monthly income	870 TL and less (breadline)	202	73.2
	871 TL-2835 TL (poverty)	69	25.0
	2836 TL and more	5	1.8
		$\bar{X} \pm SD$	
Age		54.21 ± 13.3	
Beck Hopelessness Scale Mean Score		3.93 ± 3.89	

**Table 2. Patients' Knowledge about the Disease Process**

		n	%
Duration of the Disease	≤ 6 months	102	37.0
	7-12 months	71	25.7
	13-60 months	79	28.6
	≥ 61 months	24	8.7
Knowing the diagnosis	Yes	141	51.1
	No	135	48.9
Reason for not telling the diagnosis	To prevent the patient from being sad	117	88.0
	To prevent the patient from being demoralized	7	5.3
	Other	9	6.8
Having undergone a surgery	Yes	132	47.8
	No	144	52.2
Practices such as biopsy, catheter, etc.	Yes	233	84.4
	No	43	15.6
Searching about the disease	Yes	65	23.6
	No	211	76.4

Source of the research	Applying to another doctor/hospital	40	62.7
	Internet	9	13.4
	Meeting with other patients	2	3.0
	Applying to another doctor/hospital and internet	8	11.9
	Other	6	9.0
Wanting to get more information	Yes	203	73.6
	No	73	26.4
Cancer area	Digestive system cancers	118	42.8
	Respiratory System Cancers	41	14.9
	Head-Neck	8	2.9
	Urogenital	77	27.9
	Hematologic	21	7.6
	Other	11	4.0

**Table 3. Patients' Knowledge about the Treatment Process**

Duration of the treatment	≤ 6 months	180	65.2
	7-12 months	45	16.3
	13-60 months	46	16.7
	≥ 61 months	5	1.8
Place of the treatment	Hospitalised	70	25.4
	In polyclinic	126	45.7
	Both	80	29.0
Believing in being able to cope with the disease	Yes	253	91.7
	No	23	8.3
Fully complying with the medical treatment among those who believe in being able to cope with the disease	Yes	251	99.2
	No	2	0.8
Practices other than medical treatments in order to get well	Does nothing	27	9.8
	Eating special food (honey, stinging nettle, special mixtures)	20	7.2
	Praying, worshipping	157	56.9
	Both	72	26.1

**Table 4. Distribution of the Patients' Beck Hopelessness Scale scores according to Demographic Features**

		S	%	$\bar{X} \pm SD$	U/KW	P
Gender	Female	130	47.1	4.59±4.38	U:7758.0	<b>.008</b>
	Male	146	52.9	3.34±3.31		
Working	Yes	46	16.7	2.93±3.40	U:3943.5	<b>.006</b>
	No	230	83.3	4.13±3.96		
Social Security	Yes	273	98.9	3.85±3.79	U:84.5	<b>.017</b>
	No	3	1.1	11.33±6.51		
Marital Status	Married	236	85.5	3.94±3.95	KW:.846	.655
	Single	14	5.1	3.86±4.60		
	Widow(er)/Divorced	26	9.4	3.81±3.09		
Education Level	Illiterate	79	28.6	5.33±5.02	KW:11.55	<b>.021</b>
	Primary school	146	52.9	3.32±2.98		
	Secondary school	19	6.9	4.47±4.54		
	High school	22	8.0	2.95±3.51		
	University	10	3.6	2.80±2.25		
Monthly income	870 TL and less (breadline)	202	73.2	4.33±4.02	KW:13.806	<b>.001</b>
	871 tl-2835 TL (poverty)	69	25.0	2.90±3.39		
	2836 TL and more	5	1.8	2.00±1.87		

**Table 5. Distribution of Patients' Beck Hopelessness Scale Scores according to Disease and Treatment Process**

		n	%	$\bar{X} \pm SD$	U/KW	p
Knowing the diagnosis	Yes	141	51.1	3.65±3.46	U:9170.0	.595
	No	135	48.9	4.21±4.29		
Undergoing surgery	Yes	132	47.8	3.95±4.09	U: 9077.5	.514
	No	144	52.2	3.91±3.71		
Believing in being able to cope with the disease	Yes	253	91.7	3.40±3.21	U:1046.0	<b>.000</b>
	No	23	8.3	9.74±5.73		
Duration of the Disease	≤ 6 months	102	37.0	3.70±3.93	KW:1.90	.593
	7-12 months	71	25.7	3.96±3.87		
	13-60 months	79	28.6	3.73±3.00		
	≥ 61 months	24	8.7	5.46±5.87		
Cancer area	Digestive system cancers	118	42.8	3.37±3.47	KW:8.33	.139
	Respiratory System Cancers	41	14.9	3.49±3.49		
	Head-Neck	8	2.9	5.88±5.77		
	Urogenital	77	27.9	4.96±4.57		
	Hematologic	21	7.6	4.00±3.49		

	Other	11	4.0	2.73±1.90		
Duration of the Treatment	≤ 6 months	180	65.2	3.81±4.15	KW:6.44	.092
	7-12 months	45	16.3	3.78±3.21		
	13-60 months	46	16.7	4.41±3.52		
	≥ 61ay	5	1.8	5.00±4.06		
Practices other than medical treatments in order to get well	Does nothing	27	9.8	3.85±4.48	KW:1.67	.642
	Eating special food (honey, stinging nettle, special mixtures)	20	7.2	4.35±3.92		
	Praying, worshipping	157	56.9	3.94±4.16		
	Both	72	26.1	3.81±3.03		
Place of the treatment	Hospitalised	70	25.4	4.53±4.71	KW:.417	.812
	In polyclinic	126	45.7	3.69±3.58		
	Both	80	29.0	3.78±3.57		

A 37% of the patients had been sick for 6 months or less, 51.1% knew their diagnosis, 52.2% did not have an operation, 84.4% underwent procedures such as biopsy, catheter, etc.; 76.4% did not search about their disease, and 73.6% wanted to learn more information about their disease and treatment. 88% of the patients who were not told about their diagnosis were reportedly treated so because their relatives did not want them to be sad, 62.7% of those who searched about their disease were found to apply to another doctor or hospital. Cancer type was digestive system cancer for the 42.8% of the patients (see Table 2).

Of all the patients, 65.2% had been having treatment for 6 months and less; 45.7% received treatment in polyclinics; 91.7% believed that they will be able to cope with their disease; and 99.2% of these patients reportedly fully complied with the treatment. 90.2% did something other than medical treatment in order to get well, 56.9% of those who did so preferred praying and worshipping (see Table 3).

An analysis of patients' Beck Hopelessness Scale mean scores according to their demographic features indicates that scores were statistically higher in women, in those who do not have a job bringing income, who do not have social security, who are illiterate, and who have monthly income of 870 TL and less ( $p<0.05$ ,  $p<0.01$ ) (see Table 4).

An analysis of Beck Hopelessness Scale mean scores according to the patients' disease and

treatment process features shows that mean scores of those who did not believe in coping with the disease were significantly higher ( $p<0.01$ ). Mean score was found to be higher in those who did not know the diagnosis, who had head-neck cancers, who ate special food beside the medical treatment, who were hospitalised, and who had treatment duration of 5 years or more; however, the difference was not statistically significant (see Table 5).

## Discussion

This study found the Beck Hopelessness Scale mean score as  $3.93 \pm 3.89$ , indicating a low hopelessness level. In other words, the participants were not hopeless. An analysis of the studies that used the same data collection tool with cancer patients indicated that the mean score was  $3.82 \pm 4.28$  in the study conducted by Kayis;  $6.5 \pm 3.6$  in the study conducted by Tan and Karabulutlu;  $5.20 \pm 4.39$  in the study conducted by Yildirim et al., and  $4.57 \pm 3.63$  in the study conducted with breast cancer patients by Fadioglu et al. Given that hopelessness scores range between 0 and 20, the participants' hopelessness scores were found to be low, which is in line with the similar studies in the literature (Kayis, 2009; Tan & Karabulutlu, 2005; Yildirim et al., 2009; Fadioglu, 2006).

Women's hopelessness level was found to be higher than that of men in this study. In their study conducted with cancer patients, Pehlivan et al. similarly found that women's

hopelessness was significantly higher (Pehlivan, 2012).

In their study conducted with adolescent cancer patients, Hendricks-Ferguson reported opposite findings; girls were found to have higher hope levels in comparison to boys (Hendricks-Ferguson, 2006). A number of studies with cancer patients, on the other hand, found no gender effect on hopelessness level (Kayis, 2009; Yildirim et al., 2009; Alacacioglu, 2007; Ozdas and Olgun, 2015; Arslan et al., 2009; Mystakidou et al., 2009). It should also be noted that patients who had low income and education level and no health insurance had low hopelessness level; hence, other socioeconomic variables might have caused more disadvantageous cases for women.

An analysis of hopelessness level according to working and income level variables showed that hopelessness level was higher in those who did not have social security, who did not have a job bringing income, and who had monthly income of 870 TL and less. In their study conducted with breast cancer patients, Fadiloglu et al. found that the group with income less than expenses had significantly higher hopelessness mean scores; and the variable of working or not did not demonstrate any significant differences (Fadiloglu et al., 2006). Other studies conducted with cancer patients found that income level, social security, and working in a job did not affect hopelessness level (Kayis, 2009; Yildirim et al., 2009; Alacacioglu, 2007; Avci et al., 2009; Arslan et al., 2009; Oztunc et al., 2013). Majority of the participants had very low income; thus hopelessness level might have been affected by the financial burden caused by the disease for people who cannot meet their basic needs. Besides, although some cost in the treatment process is met by social security, those who do not have social security cannot benefit from this opportunity and have to provide financial resource for the treatment, which could be possible with a job bringing income. All these factors might have contributed to the participants' hopelessness levels.

An analysis of hopelessness levels according to education level indicated that hopelessness was significantly higher in those who were illiterate. In their study conducted with cancer patients, Pehlivan et al. found that hopelessness level

was significantly higher in those who were illiterate. Arslan et al. also investigated cancer patients' hopelessness level and found that hopelessness score decreased significantly with the increase in education level. In their study conducted with breast cancer patients, Oztunc et al. found that hopelessness mean score was significantly higher in those who were illiterate. Aslan et al. found that patients had higher hope scores as their education level increased (Pehlivan, 2012; Arslan et al., 2009; Oztunc et al., 2013; Aslan et al., 2007). Findings of the present study are in line with these studies. Some studies that investigate hopelessness level in cancer patients found that education level had no effects on hopelessness level (Kayis, 2009; Yildirim et al., 2009; Alacacioglu, 2007; Ozdas and Olgun, 2015; Avci et al., 2009; Mystakidou et al., 2009). Education level might have affected hopelessness level through the relationship it has with factors such as coping behaviours, financial situation and life conditions.

This study found that hopelessness level was lower in those who do not believe in being able to cope with the disease. In their study conducted with cancer patients, Felder and Vellone et al. found a positive, significant relationship between coping behaviours and hope levels (Felder, 2004; Vellone et al., 2006). Coping, which involves cognitive and behavioural reactions in order to adapt the needs, requirements and changes in the disease process is affected by experience, personality traits, and perception about the disease (Kocaman, 2008; Penley, 2002). Type of coping with chronic stressors such as cancer could change in time, and methods that were effective at the beginning might lose their effectiveness. Type of coping affects the patients' psychosocial reactions (Kocaman, 2008; Penley, 2002).

The present study found that hopelessness level was higher in those who did not know the diagnosis in comparison to those who knew it, but the difference was not statistically significant. In their study conducted with breast cancer patients, Jo and Son found a negative, significant relationship between uncertainty and hope. In the study conducted with cancer patients and patient relatives, Alacacioglu found that knowing the disease had no effects on hopelessness level. In their study conducted with cancer patients, Vellone et al. detected no

relationship between knowing the diagnosis and hopelessness level (Jo & Son, 2004; Alacacioglu, 2007; Vellone et al., 2006). Findings of this study are in line with these studies.

The present study found that marital status, undergoing an operation, duration of the disease, cancer area, treatment duration, practices other than the medical treatment, and the place of medical treatment had no effects on the hopelessness level. Other studies also found that marital status did not affect hopelessness level (Fadiloglu, 2006; Kayis, 2009; Yildirim et al., 2009; Aslan et al., 2007; Alacacioglu, 2007; Pehlivan et al., 2012; Ozdas and Olgun, 2015; Arslan et al., 2009; Oztunc et al., 2013). Two studies on cancer patients found that duration of the disease did not affect hopelessness level (Yildirim et al., 2009; Aslan et al., 2007).

In the study conducted with cancer patients and patient relatives, Alacacioglu found that cancer type and place of treatment had no effect on hopelessness level, but those who had been diagnosed with cancer for more than six months were found to have significantly higher hopelessness levels. Pehlivan et al., in their study conducted with cancer patients, found that cancer type did not affect hopelessness level. Arslan et al. investigated hopelessness level in cancer patients and found no significant differences in terms of treatment duration and cancer type. In their study conducted with breast cancer patients, Oztunc et al found that duration of the disease did not affect hopelessness level. In their study with cancer patients, Mystakidou et al. found that cancer type did not affect hopelessness level. Vellone et al. found no significant relationship between hopelessness level and duration of the disease (Alacacioglu, 2007; Pehlivan et al., 2012; Arslan et al., 2009; Oztunc et al., 2013; Mystakidou et al., 2009; Vellone et al., 2006). In line with the findings of this study, several studies indicate that marital status and diagnosis and duration of treatment had no significant effects on hope levels.

The present study found that the participants did not have feelings of hopelessness, and knowing or not knowing the diagnosis did not affect hope levels. Female patients and patients who had low education and income level were found to be more hopeless. More effort should be made in order to increase hope levels among

cancer patients in socioeconomically disadvantaged groups. Future studies could make a more in-depth analysis of type of receiving informed consent which explains diagnosis and treatment processes, patients' satisfaction about this, and the effects of this case on hope levels.

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