

The effects of illness perception on death anxiety and satisfaction with life in patients with advanced gastrointestinal cancer

Original Article

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Abstract

Objectives. This study was conducted to determine the effects of illness perception on death anxiety and satisfaction with life in patients with advanced gastrointestinal cancer.

Methods. This cross-sectional and correlational study was conducted with 125 patients with cancer who were admitted to the oncology clinic of a university hospital in the Central Anatolian Region of Turkey between March and December 2022 and who met the research criteria and accepted to participate in the study. The data were collected with “Patient descriptive information form,” “Brief Illness Perception Questionnaire (BIPQ),” “Scale of Death Anxiety (SDA),” and “Satisfaction with Life Scale (SWLS).”

Results. It was found that mean BIPQ score of the patients was 39.54 ± 12.82 , the mean SDA score was 8.02 ± 3.16 , and the mean SWLS score was 14.74 ± 5.19 . BIPQ total score was found to affect SDA total score positively ($\beta = .751$) and SWLS total score negatively ($\beta = -.591$). SDA total score was found to affect SWLS total score negatively ($\beta = -.216$) ($p < .05$).

Significance of results. It was found that patients with advanced gastrointestinal cancer had moderate level of illness perception and life satisfaction, and high death anxiety. It was found that as illness perception of the patients increased, their death anxiety increased and satisfaction with life decreased. In addition, it was found that as the death anxiety of patients increased, their satisfaction with life decreased.

Introduction

Gastrointestinal cancer includes cancers of the esophagus, liver, stomach, gallbladder and biliary tract, pancreas, gastrointestinal stromal tumors, small intestine, colorectal, and anal (World Cancer Research Fund and American Institute for Cancer Research 2018). The worldwide prevalence of gastrointestinal cancers is as follows: colorectal cancers (19.5%), stomach (11.1%), and liver (9.5%). Colorectal cancers (9.1%) are the third most common type of cancer in both genders in Turkey (Globocan 2020). Gastrointestinal cancers are diagnosed at an advanced stage in some patients. Advanced cancer is defined as the type of cancer that has spread from where it first started to nearby tissues, lymph nodes, or other parts of the body and that is unlikely to be controlled with treatment (National Cancer Institute 2023). Advances in cancer treatments have changed the course and prognosis of the disease, and patients diagnosed with advanced cancer can live longer (Thorne et al. 2013). Like other types of cancer, advanced gastrointestinal cancer has many physical and psychosocial difficulties (Lim et al. 2022). The strength to cope is important to overcome psychosocial difficulties. Coping strategies are affected by illness perceptions of individuals (Lan et al. 2019).

Illness perception is patients' views, beliefs, and emotional responses to illness and treatment (Hopman and Rijken 2015). Patients with cancer who have a positive illness perception have a high quality of life and experience lower cancer and treatment-related symptom intensity (Ósmiałowska et al. 2022). Illness perception has a mediating role between symptom clusters and quality of life (Zhang et al. 2022). Patients with a good illness perception have lower hopelessness levels (Nehir et al. 2019). As illness perception decreases, patients' quality of life as well as physical and social well-being increase (Aydın Sayılan and Demir Doğan 2020). Illness perception may be an underlying risk factor for chemotherapy-associated nausea and vomiting (Kus et al. 2021).

Patients with advanced cancer are closer to death, and they report high death anxiety (Hong et al. 2022). North American Nursing Diagnosis Association International (NANDA-I) defines death anxiety as “a vague, restless feeling of discomfort or fear caused by the perception of a real or imagined threat to one's existence” (North American Nursing Diagnosis Association International 2007). As death anxiety increases, depression and anxiety levels increase

in patients receiving cancer treatment (Su et al. 2022). Determining death anxiety is important in meeting the end-of-life care needs of patients with advanced gastrointestinal cancer. Although patients with advanced cancer have high death anxiety, death anxiety of patients and their physical and psychological reflections are still not routinely questioned. Death anxiety is negatively associated with life satisfaction (Taghiabadi et al. 2017).

Satisfaction with life “is a cognitive component of subjective well-being and includes cognitive judgments about one’s life” (Diener 1984) and has been defined as “an overall assessment of individuals’ quality of life, based on their selected criteria” (Shin and Johnson 1978). Low satisfaction with life is associated with psychiatric symptoms such as anxiety, depression, and low quality of life (Lorenzo-Seva et al. 2019). Patients with advanced cancer often experience a lower quality of life due to the burden of physical symptoms and psychosocial problems (Van Roji et al. 2022), and quality of life is affected by death anxiety (Neel et al. 2015). In patients with cancer, life satisfaction is associated with resilience and coping strategies (Adamkovič et al. 2022) and coping styles are affected by illness perception (Richardson et al. 2017).

Nurses have an important role in the care of individuals with advanced cancer. Well-planned nursing care improves quality of life and alleviates psychological and physical symptoms in patients with advanced cancer (Tang et al. 2019). In this period, in addition to knowing about the illness perception, death anxiety, and satisfaction with life levels of individuals, knowing the effects of sociodemographic characteristics on these variables is also important in the planning and implementation of nursing care, as well as in dealing with the psychosocial aspect of cancer treatment. Knowing the effect of the perception of illness on death anxiety and satisfaction with life and providing a positive perception of illness can be effective in reducing the physical and psychosocial symptoms experienced by patients with advanced gastrointestinal cancer and can facilitate adherence to treatment. This research has been conducted to determine the effects of illness perception on death anxiety and life satisfaction in patients with advanced gastrointestinal cancer and will be a pioneer for similar studies.

Research questions

- 1) What is the illness perception, the death anxiety, satisfaction with life levels of patients with advanced gastrointestinal cancer?
- 2) What is the effect of sociodemographic characteristics on illness perception, death anxiety and satisfaction with life in patients with advanced gastrointestinal cancer?
- 3) Does illness perception affect death anxiety and satisfaction with life in patients with advanced gastrointestinal cancer?

Methods

Study design

The present study has a cross-sectional and correlational design.

Study setting and sample

Population of the study consisted of patients with advanced-stage gastrointestinal cancer who were admitted to the oncology clinic of a university hospital in the Central Anatolia Region of Turkey between March and December 2022. Sample group consisted of patients (1) who met the criteria for inclusion in the study between

these dates (ages between 18 and 80 years, (2) having a diagnosis of Stage 4 gastrointestinal system cancer (esophagus, stomach, colon, rectum, pancreas, liver), (3) knowing about being diagnosed with advanced-stage gastrointestinal cancer, (4) being open to communication and cooperation, (5) being conscious and able to answer questions, and (6) accepted to participate in the study. In order to determine the sample size of the study, mean death anxiety score of Salehi Zahabi and Mahmoudi (2017) in patients with breast cancer was used. As a result of the priori power analysis made in the G*Power 3.1.9.2 statistics program, the minimum required sample size was 125 individuals which was determined with 95% confidence ($1 - \alpha$), 95% test power ($1 - \beta$), $d = 0.333$ effect size and 2-way t test. In the study, 125 individuals were reached between these dates. These values indicate that the sample size is at the desired level.

This sample size did not meet the minimum sample size of 200 people required for performing structural equation modeling suggested by Kline (2023). Therefore, structural equation modeling could not be performed in the research.

Measurement instruments

Research data were collected in 10–15 min through face-to-face interviews with patients. “Patient Descriptive Information Form,” “Brief Illness Perception Questionnaire (BIPQ),” “Scale of Death Anxiety (SDA),” and “Satisfaction with Life Scale (SWLS)” were used to collect data.

Patient Descriptive Information Form

The form prepared by the researchers consists of 11 questions in total, including age, gender, marital status, educational status, employment status, income level, disease duration, disease stage, metastasis status, diagnosis, and body mass index.

Brief Illness Perception Questionnaire

It was developed by Broadbent et al. (2006). Turkish validity and reliability of the scale in patients with cancer was conducted by Karatas et al. (2017). Turkish version of the scale consists of 7 items and an additional item in which causal factors are questioned. Except for the eighth item, in which the causal factors of the disease are questioned, the remaining 7 items have a Likert-type scoring scale between 0 and 10. Items 2, 3, and 6 are reversed to calculate the scale score. The scale consists of 2 subdimensions. Emotional illness representations subdimension consisted of Items 1 (consequences), 4 (illness identity), 5 (concern), and 7 (emotions). Cognitive illness representations subdimension consisted of Items 2 (personal control), 3 (treatment control), and 6 (coherence). An increase in the total score indicates that the disease is more alarming and threatening. In other words, high scores from the scale indicate more negative illness perceptions. Cronbach’s alpha value is 0.85 in the Turkish validity and reliability study (Karatas et al. 2017). Cronbach’s alpha value was found as 0.74 in the present study.

Scale of Death Anxiety

SDA was developed by Templer (1970) to evaluate death anxiety. It was adapted to Turkish by Akça and Köse (2008). The scale consists of 15 items and it is a 2-item Likert-type scale with the options of correct and incorrect. Items 1, 4, and 8–14 of the scale are accepted as correct and other items as incorrect. The score range is between 0 and 15 in the scale. When the mean score in the scale is 7 and above, it is interpreted as high level of death anxiety. As the scale

score increases, it shows that there is an increase in death anxiety. Cronbach's alpha value of the scale was found as 0.75 (Akça and Köse 2008). Cronbach's alpha value was found as 0.70 in the present study.

Satisfaction with Life Scale

SWLS was developed by Diener et al. (1985) to evaluate satisfaction with life, which is the cognitive and judgmental dimension of subjective well-being. It was adapted to Turkish, and its validity and reliability study were conducted by Dağlı and Baysal (2016). Turkish version of the scale consists of 1 factor, 5 items, and 5-item Likert-type scale. Minimum possible score from the scale is 5, while the maximum possible score is 25. Cronbach's alpha value of the scale was found as 0.88 (Dağlı and Baysal 2016). Cronbach's alpha value was found as 0.91 in the present study.

Data assessment

SPSS version 22.00 statistical program was used for data assessment. Percentage, mean, and standard deviation descriptive statistics were used. Kurtosis and skewness coefficients were used to analyze the normality distribution of the data. Simple and multiple regression analyses were performed. $p < 0.05$ was accepted as the level of significance.

Results

Mean age of the patients who participated in the study was 63.21 ± 10.70 years, mean duration of disease was 16.91 ± 17.72 months, and mean body mass index score was 24.25 ± 4.69 . In this study, 56% of the patients were male, 84.8% were married, 65.6% were primary school graduates, 70.4% had an income equal to their expenses, 92% were unemployed, 41.6% had colorectal cancer, 98.4% had metastasis, and 97.6% perceived their disease stage as stage 4 (Table 1).

It was found that the mean SDA total score of the patients who participated in the study was 8.02 ± 3.16 and the mean SWLS total score was 14.74 ± 5.19 (Table 2). The mean BIPQ total score was 39.54 ± 12.82 , emotional illness representations subdimension mean score was 26.06 ± 8.66 , and cognitive illness representations subdimension mean score was 13.40 ± 6.86 .

Multiple regression analysis was performed to estimate the variables—such as age, gender, marital status, educational status, employment status, income level, disease duration, disease stage, metastasis status, disease diagnosis, and body mass index—and mean scores of B-IPQ, SDA, and life satisfaction. When the analysis result for mean BIPQ score is examined, it can be seen that the model created was found to be statistically significant ($F(19,105): 2.301, p = .004$). Among the variables included in the model, education level ($\beta = -.408; \beta = -.275$) was found to be a statistically significant negative predictor of illness perception, while metastasis status ($\beta = .267$) was found to be a statistically significant positive predictor of illness perception. When the analysis result for life satisfaction is examined, the model created was found to be statistically significant ($F(19,105): 2.576, p = .001$) and disease duration ($\beta = -.198$) was found to be a statistically significant negative predictor of satisfaction with life. When the analysis result for SDA is examined, the model created was found to be statistically significant ($F(19,105): 2.202, p = .013$). In addition, it was found that disease duration ($\beta = .199$) was a statistically significant positive predictor of death anxiety, while body mass index ($\beta = -.206$)

Table 1. Sociodemographic characteristics of the patients

Characteristics	Number ($n = 125$)	%
Gender		
Female	55	44
Male	70	56
Marital status		
Married	106	84.8
Single	19	15.2
Educational status		
Illiterate	11	8.8
Primary education	82	65.6
Secondary education	16	12.8
Undergraduate	8	6.4
University	8	6.4
Income status		
Income < expense	25	20
Income = expense	88	70.4
Income > expense	12	9.6
Employment status		
Employed	10	8
Unemployed	115	92
Disease		
Colorectal CA	52	41.6
Stomach CA	28	22.4
Pancreas CA	20	16
Esophagus CA	2	1.6
Hepatobiliary CA	22	17.6
Ileum CA	1	1
Presence of metastasis		
Present	123	98.4
Not present	2	1.6
Disease stage		
Stage 3	3	2.4
Stage 4	122	97.6
Continuous variables		
	X \pm SD	Min–Max
Age	63.21 \pm 10.70	36–90
Disease duration (months)	16.91 \pm 17.72	1–108
Body mass index	24.25 \pm 4.69	15–42

CA: cancer; X = Mean, SD = standard deviation.

and education level ($\beta = .346$) were statistically significant negative predictors of death anxiety (Table 3).

As a result of the regression analysis, it was found that the independent variable significantly ($F(1,123) = 161,783, p < .05$) affected the mean SWLS total score, which was the dependent variable, and explained 56% of it. It was also found that the independent variable was a negative predictor of the SWLS total score average

Table 2. The mean B-IPQ, SDA, and SWLS scores of the patients

	Scales	No. of items	Min.	Max.	X ± SD
B-IPQ total and subdimension scores	B-IPQ total score	7	0	63	39.54 ± 12.82
	Emotional illness representations	4	0	40	26.06 ± 8.66
	Consequences	1	0	10	7.61 ± 2.57
	Illness identity	1	0	10	7.17 ± 2.30
	Concern	1	0	10	5.37 ± 3.53
	Emotion	1	0	10	5.94 ± 3.20
	Cognitive illness representations	3	0	27	13.40 ± 6.86
	Personal control	1	0	10	5.10 ± 3.15
	Treatment control	1	0	10	3.78 ± 2.91
	Coherence	1	10	10	4.52 ± 2.83
SDA total score		15	2	15	8.02 ± 3.16
SWLS total score		5	5	25	14.74 ± 5.19

B-IPQ = Brief Illness Perception Questionnaire, SDA = Scale of Death Anxiety, SWLS = Satisfaction with Life Scale, X = Mean, SD = Standard deviation.

Table 3. Regression analysis results in terms of sociodemographic characteristics

Dependent variables	Model	Independent variables	B	SE	β	t	p	95% Confidence interval	
								Lower	Upper
B-IPQ total	1	Constant	16.607	17.397		.955	.342	-17.888	51.103
		Education (University)	-21.280	6.130	-.408	-3.471	.001*	-33.434	-9.125
		Education (High school)	-14.369	6.318	-.275	-2.274	.025*	-26.896	-1.842
		Metastasis (Present)	27.237	10.497	.267	2.595	.011*	6.422	48.051
		R = .542 F(19,105) = 2.301 R ² = .294 p = .004*							
SWSL total	2	Constant	12.985	6.922		1.876	.063	-.740	26.709
		Disease stage (stage 4)	-.058	.026	-.198	-2.228	.028*	-.110	-.006
		R = .564 F(19,105) = 2.576 R ² = .318 p = .001*							
SDA total	3	Constant	7.584	4.375		1.733	.086	-1.092	16.259
		Body mass index	-.139	.061	-.206	-2.275	.025*	-.260	-.018
		Education (University)	-4.461	1.542	-.346	-2.893	.005*	-7.517	-1.404
		Disease stage (stage 4)	4.095	1.992	.199	2.056	.042*	.145	8.044
		R = .517, F(19,105) = 2.012 R ² = .267 p = .013*							

*p < .05. B-IPQ: Brief Illness Perception Questionnaire; SDA: Scale of Death Anxiety, SWLS: Satisfaction with Life Scale.

($\beta = -.591$). In the study, it was found that the independent variable in the second model significantly ($F(1,123) = 158.972, p < .05$) affected the total mean score of SDA, which is the dependent variable. In the regression analysis, it was found that the independent variable had a positive effect on the total mean score of SDL ($\beta = .751$) (Table 4).

Discussion

Examining the effect of illness perception on death anxiety and satisfaction with life in patients with advanced gastrointestinal cancer may help to better understand the psychosocial adjustment

in this patient population. At the same time, no study has been found examining the effect of illness perception on death anxiety and life satisfaction in patients with advanced gastrointestinal cancer.

In this study, it was found that the participants had moderate level of illness perception. Illness perception questionnaire has questions on parameters such as being affected by the illness, duration, belief in treatment, understanding the illness, and emotional effects increase total score. From this point of view, it can be seen that the participants had a moderate level of negative illness perception. In a study by Miceli et al. (2019) in patients with advanced gastrointestinal cancer, it was found that patients had moderate

Table 4. Regression analysis results

Dependent Variables	Model	Variables	B	SE	β	t	p	95% Confidence interval		
								Lower	Upper	
SWLS	1	Constant	27.058	.982		27.554	.000*	25.114	29.00	
		B-IPQ	-.239	.036	-.591	-6.727	.000*	-.310	-.169	
		R = .754	R ² = .568							
		F(1,123) = 161.783	p = .000*	DW = 1.636						
SDA	2	Constant	.696	.611		1.139	.257*	-.513	1.905	
		B-IPQ	.185	.015	.751	12.608	.000*	.156	.214	
		R = .751,	R ² = .564							
		F(1,123) = 158.972	p = .000*	DW = 1.808						

*p < .05. B-IPQ: Brief Illness Perception Questionnaire; SDA: Scale of Death Anxiety, SWLS: Satisfaction with Life Scale; DW: Durbin-Watson.

level of illness perception. In a study conducted by Uysal and Akpınar (2013) with type 2 diabetes patients, it was found that the patients had a negative illness perception. In a study by Küçükkaya and Erçel (2019) on patients with gynaecological cancer, it was found that the patients had moderate level of illness perception. Similarly, in studies conducted on different groups, patients were found to have a moderate level of illness perception (Demir and Demir 2022; Miyazaki et al. 2018; Süt 2017). Our research results show similar results with the literature. Based on these results, it can be said that patients with advanced gastrointestinal cancer consider their disease as frightening and threatening.

In this study, it was found that the participants had a high level of death anxiety. Similar to our research, studies conducted on patients with advanced cancer have found that patients experience high levels of death anxiety (Hong et al. 2022; Vehling et al. 2017). In different studies conducted on patients with cancer, it was found that the patients had high death anxiety (Nazari et al. 2023; Shakeri et al. 2022; Soleimani et al. 2020, 2016; Turan and Dural 2022). At the same time, it has been observed in studies that patients with cancer experience death anxiety frequently (Neel et al. 2015; Shakeri et al. 2022). Being diagnosed with cancer is a painful experience for patients and since it is constantly associated with death, it causes patients to experience many fears and anxiety about death (Bibi and Khalid 2020). In this context, it can be concluded that patients with advanced gastrointestinal cancer may have many fears about death and this will lead to more death anxiety.

In this study, it was found that the participants had moderate level of satisfaction with life. In some studies similar to our study, it was found that patients with cancer had a moderate level of satisfaction with life (Hamdan-Mansour et al. 2015; Jafari et al. 2010; Polański et al. 2020; Vazquez et al. 2015). In another study conducted, it was found that more than 47.4% of patients with cancer were moderately, highly or extremely satisfied with their lives (Rustøen et al. 2010). However, in some studies, unlike our study, patients with cancer were found to be highly satisfied with life (Fonseca et al. 2014; Hamdan-Mansour et al. 2015). The results of the study show both similarities and differences with the literature. This may be due to the fact that the studies were conducted at different periods and in different regions. In addition, the fact that satisfaction with life was not low in our study is an important positive result, and it can be said that patients with cancer do not necessarily consider the disease as an indispensable interruption of life, but as a challenge and a chance to reflect and change their behavior and life.

In the study, it was found that the increase in education level of the participants affected illness perception negatively, and the presence of metastases affected illness perception positively. In their study, Küçükkaya and Erçel (2019) found that patients with metastases had higher disease perception scores and a negative illness perception. It was also found in literature that patients with low education level had high illness perception scores (Süt 2017; Yorulmaz et al. 2013; Zhang et al. 2016). Results of the study are similar with the literature. Patients with a low education level perceive the disease less well, they think that it will be chronic, they are affected more emotionally, they perceive the complaints related to the disease negatively, they perceive that they have no control over their disease, and their general health perception worsens (Süt 2017). Therefore, in our study, it is expected for illness perception scores to decrease; in other words, for illness perception to be positively affected as the education level increases.

In the study, it was found that as the participants' duration of illness increased, their satisfaction with life decreased. Cancer affects individuals and their families physically, emotionally, spiritually, cognitively, socially, and economically and causes their lifestyle, expectations and quality of life to be negatively affected. At the same time, it is known that the quality of life in patients with cancer is negatively affected as the duration of the disease increases (Kumsar and Yılmaz 2014). Considering all these, a negative relationship between life satisfaction and disease duration is expected in our study.

In the study, it was found that the increase in the duration of illness affected death anxiety positively, while the increase in education level and body mass affected death anxiety negatively. In a study, it was determined that there was a positive correlation between the time that passed since diagnosis and death anxiety in patients with cancer (Soleimani et al. 2016). Bjelland et al. (2008) reported that high level of education had a protective effect against anxiety that accumulated throughout life. Education also enables individuals to understand the disease process and complications correctly and facilitates their management of the disease process (Ganasegeran et al. 2014). It is estimated that more than half of all patients with cancer develop a cachexia syndrome with anorexia and progressive loss of adipose tissue and skeletal muscle mass (Aoyagi et al. 2015). This situation is an insidious syndrome that does not only have a dramatic impact on the patients' quality of life but also causes poor responses to chemotherapy and it complicates survival (Aoyagi et al. 2015; Dewys et al. 1980). Cachexia is seen in the majority of patients with fatal cancer. According to

Warren (1932), it has been reported to be responsible for the death of 22% of patients with cancer. Our research results show similar features with the literature.

In this study, it was found that the participants' illness perception had a positive effect on death anxiety. There are no studies in the literature examining the relationship between illness perception and death anxiety. For this reason, it is thought that the study findings will support the literature. In line with this result of our study, it is thought that the participants' thinking that they have no control over the disease due to their negative perception of the disease, that the treatment has no effect on the disease and does not reduce the symptoms of the disease, that it increases the existing anxiety instead of reducing it, that they do not fully understand the disease, and that their emotional state is negatively affected causes an increase in death anxiety.

In this study, it was found that the participants' illness perception affected their satisfaction with life negatively. There are no studies in the literature examining the relationship between illness perception and satisfaction with life. For this reason, it is thought that the results of the study are important in terms of filling this gap in the literature. Based on the results of this study, considering that the patients' perception, interpretation, and evaluations of their illness affect their emotional and behavioral reactions, coping style, psychosocial status, and quality of life directly (Karabulutlu and Karaman 2015), it is considered that it is inevitable for satisfaction with life to decrease with the increase in negative illness perception.

Limitations of the study

This study has some limitations. First, the data were collected via self-report scales, so the possibility of widespread method biases should be considered. Second, the study has a cross-sectional design. Therefore, experimental and longitudinal studies are recommended for future research to investigate the relationships between these variables. Third, it cannot be generalized to the whole population because it is a single-center research and includes patients with advanced gastrointestinal cancer. Fourth, the sample size is small.

Conclusion

In this study, it was found that patients with advanced gastrointestinal cancer had moderate levels of illness perception and satisfaction with life, and high level of death anxiety. It was found that as patients' illness perception increased, their death anxiety increased and life satisfaction decreased. In line with these results, it is recommended for nurses to place more importance to the evaluation of patients' illness perception in care practices, and to implement interventions to improve illness perception in patients, to eliminate problems related to illness and treatment, and to increase compliance with illness and treatment. At the same time, the results of this study will contribute to the nursing literature and will be useful for future interventional research.

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