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Alexithymia and perception of illness in patients with cancer

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This study aimed to determine how alexithymia affects the perception of illness in patients with cancer. This was a descriptive study conducted at the Atatürk University Health, Research and Practice Hospital and the Erzurum Regional Training and Research Hospital's Medical Oncology Clinic and Chemotherapy Unit. The study data were collected between July 2013 and January 2014. In total, data were collected from 283 patients with cancer. The data were collected using questionnaires enquiring about demographic and medical information: the IPQ and TAS-20. The study concluded that 50.5% of the participating patients had alexithymia. It was found that the alexithymic patients with cancer perceived the negative outcomes of their illness more strongly, and their negative feelings about the illness were more intense. This study suggests that further research should be carried out on alexithymia in patients with cancer and that their positive beliefs about the illness could be enhanced using psychosocial interventions.

KEYWORDS
alexithymia, cancer, perception of illness

1 | INTRODUCTION

Cancer has a unique place among chronic illnesses. It is an important illness that changes individuals' lives by affecting their physical, social and spiritual dimensions (Dülgerler & Çam, 2016). For this reason, it is important to determine how patients with cancer perceive their illness, in addition to the factors that affect this perception, in order to reduce their psychological anxiety and pain, allow them to adapt to treatment, increase their quality of life and help them express their feelings. In particular, people who have chronic illnesses such as cancer often have difficulty adapting to their illness, getting acquainted with their physical and emotional symptoms and explaining these symptoms verbally.

The concept of "alexithymia" is defined as difficulty in describing and expressing emotions, and it first emerged during the observation of patients with psychosomatic illnesses in clinics. Researchers determined that alexithymic patients cannot express their feelings, so they instead develop somatic symptoms as a way of expressing their emotions (Bailey & Henry, 2007; Mattila et al., 2008). Alexithymia is a problem that manifests as difficulty in individuals' emotional functioning and interpersonal relations and is characterised by difficulty explaining and distinguishing emotions (Kooiman, Bolk, Brand, Trijsburg, & Rooijmans, 2000). Alexithymic traits reduce individuals' power to resist stress, restrict their adaptation capacity, cause them to exaggerate bodily sensations that depend on emotions and develop new bodily symptoms (Hintistan, 2012).

Researchers have stated that individuals with alexithymia have greater problems in experiencing, recognising, understanding or caring about physical and psychological symptoms in themselves and others (Hintistan, 2012). The most obvious characteristic of people with alexithymia is "having difficulty with recognising and expressing their feelings." For this reason, these individuals have difficulty recognising their physical symptoms and might perceive them at exaggerated levels (Kooiman et al., 2000).

Cancer is an illness that causes many physical symptoms due to the illness process and its treatments (Seven, Akyüz, Sever, & Dinçer, 2013). In addition, it is perceived as an illness that evokes much uncertainty, is associated with a painful death and can lead to feelings of guilt, abandonment, panic and anxiety (Kavradım & Özer, 2014). Relevant studies have found that the negative feelings

about the severity of cancer as well as its functionality in physical, social and psychological terms are strong (Scharloo et al., 2010). It is important that patients be able to recognise and explain these feelings in order to receive early and effective treatment and care (Hintistan, 2012). Researchers have determined that alexithymic features are stronger in patients with cancer than in individuals without cancer (Brandão, Tavares, Schulz, & Matos, 2016). It has also been shown that alexithymia affects the treatment and recovery process of patients with cancer (Messina, Fogliani, & Paradiso, 2011).

A review of the international literature revealed studies investigating the correlation between alexithymia and numerous variables, including somatisation, depression, stress, pain, coping and quality of life (Baudic et al., 2016; Manna et al., 2007; Mantani et al., 2007; Porcelli, Tulipani, Maiello, Cilenti, & Todarello, 2007; Ripetti, Ausania, Bruni, Campoli, & Coppola, 2008). However, no studies have examined the correlation between alexithymia and illness perception, which affects the course of illness, treatment process, adaptation and quality of life.

The perception of illness directly affects both individuals' experience of the illness process, the process itself, coping strategies and psychopathology. People vary in their emotional reactions based on the way they perceive their illness. People's perception of such events affects not only their psychological, physiological or psychosocial wellness but also their quality of life or even the course of their physical illness (Petrie & Weinman, 2006). When the illness is perceived as a threat, feelings of fear and anxiety emerge frequently as well as anger, which is observed occasionally. When the illness is perceived as a punishment, emotional reactions such as depression, anger or embarrassment usually emerge. On the other hand, when the illness is perceived as a loss of health, order, independence or even one's entire life and capabilities, then it is perceived as a loss. The important point is that patients recognise their emotions and be allowed to express them in an accurate and open way. When patients cannot express these feelings, they might develop different symptoms, including social isolation, mourning, depression and turning in upon themselves (Küçükbakar, 2011).

Determining the way that patients with cancer perceive their illness, helping them recognise their own feelings and helping them express those feelings are among the important responsibilities of nursing care. In this context, nurses can play a key role in recognising their patients' feelings correctly and revealing them to the patient. This study was conducted to determine how alexithymia affects cancer patients' perception of their illness and aims to contribute to the relevant literature on this subject.

2 | METHODS

2.1 | Design and sample

This was a descriptive study conducted at the Atatürk University Health, Research and Practice Hospital and the Erzurum Regional Training and Research Hospital's Medical Oncology Clinic and Chemotherapy Unit. The study data were collected between July 2013 and January 2014.

The study population included 327 patients with cancer who stayed in the clinic between these dates and came to the chemotherapy unit for treatment. The study sample included 283 individuals aged 18 years or older who were capable of communicating, participated in the study voluntarily and did not have any physical or mental disabilities that would prevent them from participating.

2.2 | Instruments

Demographic and medical information form

This form included questions about patients' demographic characteristics, including sex, age, marital status and education level as well as the illness diagnosis.

Illness perception scale

The Illness Perception Scale (IPQ) was created by Weinman, Petrie, Moss-Morris, and Horne (1996) and revised by Moss-Morris et al. (2002). Kocaman, Özkan, Armay, and Özkan (2007) conducted a validity and reliability analysis of the scale for Turkish society. The IPS includes several dimensions as follows: type of illness, opinions about the illness and reasons for the illness.

The dimension of opinions about the illness: This dimension includes 38 five-point Likert-type scale items comprising seven subdimensions. These are (1) duration (acute/chronic), (2) outcomes, (3) personal control, (4) treatment control, (5) capability of understanding the illness, (6) periodic (cyclical) representations and (7) emotional representations. The subdimension focusing on duration investigates individuals' perception of the length of their illness and categorises this period as acute, chronic or cyclical. The subdimension focusing on outcomes investigates individuals' beliefs about the possible effects of the severity of their illness on their physical, social and psychological functioning. The personal control subdimension investigates the person's internal control perception regarding the period, course and treatment of the illness. The treatment control subdimension asks about individuals' beliefs about the effectiveness of the treatment administered to them. The subdimension focusing on the capability of understanding the illness questions the extent to which individuals understand or comprehend their illness. Emotional representations (6 and 7) investigate what individuals feel about their illness.

Toronto alexithymia scale

The Toronto Alexithymia Scale (TAS-20) is a self-evaluation scale that consists of 20 Likert-type scale questions. TAS-20 was developed by Bagby, Taylor, and Parker (1988). Items 4, 5, 10, 18 and 19 are scored in an adverse manner. The plain items are scored as "Strongly disagree" (1), "Disagree" (2), "Neither agree nor disagree" (3), "Agree" (4) or "Strongly agree" (5). The positive items are scored as "Strongly disagree" (5), "Disagree" (4), "Neither agree nor disagree" (3), "Agree" (2) or "Strongly agree" (1). On the scale, 61 points and above indicate alexithymic features in an individual; higher scores indicate higher alexithymia levels.

The TAS-20 consists of three subscales: Difficulty Identifying Feelings (TAS-1), Difficulty Describing Feelings (TAS-2) and Externally Oriented Thinking (TAS-3). The subscale "Difficulty Identifying Feelings" has seven items (items 1, 3, 6, 7, 9, 13 and 14) that describe difficulty recognising feelings and distinguishing them from the bodily sensations that accompany emotional stimulation. The subscale "Difficulty Describing Feelings" has five items (items 2, 4, 11, 12 and 17) that describe difficulty verbally conveying feelings to another person. The subscale "Externally Oriented Thinking" has eight items (items 5, 8, 10, 15, 16, 18, 19 and 20) that describe an external cognitive structure, internal thinking style and weakness of imagination. The TAS-20 was translated into Turkish by Sayar, Güleç, and Ak (2001). The validity and reliability studies revealed that the cut-off point indicating alexithymia was 61. In this study, the total Cronbach's alpha coefficient for alexithymia was 0.71.

2.3 | Ethical considerations

The researcher obtained the permission of the Ethical Board of Atatürk University's Health Sciences Faculty and the Atatürk University Health Research and Practice Hospital. The researcher also obtained oral approval from the patients after informing them about the objective of the study. The study was conducted based on the principles of voluntariness and confidentiality.

2.4 | Data collection

The study data were collected during interviews with patients. Each interview lasted for approximately 10 min. The study data were encoded and analysed using SPSS software version 19.

2.5 | Data analysis

The percentage test was used to determine patients' demographic characteristics, illness features and alexithymic status. Mean was used to determine the average scores in illness perception and alexithymia, and t test was used to determine the illness perception depending on the presence of alexithymia.

3 | RESULTS

The average age of the patients was 54.24 ± 1.40 years. Of the 283 patient participants, 54.4% were males, 89.7% were married, 51.2% were secondary school graduates and 64.3% perceived their economic level as moderate. Of the patients, 49.8% had been diagnosed with gastrointestinal cancer, and 76.0% had been informed about their illness (Table 1).

It was determined that 50.5% of the patients were alexithymic. It was also determined that the mean score on externally oriented thinking (24.37 ± 3.66), one of the subdimensions of alexithymia, was higher than for other subdimensions. The total alexithymia score of the patients was 61.33 ± 8.34, above the cut-off point of the TAS-20 scale

TABLE 1 Socio-demographic characteristics of patients with cancer (n = 283)

Socio-demographic characteristic	Number (n)	Percentage (%)
Sex		
Female	129	45.6
Male	154	54.4
Education		
Illiterate (no school degree)	17	6.0
Primary school	19	6.7
Secondary school	145	51.2
Higher education	102	36.0
Marital Status		
Married	254	89.7
Single	29	10.3
Working Status		
Employed	168	59.4
Unemployed	115	40.8
Perceived Economic Level		
Poor	58	20.5
Moderate	182	64.3
High	42	14.8
Very high	1	0.4
The type of cancer		
Digestive system	141	49.8
Stomach	40	14.1
Lung	70	24.7
Urinary system	11	3.9
Other	21	7.5
Duration of cancer		
1 month–<1 year	157	55.5
1–<2 years	60	21.2
2–<3 years	25	8.8
≥3 years	41	14.5
Status of being informed about the illness		
Informed	215	76.0
Receiving information	68	24.0
Thoughts about the information provided to them		
Sufficient	115	50.2
Partially sufficient	87	38.0
Insufficient	27	11.8
People providing support to the patients during the illness		
Family	273	96.7
Friends	2	0.8
Health professionals	7	2.5
	Mean ± SD	
Age (years)	54.24 ± 1.40	

(Table 2). Considering the mean scores of subscales and IPS in Table 2, the mean score of the treatment control subscale (3.74 ± 0.61) was found to be higher than the mean scores of other subscales.

Table 3 indicates that treatment control perception and understanding the illness were stronger in non-alexithymic patients than in alexithymic ones ($p < .5$) (Table 3).

4 | DISCUSSION

In recent years, many researchers have studied factors that affect cancer patients' reactions to their disease (Hopman & Rijken, 2015; Iskandarsyah et al., 2013; Keeling, Bambrough, & Simpson, 2013; McCorry et al., 2013; Mickeviclene, Vanagas, Jlevaltas, & Ulys, 2013). This study investigated the effect of alexithymia on the perception of illness, about which few studies have been conducted. This study identified more than half of its participants (143/283) as alexithymic. A general evaluation revealed that patients' alexithymia levels were 61.33 ± 8.34, above the 61-point alexithymia scale cut-off. This shows that the patients had a strong tendency towards alexithymia. In relevant literature, previous researchers have reported that severe illnesses such as cancer, which can emerge from a serious and chronic underlying condition, can create a foundation for the development of alexithymia. It was found that 26.0% of patients with cancer overall and 36.2% of patients with colon cancer were alexithymic (Lauriola, Panno, Tomai, Ricciardi, & Potenza, 2011; Travado, Grassi, Gil, Ventura, & Martins, 2005). The mean alexithymia score in patients with colon cancer was 50.1 ± 12.0 compared with 49.6 ± 9.6 in patients with breast cancer (Lauriola et al., 2011; Mantani et al., 2007). Porcelli et al. (2007) found that the mean alexithymia score of patients with breast cancer was 54.6 ± 13.9. We compared the results of this study with those of other studies and found that the present study sample had a greater tendency towards alexithymia than those of previous studies. One conclusion is that this tendency was caused by the patients' cultural characteristics. Some experts claim that alexithymia is an entirely sociocultural phenomenon. In most eastern societies, emotions are externalised. In this respect, Turkey is culturally closer to eastern societies, where emotions often may be expressed as somatic reactions (Koçak, 2002).

In this study, the mean score of externally oriented thinking, one of the alexithymia subdimensions, was higher than for other subdimensions. Porcelli et al. (2007) also found this mean score to be higher than for other alexithymia subdimensions in patients with breast cancer. Alexithymic individuals have primarily extroverted personalities, and as a result, external stimuli are dominant in their relationships with their environment. Thus, they are inclined to have a perception of external control and to be dependent in their relationships (Taylor, Bagby, & Parker, 1991). Among patients with cancer, it is a common problem that the illness becomes more serious, recurs or becomes uncertain in its prognosis; as a consequence, patients' body image and self-image deteriorate, relationships are disrupted, and patients are afraid of becoming dependent on others (Hocaoğlu, Kandemir, & Civil,

TABLE 2 Alexithymia status and mean TAS-20 and IPS scores of patients with cancer (N = 283)

	n (%)
Alexithymia status	
Alexithymic patients (≥61 on TAS-20)	143 (50.5)
Non-alexithymic patients (<61 on TAS-20)	140 (49.5)
TAS-20 Subdimension Score	*X* ± SD
Difficulty Identifying Feelings	21.66 ± 4.92
Difficulty Describing Feelings	15.29 ± 2.80
Externally Oriented Thinking	24.37 ± 3.66
Total score	61.33 ± 8.34
Illness Perception Scale (IPS)	*X* ± SD
Timeline (acute/chronic)	2.69 ± 0.81
Consequences	3.36 ± 0.92
Personal control	3.50 ± 0.66
Treatment control	3.74 ± 0.61
Understanding illness	2.10 ± 0.47
Timeline cyclical	2.44 ± 0.64
Emotional representations	3.06 ± 1.04

TAS-20 = Toronto Alexithymia Scale.

TABLE 3 Comparison of perception of illness of alexithymic and non-alexithymic patient

Illness perception scale (IPS)	Alexithymia scale score			
The dimension of opinions about the illness	Alexithymic patients	Non-alexithymic patients	Test value (*t*)	*p* Value
Timeline (acute/chronic)	2.75 ± 0.80	2.63 ± 0.83	−1.244	.215
Consequences	3.49 ± 0.89	3.23 ± 0.94	−2.364	.19
Personal control	3.41 ± 0.75	3.59 ± 0.55	2.287	.23
Treatment control	3.63 ± 0.63	3.86 ± 0.58	**3.142**	**.02**
Understanding illness	2.02 ± 0.47	2.19 ± 0.45	**3.168**	**.02**
Timeline cyclical	3.22 ± 0.97	2.90 ± 1.09	−1.844	.66
Emotional representations	2.51 ± 0.64	2.37 ± 0.63	−2.579	.10

Data in bold indicate significant result.

2007). Patients in turn tend to think in a more externalised manner because of these fears.

In this study, it was found that patients strongly believe that the treatment of cancer is effective. Advances in the treatment of cancer in recent years may have contributed to this belief of the patients. When we look at the relevant literature, we see that there are studies reporting that the perception of treatment of control was higher in patients with cancer (Fischer et al., 2013; Hopman & Rijken, 2015; Zhang et al., 2016).

In this study, 76% of patients stated that the information given to them about their illness was not informed. The researcher believes that this experience had a negative effect on the perception of understanding the illness. In previous studies on this subject, patients scored higher on their level of comprehending their illness (Iskandarsyah et al., 2013; Živković, Dediol, Ljubičić, & Šitum, 2012). Patients need some support to understand and internalise their new situation (Başkale, Serçekuş, & Günüşen, 2015). Nurses are an important source of informational support as they are the health professionals who spend the most time with patients and communicate with them most frequently (Başkale et al., 2015). For this reason, nurses have a great responsibility for making a positive change in cancer patients' perception of understanding their illness. This result emphasises the necessity of reviewing the information provided to patients and providing personal training programs.

As a result of this study, the timeline, consequences, personal control and emotional representation perceptions of alexithymic and non-alexithymic patients with cancer were found to be similar. However, the perception of illness is closely associated with patients' awareness of their feelings and ability to express them accurately. Researchers have reported that alexithymic individuals have more difficulty experiencing, recognising, understanding and caring about their physical and psychological symptoms (Koçak, 2002). Alexithymic individuals with chronic illness have difficulty adapting to and perceiving their illness as well as recognising and explaining their physical and emotional symptoms. However, it is particularly important that they recognise and explain their feelings to receive early and effective treatment and care (Hintistan, 2012). Patients who have difficulty recognising and explaining their emotions have increased physical and psychological symptoms, leading to a more negative perception of their illness. For this reason, when evaluating patients' perceptions of illness, alexithymic characteristics contribute to these symptoms.

Past studies have concluded that alexithymic cancer patients' positive beliefs about their treatment control were weaker than those of the non-alexithymic patients. Studies have also found that alexithymia is a potential risk factor for illness symptoms and illness behaviours (Baudic et al., 2016; Friedlander, Lumley, Farchione, & Doyal, 1997; Lumley, Neely, & Burger, 2007; Porcelli et al., 2007). The physical and emotional symptoms of cancer and its treatments make it difficult for patients to recognise their feelings and express them verbally, thus preventing them from receiving effective and early treatment and care (Hintistan, 2012). The researcher believes that this situation has a negative effect on patients' perception that their treatment can be controlled.

Alexithymic patients with cancer have lower levels of understanding their illness than non-alexithymic patients with cancer. Researchers have reported that alexithymic individuals have greater problems understanding their illness, experiencing their symptoms and recognising and caring about them (Friedlander et al., 1997). Alexithymic individuals have underlying social and relational problems, including avoidance of building close relationships and failing to maintain healthy and deep relationships. Alexithymic individuals are also weaker and less sociable in interpersonal relationships (Epözdemir, 2012). Presumably, these traits also affect cancer patients' perceptions of illness and their relationships with health professionals. When patients have the opportunity to talk to each member of the treatment and care team regularly (e.g. receiving information that would help them cope with their illness, being informed about the possible side effects of treatment), this helps them feel better and fulfils an important need that is accompanied by positive behaviour changes regarding their health (Lam et al., 2011). For this reason, health professionals should evaluate patients using a holistic perspective.

5 | CONCLUSIONS

This study showed that more than half of patients with cancer were alexithymic, and externally oriented thinking was the most common alexithymic trait among them. Alexithymic patients with cancer had a more negative perception of their illness. It was also found that these alexithymic patients with cancer perceived the negative outcomes of their illnesses more strongly, and their negative feelings about their illness were more intense. They also had more negative beliefs about the control and treatability of their illness. The study suggests that further research should be carried out on alexithymia in patients with cancer and that positive beliefs about their illness could be enhanced using psychosocial nursing interventions.

CONFLICT OF INTEREST

None of the authors report conflict of interests.

AUTHOR CONTRIBUTIONS

Ayşe OKANLI, Elanur Yılmaz KARABULUTLU, Sibel ASİ KARAKAŞ and Özlem ŞAHİN ALTUN conceived and designed the study. Ayşe OKANLI, Elanur Yılmaz KARABULUTLU, Sibel ASİ KARAKAŞ, Özlem ŞAHİN ALTUN and Naci YILDIRIM collected and analysed the data. Ayşe OKANLI, Elanur Yılmaz KARABULUTLU, Sibel ASİ KARAKAŞ and Özlem ŞAHİN ALTUN drafted the manuscript. Ayşe OKANLI and Elanur Yılmaz KARABULUTLU critically revised the study for important intellectual content and supervised the study. Ayşe OKANLI, Elanur Yılmaz KARABULUTLU and Sibel ASİ KARAKAŞ contributed to statistical expertise. Ayşe OKANLI, Elanur Yılmaz KARABULUTLU, Sibel ASİ KARAKAŞ, Özlem ŞAHİN ALTUN and Naci YILDIRIM provided administrative/technical/material support.

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