

# **ORIGINAL PAPER**

# THE QUALITY OF LIFE IN COLORECTAL CANCER PATIENTS: A MIXED-METHODS STUDY

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#### **Abstract**

Aim: This study was carried out to determine quality of life in patients who have had colorectal cancer surgery. Design: A sequential explanatory mixed methods design was used. Methods: The study sample consisted of 120 patients who had had colorectal cancer surgery, met the inclusion criteria for the study, and agreed to participate in the study. In-depth interviews were conducted with 20 of the patients from the study sample. The quantitative data were collected using the "Introductory information form" and the The Functional Assessment of Cancer Therapy-Colorectal Version "FACT-C scale", while the qualitative data were collected using the "Introductory information form" and the "Semi-structured interview form". Results: The FACT-C scale total mean score of the patients was  $100.95 \ (\pm 10.07)$  before the surgery and  $88.90 \ (\pm 10.55)$  after the surgery. From the in-depth interviews performed with the patients, the factors affecting the patients' physical, mental, and social well-being after discharge from hospital were identified. Conclusion: According to the results of this research, following colorectal cancer surgery, the patients faced problems that affected their physical, mental, and social well-being, and their quality of life diminished.

**Keywords:** colorectal cancer surgery, FACT-C scale, mix methods, nursing, quality of life, qualitative research.

#### Introduction

Colorectal cancer is a serious cause of morbidity and mortality in Western societies. According to the International Agency for Research on Cancer, colorectal cancer is the second and third most common cancer type in women and men, respectively (Globocan, 2020). According to Turkey cancer statistics from 2016, cancer was the third most common disease in both males (9.9%) and females (8%) (Turkish Public Health Institution, 2016). immunotherapy, chemotherapy, radiotherapy are the main treatment methods for this disease. Surgery is performed palliatively or curatively in the treatment of this cancer type (Özkan, 2011). After surgery, patients may experience a number of physiological problems, such as pain, nausea, vomiting, loss of appetite, fatigue, fecal incontinence, diarrhea, and constipation (Landers et al., 2012; Lithner et al., 2015a; Wilson et al., 2010). Subsequently, patients tend to feel anxious about physical disability, changes in lifestyle, prognosis of the disease, inability to fulfill their roles, and financial problems (Surrena,

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The problems experienced by patients have an adverse effect on their social and daily life activities, and their quality of life is thereby diminished. In addition, in patients with stoma, body image may be altered, and psychological problems such as anxiety and depression, and physiological problems such as excess gas, odor, and skin irritations, may occur (Brown, 2017; Kinoshita et al., 2017; Taylor & Morgan, 2011).

A review of the literature showed that various studies examining the quality of life of patients with colorectal cancer and the factors affecting it have been conducted (Marijnen et al., 2005; Sjövall et al., 2011; Steginga et al., 2009; Uwer et al., 2011; Wong et al., 2013; Yoo et al., 2005). These studies were largely conducted on patients receiving adjuvant chemotherapy / radiotherapy, or on patients with a stoma (Marijnen et al., 2005; Sjövall et al., 2011; Steginga et al., 2009; Uwer et al., 2011; Wong et al., 2013). Only a very limited number of studies have been conducted to assess patient quality of life after surgical intervention in the region where this study was performed. Since it is necessary to determine the factors affecting the quality of life of patients after colorectal cancer surgery in order to provide more comprehensive nursing care and to provide discharge education in line with the needs of the patients, more research is needed in this area.

#### Aim

This study aimed to assess postoperative quality of life of colorectal cancer patients with and without a stoma, and also to examine factors affecting quality of life.

#### Methods

# Design

In the research, a sequential explanatory design was used. In this design, a researcher first collects and analyzes the quantitative data. Qualitative data are then collected and analyzed to help explain, or elaborate on, the quantitative results obtained in the first phase (Creswell & Plano, 2007). The quantitative data aimed to establish the quality of life of those who had undergone colorectal cancer surgery. To further understand the quantitative results, qualitative data was collected using semi-structured in-depth interviews.

# Sample

The target population for the research was patients who had undergone colorectal cancer surgery in a training-research hospital in the region and the university hospital in Erzurum, in the east of Turkey. In the quantitative phase, a convenience sample (n = 120) of patients who met the study criteria and had undergone colorectal cancer surgery between September 2013 and March 2016 was used. The study subjects consisted of patients who were scheduled to undergo colorectal cancer surgery for the first time and who met the following inclusion criteria: 18–75 years old, and the ability to speak Turkish. Criteria for exclusion were mental disability, and distant organ metastases.

In-depth interviews were conducted with 20 patients who were selected from this sample using a non-probability homogeneous sampling method.

#### Data collection

## Quantitative data collection

The quantitative data for the research were collected using the "Introductory information form" and The Functional Assessment of Cancer Therapy-Colorectal Version "FACT-C scale" in both the preoperative period, when the patients were hospitalized before surgery, and in the postoperative period, when they came to the hospital for a routine check-up one month after undergoing surgery. It took approximately 15–20 minutes to administer the data collection tools. The answers to these questions were obtained through face-to-face interviews with the patients and from their patient files.

The introductory information form: This form contains 14 questions relating to certain sociodemographic variables (including age, education level, marital status, number of children, and social security and income status) and disease-related information (including the presence of any chronic illnesses, previous experience of surgery, type of surgery, and diagnosis of the illness).

The Functional Assessment of Cancer Therapy-Colorectal Version, FACT-C: The FACT-C scale is a five-point Likert-type scale, with responses ranging from 0 ("no") to 4 ("very high"). The scale consists of 36 items, which were developed by the FACIT organization to determine health-related quality of life in colorectal cancer patients. The FACT-C scale, which has been translated into many different languages by the FACIT organization, includes five sub-dimensions: Physical well being (PWB) (seven questions); Social / Family well being (SWB) (seven questions); Emotional well being (EWB) (six questions); Functional well being (FWB) (seven questions); and Colorectal cancer subsscale (CCS) (nine questions). Other scale sub-dimensions, excluding that of concerns about colorectal cancer, can be used for all cancer types. The maximum scores that can be obtained from the subscales are as follows: 28 points for physical status; 28 points for social life and family status; 24 points for emotional status; 28 points for activity status; and 28 points for other concerns. The total score is obtained by adding all the subscale scores together. Higher total scores indicate higher quality of life for the patient (FACIT Measurement System, 2013).

#### Qualitative data collection

The qualitative research was carried out on the basis of the results of the quantitative part of the research. Qualitative data were collected through semistructured in-depth interviews with the patients. The interviews of 15 patients were held in a suitable room in the outpatient clinic when they came to the hospital for routine check-up one month after being discharged. Upon request, the interviews of the remaining five patients were conducted at their homes, in a room where only the researcher and the interviewer were present. These interviews lasted around 30-45 minutes. The interviews were recorded with a voice recorder and written notes were taken during the interviews. Two of the patients requested that their interviews not be recorded, and, therefore, in these two cases, the researcher only took notes of the interviews.

The semi-structured interview form: This form contains the following six open-ended questions, which were prepared by the researcher using

information derived from the relevant literature (Karaveli et al., 2014; Landers et al., 2012; Lim et al., 2015; McCaughan et al., 2011; Sjövall et al., 2011; Worster & Holmes, 2008).

- 1) How have you felt since your surgery?
- 2) Have you been faced with anything to make you worry or to restrict your life since surgery? If so, could you please explain?
- 3) Did physical problems that you experienced after surgery affect your relationship with your partner? If so, could you please explain?
- 4) Do you have any concerns about your business life? If so, could you please explain?
- 5) Do you have concerns about the future? If so, could you please explain?
- 6) Could you tell us your thoughts on the stoma? Are you having any problems with the stoma? If so, could you please explain?

#### Data analysis

# Quantitative data analysis

The quantitative data were analyzed using the SPSS for Windows 22.00 statistical package program. Percentage distribution was used for the analysis of patients' descriptive characteristics, while the t-test was used for comparison of the variables, including gender, stoma, operation type, diagnosis, and the subscales.

## Qualitative data analysis

The qualitative data were obtained through interviews, the results of which were transferred into Microsoft Office Word 2007 within 24 hours, without any changes being made. Two people experienced in qualitative research were consulted to check the reliability of the research findings. The descriptive analysis method was used in the evaluation of qualitative data.

#### **Results**

# Demographic and clinical characteristics

The mean age of the participants constituting the study's quantitative sample was  $57.69~(\pm~11.87)$  years. Among the patients, 56.7% were male, 57.5% were literate or primary school graduates, and 75.8% had incomes lower than their expenses. Regarding characteristics related to the disease, 56.7% had colon cancer, 65.9% had had laparoscopic surgery, 70.8% had no postoperative stoma, and 20% had received preoperative adjuvant treatment (Table 1).

The mean age of the study's qualitative sample was  $58.2~(\pm\,10.95~\text{years})$ , and 55% of the patients were female, 90% were married, and 65% were literate or primary school graduates. Regarding the characteristics related to the disease, it was found that among the patients, 55% had colon cancer, 70% had had laparoscopic surgery, 75% had no stoma, and 20% had received preoperative adjuvant treatment (Table 1).

Table 1 Sociodemographic and clinical data

|                        |                              | Quantitative sample $(n = 120)$ | Qualitative sample $(n = 20)$ |
|------------------------|------------------------------|---------------------------------|-------------------------------|
|                        |                              | n (%)                           | n (%)                         |
| Age (mean, SD)         |                              | 57.69 (11.87)                   | 58.2 (10.95)                  |
| Gender                 | male                         | 68 (56.7)                       | 9 (45.0)                      |
|                        | female                       | 52 (43.3)                       | 11 (55.0)                     |
| Marital status         | married                      | 104 (86.7)                      | 18 (90.0)                     |
|                        | single                       | 16 (13.3)                       | 2 (10.0)                      |
| <b>Education level</b> | none                         | 41 (34.2)                       | 5 (25.0)                      |
|                        | primary and secondary school | 69 (57.5)                       | 13 (65.0)                     |
|                        | high school                  | 10 (8.3)                        | 2 (10.0)                      |
| Socio-economic status  | low                          | 91 (75.8)                       | 15 (75.0)                     |
|                        | middle                       | 23 (19.2)                       | 3 (15.0)                      |
|                        | high                         | 6 (5.0)                         | 2 (10.0)                      |
| Cancer diagnosis       | colon cancer                 | 68 (56.7)                       | 11 (55.0)                     |
| _                      | rectal cancer                | 52 (43.3)                       | 9 (45.0)                      |
| Operation type         | laparoscopic surgery         | 79 (65.9)                       | 6 (30.0)                      |
|                        | open surgery                 | 41 (34.1)                       | 14 (70.0)                     |
| Stoma                  | yes                          | 35 (29.2)                       | 5 (25.0)                      |
|                        | no                           | 85 (70.8)                       | 15 (75.0)                     |
| Neoadjuvant treatment  | yes                          | 24 (20.0)                       | 4 (20.0)                      |
| -                      | no                           | 96 (80.0)                       | 16 (80.0)                     |

SD – standard deviation

#### Quantitative data results

Table 2 presents the patients' mean quality-of-life scores in pre-operative and post-operative periods. According to the results, the mean FACT-C total score was  $100.95~(\pm~10.07)$  in the preoperative period and  $88.90~(\pm~10.55)$  in the postoperative period (p < 0.05). The mean score obtained by patients for all subscales decreased significantly in the postoperative period.

When the quality-of-life mean scores of the patients with and without stoma in the postoperative period

were compared, the mean score of the patients without stoma  $(91.34 \pm 9.01)$  was found to be higher than that of the patients with stoma  $(83.00 \pm 11.77)$  (t = -4.200, p = 0.000) (Table 3). Moreover, when their quality-of-life mean scores by operation type were compared, the mean score of the patients who had undergone laparoscopic surgery  $(91.34 \pm 9.30)$  was found to be higher than that of the patients who had had open surgery (t = -4.881; p = 0.000) (Table 3).

Table 2 Comparison of the quality-of-life scores in pre-operative and post-operative periods

|        |      |      | Preoperative       | Postoperative     |        |             |
|--------|------|------|--------------------|-------------------|--------|-------------|
| FACT-C | min. | max. | $mean \pm SD$      | $mean \pm SD$     | t-test | p-value     |
| PWB    | 0    | 28   | $23.45 \pm 3.13$   | $20.40 \pm 3.91$  | 6.933  | $0.000^{a}$ |
| SFWB   | 0    | 28   | $21.87 \pm 2.94$   | $18.51 \pm 4.24$  | 7.122  | $0.000^{a}$ |
| EWB    | 0    | 24   | $20.39 \pm 5.79$   | $19.64 \pm 5.37$  | 2.668  | $0.009^{a}$ |
| FWB    | 0    | 28   | $17.95 \pm 4.38$   | $14.91 \pm 4.59$  | 0.328  | $0.000^{a}$ |
| CCS    | 0    | 28   | $16.28 \pm 2.44$   | $15.43 \pm 3.58$  | 2.503  | $0.014^{a}$ |
| FACT-C | 0    | 136  | $100.95 \pm 10.07$ | $88.90 \pm 10.55$ | 9.062  | $0.000^{a}$ |

CCS – Colorectal cancer subsscale; EWB – Emotional well being; FACT-C – The Functional Assessment of Cancer Therapy-Colorectal Version; FWB – Functional well being; PWB – Physical well being; SFWB – Social / Family well being; aSignificance; min. – minimum; max. – maximum; SD – standard deviation

**Table 3** Comparison of the quality-of-life scores by stoma and operation type in postoperative period

|                |                                   | FACT-C total score | t-test | p-value     |
|----------------|-----------------------------------|--------------------|--------|-------------|
| Stoma          | patients with stoma $(n = 35)$    | $83.00 \pm 11.77$  | -4.200 | $0.000^{a}$ |
|                | patients without stoma $(n = 85)$ | $91.34 \pm 9.01$   |        |             |
| Operation type | laparoscopic surgery (n = 79)     | $91.34 \pm 9.30$   | -4.881 | $0.000^{a}$ |
|                | open surgery $(n = 41)$           | $81.27 \pm 10.75$  | -4.001 | 0.000       |

 $FACT-C-The\ Functional\ Assessment\ of\ Cancer\ Therapy-Colorectal\ Version;\ ^aSignificance$ 

# Qualitative data results

The findings in the qualitative phase of the study were examined under the following three categories:

- 1) "Factors affecting physical well-being"
- 2) "Factors affecting psychological well-being" and
- 3) "Factors affecting social well-being".

# 1) Factors affecting physical well-being

# Pain

Most of the patients stated that they had not had much pain at home, while some patients stated that their pain had continued in the abdominal region and in the area of the surgical sutures. "I am very uncomfortable with the sutures on the surgical wound." (F, 65 years old, colon cancer)

# Problems with bowel / rectal discharge

Some patients mentioned that they had constipation, diarrhea, and gas complaints and frequently needed the toilet. "I still suffer from constipation and gas. I am very relaxed when I pass wind" (M, 61 years

old, colon cancer). "I cannot eat anything. After eating, I have an urgent desire to go to the toilet" (F, 64 years old, rectal cancer).

## 2) Factors affecting psychological well-being

# Surgical related feelings

While some of the patients expressed a sense of relief after surgery, others stated that they had felt very good before the operation; however, afterwards they had experienced anger and regret: "Thank God! I feel good. I had a lot of trouble and extreme pain before surgery. Now I have got rid of those pains" (M, 61 years old, colon cancer). "I do not feel well at all. I have continuous constipation ... If I had known that the surgery was going to result in these problems, I would not have gone to the hospital and had the surgery" (F, 72 years old, rectal cancer).

# Concerns for future life

Some of the patients expressed concerns for their children: "I was shocked when I was diagnosed with cancer. I was very sad. The kids were also very sad.

My daughter especially was the most impacted. When I did not eat, my daughter did not eat with me ... I always think about my children and want them not to worry anymore" (F, 66 years old, colon cancer). The majority of patients stated that they did not want to think about the future, as they believed that they were living out their destiny and could not escape from their fate: "All must be as God wills. I leave everything to destiny. Nonetheless, I do not want to die. I believe in luck and say to myself: if you do not take care of yourself, the disease will beat you ..." (M, 39 years old, colon cancer). "I do not think too much about it. If I sit and think about the disease and my future ... I'm trying not to think about it. But sometimes unavoidably I do so" (F, 52 years old, colon cancer). One patient stated that she was afraid of dying: "I constantly think of this disease. I do not want to die just because of this disease ..." (F, 65 years old, colon cancer).

# 3) Factors affecting social well-being

# Failure to perform role functions

Patients stated that they could not work due to fear of opening the sutures, pain, fatigue, and post-operative complications; therefore, family members helped them in this process: "I think of my children because they are still small. I feel bad for not taking care of them. I have neglected them before and after surgery. Now their grandparents are interested in watching them. I hope, if God pleases, I will recover soon and be able to meet all of their needs ..." (F, 36 years old, colon cancer).

In addition, the patients stated that could not change stoma bags by themselves, so family members had to take on the task of providing stoma care: "I tried, but I could not change it. I dared myself to do it but could not when I saw it there ... more precisely ... my husband is doing everything" (F, 42 years old, rectal cancer, with stoma). All of the married patients interviewed indicated that their spouses were always there with them and that they were very supportive of them.

# Problems with sexual life

The majority of patients did not want to give detailed information about their sexual lives. The patients with whom we talked about this issue stated that they had no sexual life: "My husband is very understanding with me about sexual life. We do not have a sexual relationship nowadays because of the stoma. I do not want to either. My husband also does not demand it because he does not want to disturb or harm me" (F, 42 years old, rectal cancer, with stoma). However, one woman with a stoma said that after the operation she thought that

she could not have a sex life anymore. She also stated that she could not ask anyone about this issue. The researcher informed this patient that the stoma does not affect sexual relations: "Can we do it with this bag? I don't know. I can't ask anyone. Since surgery, we've been sleeping in separate beds" [Did your husband ask you to sleep separately?] "Yes, he wanted this." [Why did he ask?] "He said that we should sleep separately because you are ill. Also, some people said: 'God forbid! You may catch an infection!' He also smokes, so we sleep in separate beds" (F, 65 years old, rectal cancer, with a stoma).

# Social isolation

Most of the patients stated that after being discharged they did not leave the house: "I can't go anywhere. My husband leaves me at home too. I stay at home alone. There is nothing to do at home; no television, no radio, so I get bored. Relatives and friends do not come to visit because of my illness, so I feel alone. This situation bothers me" (F, 65 years old, colon cancer).

## Economic challenges

Most of the patients participating in this study indicated that they were not materially affected by this process, while some patients stated that they had been negatively affected: "It definitely affected us in an economic sense. My medical bills are costing me 1500 TL per month. This disease has affected me too much economically. If I did not have my children, I would be in a lot of trouble" (M, 44 years old, colon cancer).

## **Discussion**

Quality-of-life reports are important for patients insofar as they allow them to assess the effects of the disease and its treatment. Nursing research has been evaluating quality of life for more than twenty years (Grant & Dean, 2011). Accurate assessments of quality of life contribute valuable information to healthcare professionals in the clinical decisionmaking process and help to identify problems in the treatment and care of patients (Gujral et al., 2008; Hokkam et al., 2013). This study attempted to determine the quality of life of patients with colorectal cancer surgery and examined the effects that problems experienced by patients in the early period after being discharged had on their quality of life, using both quantitative and qualitative research methods.

It has been reported in the literature that the quality of life of patients after colorectal cancer surgery is lower than before surgery (Ihnát et al., 2014; Sharma et al., 2007; Yoo et al., 2005). In this study, the mean

quality-of-life scores of the patients were found to be lower after surgery than before surgery. The causes attributed to the decrease in the quality of life of patients after surgery include physiological, psychological, and social aspects & Leventoğlu, 2010). These problems can decrease the quality of life of patients after surgery. Open surgical intervention is one of the important factors responsible for decreasing the quality of life in colorectal cancer patients. Post-operative trauma and psychological stress are more common after open surgery than after other types of colorectal surgical intervention, and this may lead to a decrease in the patients' quality of life (Tjandra & Chan, 2006; Vlug et al., 2009). In this study, it was determined that after surgery, the quality of life of patients who had undergone laparoscopic surgery was higher than that of patients who had undergone open surgery. Similarly, in another study, it was also found that after surgery, the quality of life of patients who had undergone laparoscopic surgery was higher than that of patients who had undergone open surgery (Ihnát et al., 2014).

As in every surgery, patients who undergo surgery for the treatment of colorectal cancer encounter a variety of post-surgical physiological problems. Pain, nausea, vomiting, loss of appetite, fatigue, difficulty in passing gas, and changes in intestinal excretion are common physiological problems that patients encounter after colorectal surgery (Jonsson et al., 2011; Landers et al., 2012; Lithner et al., 2015b; McCaughan et al., 2011; Taylor et al., 2010). This present study obtained results similar to those presented in the literature. In particular, it was determined that patients' mean scores on the PWB and the Other Concerns subscales significantly decreased statistically after surgery, and from the interviews, it was found that patients also experienced some physiological problems. There are many factors involved in the development of these problems. The patients' lack of training on the prevention and management of physiological problems may be one factor responsible for the development of these problems and the consequent reduction in quality of life. For example, patients should carefully monitor their diet and take regular walks to avoid problems with intestinal discharge (Pace et al., 2014). It is in this area of treatment that nurses have important responsibilities, since they can improve the quality of life of patients by training them in how to cope with physiological problems, and by carrying out patient follow-up activities at their homes.

The physiological problems that patients experience as a consequence of diseases decrease their quality

of life by preventing them from fulfilling their social and daily life activities (Lithner et al., 2015b). The present study found a decrease in the mean scores of the FWB and the SFWB subscales in the postoperative period compared to the preoperative period. The qualitative findings of the research also support this result. The patients stated in the interviews that they did not fulfill their roles at home or in work life and had to receive support from family members due to the physical problems they had experienced in the post-operative period. This situation (i.e., receiving support from family members) had a positive effect on the quality of life of these patients. Patients are able to cope with physical and / or psychological problems more easily through the support provided by the people around them (Khorshid & Gürol Arslan, 2006).

After undergoing colorectal cancer surgery, patients negatively affected emotionally. Psychological problems, such as excessive anxiety, depression, deterioration of body image, fear, and regret, can be seen in patients (Hoon et al., 2013; Karaveli et al., 2014). When the qualitative data of the study were examined, the mean score on the EWB subscale was found to be lower in the postoperative period compared to the preoperative period. However, in looking at the maximum score that can be taken from the EWB subscale, the patients were seen to have high EWB mean scores both in the preoperative and postoperative periods. Most of the patients stated in the interviews that they were thankful that the cancerous tissue had been removed through surgery. However, some patients expressed regret at having undergone the surgery because of the problems they had experienced following it.

A stoma (colostomy / ileostomy) can be surgically created on the patient when needed in colorectal cancer surgical operations. In this study, the mean quality of life score of the patients with a stoma was found to be lower than of the patients without a stoma. Patients with a stoma experience intense anxiety and stress in the early period, especially after surgery, as well as physical problems related to the use of the stoma (Susanty & Rangki, 2016). This can decrease the quality of life of patients by negatively affecting their emotional states. In this study, the elderly patients with a stoma stated that they felt saddened about having to use a stoma, while the young women patients with a stoma stated that they had difficulty accepting the stoma and even thought about committing suicide. Therefore, it is recommended that patients be allowed to express their feelings and thoughts about the stoma, have any

misconceptions about stoma corrected, and be directed to seek psychological help, if necessary. The findings of this study are limited to the answers of the participants. Another possible limitation of the study is that the sample of qualitative data was 20. However, there is no rule for determining the sample size in qualitative research and it is impossible to determine the sample size in advance. Data collection is continued until the data start to repeat and the saturation point is reached. In this study, interviews were continued until the data reached the saturation point, and in-depth interviews were conducted with a total of 20 patients.

#### Conclusion

This study found that the quality of life of the patients who had undergone colorectal cancer surgery was adversely affected in the early postoperative period. Moreover, this study determined that compared to the patients who had undergone laparoscopic surgery, the patients who had undergone an open surgical intervention and had a stoma after surgery had a lower quality of life in both preoperative and postoperative periods.

The study provides useful information for nurses in their efforts to develop and improve clinical practice in colorectal cancer surgery. Knowledge of the problems which decrease the quality of life the patients who have had colorectal cancer surgery could be useful for nursing professionals in planning patient education and treatment. In light of these results, the following is recommended: the planning of patient education and nursing interventions to improve the preoperative physical psychological well-being of patients; the provision of comprehensive discharge education to patients about the problems they may encounter after surgery; the follow-up of patients at home after discharge; and the planning of nursing interventions to increase the quality of life of patients before and after surgery.

## **Ethical aspects and conflict of interest**

The authors are not aware of any conflict of interest that would threaten fundamental publication principles. The necessary consent and written permissions were obtained from both the Atatürk University Health Sciences Faculty Ethics Committee and the hospitals where the research was conducted. Before the interviews were conducted, patients' verbal and written consents were received after they had been informed about the disease, the aim of the research, and the interview procedure and voice recordings.

# **Funding**

This research received no specific grant from any funding agency, commercial or not-for-profit sectors.

# Acknowledgement

The authors thank all the research participants and clinic staff's for their kind cooperation.

## **Author contributions**

Conception and design (NK, DG), data analysis and interpretation (NK, DG), manuscript draft (NK, DG), critical revision of the manuscript (NK, DG), final approval of the manuscript (NK, DG).

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