



# Quality of Life of Patients with Stoma: A descriptive study

## Stomalı Hastaların Yaşam Kalitesi: Tanımlayıcı bir çalışma

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### ABSTRACT

**Aim:** The opening of the stoma causes patients to experience various problems in terms of physiological, social, psychological, and sexual aspects. All these experienced problems can affect the quality of life of the patients negatively. This study aims to evaluate the quality of life patients with stoma. **Method:** This descriptive, cross-sectional study includes 115 patients with stoma for at least three months. Data were collected with the City of Hope Ostomy Quality of Life (QoL) Questionnaire between March 2015 and June 2016. The ethics committee approval and informed consent from patients have been taken. The descriptive statistics, Kruskal Wallis test, Student t-test, and Mann-Whitney U test were used.

**Results:** Of the 115 participants, the duration of stoma was 17.5±23.2 months. There is colostomy in 54.8% of patients, ileostomy in 47.8%, urostomy in 6.1%. The overall QoL score was 5.37±1.32, subscale scores were, physical 4.42±2.78, psychological 5.33±1.45, social 5.37±1.32 and spiritual 6.97±1.70, respectively. A statistically significant difference was found between psychological, social subscale and overall QoL score of patients with a permanent and temporary stoma ( $p<.05$ ), and between psychological subscale score of the patient received adjuvant chemotherapy and not received ( $p<.05$ ).

**Conclusion:** The overall quality of life of the patients was adversely affected, especially in the physical area. Patient-centered nursing interventions should be planned to improve the QoL of patients in the context of holistic nursing care.

**Keywords:** Quality of life, stoma, ostomy, colorectal surgery

### ÖZ

**Amaç:** Stomanın açılması hastaların fizyolojik, sosyal, psikolojik ve cinsel yönden çeşitli sorunlar yaşamasına neden olur. Yaşanan tüm bu sorunlar hastaların yaşam kalitesini olumsuz etkileyebilmektedir. Bu çalışma stomalı hastaların yaşam kalitesini değerlendirmeyi amaçlamaktadır.

**Yöntem:** Bu tanımlayıcı, kesitsel çalışma, en az üç aydır stoması olan 115 hastayı içermektedir. Veriler Mart 2015 - Haziran 2016 tarihleri arasında Umud Merkezi Ostomi Yaşam Kalitesi Ölçeği (UMYKÖ) ile toplandı. Etik kurul onayı ve hastalardan bilgilendirilmiş onam alındı. Tanımlayıcı istatistikler, Kruskal Wallis testi, Student t testi ve Mann Whitney U testi kullanıldı.

**Bulgular:** 115 hastanın ortalama stoma süresi 17.5 ± 23.2 aydır. Hastaların% 54,8'inde kolostomi,% 47,8'inde ileostomi,% 6,1'inde ürostomi vardır. Stomalı hastaların UMYKÖ genel puan ortalaması 5.37 ± 1.324, alt boyut puan ortalamaları ise sırasıyla fiziksel 4.42 ± 2.78, psikolojik 5.33 ± 1.45, sosyal 5.37 ± 1.32 ve manevi 6.97 ± 1.70'dir. Ameliyat sonrası kemoterapi alan ve almayan hastaların psikolojik alt boyut puan ortalaması arasında istatistiksel olarak anlamlı fark saptandı ( $P < .05$ ). Stoması kalıcı ile geçici olan hastaların psikolojik ve sosyal alt boyut ve genel ölçek puan ortalaması arasında istatistiksel olarak anlamlı fark saptandı ( $P < .05$ ).

**Sonuç:** Hastaların genel yaşam kalitesi özellikle fiziksel alanda olumsuz etkilenmiştir. Bütüncül hemşirelik bakımı çerçevesinde hastaların yaşam kalitesini iyileştirmek için hasta merkezli hemşirelik girişimleri planlanmalıdır.

**Anahtar Kelimeler:** Yaşam kalitesi, stoma, ostomi, kolorektal cerrahi

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## Introduction

Quality of life (QoL) is a complex concept involving social, psychological, spiritual, and physical well-being. It defines the prosperity related to individual's life, the level of gladness, and the extent to which this level is affected by the disease, from accidents and treatments. It can be observed that the physical, social, psychological, and sexual problems that people with stoma had been through adversely affect their QoL. As the QoL decrease, the adoption of patients to stoma decreases, the adoption period is extended, the body image disturbance and self-care needs are increases and self-reliance decreases.<sup>1-4</sup> The stoma may cause some physical problems like irritation and rash around the stoma opening, gas or bad smell.<sup>1,5</sup> In consequences of having stoma patients may face with clothing problems as wearing plus size t-shirts and pants or wearing suspender instead of a belt.<sup>1,6</sup> The fear of leakage from stoma may cause difficulties while performing religious rituals.<sup>1,2,7</sup> The patient may come across some psychosocial problems like social isolation, adjustment to the stoma, negative changes of body sense and a decrease of self-respect and unwillingness to attending family meetings or social activities due to the bad smell.<sup>1,5-8</sup> The person may have financial problems as affording ostomy bag and other equipment due to quitting a job or changing job, and sexual problems are also possible such as embarrassment, erectile dysfunction, diminished sexual desire or dissatisfaction may occur.<sup>1,2,9,10</sup> The whole physical, social, psychosocial and sexual problems adversely affect the QoL of patients with stoma.<sup>1-4,11-15</sup> Therefore, interventions should be planned to improve the QoL of patients with stoma by evaluating their QoL with specially developed the QoL scales. The City of Hope Quality of Life Ostomy Questionnaire (COH-QoL-Ostomy) is one of the scales that developed to evaluate all subscales of the QoL of patients with a stoma (colostomy, ileostomy, and urostomy).<sup>16,17</sup> This study aims to evaluate the QoL of patients with stoma by using COH-QoL-Ostomy which developed for all the people with stoma.

## Materials and Methods

The sample of this cross-sectional descriptive study was composed of 115 patients with a stoma from the General Surgery and Urology wards and the Stomatherapy Unit of a university hospital. Data were collected from March 2015 to June 2016 via face-to-face and telephone interview method. The inclusion criteria: to have stoma at least three months and aged over 18. The exclusion criteria: patient with dementia, not read and understand Turkish. Data were collected with The Patient Identification Form and the City of Hope Quality of Life Ostomy Questionnaire (COH-QoL-Ostomy).

**Informed consent:** The written and oral informed consent was obtained from all patients included in the study.

**Ethics approval:** This study was approved by Noninvasive Research Ethics Board (No:2153-GOA, decision number 2015/21-33,). The permission from the hospital was received.

### The Patient Identification Form

The form consists of descriptive information about socio-demographic and stoma. For example age, sex, education situation, chronic disease, stoma type, indication for the stoma, surgical operation, etc.

### The City of Hope Quality of Life Ostomy Questionnaire (COH-QoL-Ostomy)

The COH-QoL-Ostomy measures life quality in terms of physical, social, sexual, and spiritual. The validity and reliability of the scale developed by Grant and his friends have been detected.<sup>17</sup> Turkish validity and reliability of the scale were investigated by Erol and Vural.<sup>16</sup> The internal consistency reliability coefficient of the four-dimensionally developed scale, especially for patients with a stoma, was 0.92, and the correlation between subscale item scores and subscale total score was between 0.21 and 0.79. The scale total score correlation was 0.82 in the test-retest reliability of the scale. The higher scores from subscales and overall scale mean better functions.<sup>16,17</sup> We performed power analysis and reached 115 patients.

### Data analysis

Statistical analyses were performed using SPSS 15 software. Descriptive analyses were performed using mean and standard deviations for normal scattering variables. Categorical variables were stated as numbers and percentages. The homogeneity of the variances was assessed by the Levene test. To determine the difference between mean scores among variables Kruskal Wallis, Students t-test and Mann Whitney U-test applied.  $P < 0.05$  were considered statistically significant.

## Results

Of the 115 patients with stoma participated in the study, 39 were female, 76 were male, age average was  $55.7 \pm 13.0$  (18-83) and the mean duration of stoma was  $17.5 \pm 23.2$  (3- 96) months. The sociodemographic and stoma characteristics of patients were shown in Table 1. Colostomy was performed in 54.8% (n = 63) of patients, ileostomy in 47.8% (n = 45) and urostomy in 6.1% (n = 7) and stoma was applied in 77.4% of patients due to cancer. Characteristics of patients regarding stoma and treatment were given in Table 2.

The overall score of COH-QoL- Ostomy for all patients with stoma in the study is  $5.37 \pm 1.324$ . The subscale mean scores

were  $4.42 \pm 2.78$  in physical,  $5.33 \pm 1.45$  in psychological,  $5.37 \pm 1.32$  in social and  $6.97 \pm 1.70$  in spiritual, respectively (Table 3). According to the COH-QoL-Ostomy mean score, it is seen that the QoL of patients with stoma is moderate.

The characteristics related to sociodemographic, stoma and treatment were compared with COH-QoL-Ostomy overall and subscale mean scores of patients with stoma. A statistically significant difference was found between the psychological subscale mean score of patients received adjuvant chemotherapy ( $5.66 \pm 1.55$ ) and those without adjuvant chemotherapy ( $4.97 \pm 1.24$ ) (Mann- Whitney U = 1234, 00; P < .05). The psychological subscale mean scores of patients received adjuvant chemotherapy was higher. The psychological subscale mean scores of patients received adjuvant chemotherapy is better than of patients who do not have.

A statistically significant difference was found between patients with permanent and temporary stoma in terms of psychological subscale mean scores (Permanent  $5.30 \pm 1.79$ , temporary  $5.36 \pm 1.18$ ; Mann- Whitney U = 1523, 00), and social subscale mean scores (Permanent  $5.30 \pm 1.61$ , temporary  $5.43 \pm 1.10$ ; Mann- Whitney U= 1399,50) and overall mean scores (Permanent  $5.30 \pm 1.61$ , temporary  $5.43 \pm 1.10$ ; Mann- Whitney U= 1399.50) (P < .05). The overall, psychological, and social subscale mean scores of

**Table 1.** Sociodemographic Characteristics of Patients with Stoma (N=115)

	X	SD
Age (year)	55.7	13.0
Duration of stoma (month)	17.5	23.2
	n	%
<b>Gender</b>		
Female	39	33.9
Male	76	66.1
<b>Education status</b>		
Primary education	65	56.5
High school	31	27.0
College/University	19	16.5
<b>Chronic disease</b>		
No	43	37.4
Yes *	72	62.6
<b>Drug use</b>		
No	55	47.8
Yes ‡	60	52.2

\* Diabetes Mellitus, Hypertension, Hyperlipidemia, Hyperthyroidism, Epilepsy, Asthma

‡ Antihypertensive, antidiabetic, antiepileptic, antiallergic, antipsychotic, statin group drugs

patients with temporary stoma were found to be higher. The psychological, social, and overall QoL of patients with a temporary stoma is better than those with permanent.

There were no statistically significant differences between overall and subscale mean scores of patients with stoma

**Table 2.** Characteristics Related to Stoma and Treatment of Patients with Stoma (N=115)

Stoma characteristics	n	%
<b>Underlying disease</b>		
Cancer (Colon, rectum, bladder)	89	77.4
Others (Crohn disease, Fournier Gangrene etc.)	26	22.6
<b>Stoma type</b>		
Colostomy	63	54.8
Ileostomy	45	39.1
Urostomy	7	6.1
<b>Stoma status</b>		
Permanent	46	40.0
Temporary	69	60.0
<b>Stoma care</b>		
Self-care	43	37.4
Partner/spouse	35	30.4
Others	21	18.3
Self-care, if required receive help	16	13.9
<b>Treatment characteristics</b>	n	%
<b>Operation status</b>		
Planned	65	56.5
Emergency	50	43.5
<b>Surgery type</b>		
Abdominoperineal Resection	15	13.0
Low Anterior Resection	27	23.5
Cystectomy + Urinary Diversion	7	5.2
Others *	67	58.3
<b>Neoadjuvant Chemotherapy</b>		
Yes	42	36.5
No	73	63.5
<b>Neoadjuvant Radiotherapy</b>		
Yes	38	33.0
No	77	67.0
<b>Adjuvant Chemotherapy</b>		
Yes	61	53.0
No	54	47.0
<b>Adjuvant Radiotherapy</b>		
Yes	27	23.5
No	88	76.5

\*Hartman procedure, Total/right/left hemicolectomy, cytoreductive surgery, total pelvic exenteration, transanal excision, transanal endoscopic microsurgery etc.

**Table 3.** The COH-QoL-Ostomy subscale mean scores of patients with stoma (N = 115)

Subscales	Min-max	X±SD
Physical	0.00 - 10.0	4.43 ± 2.78
Psychological	0.92 - 9.69	5.33 ± 1.45
Social	2.98 - 9.09	5.37 ± 1.32
Spiritual	1.86 - 10.0	6.97 ± 1.70
Overall QoL	2.98 - 9.09	5.37 ± 1.32

according to sociodemographic characteristics (e.g. sex, marital status, educational status, chronic illness/drug use status, working status, social security, patients whom they live together), stoma characteristics (cause of stoma opening, type of stoma, patients who take care of stoma) and treatment characteristics (e.g. emergency surgery/planned surgery, surgery type, neoadjuvant chemotherapy, neoadjuvant and adjuvant radiotherapy) of patients with stoma ( $p > .05$ ).

## Discussion

In literature, it was reported that opening stoma may cause various problems and adversely affect patients' QoL in terms of physical, social, psychological and sexual.<sup>1,11-15</sup> In this study, the QoL of patients with stoma for at least three months was evaluated with COH-QoL-Ostomy. When the mean scores of COH-QoL-Ostomy ( $5.37 \pm 1.32$ ) were examined, it is seen that the QoL of patients was moderate and the QoL decreased after the stoma was opened. When Anaraki et al.<sup>18</sup> applied the same scale ( $n = 102$ ), the overall QoL score was found to be  $7.48 \pm 0.9$  (good level). In Gomez et al.<sup>15</sup> study, it was found that the QoL of patients with stoma was moderate-good level. In our study, it was reported that stoma mostly affects the QoL in terms of physical functions, but in the study of Anaraki et al.<sup>18</sup> social functions were more affected. In the studies, it was stated that the opening of stoma negatively affected QoL in different subscales. In our study, it is observed, mostly in the physical subscale, the QoL adversely was affected in all subscales. Similar to the studies, the QoL of all patients with stoma was negatively affected and the QoL was decreased by opening the stoma. There was no statistically significant difference between patients' QoL mean scores; firstly, according to the sociodemographic characteristics such as sex, marital status, working status, educational status, chronic illness, and drug use; secondly, characteristics of stoma such as type of stoma (colostomy, ileostomy, and urostomy), the reason of stoma, whom caring stoma; lastly, according to the treatment characteristics as, type of surgery and neoadjuvant or adjuvant radiotherapy. In the literature,

unlike the results,<sup>13,14,18,19</sup> some studies determined the difference in the QoL mean scores between patients according to sociodemographic, stoma, and treatment characteristics. In the study of Liao and Qin<sup>5</sup> examining the factors affecting the QoL, ( $n = 76$ ) it was found that stoma duration, the hopefulness of patients affected general satisfaction, skills of caregivers impacted sexual life, and also gender, education status, hope, and care skills affected the social life. Similarly, in the study of Pazar et al.<sup>13</sup>, the marital and educational status did not affect the QoL of patients with urostomy. In the studies of Anaraki et al.<sup>18</sup> and Karaveli and Ozbayir,<sup>14</sup> there was no difference between patients' QoL scores according to stoma type and self-care status. The QoL is a multidimensional concept and is influenced by many factors such as personal characteristics, social environment, and cultural factors. The perception of QoL is affected by patient characteristics, a coping mechanism, family support, self-care status. Because of this reason, it is seen in our study that the QoL of all patients with stoma was negatively affected by the opening of stoma without any difference in sex, stoma type, and education status.

### Physical functions

In our study, it was determined that patients with stoma had the lowest score in physical subscale ( $4.43 \pm 2.78$ ) in COH-QoL-Ostomy. Patients with stoma were found to have a lower mean score on physical subscale than other subscales. In the study of Karaveli and Ozbayir<sup>14</sup> ( $n = 60$ ) unlike our study, the patients with stoma scored the highest physical subscale. Patients with stoma experience physical problems such as retraction, mucocutaneous separation, prolapse, granuloma, and peristomal complications (erythema, maceration, ulceration, irritation, erosion, and dermatitis) with physical limitations (reduced hand strength) with aging.<sup>20-23</sup> All these physical problems and restrictions reduce the QoL of patients. In our study, it is thought that the lower mean score in the physical subscale might be due to these physical problems mentioned in the literature. Patients' comorbid disease (e.g. Diabetes mellitus, hypertension) may increase the development of physical problems; moreover, reduce the QoL of patients with stoma by suggesting that education given on stoma management are forgotten over time with aging and have difficulties in performing stoma care.

### Spiritual functions

In our study, it was determined that patients with stoma had the highest score in the spiritual subscale ( $6.97 \pm 1.70$ ). The QoL in the spiritual subscale of patients with stoma decreased. In the study of Karaveli and Ozbayir<sup>14</sup> ( $n = 60$ ), unlike our study, the patients with stoma scored the lowest in the spiritual subscale. It was reported that the existence of the stoma does not prevent religious worship.

Nevertheless, patients may still be anxious about religious worship and abandoned pray. There was a decrease in the rate of attending the religious worship of patients depending on stoma surgery.<sup>7,24</sup> In the study of Cavdar et al.,<sup>24</sup> while 74.9% of patients with stoma attended regular worship before surgery, this rate has been dropped to 53% after surgery. The fact that, in our study, the spiritual subscale was less affected than the other studies suggests so that it is thought that patients do not attend religious worship regularly before surgery or they continue to worship in the same way despite the opening of the stoma.

### Social functions

In our study, the QoL in the social subscale of patients with stoma decreased. Patients with stoma were afraid of participating in social activities because of fear of gas and smell from the stoma, fear of leakage, not finding a suitable place to exchange bags, and may experience social isolation considering that they feel stigma due to stoma.<sup>6,25</sup> It was reported that they experience anxiety and embarrassment due to the fear of not being able to find a clean bathroom for stoma care, the lack of napkins in public toilets, the fact that the toilets are too low and unclean and they less travel due to the troubles caused by the seat belt in the vehicle<sup>3-5</sup>. Patients with stoma were found to have fewer social meetings with their relatives and friends, and also leisure activities and social activities were reduced.<sup>26</sup> In Leyk's study,<sup>27</sup> it was found in patients with permanent stoma as the time passed, the social support of family and friends increased so the QoL increased. In our study, it is thought that the low QoL of patients with stoma depends on keeping them away from the social environment as reported in the literature.

### Psychological functions

In our study, the QoL in the psychological subscale of patients with stoma decreased. In other studies, it was found that patients with stoma felt stigma due to the stoma, had worries about living with a stoma, worried about the closure of stoma, experienced loss of control, and change of self-perception family members and spouses had difficulties in accepting and adjusting stoma.<sup>6,8,25</sup> It was also reported that the body image of patients with a stoma is negatively affected. Patients whose body image is impaired may experience psychological anxiety and depression and may avoid social activities.<sup>6,19,28</sup> In our study, it is stated that rather than the type of stoma, stoma status (permanent or temporary) more affected the QoL of patients. The psychological and social QoL of patients with temporary stoma was found to be better. In the study of Anaraki et al.<sup>18</sup>, it was found that the QoL of patients with temporary stoma was higher in the psychological subscale. In our study, it is thought that patients with temporary stoma maintain their hope to regain

their health, strength before surgery because of having temporary stoma and stoma will be closed, that the negative body image will disappear with the closure of stoma and therefore, it was thought they have psychologically more positive thoughts. It is seen that the QoL is better in the psychological subscale of patients received adjuvant chemotherapy. Adjuvant chemotherapy is applied after 5-12 weeks postoperatively to prevent recurrences and to increase survival. In the study of Oliphant et al.,<sup>29</sup> it was determined that the patients with loop ileostomy received adjuvant chemotherapy experienced more complications in the third postoperative month and that chemotherapy's side effects and complications adversely affected the QoL of patients with stoma. In our study, the lower mean score of the psychological subscale of patients with stoma might be due to the less favourable side effects of chemotherapy and its complications, as well as the belief that the chemotherapy can achieve full recovery, disease-free survival, and have more positive thoughts.

### Limitations

Because of the low number of patients with a urostomy, the outcomes are limited in terms of patients with all types of the stoma.

### Conclusion

In our study, it is seen that the QoL of all patients with a stoma is adversely affected in all subscales and the opening of the stoma decreases the overall QoL. Nurses should evaluate the QoL of patients with stoma perioperative period. Patient-specific evidence-based nursing interventions should be planned in all affected subscales of QoL of a patient with a stoma in the context of holistic nursing care. To increase the QoL of patients with a stoma, it is suggested interventions for nurses such as giving perioperative education and counseling, planning support groups during follow up, evaluation, and management of postoperative stomal and peristomal complications, acquiring self-confidence in the care of patients.

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