



Quality of Life of Patients with a Stoma: A Descriptive Study

Stomalı Hastaların Yaşam Kalitesi: Tanımlayıcı Bir Çalışma

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ABSTRACT

Aim: Stoma opening causes patients to experience various problems in terms of physiological, social, psychological, and sexual aspects. All these problems negatively affect the quality of life (QoL) of patients; thus, this study aimed to evaluate the QoL of patients with a stoma.

Method: This descriptive cross-sectional study includes 115 patients with a stoma for at least 3 months. Data were collected using the City of Hope Ostomy QoL Questionnaire between March 2015 and June 2016. Approval from the ethics committee and informed consent from participants were obtained. 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. A colostomy is present in 54.8% of patients, ileostomy in 47.8%, and urostomy in 6.1%. The overall QoL score was 5.37±1.32, with subscale scores as follows: physical 4.42±2.78, psychological 5.33±1.45, social 5.37±1.32, and spiritual 6.97±1.70. A statistically significant difference was found between psychological, social subscale, and overall QoL scores of patients with a permanent and temporary stoma (p<0.05), and between psychological subscale score of patients receiving adjuvant chemotherapy and those who do not (p<0.05).

Conclusion: The overall QoL of patients was adversely affected, especially the physical aspect. 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: Yüz on beş 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<0,05). Stoması kalıcı ile geçici olan hastaların psikolojik ve sosyal alt boyut ve genel ölçek puan ortalaması arasında istatistiksel olarak anlamlı fark saptandı (p<0,05).

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 wellbeing. It defines the prosperity related to an individual's life, level of gladness, and the extent to which disease, accidents, and treatments affect this level. The physical, social, psychological, and sexual problems that people with a stoma experience can be observed to adversely affect their QoL. As the QoL decrease, the adoption of patients to stoma decreases, the adoption period extends, body image disturbance and self-care need increases, and self-reliance decreases.^{1,2,3,4} The stoma may cause some physical problems like irritation and rash around the stoma opening, gas, or foul odor.^{1,5} As a consequence of having a stoma, patients may face clothing problems, such as wearing plus size t-shirts and pants or wearing suspenders instead of a belt.^{1,6} The fear of stoma leakage causes difficulties while performing religious rituals.^{1,2,7} The patient comes across some psychosocial problems like social isolation, stoma adjustment, negative body sense changes, decreased self-respect, and unwillingness to attend family meetings or social activities due to the foul odor.^{1,5,6,7,8} The person encounters financial problems, such as affording an ostomy bag and other equipment due to quitting a job or changing job, and sexual problems also occur such as embarrassment, erectile dysfunction, diminished sexual desire, or dissatisfaction.^{1,2,9,10} The whole physical, social, psychosocial, and sexual problems adversely affect the QoL of patients with a stoma;^{1,2,3,4,11,12,13,14,15} therefore, interventions should be planned to improve the QoL of patients with a stoma by evaluating their QoL with specially developed QoL scales. The City of Hope QoL Ostomy Questionnaire (COH-QoL-Ostomy) is one of the scales developed to evaluate all subscales of the QoL of patients with a stoma (colostomy, ileostomy, and urostomy).^{16,17} This study aimed to evaluate the QoL of patients with a stoma by using the COH-QoL-Ostomy, which was developed for all people with a stoma.

Materials and Methods

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 methods. Inclusion criteria: having a stoma for at least 3 months and aged over 18 years. Exclusion criteria: patients with dementia and those who are unable to read and understand Turkish. Data were collected using The Patient Identification Form and the COH-QoL-Ostomy.

Patient Identification Form

The form comprises descriptive information about sociodemographic and stoma. For example, age, sex,

education situation, chronic disease, stoma type, stoma indication, and surgical operation.

The COH-QoL-Ostomy

The COH-QoL-Ostomy measures QOL in terms of physical, social, sexual, and spiritual aspects. The validity and reliability of the scale developed by Grant and friends were detected.¹⁷ Erol and Vural¹⁶ investigated the Turkish validity and reliability of the scale. 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. Higher scores from subscales and overall scale mean better functions.^{16,17} Power analyses were performed and reached 115 patients.

Statistical Analysis

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

Results

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

The overall score of COH-QoL-Ostomy for all participants is 5.37 ± 1.324 . The subscale mean scores were 4.42 ± 2.78 in physical, 5.33 ± 1.45 in psychological, 5.37 ± 1.32 in social, and 6.97 ± 1.70 in spiritual (Table 3). According to the COH-QoL-Ostomy mean score, the QoL of participants is moderate.

Characteristics related to sociodemographic, stoma, and treatment were compared with COH-QoL-Ostomy overall and subscale mean scores of participants. A statistically significant difference was observed between the psychological subscale mean scores of participants receiving

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	%
Gender		
Female	39	33.9
Male	76	66.1
Education status		
Primary education	65	56.5
High school	31	27.0
College/university	19	16.5
Chronic disease		
No	43	37.4
Yes *	72	62.6
Drug use		
No	55	47.8
Yes ‡	60	52.2

*Diabetes mellitus, hypertension, hyperlipidemia, hyperthyroidism, epilepsy, asthma

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

SD: Standard deviation

adjuvant chemotherapy (5.66 ± 1.55) and those without adjuvant chemotherapy (4.97 ± 1.24) (Mann-Whitney $U = 1234, 00$; $p < 0.05$). The psychological subscale mean scores of patients receiving adjuvant chemotherapy are higher than those who do not.

A statistically significant difference was observed between participants with a permanent and temporary stoma in terms of psychological subscale mean scores (permanent 5.30 ± 1.79 , temporary 5.36 ± 1.18 ; Mann-Whitney $U = 1523, 00$), social subscale mean scores (permanent 5.30 ± 1.61 , temporary 5.43 ± 1.10 ; Mann-Whitney $U = 1399, 50$), and overall mean scores (permanent 5.30 ± 1.61 , temporary 5.43 ± 1.10 ; Mann-Whitney $U = 1399, 50$) ($p < 0.05$). The overall, psychological, and social subscale mean scores of participants with temporary stoma were found to be higher. The psychological, social, and overall QoL of participants with a temporary stoma is better than those with permanent.

No statistically significant differences were observed between the overall and subscale mean scores of participants according to the sociodemographic characteristics (e.g., sex, marital status, educational status, chronic illness/drug use status, working status, social security, and persons with whom they live together), stoma characteristics (cause of

Table 2. Characteristics related to stoma and treatment of patients with stoma (N=115)

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

stoma opening, type of stoma, patients who take care of stoma), and treatment characteristics (e.g., emergency surgery/planned surgery, surgery type, neoadjuvant chemotherapy, and neoadjuvant and adjuvant radiotherapy) ($p > 0.05$).

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

Subscales	Min-max	$\bar{X} \pm SD$
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

Min: Minimum, Max: Maximum, SD: Standard deviation, COH-QoL: City of Hope QoL Ostomy Questionnaire

Discussion

In literature, opening a stoma was reported to cause various problems and adversely affect the patients' QoL in terms of physiological, social, psychological, and sexual aspects.^{1,11,12,13,14,15} In this study, the QoL of participants was evaluated with COH-QoL-Ostomy. The mean scores of COH-QoL-Ostomy (5.37±1.32) revealed that QoL of participants was moderate and the QoL decreased after the stoma was opened. A study by Anaraki et al.¹⁸ applied the same scale (n=102), and the overall QoL score was 7.48±0.9 (good level). In the study by Gomez et al.¹⁵, QoL of patients with a stoma was found to be at moderate-good levels. In our study, the stoma was reported to affect QoL in terms of physical functions, whereas in the study of Anaraki et al.¹⁸, social functions were more affected. Other studies revealed that stoma opening negatively affected QoL in different subscales. In our study, the physical subscale was most affected, and the QoL was adversely affected in all subscales. Similar to other studies, the QoL of all participants was negatively affected, and stomal opening decreased the QoL. No statistically significant difference was observed between the patients' QoL mean scores; first, according to the sociodemographic characteristics, such as sex, marital status, working status, educational status, chronic illness, and drug use; second, characteristics of stoma, such as the type of stoma (colostomy, ileostomy, and urostomy), stoma indication, the person caring for the stoma; and lastly, according to the treatment characteristics, such as the type of surgery and neoadjuvant or adjuvant radiotherapy. In the literature, unlike our results,^{13,14,18,19} 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 Qin⁵ examining the factors affecting the QoL, (n=76) stoma duration and hopefulness of patients affected the general satisfaction, skills of caregivers impacted the sexual life, and gender, education status, hope, and care skills affected social life. Similarly, in the study by Pazar et al.¹³,

the marital and educational status did not affect the QoL of patients with a urostomy. In the studies by Anaraki et al.¹⁸ and Karaveli Cakir and Ozbayir¹⁴, no difference was found between the patients' QoL scores according to the stoma type and self-care status. Personal characteristics, social environment, and cultural factors influenced QoL, which is a multidimensional concept. Patient characteristics, coping mechanisms, family support, and self-care status affect the perception of QoL; thus, the stoma opening negatively affected the QoL of all participants in our study without any difference in sex, stoma type, and educational status.

Physical Functions

In our study, participants were determined to have the lowest score in the physical subscale (4.43±2.78) from the COH-QoL-Ostomy. Participants were found to have a lower mean score on the physical subscale than other subscales. In the study of Karaveli Cakir and Ozbayir¹⁴ (n=60), unlike our study, patients with stoma scored the highest in the 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.^{20,21,22,23} All these physical problems and restrictions reduce the QoL of patients. In our study, the lower mean score in the physical subscale was 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, reduced QoL of patients with a stoma by suggesting that education given on stoma management is forgotten over time with aging and difficulties in performing stoma care are encountered.

Spiritual Functions

In our study, participants were determined to have the highest score in the spiritual subscale (6.97±1.70). The QoL in the spiritual subscale of participants decreased. In the study of Karaveli Cakir and Ozbayir¹⁴ (n=60), unlike our study, participants 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 praying. A decreased rate of attending religious worship of patients depending on the stoma surgery was observed.^{7,24} In the study by Cavdar et al.²⁴, 74.9% of participants attended regular worship before surgery; however, this rate dropped to 53% after surgery. The fact that, in our study, the spiritual subscale was less affected than other studies suggests 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 participants decreased. Participants were afraid to participate in social activities because of fear of gas and foul odor from the stoma, leakage, not finding a suitable place to change the bags, and social isolation experience considering that they feel the stigma due to the stoma.^{6,25} Participants experienced anxiety and embarrassment due to the fear of being unable to find a clean bathroom for stoma care, lack of napkins in public toilets, and too low and unclean toilets, and they travel less due to the troubles caused by the seat belt in the vehicle.^{3,4,5} Patients with stoma were found to have fewer social meetings with their relatives and friends, with reduced leisure and social activities.²⁶ Leyk's study²⁷ revealed that the social support from family and friends increased; thus, the QoL increased in patients with a permanent stoma as time passed. In our study, the low QoL of participants 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 participants decreased. In other studies, participants were found to feel the stigma due to the stoma, worries about living with a stoma and stoma closure, experienced loss of control, and change of self-perception from family members and spouses with difficulties in accepting and adjusting with the stoma.^{6,8,25} Additionally, the body image of participants is negatively affected. Patients whose body image is impaired experience psychological anxiety and depression and avoid social activities.^{6,19,28} Our study revealed that stoma status (permanent or temporary) affected the QoL of patients more than the type of stoma. The psychological and social QoL of patients with a temporary stoma were found to be better. In the study by Anaraki et al.¹⁸, the QoL of patients with a temporary stoma was found to be higher in the psychological subscale. In our study, patients with a temporary stoma were thought to maintain their hope to regain their health and strength before surgery due to temporary stoma and stoma closure, and that the negative body image will disappear with stoma closure, therefore, psychologically gaining more positive thoughts. The QoL was better in the psychological subscale of patients receiving adjuvant chemotherapy. Adjuvant chemotherapy is applied after 5-12 weeks postoperatively to prevent recurrences and increase survival. In the study by Oliphant et al.²⁹, patients with loop ileostomy receiving adjuvant chemotherapy experienced more complications in the third postoperative month, and the side effects and complications of chemotherapy adversely affected the QoL of patients. In our study, the lower mean score of the psychological subscale of participants is due

to the less favorable side effects of chemotherapy and its complications, as well as the belief that chemotherapy can achieve full recovery, disease-free survival, and more positive thoughts.

Study Limitations

Outcomes are limited in terms of patients with all types of stoma due to the small number of patients with a urostomy.

Conclusion

In our study, the QoL of all participants is adversely affected in all subscales and the stoma opening decreased overall QoL. Nurses should evaluate QoL of patients with stoma perioperatively. 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. Nursing interventions, such as giving perioperative education and counseling, planning support groups during follow-up, evaluation and management of postoperative stomal and peristomal complications, and acquiring self-confidence in the care of patients, are suggested to increase the QoL of patients with a stoma.

Ethics

Ethics Committee Approval: This study was approved by the Non-invasive Research Ethics Board (no:2153-GOA, decision number 2015/21-33). The permission was received from the hospital.

Informed Consent: The written and oral informed consent was obtained from all participants.

Peer-review: Externally peer reviewed.

Authorship Contributions

Concept: F.V., E.S., Design: F.V., E.S., Data Collection or Processing: E.S., Analysis or Interpretation: F.V., E.S., Literature Search: F.V., E.S., Writing: F.V., E.S.

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