

Living with ostomy: a quality of life study

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Abstract

Introduction: Temporary or permanent ostomy creation can sometimes be mandatory in a variety of urgent or elective situations. The aim of the present study is to evaluate the problems faced by patients with different types of intestinal stomas by using a stoma quality of life scale.

Material and methods: The quality of life (QoL) of 61 patients with an ostomy (colostomy, ileostomy) who underwent operation at our hospital was identified from our outpatient registry. A trained research nurse administered a questionnaire with socio-demographic variables including age, gender, area of residence, marital status, education and clinical variables including type of stoma, median years since surgery and underlying disease and a Stoma Quality of Life Scale. The scores based on the answers were calculated and statistical analysis was performed.

Results: The participants answered almost all questions apart from a few patients who preferred not to score sexuality/body image questions. People with a colostomy have significantly worse QoL scores due to skin irritation ($p = 0.019$). There is no statistically significant difference between patients with an ileostomy and a colostomy with respect to QoL scales apart from the financial impact controlling for age ($p = 0.041$). The younger patients had significantly less financial concern than older patients given their ostomy type. Multiple regression results indicate that skin irritation decreases significantly as ostomy time increases ($p = 0.044$). The life satisfaction of patients is considerably affected and has dropped significantly since last month ($p < 0.001$).

Conclusions: Bearing in mind our limited patient data we can suggest that a stoma affects a patient's QoL considerably and an ileostomy has a slight advantage for patients' QoL in terms of skin irritation compared to the patients with a colostomy.

Key words: ostomy, quality of life, questionnaire.

Introduction

Intestinal stomas (ostomies) are created for a variety of reasons, including inflammatory bowel disease, cancer, trauma, and acute diverticulitis. The term 'quality of life' refers to a multidimensional concept

that encompasses physical, mental and social dimensions [1]. Quality of life (QoL) can be determined by applying comprehensive interviews or standardized self-administered questionnaires. There are several reports which showed that patients with ostomies have a worsened health-related quality of life [2–4]. Problems and concerns of patients with ostomies include incontinence, rectal discharge, inability to control gas, difficulties and adjustments of returning to work, reduced sexual activity, and challenges in activities of travel and leisure [5]. In the current health management guidelines, patient satisfaction is of paramount importance when planning future care and treatment, but information on how to achieve this for stoma patients is lacking. There is still debate whether the QoL is affected by the type of the stoma (ileostomy, colostomy, permanent, temporary, etc.). In some circumstances, it would be questionable to create a temporary ileostomy or colostomy in the course of an operation. Knowing whether one is better than the other concerning QoL would help the surgeon to make a much more informed choice about this situation.

The aim of the present study is to evaluate the problems faced by patients with different types of intestinal stomas by using a stoma quality of life scale.

Material and methods

The patients included in the study underwent an operation who had finally had a stoma at our clinic. Each participant signed an informed consent

form. Because this was a questionnaire-based study, ethical approval was not obtained. From our outpatient registry, the QoL of 61 patients with an ostomy (colostomy, ileostomy) was analyzed. The clinical characteristics of stoma patients are presented in Table I. Eligible patients were aged 18 years or older, had no other pathologies or consequences of trauma with painful or disabling symptomatology, no complications related to stoma surgery, no ongoing adjuvant therapy (radio-chemotherapy), good mental health, and could speak and write Turkish. No patients refused to be enrolled. A trained research nurse administered a questionnaire with socio-demographic variables including age, gender, area of residence, marital status, education and clinical variables including type of stoma, median years since surgery and underlying disease. In a recent article Baxter *et al.* [6] described a Stoma Quality of Life Scale (SQOLS). According to this SQOLS we conducted the questionnaire and calculations were performed as outlined in the article. In this way, we rated the patients' overall satisfaction at present and during the previous month, on a scale of 0 to 100, with 0 being totally unsatisfied and 100 being totally satisfied. Additionally, the patients answered the 21-item questionnaire as never '1', seldom '2', occasionally '3', frequently '4', always '5'. According to the given answers, the scale was calculated as mentioned above and three featured scales were evaluated as follows: Work/Social Function (6 items), Sexuality/Body Image (5 items), and Stoma Function (6 items). Also, financial impact and skin irritation were assessed separately.

Table I. Clinical and demographic characteristics by stoma status

Parameter	Permanent (N = 39)	Temporary (N = 22)	P-value
Age at time of surgery, mean ± SD	55.61 ±12.40	45.33 ±12.14	0.003*
Ostomy time, median ± SD	18 ±13.98	12 ±29.52	0.004*
Gender, n (%):			0.201
Male	26 (70)	11 (30)	
Female	13 (54)	11 (46)	
Type of stoma, n (%):			0.456
Ileostomy	9 (56)	7 (44)	
Colostomy	30 (67)	15 (33)	
Education, n (%):			0.765
Primary	17 (63)	10 (37)	
College and university	22 (52)	11 (48)	
Cause of stoma, n (%):			0.001*
Cancer	34 (79)	9 (21)	
Trauma and other	5 (28)	13 (72)	

*Significant at 0.05 level. SD – standard deviation.

Statistical analysis

All statistical analyses were performed using SPSS (version 22.0 for Windows. SPSS Inc., Chicago, IL). The Shapiro-Wilk test was used to determine whether the distributions of continuous variables were normal, and the homogeneity of variables was determined by Levene test. The mean values are reported if the distribution is normal and median values otherwise. Descriptive statistics were presented as the primary stoma-related issues and clinical variables. Differences in demographic and clinical parameters between groups were compared using the χ^2 test or *t*-test when appropriate. If normality and homogeneity assumptions were violated, nonparametric tests were used. Differences were considered significant at $p < 0.05$.

Comparisons between the type of stoma (ileostomy vs. colostomy) and stoma status (temporary vs. permanent) according to the QoL mean scores were performed using multiple regression. Both

groups were grouped by age at the time of query (≤ 50 and > 50 years).

For this analysis, types of stoma (permanent and temporary) are grouped by age (≤ 50 years and > 50 years). The descriptive statistics of each scale in the survey for each group are given in Table II. Comparisons between the type of stoma according to the QoL items were performed using multiple regression, adjusted for age. The coefficients and *p* values for each variable are given in Table II. In addition, types of ostomy (ileostomy and colostomy) are grouped by age (≤ 50 years and > 50 years). The descriptive statistics of each scale in the survey for each cell are given in Table II. Comparisons on the QoL items were performed using multiple regression, adjusted for age. The coefficients and *p*-values for each variable are presented in Tables II and III.

Comparisons between the stoma status (temporary vs. permanent) and the type of ostomy (ileostomy and colostomy) on the QoL mean scores were performed using multiple regression consid-

Table II. Mann-Whitney *U* test results for ostomy type and stoma status

Variable	Ostomy type			Stoma status		
	Ileostomy Mean Median (SD)	Colostomy Mean Median (SD)	<i>P</i> -value	Permanent Mean Median (SD)	Temporary Mean Median (SD)	<i>P</i> -value
Work/social function	62.07 67 (20.63)	60.62 63 (17.88)	0.515	62.16 63 (18.70)	58.68 63 (18.27)	0.330
Sexuality/body image	59.67 65 (22.87)	56.90 55 (18.67)	0.478	57.37 55 (20.39)	58.16 65 (18.72)	0.727
Stoma function	64.53 63 (16.63)	62.57 63 (11.21)	0.855	63.45 63 (12.50)	62.37 63.52 (13.47)	0.698
Financial impact	90.00 100 (15.81)	85.12 75 (14.67)	0.262	84.21 75 (13.53)	90.79 100 (17.10)	0.354
Skin irritation	93.33 100 (19.97)	82.74 100 (21.02)	0.019*	86.84 100 (19.91)	82.89 100 (23.65)	0.830

*Significant at 0.05 level. SD – standard deviation.

Table III. Mean scores (SD) of disease specific health status by stoma status stratified by age at time of surgery (≤ 50 years and > 50 years)

Variable	Permanent		Temporary		Multiple regression	
	Age ≤ 50 (n = 14)	Age > 50 (n = 25)	Age ≤ 50 (n = 15)	Age > 50 (n = 7)	Stoma status	Age effect (age > 50)
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Coef (SD)	Coef (SD)
Work/social function	65.15 (5.5)	61.04 (3.79)	62.29 (3.22)	42.40 (9.99)	-1.24 (5.34) <i>p</i> = 0.816	-4.83 (4.70) <i>p</i> = 0.309
Sexuality/body image	60.38 (6.08)	56.25 (4.11)	61.92 (3.28)	44 (12.19)	-1.74 (5.98) <i>p</i> = 0.772	-6.91 (5.26) <i>p</i> = 0.195
Stoma function	62.69 (4.11)	64.42 (2.31)	63.85 (2.09)	61.80 (10.69)	-0.29 (3.77) <i>p</i> = 0.939	1.01 (3.32) <i>p</i> = 0.761
Financial impact	84.62 (4.51)	83.33 (2.46)	94.23 (3.04)	80 (12.25)	-3.69 (4.88) <i>p</i> = 0.453	-8.77 (4.30) <i>p</i> = 0.05
Skin irritation	86.54 (6.081)	86.46 (3.98)	90.38 (5.33)	70 (12.25)	-11.51 (6.32) <i>p</i> = 0.074	-4.85 (5.56) <i>p</i> = 0.387

*Significant at 0.05 level. SD – standard deviation.

ering variables other than age. Confounding variables were determined a priori. Variables included for adjustment were age, type of stoma, gender, education, the cause of stoma, ostomy time and stoma status. The results are given in Table IV.

The paired *t*-test was also performed to measure overall life satisfaction of patients.

Statistical differences were indicated if a *p*-value < 0.05, and reported *p*-values are two-sided.

Results

Clinical and demographic data

In total, 61 patients were included in the questionnaire. The patient group in the study consists of 37 (60.7%) males and 24 (39.3%) females. Twenty-two (36.1%) of them have temporary, and 39 (63.9%) of them have permanent stomas, 45 (73.8%) of them have a colostomy, and 16 (26.2%) of them have an ileostomy. The participants answered almost all questions apart from a few patients who preferred not to score sexuality/body image questions.

As may be expected, people with permanent stoma are significantly older than individuals with a temporary stoma (*p* = 0.003). The duration of ostomy is significantly longer for people with a permanent stoma than those with a temporary stoma (*p* = 0.004). There is no significant difference between males and females concerning ostomy type (*p* = 0.201). The cause of stoma was initially categorized as cancer, trauma and other; however, due to few observations in cells, trauma and other causes group were combined to satisfy the assumption of expected counts for the χ^2 test. In addition, education was divided into three categories – primary, college and university – but for the same reason college and university groups are combined so that the assumption of the expected

count for the χ^2 test is satisfied. As may be expected, according to the result of the χ^2 test in Table I, people who are diagnosed with cancer are more likely to have a permanent stoma (*p* = 0.001).

According to Table V, individuals who had a colostomy are significantly older than people who had an ileostomy (*p* = 0.04).

The results in Table II can be summarized as follows: there is no difference between stoma status and ostomy type concerning QoL scales except that people with a colostomy have a significantly lower mean level of skin irritation. A better way to compare those groups should be done considering confounding effects such as age. The results in Table III can be summarized as follows: there is no statistically significant difference between patients with permanent and temporary stomas as regards QoL scales controlling for age.

On the other hand, Table IV can be summarized as follows: there is no statistically significant difference between patients with an ileostomy and a colostomy in QoL scales apart from financial impact controlling for age. The younger patients have significantly less financial concern than older patients given their ostomy type.

Table VI provides the results of adjusted multiple regression results. Variables included for adjustment were age, type of stoma, gender, education, the cause of stoma, ostomy time and ostomy status. According to the results in Table VI, skin irritation decreases significantly as ostomy time increases (*p* = 0.044) keeping other factors constant.

There were also two questions in the survey to measure overall life satisfaction of patients. The mean overall satisfaction level during the last month is 60% with a standard deviation of 19.16%, while the mean overall satisfaction level at present is 53.77% with a standard deviation of

Table IV. Mean scores (SD) of disease-specific health status by ostomy type stratified by age at time of surgery (≤ 50 years and > 50 years)

Variable	Ileostomy		Colostomy		Multiple regression	
	Age ≤ 50 (n = 9)	Age > 50 (n = 7)	Age ≤ 50 (n = 20)	Age > 50 (n = 25)	Ostomy type	Age effect (age > 50)
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Coef. (SD)	Coef. (SD)
Work/social function	66.89 (3.62)	54.83 (12.24)	62.35 (4.42)	58.61 (3.66)	6.353 (5.05) <i>p</i> = 0.213	-6.84 (4.85) <i>p</i> = 0.164
Sexuality/body image	65.56 (4.82)	50.83 (12.74)	58.82 (4.51)	55.00 (3.96)	2.08 (5.90) <i>p</i> = 0.726	-7.79 (5.56) <i>p</i> = 0.167
Stoma function	64.33 (2.97)	64.83 (10.38)	62.71 (3.14)	63.74 (1.99)	1.62 (3.61) <i>p</i> = 0.656	0.504 (3.47) <i>p</i> = 0.885
Financial impact	97.22 (2.78)	79.17 (7.68)	85.29 (3.75)	83.70 (2.99)	1.16 (4.70) <i>p</i> = 0.806	-9.45 (4.52) <i>p</i> = 0.041*
Skin irritation	97.22 (2.78)	87.50 (12.50)	83.82 (5.65)	82.61 (3.99)	3.40 (6.21) <i>p</i> = 0.586	-6.91 (5.97) <i>p</i> = 0.252

*Significant at 0.05 level. SD – standard deviation.

Table V. Clinical and demographic characteristics by ostomy type

Parameter	Ileostomy (N = 16)	Colostomy (N = 45)	P-value
Age at time of surgery, mean ± SD	46.31 ±14.70	54.05 ±12.08	0.04*
Ostomy time, median ± SD	13 ±4.78	17 ±23.36	0.06
Gender, n (%):			0.674
Male	9 (24)	28 (76)	
Female	7 (29)	17 (71)	
Type of stoma, n (%):			0.456
Permanent	9 (23)	30 (77)	
Temporary	7 (32)	15 (68)	
Education, n (%):			0.06
Primary	4 (15)	23 (85)	
College and university	12 (36)	21 (64)	
Cause of stoma, n (%):			0.146
Cancer	9 (21)	34 (79)	
Trauma and other	7 (39)	11 (61)	

*Significant at 0.05 level. SD – standard deviation.

Table VI. Multiple regression results (coefficients and p-values*) considering confounding factors

Independent variables	Dependent variables				
	Work/social function	Sexuality/body image	Stoma function	Financial impact	Skin irritation
Age (> 50)	-6.36 (5.38) p = 0.242	-7.26 (6.06) p = 0.237	0.97 (3.94) p = 0.807	-6.76 (4.98) p = 0.181	-6.86 (6.23) p = 0.276
Stoma status (permanent)	4.88 (5.81) p = 0.405	-0.11 (6.94) p = 0.988	3.33 (4.26) p = 0.438	4.81 (5.38) p = 0.376	6.40 (6.73) p = 0.347
Gender (female)	2.22 (5.12) p = 0.666	-7.43 (5.82) p = 0.208	3.41 (3.75) p = 0.368	-2.38 (4.74) p = 0.618	5.54 (5.93) p = 0.355
Education (primary)	-7.02 (5.03) p = 0.169	-7.86 (5.50) p = 0.160	2.33 (3.69) p = 0.530	1.26 (4.66) p = 0.788	3.88 (5.83) p = 0.509
Cause of stoma (cancer)	3.76 (6.52) p = 0.567	4.52 (7.45) p = 0.547	-3.39 (4.78) p = 0.481	-10.3 (6.04) p = 0.095	0.43 (7.56) p = 0.955
Ostomy time [months]	0.16 (0.126) p = 0.222	0.11 (0.146) p = 0.452	-0.06 (0.092) p = 0.556	0.06 (0.116) p = 0.599	-0.30 (0.15) p = 0.044*
Ostomy type (colostomy)	-2.85 (5.95) p = 0.634	-3.03 (6.59) p = 0.648	-0.71 (4.37) p = 0.871	-3.66 (5.52) p = 0.510	-8.83 (6.90) p = 0.207

*P-values were significant at the 0.05 level and adjusted for the confounding variables age, stoma status, gender, education, cause of stoma, ostomy time and ostomy type.

19.83%. It can be concluded from the paired *t*-test that the life satisfaction of patients has dropped considerably since last month ($p < 0.001$).

Discussion

Having a stoma has a great impact on the patient's daily life according to the overall life satisfaction of patients' measurements. Living with a stoma is a challenging situation for various reasons including gas, odor, diarrhea, and leakage around the stoma or appliance. It would take several months for the patients to adjust to this diffi-

cult time. At that point the patients' QoL becomes paramount for the remaining time.

In this study we investigated which factors affect this QoL scale most. In the literature various QoL instruments have been developed for use in patients with a stoma. For instance, one of them was introduced to investigate the concerns of cancer patients and their partners with a quite long questionnaire (41 items) [7]. The other one was established to measure adjustment after ostomy for patients with inflammatory bowel disease [8]. So we preferred the SQOLS questionnaire, which was not specific to any disease status given the

broad indications of our patients leading to stoma creation and easily adopted the items to our patient profile.

Permanent ostomy did not make a significant difference regarding QoL of our patients, whereas skin irritation was worsened in the patients with a colostomy. Nonetheless, multiple regression results showed that this skin irritation problem worsens as time progresses. In one study, Sjö Dahl *et al.* [9] concluded that about 80% of patients with a permanent sigmoid colostomy had an acceptable QoL as measured with the Short Health Scale (SHS). Their results indicated that a permanent stoma did not have an adverse impact on QoL as patients often fear. Gooszen *et al.* [10] investigated the complications and social well-being of 37 patients with a loop ileostomy and 39 patients with a loop colostomy and concluded that leakage and skin irritation had frequently been observed and seemed to be the primary determinants of social isolation. The psychosocial adaptation to a stoma has been studied prospectively in patients with a permanent stoma [11]. The role of self-efficacy (one's hopes regarding the capability to perform specific tasks related to social functioning and stoma care ability) has been found to be essential for the process of compliance. The majority of our patients in the study, unfortunately, got help from their relatives for their stoma care.

In our study, some patients did not answer sexuality/body image questions. This may be attributed to Turkish socio-cultural life. Some people still believe it is a shame to talk about sexuality in Turkey and have strict taboos. On the other hand, this belief decreases with education. The condition mentioned above is common also in other studies where a large proportion of questions related to sexual life remain unanswered. Nugent *et al.* reported that 80% of 391 patients with a stoma experienced a change in lifestyle after stoma surgery, with 40% having impaired sexual activity [12].

The National Health Service in Turkey provides stomal appliances free of charge, and most patients are sent home with a free usage report written by the physicians. In our study, the financial impact scores were comparable between groups, but when patients were stratified by age, the younger patients had significantly less financial concern than older patients regarding their ostomy type. This may be because substantially older patients have only a pension to live on when they retire, and younger patients may have alternative income apart from social insurance.

In a variety of cases, it is mandatory to perform a stoma to secure the patient's health. Traditionally success of the medical treatment has been accepted as the long-term, overall or disease-free survival. QoL is also becoming an important end point particularly for cancer management [13].

In conclusion, QoL rates can be improved by education of the patient. This educational training is the responsibility of the surgeon, with support from the enterostomal therapist and the clinical care team. Interventions regarding rehabilitation should continue soon after surgery, and stoma treatments should be individualized based on a patient's underlying disease state.

As a limitation of our study, our patient sample size is relatively small. Despite this, we feel that the patients provided adequate data saturation to provide insight into the research. With respect to our limited patient data, we can suggest that a stoma negatively affects a patient's lifestyle. An ileostomy has a slight advantage for patients' QoL as a result of skin irritation compared to the patients with a colostomy. Larger series are needed to reach a definite conclusion.

Conflict of interest

The authors declare no conflict of interest.

References

1. Felce D. Defining and applying the concept of quality of life. *J Intellect Disabil Res* 1997; 41: 126-35.
2. Engel J, Kerr J, Schlesinger-Raab A, et al. Quality of life in rectal cancer patients: a four-year prospective study. *Ann Surg* 2003; 238: 203-13.
3. Klopp AL. Body image and self-concept among individuals with stomas. *J Enterostomal Ther* 1990; 17: 98-105.
4. Krouse R, Grant M, Ferrell B, et al. Quality of life outcomes in 599 cancer and non-cancer patients with colostomies. *J Surg Res* 2007; 138: 79-87.
5. Sprangers MA, Taal BG, Aaronson NK, et al. Quality of life in colorectal cancer. Stoma vs. nonstoma patients. *Dis Colon Rectum* 1995; 38: 361-9.
6. Baxter NN, Novotny PJ, Jacobson T, et al. A stoma quality of life scale. *Dis Colon Rectum* 2006; 49: 205-12.
7. Kluka S, Kristjanson LJ. Development and testing of the ostomy concerns scale: measuring ostomy-related concerns of cancer patients and their partners. *J Wound Ostomy Continence Nurs* 1996; 23: 166-70.
8. Olbrisch ME, Ziegler SW. Psychological adjustment and patient information in inflammatory bowel disease: development of two assessment instruments. *J Chron Dis* 1982; 35: 649-58.
9. Sjö Dahl R, Schulz C, Myrelid P, et al. Long-term quality of life in patients with permanent sigmoid colostomy. *Colorectal Dis* 2012; 14: e335-8.
10. Gooszen A, Geelkerken R, Hermans J, et al. Quality of life with a temporary stoma. *Dis Colon Rectum* 2000; 43: 650-5.
11. Bekkers M, Van Knippenberg F, Van Den Borne H, et al. Prospective evaluation of psychosocial adaptation to stoma surgery: the role of self-efficacy. *Psychosom Med* 1996; 58: 183-91.
12. Nugent KP, Daniels P, Stewart B, et al. Quality of life in stoma patients. *Dis Colon Rectum* 1999; 42: 1569-74.
13. Decosse JJ. Quality of life. *J Surg Oncol* 1997; 65: 231.