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A Descriptive Survey Study to Evaluate the Relationship Between Socio-demographic Factors and Quality of Life in Patients with a Permanent Colostomy

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Abstract

The impact of having a stoma on quality of life is increasingly recognized and studied. A descriptive survey study was conducted between January 2006 and December 2011 among 44 patients (18 women, 26 men) with a permanent stoma receiving care at the Kartal Training and Research Hospital, Istanbul, Turkey, to evaluate socio-demographic factors that may affect the quality of life in Turkish Muslim patients with an enteral stoma. A socio-demographic questionnaire, a 10-item Religious Orientation Scale (Modified Allport-Ross ROS), and the Medical Outcomes Study Short Form 36 Quality of Life survey were administered by a stoma therapy nurse at least 6 months after completion of all surgical and oncological treatments. The mean follow-up period was 15.3 ± 9.7 (range 6–44) months since completion of all treatments. Data were collected using paper/pencil instruments and entered for data analysis using Student's *t*-tests or one-way ANOVA univariate and multivariate analyses. No significant differences were observed for income, education level, surgical history, or religion score. Gender, geographic region, and household status were found independently related to quality of life in stoma patients. Female patients had significantly lower scores than males in general health perception ($P = 0.049$), role emotion ($P = 0.02$), mental health perception ($P = 0.026$), and mental component ($P = 0.007$). Patients living in a village (four) had significantly lower scores than patients living in a big city (33) in all scales ($P < 0.05$ for all comparisons). Village-dwelling patients also had significantly lower scores than patients living in a town (seven) in physical function ($P = 0.001$), vitality ($P = 0.012$), social function ($P = 0.003$), and mental component scores ($P = 0.021$). Patients living alone (seven) had significantly lower scores than patients living with a partner (11) in three of eight scales (physical functioning [$P < 0.001$], role-physical [$P = 0.047$], and bodily pain [$P = 0.015$]) and physical component scores ($P < 0.001$); they also had significantly lower scores than patients living with their families (26) in four of eight scales (physical functioning [$P < 0.001$], role-physical [$P = 0.032$], bodily pain [$P = 0.02$], and general health perception [$P = 0.036$]) and physical component scores ($P < 0.001$). Although these findings provide evidence for the relationship between some socio-demographic factors on quality of life of patients with a stoma, the results of the study should be interpreted with caution; multicenter, prospective, controlled studies are needed to substantiate and clarify the relationships among these variables.

Keywords: descriptive study, ostomy, colorectal surgery, quality of life, demographics

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Potential Conflicts of Interest: none disclosed

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Introduction

With advances in surgical techniques, sphincter-preserving surgery has become the preferred treatment for rectal cancers; however, abdominoperineal resection with permanent colostomy is still the standard treatment when the rectal cancer is located too close to the anal sphincter.¹ Total proctocolectomy with permanent ileostomy continues to be one of the choices for surgical treatment of patients with ulcerative colitis, familial adenomatous polyposis, and megacolon.² Thus, millions of people around the world live with a permanent stoma.³

Enteral stomas alter a person's physical appearance and bodily function. Patients with a stoma face several physical and psychological challenges, including negative self-image, restrictions in social activities, and changes in lifestyle, including problems in their sex life.⁴ A stoma on the belly is quite a change in how they look; they can feel anxious and self-conscious. It is likely their partners may be afraid of hurting their stoma or dislodging the pouch and will be anxious about sex. Moreover, men may have trouble getting and keeping an erection and women sometimes experience dyspareunia after rectal surgery.⁵

Quality of life (QoL) is an increasingly important outcome measure in surgery. Various prospective and retrospective studies have shown patients with a stoma have to deal not only with daily maintenance of the stoma, but also with the associated alterations in body image,^{4,6-9} social activities,¹⁰ sexual functions,^{5,11,12} and sleep.¹³ Subsequently, they usually experience a decrease in their QoL.

Assessing QoL and its determinants in patients with a stoma will help practitioners better understand and improve patient QoL. Although many studies have addressed QoL in stoma patients, less is known about the potential effects of socio-demographic factors on QoL in patients with a stoma. The purpose of this prospective, descriptive study was to evaluate the relationship between socio-demographic factors and QoL in Turkish Muslim patients with a permanent stoma.

Methods

Participants. All patients undergoing colorectal surgery and needing a permanent stoma at Kartal Training and Research Hospital, Istanbul, Turkey, between January 2006 and December 2011 were eligible to participate at least 6 months after completing all surgical and oncological (if necessary) treatments. The Kartal Training and Research Hospital Ethics Board approved the design and content of the study before data collection (Reference Number: B104ISM4340). Exclusion criteria included: refusal to participate in the survey; serious preoperative comorbidities (preoperative American Society of Anesthesiologists [ASA] score higher than 2); noncurative resections; metastatic disease; presence of stoma complications (hernia, prolapsus, and stricture); intellectual disability (unable to read/understand/answer questions), and being non-Muslim. Before

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Key Points

- Studies have shown the creation of a stoma can have a negative effect on patient quality of life (QoL).
- The authors of this prospective, descriptive study evaluated the relationship between QoL scores and several socio-demographic variables among 44 Turkish Muslim patients with a stoma.
- In this population, several QoL scores were significantly lower in women and in patients living in a rural community or living alone.
- Additional studies are needed to further clarify the relationship among these variables.

participating in the study, all patients signed an informed consent form; their anonymity was ensured.

Instruments. A socio-demographic questionnaire that included the Religious Orientation Scale and a QoL survey were administered by a stoma care nurse during a regular follow-up visit at the hospital. During the survey, patients were alone with nurse. Patients read and completed all questions themselves.

Socio-demographic questionnaire. The socio-demographic questionnaire, developed for this study, included seven items regarding age, gender, geographic living area (city, town, village), marital status (single, married, divorced/windowed), household status (alone, with wife/husband/partner, with big family), income level (classified as low, medium, and high according to Turkish Statistical Institute's¹⁴ income distribution data), and education level (some school, completed high school, completed university).

Religious Orientation Scale. A modified Allport-Ross Religious Orientation Scale (ROS)¹⁵ was adapted to the Muslim-Turkish population for use in this study. Responses to 10 items were rated on a 4-point Likert scale, ranging from strongly disagree to strongly agree (see Table 1). Scores could range from 10 to 40, with higher scores indicating a stronger religious orientation. Reliability and validity of this modified ROS for Turkish population were reviewed by Yapici¹⁵; Cronbach's alpha reliability coefficient was found to be 0.78.

QoL. QoL was evaluated using the Medical Outcomes Study Short Form 36 (SF-36), a 36-question multipurpose, health survey that yields an eight-scale profile of functional health and well-being score, psychometrically based physical and mental health summary measures, and a preference-based health utility index (see Table 2).¹⁶ It has been validated in Turkish cancer patients (N = 419) by Pinar¹⁷; Cronbach's alpha reliability coefficient was 0.70 and results of the test-retest method showed the stability coefficients for the eight subscales of the SF-36 ranged between 0.81 and 0.94. Normative SF-36 data for the Turkish population was obtained from Demiral et al's¹⁸ cross-sectional study (N = 1,279).

Table 1. Modified Religious Orientation Questionnaire

How much do you perceive yourself to be religious?
How important is religion to you?
Do you pray daily (do you perform namaz daily)?
Are you fasting in Ramadan?
Do you participate in Qadir and Qorban Salats?
Do you read literature about faith (or mosques)?
Do you sacrifice an animal on Festival of Sacrifices?
Do you donate on religious occasions?
Do you visit the Prophet's or Imam's descendents?
Do you visit a mosque regularly?

Clinical factors. The clinical factors that might affect QoL, including operation techniques (open or laparoscopic) and oncological therapy (neoadjuvant-adjuvant or none of them), also were investigated.

Data collection and statistical analyses. Data were collected using paper/pencil instruments and entered into a computer by statistical staff. All data were analyzed using SPSS 17.0 for Windows (SPSS Inc, Chicago, IL). Socio-demographic factors were evaluated for predictive significance using either Student's *t*-tests or one-way ANOVA as univariate analysis. Multivariate analyses were used to evaluate the joint significance of those socio-demographic factors and SF-36 scales that were shown to be predictive in univariate analyses. The correlations between age and SF-36 scales were analyzed with Pearson's bivariate test. A difference was considered to be statistically significant if the *P* value was <0.05.

Results

During the study period, 60 patients required the creation of a permanent stoma. Sixteen patients were excluded from the study for the following reasons: death (six patients), serious comorbidities (four), missing during follow-up (three), and noncurative resections or presence of metastatic disease (three). Eventually, 44 patients (26 men, 18 women, mean age 56.6 ± 12.8 [range 28–76] years) with a permanent stoma were included in this study. All had undergone abdomino-perineal resection because of rectal cancer. The mean follow-up period was 15.3 ± 9.7 (range 6–44) months since completion of all treatments.

The mean scores in all SF-36 scales were lower than Turkish general population scores¹⁸ (see Table 2). No significant

Table 2. SF-36 scores study patients and Turkish general population

Scales	Study	General population ^a
Physical functioning	85.6±22.8	86.6±25.2
Role-physical	77.6±34.6	89.5±29.6
Bodily pain	63.4±33.6	86.1±20.6
General health	63.7±24.6	73.9±17.5
Vitality	61.7±19.9	67.0±13.8
Social functioning	73.2±24.3	73.5±11.6
Role-emotional	80.4±29.9	94.7±20.9
Mental health	69.4±21.1	94.8±14.2
Physical component summary	48.6±8.5	52.6±8.8
Mental component summary	48.4±10.2	51.7±5.6

^aData obtained from Demiral et al¹⁸

correlation was found between age and SF-36 scales scores (*P* ≥0.05 for all correlations). No significant differences in QoL scores related to clinical factors including operation techniques (open versus laparoscopic) and neoadjuvant or adjuvant therapy were observed (*P* ≥0.05 for all comparisons) (see Table 3).

Socio-demographic factors.

Gender. In multivariate analysis, female patients had significantly lower scores than males in general health perception (*P* = 0.049), role emotion (*P* = 0.02), mental health perception (*P* = 0.026), and mental component (*P* = 0.007). Other scale scores were similar in both genders (*P* ≥0.05 for all comparisons) (see Table 4).

Marital status and household status. Although QoL was not affected by patient marital status, patients living alone (seven) had significantly lower scores than patients living with a partner (11) in three of eight scales (physical functioning [*P* <0.001], role-physical [*P* = 0.047], and bodily pain [*P* = 0.015]) and physical component scores (*P* <0.001); they also had significantly lower scores than patients living with their families (26) in four of eight scales (physical functioning [*P* <0.001], role-physical [*P* = 0.032], bodily pain [*P* = 0.02], and general health perception [*P* = 0.036]) and physical component scores (*P* <0.001). No significant difference was found between patients living with a partner (11) and those living with their families (26) (*P* ≥0.05 for all comparisons) (see Table 4).

Region. Patients living in a village (four) had significantly lower QoL scores than patients living in a big city (33) in all scales and component scores (*P* <0.05 for all comparisons) and significantly lower scores than patients living in a town (seven) in physical function (*P* = 0.001), vitality (*P* = 0.012), social function (*P* = 0.003), and mental component

Table 3. Clinical factors and quality-of-life variables

SF-36 variables	PF	RP	BP	GH	VT	SF	RE	MH	PCS	MCS
Operation techniques										
Open (n=27)	83.5±25.9	73.8±38.3	62.2±34.7	62.4±26.2	63.3±21.4	72.2±21.9	77.2±33.7	68.1±22.3	47.9±9.7	48±11.1
Laparoscopic (n=17)	90.6±11.3	86.8±19.9	66.4±28.5	66.5±19.3	57.9±15.4	75.6±21.3	88.2±16.5	72.5±18.2	50.4±4.5	49.5±7.6
P value	0.287	0.192	0.673	0.572	0.355	0.632	0.207	0.478	0.298	0.608
Neoadjuvant/Adjuvant therapy										
Yes (n=35)	83.3±24.1	78.2±33.6	61±33.5	63.1±26.2	59.6±19.7	71.2±25.5	79.4±30.7	67.8±21.6	48.3±8.7	47.5±10.6
Number (n=9)	95.4±11.9	75±38.7	73.6±33.3	66.2±17.1	70.9±18.8	81.4±16.8	84.8±27.4	76±18.7	50±8.1	52.4±7.1
P Value	0.112	0.784	0.266	0.709	0.088	0.217	0.595	0.252	0.558	0.148

PF: Physical functioning; RP: Role-physical; BP: Bodily pain; GH: General health; VT: Vitality; SF: Social functioning; MH: Mental health; PCS: Physical component summary; MCS: Mental component summary

scores ($P = 0.021$). No significant difference was noted between patients living in a big city (33) and those living in a town (seven) ($P \geq 0.05$ for all comparisons) (see Table 4).

Education and income level. SF-36 scores were not affected by education and income levels of the patients ($P \geq 0.05$ for all comparisons) (see Table 4).

Religious orientation. Of the 44 patients, 19 (43.1%) agreed to participate in the ROS questionnaire. All were Muslim; the mean ROS score was 32.5 ± 2.8 (range 29–38). No significant correlation was found between ROS and SF-36 scale scores ($P \geq 0.05$ for all correlations).

Discussion

The present study demonstrated physical and psychological QoL was worse in patients with a permanent stoma than in the Turkish healthy general population as reported by Demiral et al.¹⁸ Similar findings were noted by Kuzu et al,¹⁹ who (using SF-36 and a questionnaire) compared QoL after abdominoperineal resection to other surgical procedures (anterior resection and low anterior resection) and also to the general population in Turkey with regard to work responsibilities, religious worship, and sexual life after rectal surgery. The authors found all eight subscales of the SF-36 were lower, indicating poorer QoL in the abdominoperineal resection group.

To the current authors' knowledge, the present study is the first to evaluate the effect of socio-demographic factors on QoL in stoma patients. Eight different socio-demographic factors were investigated, and using multivariate analyses, three of them (gender, living region, and household status) were found independently related to QoL in stoma patients, regardless of age, marital status, religious orientation, income, and education levels. Mitchell et al's²⁰ cross-sectional, correlational study of 239 patients treated in three veteran affairs medical centers evaluated the effects of socio-demographic factors on a stoma patients' life related to embarrassment. The authors found younger participants were significantly more likely to be embarrassed compared to older patients ($P < 0.001$). Additionally, they found participants who were married or living with a partner at the time of the survey were less likely to be embarrassed than those who were not. In their study, ethnicity, gender, income level, and education level were not significantly related to the level of embarrassment.

No significant correlation between age and SF-36 scale scores was noted in the current study. This finding is concordant with a retrospective study by Stryker et al²¹ that examined 675 patients with ileostomies. In all categories of QoL assessment, older patients (>60 years) scored as well or higher than the younger patients.²¹ Also, a retrospective study by Scarpa et al²² involving 34 patients with ileostomies following colorectal cancer showed QoL scores were similar in three age groups (<50, 50–70, and >70 years), but older patients required more additional support taking care of their stomas. In a prospective pilot study including 49 patients ages 23 to 86 years, Ma et al²³ found older (>70 years) patients with a stoma had lower QoL and improved less than the younger patients over a 12-month period.

In the current study, female patients had significantly lower scores than males in general health perception, role-emotion, mental health perception, and mental component scores. This finding was partly concordant with Baldwin et al's¹³ cross-sectional study in which the effects of gender differences in sleep disruption and fatigue on QoL among stoma patients were investigated; female patients' physical component and mental component scores were lower than their male counterparts.

One of the interesting findings of the current study was that while QoL was not affected by marital status, it was strongly related in physical aspect by the number of people in the household. Loneliness was found to be a significant negative factor in the physical component of SF-36, and the highest SF-36 scores were achieved by patients who lived their families. Another important finding was that stoma patients living in rural areas (village) had very low SF-36 scores, perhaps associated with problems managing their stomas because of a lack of appropriate supportive care and ostomy associations.

Table 4. Univariate and multivariate analysis of socio-demographic factors

SF-36 Variables	Status (n)	PF	RP	BP	GH	VT	SF	RE	MH	PCS	MCS
Gender	Male (26)	87.9±16.4	86.1±24.9	63.6±33.4	70.2±19.2	65.6±17.2	79.0±19.2	89.8±19.3	76.8±15.4	49.6±6.6	52.1±6.8
	Female (18)	81.8±30.5	63.6±42.8	63.2±34.7	53.0±29.03	55.5±22.6	63.6±28.9	65.1±37.8	57.3±23.9	47.1±11.0	42.3±11.9
<i>P</i> values	Univariate	0.327	0.014	0.972	0.009	0.059	0.018	0.002	<0.001	0.286	0.002
	Multivariate	0.162	0.216	0.265	0.049	0.559	0.249	0.020	0.026	0.432	0.007
Marital status	Never Married (3)	84±17.8	70±41.1	33.7±28.9	62.3±18.6	58±13.5	70±22.1	80.3±29.9	69.3±21.1	45.7±9.2	44.7±6.6
	Married (35)	85.6±22.6	78.3±33.6	64.9±32.6	64.5±23.4	62.9±19.2	74.6±22.3	81.2±31.1	71.9±20.2	48.8±7.8	49.3±10
	Widowed/ (6) Divorced	87.2±29.7	78.5±39.3	75.3±35.6	59.4±37.7	56.4±28.2	66±38.6	80.7±26.3	62.9±27.5	49.8±12.8	44.8±6.9
<i>P</i> values	Univariate	0.973	0.878	0.084	0.877	0.663	0.662	0.860	0.168	0.682	0.412
	Multivariate	0.890	0.629	0.164	0.779	0.516	0.870	0.715	0.167	0.671	0.570
Household	Alone (7)	56.9±36.9	40.6±44.2	29.5±24.4	45.5±25.4	46.9±21.2	56.6±31.1	54.1±35.4	48.5±22.6	37.6±11.9	40.8±10.5
	Wife/Husband (11)	88.7±20.4	77.6±36.2	67.2±30.3	61.6±25.4	62.9±21.4	79.8±18.9	82.4±28.1	72±17.5	48.3±7.7	50.1±8.7
	Family (26)	91.1±12.6	87.1±23.2	69.9±32.9	69.5±22.1	64.8±17.3	73.3±24.1	86±26.9	73.1±20.2	51.7±5.1	49.3±10.4
<i>P</i> values	Univariate	<0.001	0.002	0.006	0.041	0.068	0.074	0.023	0.008	<0.001	0.072
	Multivariate	<0.001	0.047	0.015	0.062	0.318	0.427	0.443	0.173	<0.001	0.674
Living area	Big City (33)	90.9±14.6	82.9±29.9	70±30.6	66.9±23.2	61.9±17.8	74.7±22.7	85.6±25.3	72.3±18.4	50.7±5.6	49.1±9.3
	Town (7)	86.9±17.9	81.3±34.7	48.7±38.6	65±22.1	76.3±17.9	84.1±20.2	83.3±30.9	73±25.3	47.4±8.9	52.8±11.7
	Village (4)	45±37.3	33.5±37.6	34.8±31.3	37.7±26.6	40.8±21.3	47.3±26.7	38.8±32.8	43.3±19.5	35.3±13.6	37.5±7.7
<i>P</i> values	Univariate	<0.001	0.003	0.020	0.021	0.003	0.011	0.001	0.004	<0.001	<0.001
	Multivariate	<0.001	0.031	0.042	0.015	0.004	0.019	0.006	0.016	0.011	0.018
Income level	Low (6)	78.3±30.4	70.9±40.1	70.3±32.4	55±26.5	53.3±28.2	59.1±37.2	83.3±27.9	59.3±27.2	46.6±12.7	44.9±11.9
	Medium (33)	87.5±21.3	76.6±35.5	65.2±33.1	66.6±22.9	62.8±19.2	76.4±22.6	80.4±29.5	69.8±20.4	49.2±8.2	48.9±8.9
	High (5)	78.4±26.9	91.6±12.9	42.6±36.6	54.6±20.4	61.8±16.6	62.6±17	77.8±40.4	76±19.9	45.8±5.9	48.4±8.9
<i>P</i> values	Univariate	0.470	0.536	0.265	0.141	0.553	0.138	0.951	0.381	0.527	0.397
	Multivariate	0.171	0.727	0.276	0.311	0.762	0.530	0.677	0.460	0.102	0.707
Education level	Some School (24)	84.9±23.5	76.2±36.2	66.5±32.9	64.6±26.6	62.9±20.8	75.1±25.8	80.9±32.2	69.3±21.7	48.7±8.9	49±10.5
	High school (13)	88.8±21.5	78.8±32	58.8±31.9	61±15.8	58.5±16.1	70.9±20.1	79.5±25.6	70.2±20.5	48.5±7.2	47.5±10.1
	University (3)	81.7±16.1	91.7±14.4	40.7±52.5	62.3±35.3	60±25.9	54.8±12.8	77.6±19.4	66.6±23.4	49±10.4	43.5±7.4
<i>P</i> values	Univariate	0.826	0.750	0.380	0.900	0.781	0.357	0.975	0.968	0.996	0.638
	Multivariate	0.262	0.989	0.544	0.660	0.414	0.242	0.881	0.654	0.632	0.189

PF: Physical functioning; RP: Role-physical; BP: Bodily pain; GH: General health; VT: Vitality; SF: Social functioning; MH: Mental health; PCS: Physical component summary; MCS: Mental component summary

Limitations


Preoperative data were not collected in this study other than historical comparisons from previous research; therefore, it is not possible to comment on changes in QoL. In addition, study participants underwent only one type of operation (abdominoperineal resection); therefore, the results of this study cannot be generalized to all stoma patients. Also, many tools for measuring QoL in stoma patients are available, but because the SF-36 was the only one to be previously validated in Turkish patients, it was used to evaluate patients. Although patients with serious comorbidities (ASA 3 and 4) were excluded from the study to minimize the effect of other health-related factors, the SF-36 is not completely ideal for measuring QoL in stoma patients. Finally, a small proportion of respondents participated in the religion part of the survey. The data collection technique could have affected the results.

Conclusion

A study to evaluate socio-demographic factors that may affect the QoL in Turkish Muslim patients with a permanent stoma may provide evidence of the effect of some important socio-demographic factors (gender, area of residence, and household status) on QoL in stoma patients. The results of the study should be interpreted with caution to avoid the assumption of causal relationships among the variables because of important limitations. Further studies with stronger research designs (multicenter, prospective, controlled) are needed to substantiate the relationships among these variables. ■

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