World J Surg (2010) 34:2872–2876
DOI 10.1007/s00268-010-0758-z

# Permanent Stoma Not Only Affects Patients' Quality of Life but also That of Their Spouses

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**Abstract**

*Background* Living with a permanent colostomy can significantly diminish a patient's quality of life. However, little is known about the effects on the patient's spouse. Therefore, the aim of the present study was to evaluate the quality of life of spouses whose partners had undergone sphincter-sacrificing surgery for rectal carcinoma.

*Methods* We studied 56 couples after one partner underwent sphincter-sacrificing surgery for rectal carcinoma: female spouses ($n = 30$) and male spouses ($n = 26$). To identify how surgery affected the life standards of the spousal population, questionnaires were constructed by the Department of Public Health, General Surgery and Psychology at the University of Ankara.

*Results* Sixteen of 26 male spouses increased time spent at home, whereas 10 of 30 female spouses increased time spent at home ($p < 0.05$, male spouses versus female spouses). All of the spouses had been sexually active before their partners' operation; however 20 of 26 male spouses and 10 of 30 female spouses were sexually inactive afterward ($p < 0.05$, male spouses versus female spouses). Ten male patients and 3 female patients wanted their colostomy care to be managed by their spouses ($p < 0.01$, female spouses versus male spouses).

*Conclusions* In a patient with a colostomy, the social and sexual aspects of the life of the patient's spouse are affected. This observation needs to be taken into account when patients are preoperatively counseled. Therefore, preoperative counseling regarding the possible problems after surgery should not only include the patient but also the spouse.

## Introduction

In some patients with distal rectal cancer, achieving a total cure precludes the use of sphincter-preserving surgery. When the sphincter cannot be saved, a permanent stoma is needed. Research has demonstrated that patients requiring a permanent stoma may face problems including adapting to the new anatomy, managing the stoma, and continuing normal activities in their sociocultural environment. In addition to changes in body image and alteration in self-concept, patients are reminded about the threat of cancer recurrence every time they care for their stoma. Because of these issues, patients may exclude themselves not only from society but also from their families [1–5]. Therefore, we hypothesized that living with a permanent stoma affects not only the patient's physical, social, and psychological aspects of lifestyle but also the quality of life (QoL) of the patient's spouse. The goal of the present study was to evaluate the QoL of spouses whose partners had undergone sphincter-sacrificing surgery for rectal carcinoma.

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This study was presented at the Fourth Annual Meeting of the European Society of Coloproctology, 23–26 September 2009, Prague, Czech Republic.

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## Patients and methods

### Patient selection

The University of Ankara Ethics Committee approved this study, and all patients and spouses gave their written informed consent to participate. The study consisted of all spouses whose partners were diagnosed with distal rectal carcinoma and who had undergone abdominoperineal resection at the University of Ankara Department of Surgery between January 2004 and June 2008.

Patients' hospital records were reviewed to determine their eligibility status and to obtain information about their surgery, follow-up, and disease-related data (e.g., TNM classification). To be eligible, patients had to meet the following inclusion criteria: (1) curative surgery for rectal adenocarcinoma, (2) no other primary malignant tumors, (3) no additional complicating or disabling disease that necessitated nursing help (e.g., mental illness), (4) at least 1 year follow-up from the time of surgery to entrance into the study, (5) no chemo-radiotherapy within the previous 4 months, (6) no admittance to a hospital during the study period for any other reasons, (7) patient and spouse living in the same house, (8) spouse without any disabling disease, and (9) patient free of clinical evidence of disease recurrence.

Eligible couples were contacted either by letter or by telephone to determine their willingness to participate in this study. When a spouse agreed to participate, an appointment was scheduled at the Department of Surgery, University of Ankara, Ibn-I Sina Hospital, where the spouse would complete a series of questionnaires.

### Demographic information

Spouses were first asked to complete a demographic questionnaire that was designed to determine their age, gender, educational level, income level, and employment prior to their partners' surgery. In addition, the patients' clinical data were reviewed.

### Life standards

In order to identify how surgery affected the life standards of the patients' spouses, a questionnaire was constructed by the Department of Public Health, General Surgery and Psychology at the University of Ankara. This questionnaire contained 28 items and covered the following areas: (1) work responsibilities (including changes in work capability and changes in household chores in daily practice for unemployed women); (2) social activity (including disruptions in the ability to engage in usual social pursuits and leisure activities, such as going to the cinema, restaurants, cafés, etc, travel-holidays, the ability to conduct normal family life, and social isolation [time spent at home]); (3) sexual life; (4) colostomy care, and (5) religious worship (3 of the 5 pillars of Islam are participation in ritual prayers [either alone or in mosques; the reward is much greater when the ritual prayers are performed in a mosque], fasting during Ramadan, and giving alms). The other 2 pillars of Islam—creed (Shahadah), which is a verbal commitment and pledge, and pilgrimage (Hajj) to Mecca, which is required once in a person's lifetime—were not included in this study.

Most of the above items were scored on a 4-point response scale (1-not at all to 4-very much). However, the items assessing sexual life and religious worship had yes/no fields or open-ended questions.

### Interview process

In order to prevent confusion and the difficulty associated with pen-and-paper assessments, the co-authors of this study administered the life standard questionnaires. The co-authors were trained to administer the questionnaires in a standard fashion and practiced using the questionnaires on healthy volunteers before the study began. To avoid embarrassing the spouses when questioning them about sexual activity and religious life, spouses were interviewed in a private room by a co-author of the same gender. When administering the questionnaires, the co-authors read from a list that contained all of the questions and recorded the answers, being careful to avoid interfering with the spouses' feelings. Data entry and scoring were also performed by the co-authors. To avoid interfering with the spouses' feelings, the co-authors read the questions as provided on the checklist and circled the answers as stated by the spouse. Any disease related-questions regarding the patients were referred to their doctors.

### Groups

For the purpose of statistical analysis, the 56 spouses were grouped according to their gender: female spouses ($n = 30$), male spouses ($n = 26$).

### Statistical analysis

Kruskal–Wallis analysis of variance was used to assess the differences between the groups. Differences between groups for discrete variables were evaluated by the chi-square and Fisher's exact tests where applicable.

## Results

Fifty-six spouses were willing to participate in the study. All interviews were conducted between October 2008 and August 2009. The demographic questionnaire and the standard of life questionnaire created by the Department of Public Health, General Surgery and Psychology at the University of Ankara were administered together, which took about 20 min to complete. There was good acceptance of the questionnaires.

### Demographics

Male and female spouses were comparable with respect to age, educational level, income level, and employment status. In addition, there were no significant differences between groups regarding the patients' tumor stage and postoperative follow-up period. The sociodemographics of the 56 spouses and patients are outlined in Table 1.

### Life standards

#### *Employment*

No difference in work habits (employment and household duties) were seen in either male or female spouses.

#### *Social functioning*

By 6 months after their partner's surgery, 20 of 26 male spouses (76.9%) and 23 of 30 female spouses (76.6%) had returned to their normal social activities. However, only 6 male spouses (23%) and 8 female spouses (26.6%) reported that their social life was unaffected by their partner's permanent colostomy. For male spouses, 19 (73%) reported a decrease in entertainment activities, 12 (46.1%) reported a decrease in travel/holidays, and 16 (61.5%) reported a decrease in family visits. For female spouses, 20 (66%) reported a decrease in entertainment activities, 12 (40%) reported a decrease in travel/holidays, and 21 (70%) reported a decrease in family visits. Sixteen male spouses (61.5%) increased the time spent at home, whereas 10 female spouses (33.3%) increased the time spent at home ($p < 0.05$, male spouses versus female spouses). Table 2 outlines the changes in social life.

**Table 1** Sociodemographic information for spouses and patients

| | Male spouses ($n = 26$) | Female spouses ($n = 30$) |
|---|---|---|
| Age, years | 62.7 (7.4) | 64.8 (8.9) |
| Educational level | | |
| Illiteracy | 8 | 12 |
| <High school | 6 | 8 |
| High school | 8 | 8 |
| University | 4 | 2 |
| Income level | | |
| Low | 5 | 7 |
| Medium | 16 | 20 |
| High | 5 | 3 |
| Employment | | |
| Employed | 6 | 8 |
| Retired | 16 | 14 |
| Unemployed | 4 | 8 |
| Stage II/III | 10/16 | 13/17 |
| Follow-up (months) | 31 (12–42) | 28 (12–48) |

#### *Sexual life*

All of the spouses had been sexually active before their partner's operation; however 20 male spouses and 10 female spouses were sexually inactive afterward ($p < 0.05$, male spouses versus female spouses). Sixteen of the 20 male spouses (80%) reported that the reason for inactive sexual life was their spouse's colostomy, which they found repulsive. Also, the frequency of sexual intercourse decreased in all sexually active spouses.

#### *Colostomy care*

Most of the patients managed their own colostomy care. However, 10 male patients (33.3%) and 3 female patients

**Table 2** Changes in social life for spouses who have a partner with a permanent colostomy

| Social variables | Male spouses ($n = 26$) | Female spouses ($n = 30$) |
|---|---|---|
| Entertainment activities | | |
| Increased | 1 | 2 |
| Unchanged | 6 | 8 |
| Decreased | 19 | 20 |
| Travel/holiday | | |
| Increased | – | – |
| Unchanged | 14 | 18 |
| Decreased | 12 | 12 |
| Family visits | | |
| Increased | – | – |
| Unchanged | 10 | 9 |
| Decreased | 16 | 21 |
| Time spent at home | | |
| Increased | 16* | 10 |
| Unchanged | 9 | 15 |
| Decreased | 1 | 5 |

* $p < 0.05$, male versus female

(11.5%) wanted their colostomy care to be managed by their spouses ($p < 0.01$, female spouses versus male spouses). The spouses' primary concern about colostomy care was the noise (reported by 25 spouses) and the odor (reported by 30 spouses) the colostomies produced during stoma actions.

### *Religious activities*

No statistically significant change in religious activities were seen in either male or female spouses (data not shown).

## Discussion

With the aid of modern surgical techniques, surgeons are able to restore bowel continuity and preserve fecal continence in many patients who undergo radical excision of the rectum for distal tumors. However, in some individuals suffering low rectal cancer, radical removal of the tumor and chance for cure can only be achieved by excision of the rectum and the sphincter muscles, which leads to the necessity for construction of a permanent stoma. Although the effectiveness of treatment in cancer management has been determined by long-term, overall or relapse-free survival, quality of life is increasingly being regarded as an important end point [6]. There have been several reports investigating the quality of life in patients with colostomies [1–5, 7–10]. Although QoL was reported to be better when compared to coloanal anastomosis in some reports [8], it is established that living with a permanent colostomy may be an immense price to pay for the affected patients. Many of the associated problems have been related directly or indirectly to the permanent stoma. Specific concerns of gas, odor, diarrhea, leakage around the stoma, persistent dissatisfaction with general appearance or body image, and depression are common in patients with a colostomy [1–5]. Moreover, playing sports, traveling, intimacy, and personal relationships can be problematic issues in these patients. For such reasons, patients may exclude themselves from society and their families. The person likely to be most affected by these changes is the patient's spouse. However, the QoL of spouses is generally overlooked. To the best of our knowledge, very little has been reported regarding spousal QoL in the literature.

The main finding of the present study is that living with a permanent stoma not only affects the patient but also negatively affects a spouse's physical, social, and psychological aspects of lifestyle. Significant differences between male and female spouses were recorded with regard to stoma management and time spent at home. Although the patients were educated about stoma management by enterostoma therapy nurses, approximately 23.2% of the patients did not want to manage the stoma care themselves. The majority of the patients who wanted their colostomy care managed by their spouses were men. This situation significantly impairs the lifestyle of female spouses. Similarly, the time spent at home was significantly increased in male spouses.

It has been documented that sexual life is also affected negatively in patients with permanent stoma [10]. In the present study, sexual life was affected in most of the couples; 53.5% of the couples did not have sexual relations after the colostomy was placed. Male spouses were significantly less sexually active than female spouses after the partner's surgery. Furthermore, 80% of the male spouses who did not continue to have sexual relations with their partners did so because they found the colostomy repulsive. This may also be influenced by the surgical technique, which has a crucial impact on the sexual life of women. Because most of the surgical margins involve the vagina, vaginal reconstruction is necessary after abdominoperineal resection, and this may preclude healthy sexual activity for these women. Similarly, in patients with breast cancer and mastectomy, sexual problems have been reported that might be related to the extent of surgery and chemotherapy or hormonal therapy, where the adverse reactions of the spouse to the scar were predictive of less marital satisfaction in those patients [11, 12]. In the present study, it is likely that some female spouses continued to have sexual relations with their partners did so because of cultural pressures, as Turkish society might be considered a male-dominant society. Our findings also suggest that men might be giving body image more importance than women.

A previous study from the same center reported that religious worship was significantly impaired in Muslim patients who had permanent colostomies [10]. In our study, no significant change in religious activities was seen in the spouses of the patients, all of whom were Muslim.

There are several limitations of the present study. Retrospective data collection, the absence of preoperative and postoperative comparison of the spouses' quality of life, and concurrent QoL changes in patients were not collected. Therefore, we are unable to comment on the actual changes in the QoL, life standards, and clinical outcomes before and after surgery in either the patients or their spouses.

In a previous study it was found that personality traits and sense of coherence were the most important factors determining quality of life of patients after major colorectal surgery. Clinical parameters also played a role, but only to a lesser degree than usually assumed. Therefore, the authors stated that factors that physicians cannot influence with their clinical and surgical skills may affect a patient's well-being more than the procedures that the physicians perform [13]. An increased sensitivity in clinicians for this issue may help allocate supportive measures more efficiently both for patients and for their spouses.

Our study demonstrates that social and sexual aspects of life are affected in the spouses of patients with colostomies. This observation needs to be taken into account when patients receive counseling. Preoperative counseling regarding the possible problems after surgery, therefore, should not only include the patient, but the spouse as well.

## References

1. Devlin HB, Plant JA, Griffin M (1971) Aftermath of surgery for anorectal cancer. Br Med J 3:413–418
2. Rubin GP, Devlin HB (1987) The quality of life with a stoma. Br J Hosp Med 38:300–306
3. Williams NS, Johnston D (1983) The quality of life after rectal excision for low rectal cancer. Br J Surg 70:460–462
4. Sprangers MA, Taal BG, Aaronson NK et al (1995) Quality of life in colorectal cancer: stoma vs nonstoma patients. Dis Colon Rectum 38:361–369
5. Camilleri-Brennan J, Steele RJ (1998) Quality of life after treatment for rectal cancer. Br J Surg 85:1036–1043
6. Gill TM, Feinstein AR (1994) A critical appraisal of the quality of quality of life measurements. JAMA 272:619–626
7. Ramsey SD, Andersen MB, Etzioni R et al (2000) Quality of life in survivors of colorectal carcinoma. Cancer 88:1294–1303
8. Grumann MM, Noack EM, Hoffmann IA et al (2001) Comparison of quality of life in patients undergoing abdomino-perineal extirpation or anterior resection for rectal cancer. Ann Surg 233: 149–156
9. McLeod RS, Churchill DN, Lock AM et al (1991) Quality of life of patients with ulcerative colitis preoperatively and postoperatively. Gastroenterology 101:1307–1313
10. Kuzu MA, Topçu O, Uçar K et al (2002) Effect of sphincter-sacrificing surgery for rectal carcinoma on quality of life in Muslim patients. Dis Colon Rectum 45:1359–1366
11. Meyerowitz BE, Desmond KA, Rowland JH et al (1999) Sexuality following breast cancer. J Sex Marital Ther 25:237–250
12. Wimberly SR, Carver CS, Laurenceau JP et al (2005) Perceived partner reactions to diagnosis and treatment of breast cancer: impact on psychosocial and psychosexual adjustment. J Consult Clin Physiol 73:300–311
13. Siassi M, Weiss M, Hohenberger W et al (2009) Personality rather than clinical variables determines quality of life after major colorectal surgery. Dis Colon Rectum 52:662–668