

Quality of life assessment in patients with a stoma due to rectal cancer

Olga ZAJĄC^{1,3}, Arkadiusz SPYCHAŁA¹, Dawid MURAWA¹,
Janusz WASIEWICZ¹, Paweł FOLTYN², Karol POŁOM¹

SUMMARY

Received: 9.01.2008

Accepted: 2.04.2008

Subject: original paper

THE AIM: The aim of the study was to assess the quality of life in patients with a stoma, created for various reasons in the course of rectal cancer treatment.

MATERIAL AND METHODS: The study included 50 patients in the early post-surgery follow-up period, visiting the Stoma Outpatient Clinic in the Great Poland Centre in Poznań. All patients underwent surgery due to rectal cancer. Quality of life was assessed using anonymous questionnaires. Participation in the study was voluntary, and patients were informed about the proceedings. Standardized EORTC QLQ-C30 questionnaire for quality of life assessment in cancer patients and QLQ-CR38 module for colorectal cancer patients were used.

RESULTS: In all domains assessed, stoma patients showed significant impairment of functioning, which negatively influenced their quality of life. In our study group scores in all functional scales (physical – 70.6, role – 71.0, emotional – 61.8, cognitive – 75.6, social – 65) differed significantly from the reference values for the healthy population. QLQ-CR38 questionnaire was used to assess which symptoms were most disturbing for the patients. Negative influence of stoma on sexual functioning in men (mostly erectile and ejaculation dysfunctions) turned out to be the most significant (54.6). In women sexual dysfunctions were significantly less expressed (26.8). Another large group of symptoms having an unquestionable influence on level of functioning comprised direct stoma-related symptoms (47.8).

CONCLUSIONS: Creation of a stoma still has a large negative impact on patients' quality of life. Influence of the stoma is most pronounced in the area of social functioning. In spite of improvement in support, the problems pertaining directly to the fact of having a stoma bag remain significant for this group of patients.

KEY WORDS: quality of life, intestinal stoma, rectal cancer

Colorectal cancer is the most common type of gastrointestinal cancer in both men and women in Poland. 11 thousand new cases are diagnosed each year. Over the years significant improvement as far as therapeutic options are concerned has been achieved. Introduction of mechanical staplers, preoperative radiation therapy and novel chemotherapy agents have favourably influenced the treatment outcomes. There has also been a change in the proportion of anterior resections of the rectum compared to abdominal excisions [1].

In many patients surgical treatment requires the creation of a stoma, especially if the

cancer is diagnosed at a later stage. In Poland, every year about 400 ileostomies and 2000 colostomies are formed [2]. Thus, in spite of progression in therapy the number of patients needing an intestinal stoma is increasing.

Nowadays, the quality of life of patients is understood as an important outcome factor, together with five-year survival rate and disease-free survival rate. Schipper was the first author to accept the notion of health status significantly influencing the level of functioning and in this way also the quality of life. Quality of life is a multidimensional term, pertaining to three domains of functioning: mental

(emotions + cognition: reflection on disease, individual definition of health); physical (signs and symptoms resulting from the disease and from the treatment); and behavioural (coping strategies).

Key factors in achieving optimal quality of life in patients are adequate therapy and support measures, which would have a minimal impact on their functional independence.

Formation of a stoma has a significant influence on general health status of the patient, in particular on his or her psychosocial adaptation process after the surgery. A stoma makes the patient unable to control defecation, and the presence of a stoma on the abdominal surface radically changes the image of one's body. It is estimated that about 70% of patients after formation of an intestinal stoma suffer from passing adaptive-depressive syndromes, and about 20.6% from frequent sexual dysfunctions [2]. Many authors point to the fact that having a stoma negatively influences the quality of life of patients, impairing their level of functioning in everyday life. Studying the mechanisms contributing to reduction of quality of life in this group of patients, the analysis of their feelings, emotions and behaviour is necessary to achieve improvement in the level of their functioning, as well as for optimization of therapeutic processes.

The aim of the present study was to assess the quality of life in patients with a stoma, created for various reasons in the course of rectal cancer treatment. Analysis of various aspects of patients' lives was performed using scales designed to assess functioning of patients. Scales for assessment of signs and symptoms were used to evaluate factors contributing to limitations in functioning.

MATERIAL AND METHODS

The study included 50 patients in the early post-surgery follow-up period visiting the Stoma Outpatient Clinic at the Great Poland Cancer Centre in Poznań. All patients underwent surgery due to rectal cancer. Age of patients ranged from 38 to 80 years (mean 62.1; median 60). There were 56% men (n=28) and 44% women (n=22) in the study group. All questionnaires were taken between December 2006 and March 2007.

Anonymous questionnaires were used to assess the quality of life. Participation in the study was voluntary, and patients were informed about the proceedings. Standardized EORTC questionnaires were used: QLQ-C30 questionnaire for quality of life assessment in cancer patients, as well as the specific QLQ-CR38 module for colorectal cancer patients. The QLQ-C30 questionnaire consists of 30 questions which assess the quality of life in five functional scales (functional, physical, cognitive, emotional, social) as well as 6 symptoms (nausea and vomiting, pain, dyspnoea, insomnia, loss of appetite, constipation/diarrhoea). Physical functioning is connected with the influence of somatic symptoms on activity of the patient. Emotional functioning includes assessment of the presence of depression, suicidal thoughts, sense of loneliness, stigmatization and low self-esteem. Problems in fulfilling one's duties at home or in the workplace are reflected on the scale of role functioning. The social functioning scale evaluates how the patient relates to his social environment.

EORTC QLQ-CR38 consists of 2 functional scales (body image, sexual functioning) and symptom scales (gastrointestinal symptoms, problems related to having a stoma and sexual symptoms). In both questionnaires, QLQ-C30 and QLQ-CR38, the scores in individual scales are summed up and converted into the 0-100 scale, according to the EORTC instructions. The results are then interpreted as follows: the higher the score in a functional scale, the better the self-assessment of the patient in relation to the ability to function normally in a given area of everyday life; the higher the score in a symptom scale, the worse is the assessed symptom, meaning worse quality of life. Reference values from the literature were used to compare the obtained results [3]. Results which differed from reference values by more than 10 points were considered as clinically relevant.

RESULTS

In all domains assessed, stoma patients showed significant impairment of functioning, which negatively influenced their quality of life. All results are shown in Table 1. Mean score of physical functioning was at the level of 70.6, which is 19.5 points less than the

Table 1. EORTC QLQ-C30 scores (functional scales)

		Mean	Standard Deviation	Reference values	Difference
Functioning	General quality of life	54.5	23.0	70.8	16.3
	physical	70.6	20.7	90.1	19.5
	in roles	71.0	25.82	88	17
	emotional	61.8	22.0	78.7	19.6
	cognitive	75.6	22.1	91.2	15.6
	social	65	26.1	91	26

reference value. Functioning in social roles was also significantly worse (71 vs 88 points). Emotional scale showed a difference of 16.9 points compared to the reference. The presence of a stoma also significantly influenced cognitive (75.6 vs 91.2 points) and social (60.6 vs 91.0) scores.

In the QLQ-CR38 questionnaire it was assessed which symptoms were the most disturbing for the patients, thus having the strongest influence on reduction of the quality of life. A negative influence of the stoma on sexual functioning in men (mostly erectile and ejaculation dysfunctions) turned out to be the most significant (54.6 points; SD=0.4 points). In women sexual dysfunctions were significantly less expressed (26.8 points; SD=9.2 points).

Another large group of symptoms having an unquestionable influence on level of functioning comprised direct stoma-related symptoms (47.8 points; SD=13 points). The patients were afraid of the smell of stool from the stoma, of leakage from the stoma bag, and of sounds coming from the stoma. Equally important for the patients were the feelings of being handicapped and of being embarrassed about having a stoma. Skin irritation around the stoma and having to take care of the stoma were perceived as less disturbing.

Body image evaluation (41.3; SD=2.8 points) showed that the greatest problem was being dissatisfied with one's own appearance and the feeling of being less attractive. The least significant factor for the patients turned out to be the loss of masculinity/femininity due to having a stoma.

Gastrointestinal symptoms also significantly contributed to the quality of life reduction (38.7; SD=7.4 points). The most significant

Table 2. QLQ-CR38 scores (symptom scales)

	Mean	SD
Body image	41.3	2.8
Attractiveness	43.3	
Sense of masculinity/femininity	38.6	
Satisfaction with one's own body	41	
Sexuality	27.8	3.5
Interest in sex	31.3	
Sexual activity	24.3	
Sense of pleasure during intercourse	27.6	
Gastrointestinal symptoms	38.7	7.4
Bloating	38.7	
Abdominal pain	39.3	
Gluteal pain	38.7	
Need to release gas	49.3	
Need to belch	28.3	
Problems related to having a stoma	47.8	13.0
Sounds coming from the stoma	57	
Smell coming from the stoma bag	61	
Possible leakage from the stoma bag	61.7	
Caring for the stoma	29.3	
Skin irritation around the stoma	36	
Feeling embarrassed because of the stoma	53.7	
Feel less complete because of the stoma	50.3	
Sexual problems in men	54.6	0.4
Erection	54.3	
Ejaculation	54.9	
Sexual problems in women	26.8	9.2
Dry vagina during intercourse	33.3	
Pain during intercourse	20.2	

ones were the need to release gas and abdominal pain. Gluteal pain and bloating were identified as less troubling.

Data from symptom scales are shown in Table 2 and Fig. 1.

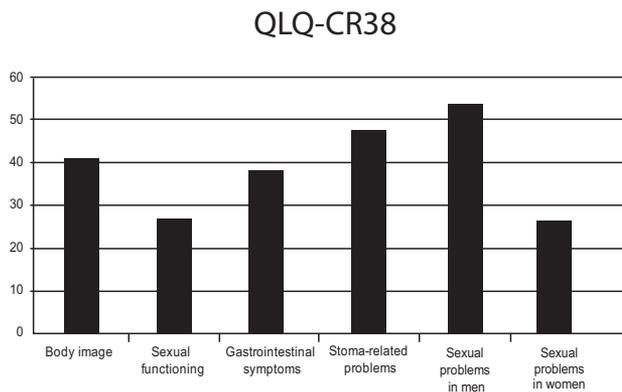


Fig. 1. QLQ-CR38 questionnaire results

DISCUSSION

Unquestionably, the presence of a stoma negatively influences the quality of life [4]. However, not enough is known about which factors are perceived as the most disturbing by the patients themselves, and in which life domains they are handicapped the most [5]. In the present study an attempt was made to analyze the factors worsening the quality of life.

The results showed that having a stoma influenced all domains of life. It should be noted that all results obtained were significantly lower in comparison with those predicted for the general population. Having a stoma had the greatest impact on social functioning (60.6), which undoubtedly can be explained by the fact that “a stoma bag is something the patients do not want to show to others” [6]. Similar results were obtained by Arndt et al. (60.6) [7], who assessed the quality of life of 439 patients with colorectal cancer. However, with the exception of social functioning in their study group the results did not differ significantly from the reference values for the general population. The authors explained their results with the remark that having a stoma would mostly impact the domain of functioning which is connected with the presence of other persons. Fear of rejection is then the most expressed.

Problems related directly with having a stoma had the highest score (53.5). The patients are afraid of leakage from the stoma bag, and that others may hear its presence. Ponczek et al. observed lower scores (36.1 points) [4]. However, their study assessed the long-term quality of life (after at least two years after the surgery), which might suggest that with time the patients adapt to having the stoma. Higher scores in the functional scales in that group also seem to support this hypothesis. This study comparing long-term results of anterior resection of the rectum and abdominal excision did not reveal significant differences in functional scales. Canadian studies of Mastrocci et al. show that problems related directly to having a stoma, especially having to take care of the stoma, are most pronounced in the oldest patients (78.6) [8].

In men sexual problems were most disturbing as far as quality of life is concerned (60.3). The results of the Norwegian study of Guren et al. [9] (68.7), and of the Polish studies of Ponczek et al. [4] (51.0 points) confirmed this observation. These problems may be related to the high risk of damage to the pelvic nexus nerves during the surgery, which may in turn impair erection and ejaculation. Allal et al. [10] explain, however, that not only the stoma itself may exert such an influence – it may also result from the general health status, emotional response to the proposed mode of surgical treatment, as well as from radiotherapy. The studies of Breukink et al. [11] on sexual functioning in patients with rectal cancer showed that this poses the most significant problem for the patients. According to these authors the quality of life, which drops significantly directly after surgical treatment, returns to preoperative or at least nearly preoperative values within a year after the surgery. Only the sexual functioning remains significantly disturbed, not returning to the level of the preoperative period. This can be explained by the damage to both autonomic nerves in the pelvis and to the pelvic diaphragm.

Numerous studies show that the quality of life of patients treated due to colorectal cancer is mostly reduced in the initial post-operative period [10, 12, 13]. The patients have high expectations as far as surgical treatment is concerned, and formation of the stoma may be

disappointing to them. With time the quality of life scores improve. This may be explained by the so-called “responsibility change”, or reformulation. Patients suffering from potentially fatal diseases, and colorectal cancer is such a disease, realize with time the value of their saved lives, which allows them to look at their daily activities more optimistically. This results in turn in better scores in quality of life assessments [10]. As a consequence, the assessment of quality of life in stoma patients is not unequivocal, and depends significantly on the time which has passed since the surgical treatment.

CONCLUSIONS

Creating a stoma still has a large negative impact on patients' quality of life.

Influence of a stoma is mostly pronounced in the domain of social functioning.

In spite of improvement in support, the problems pertaining directly to the fact of having a stoma bag remain significant for this group of patients.

REFERENCES

1. Audisio A, Filiberti A, Geraghty G i wsp. Personalized surgery for rectal tumours: the patient's opinion counts. *Supp Care Canc* 1997; 5:17-21
2. Bielecki K: Dobra Stomia. V Sympozjum Polskiego Klubu Koloproktologii, Zamość 12-23, października 2004 - Proktologia Supplement 1/2004, 27-28.
3. Kopp I, Bauhofer A, Koller M. Understanding quality of life in patients with colorectal cancer: comparison of data from randomised controlled trial, a population based cohort study and the norm reference population. *Inflamm Res*. 2004 Aug;53 Suppl 2: S130-5.
4. Ponczek D, Nowicki A, Zegarski W i wsp. Ocena jakości życia chorych leczonych z powodu raka odbytnicy metodą resekcji przedniej niskiej lub wycięcia brzuszno-kroczonego, bez radioterapii przedoperacyjnej. *Współcz Onkol* 2005; 9: 359-364.
5. Ponczek D, Nowicki A, Zegarski W i wsp. Ocena jakości życia chorych leczonych z powodu raka odbytnicy w aspekcie czynników społeczno-demograficznych. *Współcz Onkol* 2006; 10: 164-170.
6. Barbari A, Parisi V, Parmeggiani U i wsp. Impact of surgical treatment on quality of life of patients with gastrointestinal tumors. *Ann Oncol* 2001; 12: S27-S30.
7. Arndt V, Merx H, Stegmaier C i wsp. Quality of life in patients with colorectal cancer one year after diagnosis compared to the general population: a population-based study. *J Clin Oncol* 2004; 22: 4777-84.
8. Mastracci TM, Hendren S, O'Connor B i wsp. The impact of surgery for colorectal cancer on quality of life and functional status in the elderly. *Dis Colon Rectum* 2006;49: 1879-84.
9. Guren MG, Eriksen MT, Wiig JN i wsp. Quality of life and functional outcome following anterior or abdominoperineal resection for rectal cancer. *Eur J C Surg* 2005; 31: 735-42.
10. Allal AS, Gervaz P, Gertsch P i wsp. Assessment of quality of life in patients with rectal cancer treated by preoperative radiotherapy: a longitudinal prospective study. *Int J Radiat Oncol Biol Phys*. 2005 Mar 15;61(4): 1129-35.
11. Breukink SO, van der Zaag-Loonen HJ, Bouma EMC i wsp. Prospective evaluation of quality of life and sexual functioning after laparoscopic total mesorectal excision. *Dis Colon Rectum* 2007; 50: 147-155.
12. Wilson TR, Alexander DJ, Kind P i wsp. Measurement of health-related quality of life in the early follow-up of colon and rectal cancer. *Dis Colon Rectum* 2006; 49: 1692-1702.
13. Arndt V, Merx H, Stegmaier i wsp. Restrictions in quality of life in colorectal cancer patients over three years after diagnosis: a population based study. *Eur J Cancer* 2006; 42: 1848-57.