

PHYSICAL DIMENSION OF QUALITY OF LIFE IN OSTOMY PATIENTS

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Colorectal cancer is the most common cancer of abdominal visceral organs. The basic principle of management is radical surgery treatment, with creation of stoma. Quality of life is of great importance for ostomy patients. Considering the fact that colostomy is mutilizing intervention which results in irreversible body changes, in most cases as a result of underlying colorectal cancer, patients have to cope with two major issues - life threatening disease and extensive surgical procedure which leads to irreversible changes in all aspects of life.

The aim of this study was to assess physical well-being in patients with ostomy regarding their gender, education level and time after surgery.

There were 67 patients of both genders who were followed up at the Specialist Polyclinic after colostomy surgery at the Clinical Center of Vojvodina. The quality of life for patients with colostomy questionnaire by M. Grant was used.

Average age of respondents was 65.87 years. Majority of them had colostomy, mainly permanent, mostly due to malignancy. The most dominant physical issues were skin irritation, diarrhea, leakage of feces from pouch and obstipation. There were no statistically significant differences in self-assessment of physical well-being among sexes; gas and diarrhea were more commonly reported in higher education level groups, while patients who had stoma longer than 12 months better perceived their physical strength. The average score of self-assessment of physical well-being was 3.91 (0 was the best, 10 was the worst), better perceived by men and patients who had stoma longer than 12 months.

Although self-assessment of physical well-being in ostomy patients was at a satisfactory level, it is necessary to provide continuous patient support in order to overcome physical problems that alter their quality of life. *Acta Medica Medianae* 2014;53(3):32-38.

Key words: ostomy, quality of life, physical health

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Introduction

During 2012, there were about 14.1 million cancer cases around the world. It is estimated that in total 23 million people worldwide have been diagnosed with cancer in the last five years or have terminated medical treatment or their treatment was in process. Colorectal cancer was the third most common type of cancer. This disease mainly requires radical surgical treatment, while mortality rates can successfully be decreased when cancer is detected in its early asymptomatic stages (1).

Colorectal cancer is usually referred to as the disease most common for high income countries compared to low- and middle-income countries, mainly because of dietary habits and unhealthy lifestyles (1, 2).

In Serbia, colorectal cancer is one of the most common tumors and accounts for approximately 30 percent of all cancers in our population. It is the third malignant tumor in men, after the cancer of lungs and prostate. Among women, it is the second most common tumor, after breast cancer, and is one of the most frequent causes of mortality due to malignant tumors. In the last 10 years, there was an increase in the incidence of colorectal cancer, so the standardized rate of the incidence in Serbia was 46 per 100.000 inhabitants (3, 4).

The etiology of colorectal cancer is still unknown. Yet, many studies have shown that there are certain risk factors that can impact on the development of this disease. There are many known factors that increase or decrease the risk of colorectal cancer; some of these factors are modifiable and others are not. Non-modifiable risk factors include a personal or family history of colorectal cancer or adenomatous polyps, and a personal history of chronic inflammatory bowel disease. Modifiable risk factors that have been associated with an increased risk of colorectal cancer in epidemiologic studies include physical inactivity, obesity, high consumption of red or

processed meats, smoking, and moderate-to-heavy alcohol consumption. A recent study found that about one-quarter of colorectal cancer cases could be avoided by following a healthy lifestyle, i.e. maintaining a healthy abdominal weight, being physically active at least 30 minutes per day, eating a healthy diet, not smoking, and not drinking excessive amounts of alcohol. Identification of risk factors is essential in planning of screening programs and monitoring of high risk population (5).

Current trend in treatment of colorectal cancer is stage-oriented. This therapy combines surgical treatment, radiotherapy and chemotherapy. Depending on the stage of the cancer, two or more of these types of treatment may be combined at the same time or used after one another. Staging of cancer is essential for cancer management, and the process of treatment planning is tailor-made for each patient (6).

Surgery is the most common treatment for colorectal cancer. For cancers that have not spread, surgical removal may be curative. A permanent colostomy (creation of an abdominal opening for elimination of body wastes) is very rarely needed for colon cancer and is infrequently required for rectal cancer. For rectal cancer, chemotherapy alone, or in combination with radiation, is often given before surgery, after surgery, or both. For colon cancer, chemotherapy is most often used after surgery for cancers that have spread to lymph nodes (7- 9).

A colostomy is a surgical procedure in which a stoma is formed by posing the healthy end of the large intestine or colon through an incision in the anterior abdominal wall and suturing it into place. This opening, in conjunction with the attached stoma appliance, provides an alternative channel for feces to leave the body. It may be reversible or irreversible depending on the circumstances (10). There are three main types of stoma - colostomy, ileostomy and urostomy and two main types of colostomy and ileostomy - loop and end. Either type of stoma may be temporary or permanent (11).

The World Health Organization defines quality of life (QoL) as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad concept affected in a complex way by a person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment." (12). Quality of life (QoL) is a uniquely personal issue; it is the subjective perception of how an individual feels about their health status and/or the non-medical aspects of their lives (13).

The assessment of quality of life has been used for a variety of investigations in the medical field, among which are the description of the nature and extent of functional and psychosocial problems

confronted by patients in various stages of the disease (14).

Stoma patients face negative reactions due to the changes that happen after stoma creation-altered body image, everyday stoma care, nutritional and clothing changes. In some cases, creation of stoma leads to social isolation, decrease of sexual activity, anxiety, depression and sometimes suicide attempts. There are also inevitable changes in social roles, both private and social (partner, relative, and friend) and in public and professional role. Because of that stoma patient is forced to adjust to a number of changes that he/she perceives as negative (15).

The aim of this study was to assess the physical dimension of quality of life of colostomy patients regarding their sex, educational level and time after ostomy.

Methodology

The survey was designed as a retrospective study of adult patients who underwent an elective stoma creation (colostomy, ileostomy, and urostomy) between January 2010 and June 2011 and had regular follow-ups at Specialistic Polyclinic in the Clinical Center of Vojvodina. According to hospital records, there were 86 patients who had ostomy during that period, however, 67 of them (77.90%) agreed to participate in this survey.

Questionnaires were administered directly by the investigator who oversaw and facilitated answering the surveys while clarifying questions. Patients were informed of the purpose of the study and provided their written consent. Anonymity was ensured.

The instrument used in this study to assess the quality of life of patients with ostomy was a questionnaire designed by M. Grant (16). The questionnaire has two components. The first component consists of 47 forced-choice and open-ended items that relate to patient sociodemographic characteristics as well as work-related items, health insurance, sexual activity, psychological support, clothing, diet, and daily ostomy care. The second component contains 43 QOL items using 10-point scales. These QOL items are divided into the four domains or subscales: physical well-being, psychological well-being, social well-being and spiritual well-being. The respondents were asked to assess every item using one of suggested marks, where 0 was the worst outcome/negative QOL and 10 was the best outcome/positive QOL. Items in domain of physical well-being which we present in this paper had to be reverse coded prior to data entry. Subscale scores are produced by adding the scores on each item with the subscale and then dividing by the number of items in that subscale.

The study was approved by the Ethics Committee of the School of Medicine in Novi Sad.

Survey data were analyzed in SPSS 18.0. Statistical analysis included descriptive and inferential analysis. Descriptive analysis included a total value expressed in absolute and relative numbers. To test for difference between sub-groups the t-test and one-way ANOVA were used for quantitative variables. Statistically significant values were considered to be at the level of $p < 0.05$.

Results

Sociodemographic characteristics

This questionnaire was administered to 86 patients who underwent an elective stoma creation between January 2010 and June 2011 and who attended follow-up visits at Specialistic Polyclinic in the Clinical Center of Vojvodina. The response rate was 77.90%, since 67 patients returned fulfilled questionnaire. There were 49.52% females and 50.75% males. The respondents were aged between 36 and 86 years. Median age was 65.87 years ($SD=10.16$). The majority of patients (44.8%) were 70 years or older. Regarding their educational level, more than half of the patients (56.7%) completed highschool, while one quarter of them (25.4%) completed elementary school.

There were 49 patients with colostomy, 11 patients with ileostomy, and 9 patients with urostomy. Two thirds of patients had permanent colostomy. Majority of stomas (90.6%) were due to malignant disease.

Important parameter in assessing QoL is time after surgery, because patients need certain time to accept the changes and adjust to life with stoma, resocialize and return to prior activities. About two thirds of patients underwent the surgery up to 12 months prior to survey, while 37.0% had surgery between 12-24 months prior

to this survey. The mean time elapsed from surgery was 11.52 months (2-24 months), $SD=5.06$ (Table 1).

Physical aspect of quality of life

Physical well-being was assessed through 11 items that analysed the following aspects:

1. physical strength
2. fatigue
3. skin surrounding the ostomy
4. sleep disorders
5. aches or pains
6. gas
7. odor
8. constipation
9. diarrhea
10. leaking from the pouch (or around the appliance)
11. overall physical well-being.

The respondents were assessing every item by giving a mark on the scale between 0 and 10, with 0 = the worst outcome/negative QOL, and 10= the best outcome/positive. After analysis it appeared that the major issues to them were skin surrounding stoma, leakage from pouch, diarrhea and constipation, while minor issues were physical strength, sleep disorders and emission of gas (Table 2).

Exploring the influence of gender on physical well-being, it was observed that there were no statistically significant differences in mean values of each item among male and female respondents (Table 3).

Problems with gases ($F=2,854$, $df=3$, $p=0,044$) and diarrhea ($F=4,976$, $df=3$, $p=0,004$) were significantly more present among better educated respondents, while on the other items of physical well-being educational level didn't have statistically significant impact (Table 4).

Table 1. Sociodemographic characteristics of respondents

| | Features | N (%) |
|-------------------|------------------------------|------------|
| Sex | Male | 34 (57.7) |
| | Female | 33 (49.3) |
| Age | ≤ 49 | 5 (7.5) |
| | 50-59 | 11 (16.4) |
| | 60-69 | 21 (31.3) |
| | ≥ 70 | 30 (44.8) |
| Education level | Uncomplete elementary school | 5 (7.5) |
| | Elementary school | 17 (25.4) |
| | High school | 38 (56.7) |
| | Bachelor degree or higher | 7 (10.4) |
| Type of ostomy | Colostomy | 47 (70.2) |
| | Ileostomy | 11 (16.4) |
| | Urostomy | 9 (13.4) |
| Time after ostomy | Up to 12 months | 42 (63.0%) |
| | 12-24 months | 25 (37.0%) |

Table 2. Items of physical well-being

| Item | N | Mean | SD | Min | Max |
|--|----|------|------|-----|-----|
| Physical strength | 67 | 3.21 | 3.62 | 0 | 10 |
| Fatigue | 67 | 0.61 | 1.41 | 0 | 8 |
| Skin surrounding the ostomy | 67 | 0.22 | 0.81 | 0 | 5 |
| Sleep disorders | 67 | 1.25 | 2.34 | 0 | 9 |
| Aches or pains | 67 | 0.57 | 1.32 | 0 | 6 |
| Gas | 67 | 0.97 | 1.47 | 0 | 8 |
| Odor | 67 | 0.67 | 0.77 | 0 | 3 |
| Constipation | 67 | 0.49 | 1.52 | 0 | 9 |
| Diarrhea | 67 | 0.39 | 1.09 | 0 | 7 |
| Leaking from the pouch (or around the appliance) | 66 | 0.47 | 1.58 | 0 | 8 |

Table 3. Items of physical well-being regarding the sex of respondents

| Item | Male | Female | p |
|--|-----------|-----------|-------|
| Physical strength | 3.14/3.42 | 3.28/3.88 | 0.877 |
| Fatigue | 0.71/1.67 | 0.50/1.07 | 0.540 |
| Skin surrounding the ostomy | 0.22/0.73 | 0.21/0.90 | 0.961 |
| Sleep disorders | 1.22/2.21 | 1.28/2.51 | 0.928 |
| Aches or pains | 0.51/1.31 | 0.62/1.33 | 0.734 |
| Gas | 0.91/1.48 | 1.03/1.46 | 0.747 |
| Odor | 0.60/0.73 | 0.75/0.80 | 0.428 |
| Constipation | 0.37/0.68 | 0.62/2.09 | 0.500 |
| Diarrhea | 0.37/0.87 | 0.40/1.29 | 0.897 |
| Leaking from the pouch (or around the appliance) | 0.61/1.92 | 0.31/1.11 | 0.437 |

Figures are mean/ standard deviation

Table 4. Items of physical well-being regarding the education level of respondents

| Item | UnES | ES | HS | B or more | p |
|-----------------------------|-----------|-----------|-----------|-----------|-------|
| Physical strength | 3.88/4.08 | 3.64/3.16 | 3.26/3.77 | 1.42/3.77 | 0.566 |
| Fatigue | 0.66/0.89 | 1.11/1.72 | 0.50/1.40 | 0.00/0.00 | 0.297 |
| Skin surrounding the ostomy | 0.00/0.00 | 0.35/0.99 | 0.23/0.85 | 0.00/0.00 | 0.727 |
| Sleep disorders | 2.20/3.34 | 1.52/2.62 | 1.23/2.27 | 0.00/0.00 | 0.390 |
| Aches or pains | 1.00/2.23 | 1.11/1.86 | 0.36/0.88 | 0.00/0.00 | 0.127 |
| Gas | 2.20/3.34 | 1.47/1.97 | 0.68/0.61 | 0.42/0.78 | 0.044 |
| Odor | 1.40/1.51 | 0.82/0.80 | 0.57/0.59 | 0.28/0.48 | 0.053 |
| Constipation | 1.80/4.02 | 0.94/2.01 | 0.21/0.41 | 0.00/0.00 | 0.062 |
| Diarrhea | 2.00/2.91 | 0.41/0.79 | 0.23/0.71 | 0.00/0.00 | 0.004 |
| Leaking from the pouch | 0.80/1.78 | 0.68/2.02 | 0.42/1.51 | 0.00/0.00 | 0.767 |

Figures are mean/ standard deviation

UnES=uncompleted elementary school; ES=elementary school; HS=high school;
B or more=bachelor or more

Table 5. Items of physical well-being regarding time after ostomy

| Item | <12 months | ≥12 months | p |
|--|------------|------------|-------|
| Physical strength | 3.61/3.84 | 1.10/2.19 | 0.010 |
| Fatigue | 0.52/1.48 | 0.30/0.65 | 0.516 |
| Skin surrounding the ostomy | 0.11/0.32 | 0.30/1.12 | 0.380 |
| Sleep disorders | 1.23/2.38 | 0.80/2.04 | 0.499 |
| Aches or pains | 0.52/1.05 | 0.10/0.30 | 0.082 |
| Gas | 0.67/0.97 | 0.60/0.59 | 0.753 |
| Odor | 0.50/0.51 | 0.45/0.60 | 0.746 |
| Constipation | 0.41/1.39 | 0.25/0.55 | 0.623 |
| Diarrhea | 0.88/2.89 | 0.20/0.41 | 0.246 |
| leaking from the pouch (or around the appliance) | 0.32/1.38 | 0.65/2.05 | 0.489 |

Figures are mean/ standard deviation

Table 6. Assessment of overall physical health regarding gender, educational level and time after ostomy

| Features | | N | Mean | SD | 95% CI |
|----------------------|------------------------------|----|------|------|-------------|
| Sex p=0.015 | Male | 35 | 2,83 | 3,23 | -4.06-0.046 |
| | Female | 32 | 5,09 | 4,14 | -4.09-0.43 |
| Education p=0.307 | Unfinished elementary school | 5 | 3.20 | 3.24 | -0.86-7.26 |
| | Elementary school | 17 | 4.23 | 3.54 | 2.41-6.05 |
| | High school | 38 | 4.31 | 3.98 | 3.00-5.62 |
| | Bachelor degree or higher | 7 | 1.42 | 3.77 | -2.06-4.92 |
| Time p=0.002 | Up to 12 months | 34 | 5,03 | 4,03 | 1.29-5.45 |
| | 12 months or more | 20 | 1,65 | 2,98 | 1.45-5.30 |

Exploring the influence of time after ostomy on self-assessment of their physical strength, ostomy patients that underwent surgical treatment 12-24 months prior to this study had significantly better perception ($t=2,675$, $df=52$, $p=0,010$). Time after ostomy didn't have statistically significant impact on the other items of physical well-being (Table 5).

The average grade of overall physical health was 3.91 (0 was the best, 10 was the worst physical health). Overall physical health was statistically better assessed by men ($t=-2,509$, $df=65$, $p=0,015$) and patients who had ostomy longer than 12 months ($t=3,260$, $df=52$, $p=0,002$), while their educational level did not statistically significant impact the distribution of answers (Table 6).

Discussion

Although the effectiveness of medical treatment has traditionally been determined by endpoints such as long-term, overall, or relapse-free survival as well as response rate, time to treatment failure, and time to progression, QOL is increasingly being regarded as an important end point especially for cancer management (17). Krouse et al. in their study described QoL issues in colostomy patients in comparison with these issues in cancer and non-cancer participants. QOL evaluation relating to the physical domain revealed common colostomy-specific concerns of gas, odor, diarrhea, and leakage around the stoma or appliance. These may lead to psychological and social concerns (18).

Quality of life substantially deteriorate immediately after intervention resulting in stoma formation. However, patients can adjust to new situation over time and learn to live with colostomy, which leads to decrease of the problems, such as shame because of changes in body appearance, anxiety about fecal leakage from the ostomy bag, offensive odor, bowel noise, and loss of libido (19).

Pittman et al. reported that the severity of skin irritation, problems with leakage, and difficulty adjusting were significantly related to demographic, clinical, and quality-of-life domains. Analyses showed that age, income, employment, preoperative care (stoma site marking and education), having a partner, ostomy type, reason for ostomy, time after surgery, total quality-of-life scores and scores in all four domains of quality of life were related to the severity of these ostomy complications. Age was inversely related to severity of all three ostomy complications (skin irritation, leakage, and difficulty adjusting). Having an ileostomy, rather than a colostomy, was associated with higher severity of skin irritation. Having had the stoma site marked preoperatively was associated with less difficulty adjusting to an ostomy, and having had preoperative ostomy education was associated with less severe problems with skin irritation and leakage (20). In research of Nugent et al. it was observed that major stoma problems included rashes, leakage, and ballooning (21). In our study it was found that sex did not have statistically significant impact on items of physical well-being, while gas and diarrhea were significantly more often reported in higher education groups. Also, physical strength was better assessed among those who had stoma surgery 12-24 months prior to this study, compared to patients who had surgery more recently.

Considering the fact that colostomy is a mutilizing intervention which results in irreversible body changes, in most cases as a result of underlying colorectal cancer, patients have to cope with two major issues – life-threatening disease and extensive surgical procedure. Quality of life of stoma patients was monitored in Montreux study by using Stoma Care Quality of Life Index. This instrument was used to measure patient quality of life in a European-wide study (16 countries) among more than 4.000 colostomy patients. The results of this study suggest that stoma patient quality of life can be improved over time, and that patient access to specialist ostomy care is particularly important in providing continuing health education, education for self-care and psychological support (22). Similar study was performed in one Mexican general hospital among 83 ostomy patients, and it was concluded that QoL was good and considered acceptable in accordance with quality of life index and was not far below QoL of normal population as well as a population with other diseases or surgical conditions, except for the physical role and general health (23).

Dabrian et al. conducted a qualitative study to explore quality of life and its dimensions in patients with permanent colostomy. After analyzing data, in the field of physical problems, it emerged that most participants complained of

irritation and rash around the ostomy site, with sleep disturbance, odour, and gas emission in the presence of others. Also, they reported that they could not lift objects weighting more than 5 kg (24). In our study participants were more bothered by irritation of skin around ostomy site, diarrhoea, leakage from pouch and constipation, while physical strength and sleep disturbance were the least dominant symptoms.

Mäkelä and Niskasaari conducted a survey about patients' general well-being and social problems. The quality of life analysis of 114 patients showed that their physical condition was better than before stoma surgery in 55 cases

(48%), unchanged in 16 (14%) and worse in 43 (38%) (25).

Conclusion

Although self-assessment of physical well-being in ostomy patients was at the satisfactory level, it is necessary to provide continuous patient support in order to overcome physical problems that alter their overall quality of life.

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FIZIČKA DIMENZIJA KVALITETA ŽIVOTA KOD BOLESNIKA SA KOLOSTOMIJOM

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Karcinom debelog creva najčešći je maligni tumor visceralnih organa trbušne duplje. Osnovni princip lečenja ovog oboljenja je radikalna hirurška intervencija, načešće sa izvođenjem stome. Kvalitet života je važno pitanje za bolesnike sa kolostomijom. S obzirom da se na njima izvodi mutilantna intervencija, koja dovodi do permanentnih promena u telesnom izgledu, a kao i zbog činjenice da se stoma izvodi najčešće usled kolorektalnog karcinoma, ovi bolesnici moraju da se suoče ne samo sa ovom teškom bolešću nego i sa ekstenzivnom hirurškom intervencijom i sledstvenim promenama u svim sferama života.

Cilj istraživanja bio je procena fizičke dimenzije kvaliteta života bolesnika sa kolostomijom u odnosu na stepen, njihov pol, stepen stručne spreme i vreme prošlo nakon izvođenja kolostomije.

Istraživanjem je bilo obuhvaćeno 67 bolesnika oba pola, koji se nakon operativnog zahvata na kolonu, sa izvedenom kolostomijom, ambulantno prate u Specijalističkoj poliklinici Kliničkog centra Vojvodine. Za potrebe istraživanja korišćen je upitnik za procenu kvaliteta života kod osoba sa kolostomijama, autora M. Granta.

Prosečna starost ispitanika iznosila je 65,87 godina. Kod većine je bila izvedena kolostomija, uglavnom trajna, kao posledica maligniteta. Prosečno vreme prošlo nakon operativnog zahvata iznosilo je 11,52 meseci. Od fizičkih tegoba, ispitanicima najviše smetaju iritacija kože oko otvora stome, dijareja, curenje fekalnog sadržaja iz stome i opstipacija. Nije bilo statistički značajnih razlika u samoproceni fizičke dimenzije kvaliteta života; problem sa gasovima i dijarejom češće prijavljuju osobe boljeg obrazovanja, a osobe koje su operisane 12-24 meseca pre istraživanja bolje percipiraju svoju fizičku snagu. Prosečna ocena sveukupnog fizičkog zdravlja iznosila je 3,91 (0 je bila najbolja, a 10 najlošija ocena) i bolja je kod muškaraca i osoba koje imaju stomu duže od 12 meseci.

Uprkos zadovoljavajućoj proceni fizičkog zdravlja, neophodna je kontinuirana podrška bolesnicima sa kolostomijom u prevazilaženju fizičkih tegoba koje narušavaju kvalitet života. *Acta Medica Medianae 2014;53(3):32-38.*

Ključne reči: kolostomija, kvalitet života, fizičko zdravlje