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Psychological and spiritual well-being aspects of the quality of life in colostomy patients

Psihološki i duhovni aspekti kvaliteta života bolesnika sa kolostomom

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Abstract

Background/Aim. Colorectal cancer and its treatment can have a negative impact on the quality of life which has become an important outcome measure for cancer patients. The aim of this work was assessment of psychological and spiritual dimension of the quality of life in colostomy patients, regarding the gender and age. **Methods.** This is a cross-sectional study conducted at the Abdominal Surgery Polyclinic in the Clinical Canter of Vojvodina among colostomy patients operated between January 2010 and June 2011. The instrument used in this study was Quality of Life Questionnaire for a Patient with an Ostomy (QOL-O). **Results.** Majority of respondents were male (M:F = 50.7% : 49.3%). The age ranged between 36–86 years. Respondents did not report difficulties in adjustment to stoma, but their great difficulty was to look at it and the sense of depression and anxiety. The care of stoma was worse perceived by younger respondents ($p = 0.014$). Respondents were mostly satisfied with their memorizing ability and having the sense of control. The lowest score was found in sensing satisfaction or enjoyment in life. The age had a significant impact on positive aspects of psychological well-being ($p < 0.05$). Higher scores were found among younger age groups. The mean score of spiritual well-being (6.47 ± 3.01) was lower than the mean score of psychological well-being (7.76 ± 2.35). There were no statistically significant differences regarding gender (t = -0.738, df = 65, $p = 0.463$) or age (F = 1.307, $p = 0.280$). **Conclusion.** Psychological and spiritual well-being in colostomy patients appeared to be at satisfactory level, but it is necessary to provide tailor made support in order to prevent and resolve negative responses to stoma.

Key words:
colostomy; adaptation, psychological; spirituality; surveys and questionnaries; treatment outcome.

Apstrakt

Uvod/Cilj: Kolorektalni karcinom negativno utiče na kvalitet života obolelih i važan je parametar ishoda lečenja bolesnika sa dijagnozom malignih bolesti. Cilj istraživanja bio je procena psiholoških i duhovnih aspekata kvaliteta života bolesnika sa kolostomom u odnosu na njihov pol i starost. **Metode.** Istraživanjem je bilo obuhvaćeno 67 bolesnika oba pola, koji su nakon operativnog zahvata na kolonu sa izvedenom kolostomom, ambulantno praćeni u Specijalističkoj poliklinici Kliničkog centra Vojvodine. Za potrebe istraživanja korišćen je Upitnik za procenu kvaliteta života pacijenata sa kolostomom [*Quality of Life Questionnaire for a Patient with an Ostomy* (QOL-O)]. **Rezultati.** Starost ispitanika iznosila je 36–86 godina. Većinu ispitanika činili su muškarci (50,7%). Većina ispitanika nije imala poteškoća kod adaptacije na stomu; najteže im je bilo da gledaju stomu, a imali su i osećaj depresije i anksioznosti. Mlađim ispitanicima je bilo teže da neguju svoju stomu ($p < 0.05$). Ispitanici su uglavnom bili zadovoljni sposobnošću pamćenja i osećanjem kontrole. Najviše ocene kod pozitivnog aspekta psihološke dimenzije kvaliteta života uočene su u mlađim dobnim grupama ($p < 0.05$). Prosečna ocena spiritualne dimenzije kvaliteta života (6,47 ± 3,01) bila je niža u odnosu na prosečnu ocenu psihološke komponente (7,76 ± 2,35), bez značajnih razlika u odnosu na pol (t = -0.738, df = 65, $p = 0.463$) ili starost (F = 1.307, $p = 0.280$). **Zaključak.** Mada su samoprocenom psihološke i duhovne komponente kvaliteta života ispitanika dobijeni zadovoljavajući rezultati, neophodno je obezbediti specifičnu podršku u cilju prevencije i otklanjanja negativnih reakcija na stomu bolesnika sa kolostomom.

Ključne reči:
kolostomija; adaptacija, psihološka; duhovnost; ankete i upitnici; lečenje, ishod.

Introduction

Colorectal cancer is the second most prevalent cancer in the Province of Vojvodina (northern region of the Reublic of Serbia) observing the rates of incidence and mortality. During 2007 about 1233 new cases (12.76 % of all cancer cases) and 778 deaths (12.69% of all deaths) were registered in Vojvodina. As in other regions worldwide, incidence and mortality rates are higher in men than in women (sex ratio 1.5 : 1). Age-specific incidence and mortality rates are incre-

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asing rapidly from the age of 50, with the highest level in the age group of 75–79 [1].

In Serbia, the standardized incidence rate for colorectal cancer is 27/100,000, 33.5 for male (M) and 21.6 for female (F), respectively. The incidence rates rise with the age, and they are at their highest at the age of 70–74 in men and 75 and more in women when considering the sex. In other countries as well as in Serbia, there is a growing evidence of higher incidence in population younger than 40 years. Colorectal cancer is the second leading cause of death in male and the third one in female population in Serbia. According to the standardized mortality rates, Serbia can be referred to the category of countries with high mortality rates. Highest mortality rates can be found at the age of 75 and older, both in men and women [2].

According to reversibility, stoma can be divided into a temporary or a permanent one [3]. Formation of stoma can significantly influence the general health status of a patient, in particular his/her psychosocial adaptation process after the surgery. Stoma patients become unable to control defecation and presence of stoma on the abdominal surface radically changes the image of one's body [4]. Patients submitted to colostomy have to face two major issues: the cancer, a disease that carries the stigma of death and suffering and the stoma, a physical mutilation, which, despite the fact that is kept hidden, brings many consequences. A stoma patient faces the loss of sphincter control caused by the opening of an intestinal stoma and is concerned about the odor, leakage and physical discomfort, which can be a factor that affects interpersonal relationships [5].

Since creation of the stoma seems to be a great stressor for a patient, early rehabilitation is necessary to be proceeded immediately after the surgery. This should include training for patients for self-care and self-help. Indeed, all rehabilitation activities should be aimed at re integration in everyday activities. The rehabilitation process has physical and psychological component – solving adaptation issues [6].

The World Health Organization defines the quality of life as "an individual's perception of their place in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" [7]. The term *quality of life* (QOL) refers to a multidimensional concept, which includes, at least, the dimensions of physical, emotional, and social functioning. Therefore, besides traditional indicators, like disease-free and overall survival time, the QOL has become an important outcome measure for cancer patients. The aassessment of QOL in patients with cancer may improve our understanding of how cancer and therapy influence the patients' lives and how to adapt treatment strategies [8].

Colostomy patients, despite fighting the cancer, have poor body image and self esteem, and experience anxiety of rejection. The awareness of the change in the physical body and suffering regarding the new lifestyle affect the physical and psychological aspects, as well as social relationships and environment, compromising the quality of life in whole. In certain cases stoma creation can lead to suicide attempts, due to social isolation, anxiety and depression. Some changes in social roles are also inevitable. Therefore stoma patients have to adjust to a number of changes that he/she perceive as negative [6, 9].

The aim of this study was an assessment of psychological and spiritual aspects of the quality of life in colostomy patients regarding the gender and the age.

Methods

Sampling design

This survey was designed as a cross-sectional study. The main criterion for inclusion in the survey was elective stoma creation between January 2010 and June 2011 and regular follow-ups at Specialistic Polyclinic in the Clinical Center of Vojvodina as well as adult age, having adequate physical and mental health and willingness to participate in the study.

All of the patients who fulfilled these criteria were asked to participate in this survey. Critera for exclusion were unwillingness to participate, insufficient knowledge of Serbian language and mental health issues.

Patients were asked to complete a questionnaire while undergoing regular check-ups. The questionnaires were administered directly to patients by the investigators who facilitated answering the questions while clarifying doubts and difficulties. Patients were informed of the purpose of the study and provided written consents. Participation in the survey was voluntary. Anonymity was ensured. The questionnaires were collected immediately after they were completed. The entire procedure took 15–20 minutes to complete.

Respondents

The total number of 86 questionnaires were distributed, but 67 of them were returned with positive response regarding participation in the study. The response rate was 77.90%.

Out of 67 participants, 49.3% were females and 50.7% were males. The mean age was 65.87 [standard deviation (SD) = 10.16] years and it ranged from 36 to 86 years. The majority of patients (44.8%) were 70 years old or older. As far as their educational level was concerned, more than half (56.7%) of the patients completed high school while one quarter (25.4%) of them completed elementary school.

Three types of stoma were observed among respondents. There were 47 (70.14%) patients with colostomies, 11 (16.41%) patients with ileostomies, and 9 (13.45%) patients with urostomies. Two-thirds of the patients had permanent colostomy. Majority (90.6%) of stomas were due to the malignant disease.

Time after surgery appeared to be an important parameter regarding the quality of life, because it takes time to accept the changes and adjust to life with stoma, re-socialize and return to prior activities. About two-thirds of the 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 the surgery was 11.52 (SD = 5.06) months (2–24 months).

Instrument

Participants' age, gender, socioeconomic status, type of colostomy and time elapsed after stoma creations were included in the demographic features.

The instrument used in this study to assess the quality of life of patients with colostomy was the Quality of Life Questionnaire for a Patient with an Ostomy (QOL-O) designed by Grant et al. [10]. The questionnaire had two components. The first component consisted of 47 forced-choices 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 colostomy care. The second component contained 43 QOL items using 10-point scales. These QOL items were divided into 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. Some items in the domain of psychological and spiritual well-being which we present in this paper had to be reversing coded prior to data entry. Subscale scores were 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.

Statistics

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

Results

Psychological aspect of quality of life

Psychological well-being was assessed through 13 items. Some negative aspects, such as difficulties in adjustment to stoma, embarrassment, difficulties to look at their stoma, difficulties in self-care, and having emotions like anxiety, depression and fear were assessed in this domain. There was one missing answer for questions regarding embarrassment for having colostomy (Table 1).

Table 1

Psychological well-being

Item	n	Mean	SD	Min	Max
Negative aspects					
How difficult has it been for you to adjust to your colostomy?	67	2,07	3.25	0	10
How much are you embarrassed by your colostomy?	66	9.55	1.96	0	10
How difficult is it to look at your colostomy?	67	9.66	1.55	1	10
How difficult is it for you to care for your colostomy?	67	9.01	2.00	0	10
How much anxiety do you have?	67	9.43	1.17	5	10
How much depression do you have?	67	9.58	1.62	0	10
Are you fearful that your disease will come back?	67	8.88	1.25	2	10
Positive aspects					
How useful do you feel?	67	8.79	1.66	1	10
How much satisfaction or enjoyment in life do you feel?	66	8.50	2.21	0	10
How good is your overall quality of life?	66	8.53	1.99	0	10
What is your ability to remember things?	67	9.28	1.50	0	10
Do you feel like you are in control of things in your life?	67	8.90	2.32	0	10
How satisfied are you with your appearance?	67	8.87	1.17	1	10

n – number of respondents; SD – standard deviation; min – minimal value; max – maximal value.

Positive aspects of physical well-being of colostomy patients were assessed through items that covered life satisfaction, memory ability, and sense of control and evaluation of self-image. Respondents were mostly satisfied with their ability to remember things and having sense of control. The lowest score was found in having sense of satisfaction or enjoyment in life. In two items (How much satisfaction or enjoyment in life do you feel?; How good is your overall quality of life?), one missing answer was found (Table 1).

When assessing the gender differences in negative aspects of psychological well-being, it was observed that there were no statistically significant differences among male and female respondents. It was obvious that self-care of stoma was worse participated by respondents in the younger age groups (p = 0.014), while in other items there were no significant differences regarding age (Table 2).

Gender differences were not statistically significant while observing items considering the positive aspects of physical well-being (Table 3). On the other hand, it was observed that higher scores were more frequent among younger age groups compared to older respondents (Table 3).

The total score of this domain was produced by adding scores of all domain items and dividing the sum by number of items. The score for the domain of psychological well-being was 7.76 (SD = ± 2.35), widely ranging from 0.80–9.60. No statistically significant differences among gender (t = -0.584, df = 35, p = 0.563) or age groups (F = 2.205, p = 0.106) were found.

Table 2

Gender and age differences in negative aspects of psychological well-being

Item	Gender, mean ± SD		Age (years), mean ± SD				
	male/ female	p	≤ 49	50–59	60–69	≥ 70	p
Adjustment to stoma	1.60 ± 2.77/ 2.59 ± 3.69	0.214	1.00 ± 1.22	3.00 ± 4.34	2.10 ± 3.65	1.90 ± 2.77	0.868
Embarrassment	9.44 ± 2.15/ 9.66 ± 1.77	0.660	10.00 ± 0.00	9.09 ± 3.22	9.95 ± 0.22	9.23 ± 0.55	0.819
Looking at stoma	9.40 ± 2.12/ 9.94 ± 0.25	0.159	10.00 ± 0.00	10.00 ± 0.00	9.90 ± 0.30	9.30 ± 2.28	0.415
Self-care of stoma	9.00 ± 1.78/ 9.03 ± 2.24	0.950	10.00 ± 0.00	9.91 ± 0.30	9.52 ± 1.17	8.17 ± 2.59	0.014*
Anxiety	9.40 ± 1.09/ 9.47 ± 1.27	0.812	9.00 ± 2.24	9.55 ± 0.93	9.48 ± 1.17	9.43 ± 1.07	0.852
Depression	9.63 ± 1.26/ 9.53 ± 1.95	0.808	10.00 ± 0.00	9.00 ± 3.00	9.67 ± 1.53	9.67 ± 1.03	0.603
Fear	8.86 ± 1.03/ 8.91 ± 1.47	0.874	040 ± 0.89	9.36 ± 0.50	9.00 ± 1.50	8.53 ± 1.50	0.170

SD – standard deviation; $p < 0.05$*

Table 3

Gender and age differences in positive aspects of psychological well-being

Item	Gender, mean ± SD		Age (years), mean ± SD				
	male/ female	p	≤ 49	50–59	60–69	≥ 70	p
Feeling of usefulness	8.83 ± 1.38/ 8.75 ± 1.93	0.848	9.20 ± 1.30	9.82 ± 0.40	9.24 ± 1.61	8.03 ± 1.73	0.004**
Satisfaction in life	8.59 ± 1.89/ 8.41 ± 2.53	0.741	8.80 ± 1.30	9.91 ± 0.30	9.24 ± 1.26	7.38 ± 2.72	0.001***
Good quality of life	8.37 ± 2.20/ 8.71 ± 1.75	0.496	9.40 ± 0.89	9.60 ± 0.70	9.29 ± 1.06	7.50 ± 2.42	0.001***
Remembering ability	9.26 ± 1.72/ 9.31 ± 1.23	0.881	9.20 ± 1.79	9.91 ± 0.30	9.67 ± 0.66	8.80 ± 1.95	0.088
Sense of being in control	8.69 ± 2.42/ 9.13 ± 2.23	0.444	10.00 ± 0.00	9.91 ± 0.30	9.52 ± 1.17	7.90 ± 3.07	0.013*
Satisfaction with appearance	8.49 ± 2.38/ 9.28 ± 1.28	0.097	9.40 ± 0.89	9.82 ± 0.40	9.52 ± 1.17	7.97 ± 2.47	0.008*

SD – standard deviation; p < 0.05*; $p < 0.05$; $p < 0.05$*****

Spiritual aspect of quality of life

Last domain in questionnaire had seven items regarding spiritual dimension of the quality of life. The mean score of negative aspect in the domain of spiritual well-being was 8.12 (SD = ± 2.97). Participants in the younger age groups showed greater level of insecurity, comparing to the older respondents (F = 6.056, p = 0.001), while differences between gender were not at statistically significant level (t = -1.086, df = 65, p = 0.281).

Positive aspect in the domain of spiritual well-being was represented with six items. One missing answer was found for two items ("How hopeful do you feel?" and "Is support you receive from personal spiritual activities such as prayer or mediation sufficient to meet your needs?"). Nine missing answers were found in the item reading as "Is support you receive from religious activities such as going to church or synagogue sufficient to meet your needs?", while item "Has having a colostomy made positive changes in your life style?" had the lowest response rate (41.8%). The best scores were found in a statement about having a sense, a reason of being alive and having a hope, while a very small number of respondents perceived positive impacts of stoma on their life (Table 4).

In this study no statistically significant differences between males and females, regarding items of spiritual well-being were found, while number of respondents who saw positive changes after having colostomy significantly decreased in older age groups ($p = 0.021$) (Table 5).

The total score of this domain was lower than in the domain of psychological well-being (6.47/SD = ± 3.01), ranging from 0.00–9.60. No statistically significant differences between gender (t = -0.738, df = 65, $p = 0.463$) or among age groups (F = 1.307, $p = 0.280$) were found.

Table 4

Spiritual well-being

Item	n	Mean	SD	Min	Max
Do you sense a reason for being alive?	67	9.13	2.08	0	10
Do you have a sense of inner peace?	67	9.46	1.51	0	10
How hopeful do you feel?	66	9.21	2.03	0	10
Is support you receive from personal spiritual activities such as prayer or mediation sufficient to meet your needs?	66	6.26	3.62	0	10
Is support you receive from religious activities such as going to church or synagogue sufficient to meet your needs?	58	5.48	3.52	0	10
Has having a colostomy made positive changes in your life style?	28	3.93	3.94	0	10

n – number of respondents; SD – standard deviation; min – minimal value; max – maximal value.

Table 5

Gender and age differences in spiritual well-being

Item	Gender, mean ± SD		Age (years), mean ± SD				
	male/ female	*p*	≤ 49	50–59	60–69	≥ 70	*p*
Sense of reason for being alive	8.77 ± 2.62/ 9.53 ± 1.16	0.137	9.00 ± 0.71	9.82 ± 0.60	9.57 ± 1.16	8.60 ± 2.85	0.252
Sense of inner peace	9.31 ± 1.98/ 9.63 ± 0.71	0.405	9.20 ± 1.10	10.00 ± 0.00	9.76 ± 0.70	9.10 ± 2.09	0.254
Feeling of hopefulness	9.21 ± 1.98/ 9.22 ± 2.11	0.980	8.00 ± 4.47	9.82 ± 0.40	9.38 ± 2.18	9.07 ± 1.67	0.389
Spiritual activities	5.88 ± 3.73/ 6.66 ± 3.52	0.390	6.00 ± 4.69	5.45 ± 4.03	4.67 ± 3.89	7.76 ± 2.49	0.019*
Religious activities	5.14 ± 3.48/ 5.83 ± 3.58	0.460	3.33 ± 4.16	4.55 ± 4.03	4.44 ± 3.50	6.85 ± 2.88	0.056
Positive changes in life due to colostomy	4.13 ± 3.67/ 3.83 ± 4.25	0.767	8.25 ± 0.96	1.86 ± 3.29	1.25 ± 2.50	4.54 ± 4.03	0.021*

SD – standard deviation; $p < 0.05$*

Discussion

There is growing evidence about rise in prevalence of colorectal cancer worldwide [11], so it can be expected that the number of patients with stoma will increase as well. Therefore, issues on the quality of life of stoma patients have to be evaluated more closely.

Ever since WHO gave the definition of the quality of life in 1948, many instruments for measuring individual well-being were developed. The assessment of the quality of life has been explored in many studies, where correlation between functional and psychological issues had been assessed [12].

In this study we evaluated two domains of the quality of life - psychological and spiritual. As a consequence of physical function and altered body appearance, some psychological issues may arise. Stoma creation causes profound changes because of physical deterioration, loss of bodily function, changes in daily routines and restriction in level of social functioning. Such changes have negative impacts on psychological well being [13].

In our study, in the domain of psychological well-being, some negative and positive aspects were assessed. As of negative psychological issues that stoma patients might experience, it was observed that they did not report difficulties in adjustment to stoma, but their great difficulty was to look at it, i.e. the sense of depression and anxiety Danielsen [14] referred to studies she reviewed and stated that depression, loneliness, suicidal thoughts and low self-esteem were significantly more prevalent in patients with stoma, compared to patients without stoma. Different results were found in a study performed by Krousse et al. [15] who came to a conclusion that both cancer and non-cancer stoma patients, did not report problems with looking at their own stoma.

Sharpe et al. [16] in their study explored relationship between body image disturbance and distress in colorectal cancer patients with and without stomas. They found out that

body image was a strong predictor of initial levels of anxiety, depression, and distress and subsequent anxiety and distress.

Positive aspect of psychological well-being showed satisfaction of respondents, mostly with their ability to remember things and having sense of control, while the lowest score was found in having sense of satisfaction or enjoyment in life. No statistically significant differences between gender groups were found. On the other hand, age had significant impact and for this reason the higher scores were more frequent among the younger age groups, compared to the older respondents in five out of six items (feeling of usefulness, satisfaction in life, good quality of life, sense of being in control and satisfaction with appearance).

In this study, gender differences in the domain of psychological well-being were not at significant level, although, regarding negative aspect of physical well-being, we found that self-care of stoma was worse perceived by respondents in younger age groups. Arndt et al. [17] discussed that younger colorectal patients might express psychosocial deficits, probably because they have fewer coping strategies for managing a life-threatening disease, comparing to their older peers. Therefore, results in their study indicated that younger colorectal cancer patients suffer from deficits in emotional and social functioning.

Liao and Qin [18] stated that sense of hope is a significant motivating and coping factor. Referring to the reviewed literature, they stated that it was demonstrated in several studies that hope can mediate a variety of psychological effects on QOL in cancer patients.

Dabirian et al. [19] conducted a qualitative study about quality of life of stoma patients in Iran on 14 subjects aged 14–57 years, of different gender and personal background, who had permanent colostomy. Some cognitive and mental issues aroused and they are fear of impact of disease on family members. They emphasised that being a member of support group would improve their self-esteem.

In the domain of spiritual well-being, the total of seven questions were offered in questionnaire - one about negative (How much uncertainty do you feel about your future?) and other six about positive aspects of spiritual well-being (Do you sense a reason for being alive?; Do you have a sense of inner peace?; How hopeful do you feel?; Is support you receive from personal spiritual activities such as prayer or mediation sufficient to meet your needs?; Is support you receive from religious activities such as going to church or synagogue sufficient to meet your needs?; Has having a colostomy made positive changes in your life style?). Regarding the sense of insecurity about one's future, it was observed that participants in the younger age groups showed greater level of insecurity, comparing to their older peers maybe because older persons perceive their physical status in a difference frame, comparing to the younger age groups [20].

When it comes to positive aspect in the domain of spiritual well-being, it is encouraging that the best scores were found in questions about having a sense of inner peace, a reason of being alive and having a hope, while a very small number of respondents perceived positive impact of stoma on their life; that was an item with both lowest score and response rate. Gender and age did not have significant impact on distribution of answers, except whether the colostomy made positive changes in ones life style; number of respondents who saw positive changes after having colostomy significantly decreased in the older age groups.

It was shown in our study that fewer respondents were engaged in religious and spiritual activities. Respondents in the older age groups received support from personal spiritual activities such as prayer or mediation more frequently than the younger respondents. On the contrary, respondents in a study performed by Dabirian et al. [19] found that a spiritual dimension and religious rituals were of great importance to them (respondents had Islamic religion). Kimura et al. [5] referred that religion can bring relief to suffering since the spiritual well-being is associated with psychological dimension as well as with cultural background.

Conclusion

Although self-assessment of psychological and spiritual well-being in colostomy patients gave satisfactory results, providing continuous support by health and social services for a stoma patient and his/her family is necessary in prevention and management of negative reactions toward stoma and improvement of their quality of life.

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