

# **Q**UALITY OF LIFE OF INTESTINAL STOMA PATIENTS

Małgorzata E. Starczewska<sup>1,A,B,D,E</sup>, Joanna Kaczmarek<sup>2,B,D,E,F</sup>, Anita Rybicka<sup>1,B,C,E</sup>, Anna Knyszyńska<sup>3,B,C</sup>, Mirosława Pankiewicz<sup>4,D,F</sup>, Joanna Błażejewska<sup>5,D,F</sup>, Marcin Sygut<sup>6,C,E</sup>, Anna Jurczak<sup>7,A,D,E</sup>

<sup>1</sup>Department of Nursing, Pomeranian Medical University, Szczecin, Poland

<sup>2</sup>Department of Nursing, Students' Scientific Circle, Pomeranian Medical University, Szczecin, Poland

<sup>3</sup>Department of Functional Diagnostics and Physical Medicine, Pomeranian Medical University, Szczecin, Poland

<sup>4</sup>Department of Social Medicine and Public Health, Pomeranian Medical University, Szczecin, Poland

<sup>5</sup>Department of Reproductive Health, Pomeranian Medical University, Szczecin, Poland <sup>6</sup>Independent Public Clinical Hospital No. 2, Szczecin, Poland

<sup>7</sup>Department of Clinical Nursing, Pomeranian Medical University, Szczecin, Poland

### **Authors' contribution:**

A. Study design/planning • B. Data collection/entry • C. Data analysis/statistics • D. Data interpretation • E. Preparation of manuscript • F. Literature analysis/search • G. Funds collection

### **Address for correspondence:**

Małgorzata E. Starczewska
Department of Nursing
Pomeranian Medical University
48 Żołnierska Str.
71-210 Szczecin, Poland
e-mail: mlary@pum.edu.pl

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### **ABSTRACT**

**Introduction:** Intestinal stoma patients require special care from a whole team of specialists. Their quality of life is determined by new everyday routines and the necessity to adapt to new life situation.

**Aim of the study:** To evaluate the quality of life in patients with intestinal stoma, taking into account socioeconomic factors and the length of time since the surgery.

**Material and methods:** The study involved 100 primary health care patients and members of Polish Stoma Association undergoing long-term or palliative treatment at home. This survey-based study was carried out using our self-developed questionnaire and the 36-Item Short Form Health Survey.

**Results:** The highest quality of life was reported in the domain of limitations connected with emotional state. Statistically significant correlations were observed between the age of respondents, the length of time following the stoma formation, and the evaluation of their quality of life using the SF-36 (p < 0.005). Statistically significant factors also included: education, marital status, and sources of income (p < 0.005). No statistically significant correlation was found between the quality of life and place of residence.

**Conclusions:** Patients' quality of life is related to their marital status. Special care should be provided to elderly patients with lower education and lower financial status. Another group of patients who require special care are those with the stoma created recently, because they tend to evaluate their quality of life much lower than those who have been living with a stoma for a longer period of time.

Key words: quality of life, stoma, patient.

### INTRODUCTION

Quality of life is a concept that can be interpreted in various ways. Originating in social sciences, it entered the sphere of medicine to describe patients' functioning in psychological, physical, and social dimensions. Although there is no clear-cut definition of the quality of life in patients suffering from a chronic disease, it can be assumed that the concept describes a subjective perception of life with a disease and its consequences in a very broad sense [1, 2].

The evaluation of life quality in intestinal stoma patients has been the subject of numerous studies, which varied as far as the application of methods and research tools was concerned. Conclusions drawn from these studies point out the most frequent problems resulting from the disease and may allow for

a proper choice of treatment, which may improve patients functioning and thus raise their satisfaction from life [2, 3].

Intestinal stoma patients require special care and treatment from a whole team of specialists. Their quality of life is determined by a number of new everyday routines and the fact that they need to adapt to their new lifestyle and accept a new life situation [4]. The creation of intestinal stoma forces patients to limit activities such as travelling, physical activity, recreation, and their functioning in the social sphere, especially in the immediate postoperative period. Patients' lack of acceptance of their new situation frequently causes them to withdraw from social life and leads to social isolation. They often choose to isolate themselves for fear of rejection and social stigma. What they experience at that time is a sense of disapproval and exclusion.

Therefore, the support of family and friends plays a crucial role in this situation. Another problem affecting the quality of life is the deterioration of patients' financial status, which results from their limitations at work. Prolonged treatment and recuperation prevent patients from leading an active professional life and might be followed by serious limitations in this sphere. Some patients never return to work. Patients' education and type of work play an important role in making this decision. People with a good professional career are more likely to return to their duties. The costs of stoma equipment may exceed the costs covered by medical insurance, which also affects patients' financial condition [5].

General health condition, possible complications, and patients' well-being are among the aspects which determine patients' quality of life. Stoma patients' self-assessment and satisfaction from life are influenced by their ability to perform everyday activities, their self-reliance, and being active.

Advances in medicine have made it possible to cure diseases that used to be considered incurable. Therefore, it is essential to focus not only on the length but also the quality of life. Providing patients with specialist care as well as education for them and their families and medical and psychological support should be viewed as key factors without which achieving life satisfaction is impossible for intestinal stoma patients [6].

The objective of the study was to evaluate the quality of life in patients who had an intestinal stoma created, taking into account socioeconomic factors and the length of time since the surgery.

## MATERIAL AND METHODS

The study was carried out in a group of 100 Primary Health Care (POZ) patients and members of the Polish Stoma Association (POL-ILKO) who were undergoing long-term or palliative treatment at home. An oral consent of the aforementioned health care facilities was obtained before the study started. Also, the staff coordinating the patients' care in these health facilities approved the study after familiarising themselves with the research tool (the questionnaire content). The respondents were informed about the aim of the study and instructed how to fill in the questionnaire. They completed the questionnaire on their own, except for situations when poor health made it impossible for them to do so, in which case the patients answered the questions verbally and the facility coordinator filled in the questionnaire. Prior to the study the following criteria for participants had been established: respondents had to be aged 18 years or more, and the length of time since their stoma was formed had to be at least six months regardless of the reasons for which the stoma was created. The following criteria excluded patients from the study: lack of verbal and logical contact with the patient, lack of informed consent, and overly short period of time since stoma creation. The respondents were informed that they could resign from the study and withdraw their consent at any time during the research without giving a reason for their resignation.

The study received approval from the Bioethics Committee of Pomeranian Medical University (PUM).

The study was based on a diagnostic survey with the application of research tools such as the authors' own questionnaire, including questions referring to sociodemographic data or the duration of the disease, and the 36-Item Short Form Health Survey questionnaire, consisting of 11 questions with 36 statements defining eight domains of quality of life: physical functioning, limitations in role functioning caused by health problems, pain perception, general health perception, vitality, social functioning, emotional functioning, and mental health.

The highest score defined the highest evaluation of quality of life, whereas the lowest score meant the lowest level of quality of life [7].

Statistical analysis was conducted by means of IBM SPSS 22. Data collection was followed by a quantitative, percentage, and statistical analysis by means of the following tests:

- in the case when the assumption of normal or ordinal distribution of the variables was not met, Spearman's correlation coefficient was used, which was applied to examine correlations between two variables, both of which are presented in (at least) ordinal scale,
- in the case of data without normal distribution, the Mann-Whitney U test was applied in order to define the differences between mean values for two different groups,
- in the case of two or more groups, the ANOVA test developed by Kruskal-Wallis was applied, which was used to examine the observations influenced by one or more simultaneous factors. It allows us to define the factors that may be responsible for the differences in the observed groups. The level of significance was assumed at p < 0.05.</li>

# **RESULTS**

The average age of respondents was  $57.13 \pm 11.64$  years, and more than a half of them were men (54%). The largest group (48%) consisted of respondents living in cities with a population below 100,000, 22% lived in the country, 18% in a city with a population of over 100,000, and 12% in a city with a population of 100,000 - 100,000 inhabitants.

Patients with primary education constituted 14% of respondents, 52% had vocational education, 20% had secondary education, and 14% had higher education.

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The majority of respondents (65%) were in formal or informal relationships, whereas 35% of them were single. More than a half (56%) lived off their disability benefit and 32% lived off their pension. 12% of respondents were professionally active, and only 2% were unemployed.

The average length of time since stoma creation in the examined group of respondents was  $3.92 \pm 3.8$  years.

The highest quality of life was reported by the respondents in the domain of their limitations resulting from their emotional state – the average score was 68.83 ±11.46. A similar result was obtained for social functioning, with an average score of 66 ±16.67. As far as pain perception was concerned, the evaluation of quality of life reached a score of 62.68 ±17.78. In the domain of physical functioning the respondents evaluated their quality of life at, on average, 58 ±19.77, whereas in the sphere of mental health it was 54.56 ±11.81; similarly, in the domain connected with role limitation in physical functioning the average score was 54.38 ±14.88, and in the domain of vitality it was 51.20 ±11.83 on average. The lowest average score in the evaluation of quality of life in the examined group was obtained for general health condition, at 29.72 ±16.84. As far as the physical dimension is concerned, the respondents scored on average 51.19 ±15.17. Taking into account the mental dimension of life, the respondents obtained higher scores as compared to the physical dimension – 60.15 ±10.51 on average.

The negative correlation between age and evaluation of the quality of life according to the SF-36 scale proved that there is a statistically significant relationship between the evaluation of the quality of life and respondents' age in the following domains: physical functioning (p=0.015), role limitation in physical functioning (p=0.01), pain perception (p=0.01), general health condition (p=0.01), and social functioning (p=0.036), as well as physical (p=0.005) and mental dimensions of quality of life (p=0.038). No

Table 1. Correlation between respondents' age and the quality of their life

Quality of life	r	р
Physical functioning	-0.242	0.015
Role limitation in physical functioning	-0.256	0.01
Pain perception	-0.255	0.01
General health condition	-0.253	0.011
Vitality	-0.178	0.077
Social functioning	-0.21	0.036
Limitations resulting from emotional state	-0.139	0.169
Mental health	-0.106	0.293
Physical dimension of quality of life	-0.278	0.005
Mental dimension of quality of life	-0.208	0.038

p – statistical significance coefficient, r – Spearman's correlation coefficient

statistically significant correlation was observed in the other domains (p > 0.05) (Table 1).

The data analysis did not show any statistically significant correlations between the evaluation of the quality of life and the respondents' place of residence (p > 0.05).

An analysis of the quality of life according to the SF-36 scale, which took into account respondents' education, proved the relationship between education in the domains of physical functioning, pain perception, vitality, and social functioning, as well as physical and mental dimensions of quality of life. Respondents with higher education tended to have a higher quality of life as compared to the population with lower level of education. Respondents with elementary or vocational education had lower quality of life than those with secondary or higher education (p = 0.016).

The quality of life in the domain of pain perception was definitely lowest in the group of patients with vocational education, and highest in the group of patients with higher education (p = 0.013). Also, in the domain of vitality the respondents with vocational education scored the lowest, whereas those with higher education scored the highest (p = 0.015). In the domain of social functioning, patients with elementary education obtained a significantly lower level of the quality of life, while the other patients scored higher in this domain (p = 0.043). In the physical dimension of the quality of life the lowest scores belonged to the patients with elementary or vocational education, and the highest to the respondents with higher education (p = 0.022). Likewise, in the mental dimension the lowest quality of life was observed in the respondents with elementary education and the highest level in the respondents with higher education (p = 0.02).

In the other domains of quality of life no statistically significant differences connected with the respondents' education were observed (p > 0.05) (Table 2).

An analysis of correlations between the quality of life and marital status showed statistically important differences in the domains of general health, limitations resulting from emotional state, and the physical dimension of quality of life. Patients who were in a relationship obtained lower scores in the domain of general health condition than single respondents (p = 0.014). On the other hand, these respondents reported a higher quality of life in the domain of limitations resulting from emotional state than single patients (p = 0.048). As far as the physical dimension of the quality of life was concerned, single respondents reported a higher quality of life than patients living in a relationship (p = 0.031). In the other domains of quality of life no statistically significant differences were found between respondents who were in relationships and those who were single (p > 0.05) (Table 3).

Table 2. The quality of life on SF-36 scale and respondents' education

Quality of life		Educ	ANOVA Kruskal-Wallis			
	Elementary n = 14	Vocational n = 52	Secondary n = 20	Higher n = 14	te	st
		Т	р			
Physical functioning	57.50	55.00	67.50	65.00	10.301	0.016
Role limitation in physical functioning	50.00	50.00	56.25	65.63	3.971	0.265
Pain perception	64.00	57.00	69.50	75.50	10.85	0.013
General health condition	20.00	27.50	30.00	45.00	4.753	0.191
Vitality	52.50	50.00	55.00	60.00	10.454	0.015
Social functioning	62.50	75.00	75.00	75.00	8.176	0.043
Limitations resulting from emotional state	70.83	75.00	75.00	75.00	2.476	0.48
Mental health	52.00	52.00	60.00	62.00	6.221	0.101
Physical dimension of quality of life	47.72	47.34	57.63	63.81	9.625	0.022
Mental dimension of quality of life	58.71	60.50	62.81	67.50	9.789	0.02

n – number, Me – median, T – ANOVA Kruskal-Wallis test, p – statistical significance coefficient

Table 3. The quality of life on SF-36 scale and respondents' marital status

Quality of life	Marital status				Mann-Whitney <i>U</i> test			
	In a relationship n = 65		Single n = 35					
	Me	M ±SD	Me	M ±SD	U	Z	р	
Physical functioning	60.00	55.46 ±19.44	65.00	62.71 ±19.79	903.5	-1.698	0.09	
Role limitation in physical functioning	50.00	52.88 ±15.59	56.25	57.14 ±13.23	969.5	-1.233	0.218	
Pain perception	57.00	60.66 ±17.07	69.50	66.41 ±18.71	886.5	-1.841	0.066	
General health condition	25.00	26.72 ±16.04	35.00	35.29 ±17.10	800.5	-2.455	0.014	
Vitality	50.00	50.38 ±11.43	55.00	52.71 ±12.56	1002.5	-0.989	0.323	
Social functioning	75.00	67.30 ±15.70	75.00	63.60 ±18.30	1027.5	-0.913	0.361	
Limitations resulting from emotional state	75.00	70.26 ±11.60	75.00	66.19 ±10.87	892.5	-1.978	0.048	
Mental health	56.00	53.91 ±12.11	56.00	55.77 ±11.31	1012.5	-0.909	0.363	
Physical dimension of quality of life	47.13	48.93 ±14.87	58.81	55.39 ±15.03	838.5	-2.161	0.031	
Mental dimension of quality of life	61.50	60.46 ±10.18	62.33	59.56 ±11.29	1135.5	-0.014	0.988	

n-number, Me-median, M-arithmetic mean, SD-standard deviation, Z-statistics Z, p-statistical significance coefficient

An analysis of the quality of life according to the SF-36 scale showed a statistically significant impact of the respondents' source of income on the following domains: general health (p = 0.029), vitality (p = 0.032), social functioning (p = 0.023), mental health (p = 0.035), and the physical (p = 0.042) and mental dimensions (p = 0.02) of quality of life. In the case of patients who lived off their disability benefit or pension, the level of their quality of life was much lower in the aforementioned domains than in the case of people who were professionally active or unemployed (p < 0.05). The quality of life in the domains of physical functioning, role limitation in physical functioning, and limitations resulting from patients' emotional state was not related to the patients' source of income (p > 0.05) (Table 4).

There was a statistically significant connection between the period of time since the stoma was formed

and the quality of life in all domains except for limitations resulting from emotional state. Patients who had lived with a stoma for a shorter period of time reported a lower quality of life as compared to the patients who had lived with a stoma for longer (p < 0.05) (Table 5).

### DISCUSSION

A considerable increase in the incidence of bowel cancer and inflammatory bowel diseases as well as various digestive system injuries may result in the decision to form an intestinal stoma. Very frequently a stoma is created in an emergency surgery. Therefore, there is very little time to educate and prepare patients for self-care after having the stoma formed. Research conducted in this group of patients proves that their quality of life is lower [8].

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Table 4. The quality of life on SF-36 scale and respondents' source of income

Quality of life	Source of income				ANOVA Kruskal-Wallis	
	Unemployed n = 2	Disability benefit n = 54	Pension n = 32	Salary n = 12	test	
		Т	р			
Physical functioning	75.00	60.00	60.00	80.00	6.091	0.107
Role limitation in physical functioning	68.75	50.00	50.00	71.88	7.711	0.052
Pain perception	81.50	69.00	57.75	69.00	5.053	0.168
General health condition	57.00	27.50	25.00	51.00	9.044	0.029
Vitality	67.50	52.50	55.00	62.50	8.835	0.032
Social functioning	81.30	75.00	75.00	75.00	9.494	0.023
Limitations resulting from emotional state	66.67	75.00	75.00	75.00	3.61	0.307
Mental health	64.00	54.00	54.00	64.00	8.586	0.035
Physical dimension of quality of life	70.56	48.16	47.06	69.47	8.185	0.042
Mental dimension of quality of life	69.85	61.21	61.21	69.13	9.84	0.02

n – number, Me – median, T – ANOVA Kruskal-Wallis test, p – statistical significance coefficient

Table 5. Connection between the period of time since the stoma was formed and respondents' quality of life

Quality of life	r	р
Physical functioning	0.218	0.029
Role limitation in physical functioning	0.258	0.009
Pain perception	0.239	0.017
General health condition	0.234	0.019
Vitality	0.249	0.013
Social functioning	0.286	0.004
Limitations resulting from emotional state	-0.039	0.701
Mental health	0.316	0.001
Physical dimension of quality of life	0.286	0.004
Mental dimension of quality of life	0.295	0.003

 $p-statistical\ significance\ coefficient,\ r-Spearman's\ correlation\ coefficient$ 

The authors' own study shows that intestinal stoma patients' quality of life is not related to their age in a statistically significant way. In their paper Bączyk et al. evaluated the level of independence of intestinal stoma patients, and their findings led to the conclusion that, regardless of their gender, patients aged 60 years or more need more time and education to be fully prepared for self-care [9]. On the other hand, Szadowska-Szlachetka et al. proved that younger patients, aged from 20 to 50 years, learn to change stoma bags much faster, but they are more likely to expect psychological support [10]. On the other hand, the analysis of 14 cross-sectional studies on the quality of life of patients with stoma, conducted by Vonk-Klassen et al., showed that age, sex, and time since ostomy appointment were not unequivocal factors affecting their quality of life [11].

The level of education of intestinal stoma patients is significantly related to their quality of life. In the authors' own research, respondents with higher education obtained the highest scores in the domains of physical and social functioning, pain perception, vitality, and the mental dimension of quality of life. The study by Cierzniakowska et al. on professional care provided to stoma patients led to the conclusion that respondents with secondary and higher education were better prepared for self-care than patients with elementary education [12]. Also, Wiraszka and Stępień, in their study on factors that affect intestinal stoma patients' self-care abilities, proved that patients' education has an enormous impact on their quality of life. Better educated patients found it easier to acquire knowledge about the disease and further treatment [13].

Family support plays a crucial role in the process of patients' adaptation to their new situation, and thus in improving their quality of life. The authors' own research proves that patients' marital status is related to their quality of life in the domains of general health condition, physical dimension, and emotional state. In turn, the study conducted by Leyk et al. shows that lonely patients have lower motivation to accept their condition and adapt to their new situation caused by stoma formation. In was concluded that the family is an indispensable element of recovery and the main source of patients' emotional support. Unstinting family support should continue throughout the whole period of disease. Unfortunately, this support frequently tends to diminish with time. Therefore, it is vital that the family support should be tailored to individual patients' needs, because its excess or inadequate form might lead to overprotectiveness and, consequently, to family conflicts or the patient's nervous break-

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down [14]. Also, in a study conducted by Ciorogar *et al.*, patients with ostomy struggled with many difficulties associated with the disease, and the support of the family and individual members' involvement in helping with the stoma were evaluated very highly [15].

In turn, other researchers showed that an established intestinal stoma had a negative impact on the family and social relationships of the patients [16, 17].

Surveys conducted among seniors prove that one of the determinants of good quality of life of elderly people is a social factor whose component is the occurrence of social support and social network, i.e. being human among other people and its connections with them [18]. Głębocka and Szarzyńska showed a statistically significant relationship between the existence of support and satisfaction with quality of life, underlining that the main support relay was a senior partner's life partner [19].

The source of income and, consequently, patients' financial status is substantially related to their quality of life. The findings of the authors' own study show that unemployed respondents or those who lived off their disability benefit or pension reported a significantly lower quality of life than those who were professionally active.

Research conducted in Brazil by Pereira et al. showed that low income is a negative factor affecting quality of life, because it limits the patient's access to health care, and affects self-care and the social and well-being of the patient [20]. The study conducted by Andruszkiewicz et al. into intestinal stoma patients' sense of self-sufficiency also proved that financial status has a big influence on patients' quality of life. As well as the sense of economic security and financial independence, patients must have adequate resources to purchase additional stoma equipment because the national health insurance does not always cover the costs of stoma bags [21]. According to the study by Piaszczyk and Schabowski, stoma had a negative impact on the quality of life and everyday functioning, and thus it was frequently a reason for unemployment, and consequently led to a difficult economic situation and lack of social acceptance [3].

The authors' own study showed that there is a significant correlation between the period of time since the stoma was formed and all domains of the quality of life except for the limitations in patients' emotional state. Leyk *et al.*, in their analysis of the quality of life of intestinal stoma patients, came to the conclusion that the period of time during which respondents lived with a stoma was considerably related to their quality of life. The longer patients live with a stoma, the fewer disease-related problems they experience, and consequently, the higher is their quality of life [22]. In their study into intestinal stoma patients' adaptation to life, Ponczek and Rozwora examined respondents who lived with a stoma for more

than one year. These respondents were satisfied with their appearance, but they were more likely to lack knowledge as far as managing and changing stoma bags was concerned [23].

### CONCLUSIONS

Patients' quality of life is influenced by their marital status; moreover, special care should be provided to elderly patients with lower education and lower financial status.

Another group of patients who require special care are those who have had the stoma created recently, because they tend to evaluate their quality of life much lower than those who have been living with a stoma for a longer period of time.

#### Disclosure

The authors declare no conflict of interest.

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