Dominik Golicki[1], Przemysław Styczeń[2,3], Marek Szczepkowski[4,5]

QUALITY OF LIFE IN STOMA PATIENTS IN POLAND: MULTICENTRE CROSS-SECTIONAL STUDY USING WHOQOL-BREF QUESTIONNAIRE

[1] Department of Experimental and Clinical Pharmacology, Medical University of Warsaw, Poland
[2] Medical Practice, Przemysław Styczen, Konopiska, Poland
[3] Convatec Polska Sp. z o.o., Warsaw, Poland (affiliation in the course of the study)
[4] Faculty of Rehabilitation, Jozef Pilsudski University of Physical Education , Warsaw, Poland
[5] Clinical Department of General and Colorectal Surgery, Bielanski Hospital, Warsaw, Poland

ABSTRACT

INTRODUCTION. Previous studies on quality of life of patients with stoma in Poland included small groups of respondents and were based either on the non-validated questionnaires created *ad hoc*, or on the disease-specific oncologic questionnaires.
OBJECTIVES. To assess quality of life of Polish patients with a stoma using validated generic questionnaire.
MATERIAL AND METHODS. Adult patients with colostomy, ileostomy or urostomy performed in Poland between July 2009 and March 2010 were included. Patients completed satisfaction survey at the discharge from the hospital, and The World Health Organization Quality of Life-BREF (WHOQOL-BREF) generic questionnaire at 3 months after surgery.
RESULTS. The study involved 737 patients (71%, 18%, 11% with colostomy, ileostomy and urostomy, respectively). The studied population was highly diversified in terms of: dependence on medical treatment, pain and discomfort, satisfaction with health and acceptance of physical appearance.
59% of patients with a stoma defined their quality of life as very good or good (mean 3.56 points; range: 1 to 5; SD 0.74). The subjects were characterized by low quality of life assessment in the physical health and psychological domains (52.9 and 60.1 pts.) and by high evaluation in the environment and social relationships domains (69.7 and 70.1 pts.).
Respondents highly assessed: the level of social support, home environment, physical environment, personal relationships. Low assessment was related to: sexual activity, ability to work, dependence on medical treatment, financial resources, satisfaction with health.
CONCLUSIONS: Quality of life in patients with a stoma, assessed at three months after the surgery, is higher when compared to typical patients hospitalized in the internal medicine ward. Identified quality of life limitations relate in particular to sexual life.

Key words: *quality of life; stoma; WHOQOL-BREF*

INTRODUCTION

Stoma is a surgically created opening of the intestine (colostomy, ileostomy) or urinary tract (urostomy) on the front wall of the abdomen, that allows the removal of feces or urine out of the body, to drain into a pouch or other collection device (1). Its performance is usually associated with the partial removal of the small or large intestine or the urinary tract (2). Different types of stoma differs in design, functioning and the type and frequency of occurring complications (3).

Stoma performance is the health-saving or life-saving surgery most frequently performed between 5th and 7th decade of life. Although the precise data are lacking, it can be estimated that in Poland, there is about 5 to 6 thousand of such procedures carried out each year (4). The number of people living with stoma - about 35,000 in Poland and about 1 million all over the world - is constantly growing.

There are many reasons for stoma performance. In the case of intestinal stoma - colostomy and ileostomy - the most common causes include tumors of the lower gastrointestinal tract, non-specific inflammatory bowel disease, abdominal trauma, obstruction or bowel ischemia. Urostomy are usually performed in tumors of the bladder or urinary tract, congenital abnormalities of the urinary tract, and because of nephrolithiasis or uretherolithiasis (2).

The result of stoma performance is loss of faecal or urinary continence ability. As there is no sphincter, excretion of feces or urine from patient's body run in an uncontrolled manner. Stoma complications may occur immediately after surgery (early complications), or later, sometimes after a few months or even years (late complications) (3). They can be local in nature (eg. skin inflammation around the stoma) or systemic (eg. dehydration or sexual dysfunction). Stoma is usually accompanied by numerous problems, such as loud flatulence, unpleasant odor, diarrhea or constipation (5). In effect, there are negative changes of body image, reduction of self-esteem and patient's self-acceptance (5).

It is widely recognized that the performance of the stoma leads to a significant reduction in quality of life and may cause a sense of disability and exclusion from the family and society (6). Improving the quality of life should be, therefore, the primary goal for carers and medical staff involved in the care of this group of patients (7,8).

Studies on quality of life in people with a stoma were conducted in Poland since 1988 (9). Previous analyses included small groups of patients (10-15) and were based either on the use of disease-specific cancer questionnaires (12,15-17), or created *ad-hoc* non-validated questionnaires (11,14). Generic (non-specific) quality of life questionnaires enable a comprehensive, objective assessment and allow comparisons of populations with different health problems (18).

The objective of our study was to assess quality of life in a broad population of patients with a stoma in Poland, using validated and widely accepted generic questionnaire.

MATERIAL AND METHODS

We included patients, aged 18 years or more, with colostomy, ileostomy or urostomy performed in Poland between 1 July 2009 and 31 March 2010. Additional eligibility criterion was the use of ConvaTec ostomy equipment (Combihesive 2S, Esteem, Stomadress, or Esteem synergy). There were no restrictions due to the nature of the primary disease, which was the indication for stoma. Patients had to give written consent to participate in the study.

Interviews were conducted by the stoma nurses who went 4-hour training in elementary methods of quality of life measurement, led by one of the authors (D.G.). The study consisted of two phases: patient satisfaction survey and quality of life measurement using the The World Health Organization Quality of Life-BREF (WHOQOL-BREF) questionnaire.

Patient satisfaction survey was completed by the stoma nurse in short interview with the patients after stoma surgery, in the period immediately preceding discharge from the hospital. The questionnaire included items on: the degree of autonomy of the patient, determination of the place of stoma performance before surgery, stoma complications, supply of ostomy equipment, the type of equipment used, the degree of satisfaction with the use of equipment and ostomy accessories.

About 3 months after surgery, stoma nurses carried out the measurement of the overall quality of life using a validated Polish version of generic questionnaire - WHOQOL-BREF (19). The direct or phone interview was carried out. WHOQOL-BREF is an abbreviated version of the WHOQOL-100 questionnaire. It consists of 26 questions (20). The results of quality of life measurement are presented with the use of 6 parameters: 1. overall assessment of the quality of life of the patient (in the five-point scale from "very poor" to "very good", question 1 of the questionnaire), 2. overall assessment of patient satisfaction with health status (five-point scale from "very dissatisfied" to "very satisfied", question 2), 3. Physical health domain (estimated on the basis of questions: 3, 4, 10, 15, 16, 17, 18), 4. Psychological domain (questions: 5, 6, 7, 11, 19, 26), 5. Social Relationships domain (questions 20, 21, 22), 6. Environment domain (questions 8, 9, 12, 13, 14, 23, 24, 25) (21).

According to the authors of the questionnaire results of each domain can be presented in two different ways: in the range from 4 to 20, to allow comparisons with the results of the full version of the WHOQOL (WHOQOL-100) or in the range from 0 to 100, to allow comparisons with the results of majority of other quality of life questionnaires (in the present study, the second approach was used).

Calculation of the result of the questionnaire requires the presence of responses for at least 21 questions. Calculation of the result for each domain requires the availability of responses for at least 6 out of 7, 5 of 6, 2 of 3 and 6 of the 8 questions for physical, psychological, social and environment domain, respectively.

For continuous variables, means, standard deviations and coefficients of variation (division of the arithmetic mean and standard deviation) were calculated. The statistical significance of the difference of response between groups were calculated using Student's t-test. Additional calculations were performed using the program StatsDirect ver. 2.7.8 (StatsDirect Ltd, England).

RESULTS

Population. Of all patients registered in the ConvaTec database between August 2009 and March 2010, 752 subjects met the basic eligibility criteria and completed the WHOQOL-BREF questionnaire. We excluded 15 patients from the final analysis: including 7 because they did not reply to a sufficient number of questions (according to the WHO the maximum number of missing questions should not exceed 20%), 2 - due to the lack of response to at least 6 questions of the physical health domain, and 6 - due to the lack of response to at least 5 questions of psychological domain.

Finally, 737 patients, aged from 17 to 93 years, were enrolled into the quality of life study (table I). In terms of the type of ostomy, colostomy patients were strongly represented (70.7%). There was a predominance of men: small in patients with colostomy or ileostomy (54%) and higher in patients with urostomy (73%). Most patients came from the provinces of Dolny Slask (15.3%), Mazowieckie (12.9%) and Wielkopolska (10.4%), the least from Opolskie (2.2%) and Swietokrzyskie (2.4%). Patients who responded to WHOQOL-BREF questionnaire were representative of all patients registered in the ConvaTec database in terms of age, sex and type of stoma.

Table I. Characteristics of the study population (information collected at the time of patient discharge from the hospital).

N	737
Age, mean (SD)	64.5 (13.4)
Female, n (%)	326 (44.2)
With determined place of performance of the stoma before surgery, n (%)	282 (38.2)
Type of stoma, n (%)	
colostomy	521 (70.7)
ileostomy	133 (18.0)
urostomy	82 (11.1)
Type of equipment, n (%)	
two-piece (Combihesive 2S)	261 (36.1)
one-piece (Esteem or Stomadress Plus)	387 (53.5)
synergistic (Esteem synergy)	75 (10.4)
Stoma complications, n (%)	
dermatitis	61 (8.3)
other	36 (4.9)
The patient requires assistance with ostomy care, n (%)	325 (44.1)

N – number; SD – standard deviation

Quality of Life according to WHOQOL-BREF domains. The majority of patients with stoma assessed their quality of life as good or very good (59%), or neither good nor bad (34%). Average rating in total studied population was 3.56 (SD 0.74) points. The degree of stoma patient satisfaction with their own health was diverse - 27% of patients were dissatisfied or very dissatisfied, while 40% satisfied or very satisfied. Average rating was 3.14 (SD 0.91) points. Patients with a stoma were characterized by a low quality of life assessment in the physical health domain (average 52.9 pts.) and psychological domain (60.1 pts.) High evaluations were noted for the environment and social relationships domains (69.7 and 70.1 pts., respectively; table II) .

Table II. Quality of life in patients with stoma according to different domains of the WHOQOL-BREF questionnaire.

Domain	Number	Mean (SD)	Observed range
Question 1: Overall QOL*	737	3.56 (0.74)	1 - 5
Question 2: Satisfaction with health*	736	3.14 (0.91)	1 - 5
Physical health**	735	52.9 (11.1)	11 - 89
Psychological**	731	60.1 (13.0)	17 - 92
Social relationships**	737	70.1 (16.1)	17 - 100
Environment**	737	69.7 (13.1)	13 - 100

n – number; QOL – quality of life; SD – standard deviation; * range of possible answers: 1 to 5; ** range of possible answers: 0 to 100.

Quality of life according to individual questions of the WHOQOL-BREF questionnaire. Table III includes the characteristics of answers of stoma patients to particular questions of WHOQOL-BREF questionnaire (in the order of presentation in the questionnaire).

Patients with stoma highly evaluated: the level of social support, home environment, physical environment, including pollution, noise, traffic, climate, personal relationships, accessibility and quality of health and social care and access to information. At the same time, patients low assessed: their sexual activity, ability to work, dependence on medical treatment, financial resources, satisfaction with health, participation in and opportunities for recreation and leisure activities.

The study population of patients with a stoma was highly diversified in terms of: sexual activity (coefficient of variation 0.37), dependence on medical treatment (0.36), work capacity (0.34) and participation and opportunities for recreation/leisure activities (0.33). At the same time the studied population was relatively homogeneous in terms of: home environment (0.17), social support (0.17) and personal relationships (0.18).

Comparison of patients with stoma and patients hospitalized in the internal medicine ward. The studied population of patients with a stoma was compared with a population hospitalized in the internal medicine ward from the study of *Pasek* et al. (2005) in terms of responses to the individual questions of WHOQOL-BREF questionnaire. The study by Pasek et al has been chosen as this is the only indentified publication concerning use of WHOQOL-BREF in Poland with data on answers for individual questionnaire questions (33).

Table III. Comparison of quality of life of patients with a stoma and patients hospitalized in the internal medicine ward: Answers to the questions of the WHOQOL-BREF questionnaire (range of possible answers: 1 to 5).

Number of item	Item	Stoma patients, mean (SD), n=737	Hospitalized on internal deseases department (Pasek 2005 study), mean (standard deviation), n=105	Difference of means	P-value (t-student test)	Domain
1	Overall quality of life	3.56 (0.74)	3.34 (0.77)	0.22	<0.01	not adequate
2	Satisfaction with health	3.14 (0.91)	2.73 (0.82)	0.41	<0.001	not adequate
3	Pain and discomfort	3.42 (1.11)	3.36 (0.93)	0.06	n.s.	Physical health
4	Dependence on medical treatment	3.07 (1.12)	3.07 (0.96)	0	n.s.	Physical health
5	Positive feelings	3.32 (0.88)	2.72 (0.91)	0.6	<0.0001	Psychological
6	Spirituality / Religion / Personal beliefs	3.82 (0.92)	2.85 (0.95)	0.97	<0.0001	Psychological
7	Thinking, learning, memory and concetration	3.80 (0.86)	2.57 (0.74)	1.23	<0.0001	Psychological
8	Freedom, physical safety and security	3.91 (0.81)	2.90 (0.70)	1.01	<0.0001	Environment
9	Physical environment (pollution, noise, traffic, climate)	4.18 (0.78)	2.85 (0.95)	1.33	<0.0001	Environment
10	Energy and fatigue	3.42 (0.95)	2.80 (1.02)	0.62	<0.0001	Physical health
11	Bodily image and appearance	3.60 (1.08)	3.39 (0.96)	0.21	0.06	Psychological
12	Financial resources	3.13 (0.99)	2.81 (0.89)	0.32	<0.01	Environment
13	Opportunities for acquiring new information and skills	3.92 (0.89)	3.10 (0.82)	0.82	<0.0001	Environment
14	Participation in and opportunities for recreation / leisure activities	3.17 (1.04)	2.53 (0.96)	0.64	<0.0001	Environment
15	Mobility	3.27 (0.87)	3.50 (1.07)	-0.23	<0.05	Physical health
16	Sleep and rest	3.42 (0.95)	3.08 (0.99)	0.34	<0.001	Physical health
17	Acitvities of daily living	3.27 (0.87)	2.99 (0.84)	0.28	<0.01	Physical health
18	Work capactiy	2.92 (0.99)	2.82 (0.91)	0.1	n.s.	Physical health
19	Self-esteem	3.55 (0.91)	3.42 (0.63)	0.13	0.07	Psychological
20	Personal relationships	4.07 (0.74)	3.65 (0.80)	0.42	<0.0001	Social relationships
21	Sexual activity	2.82 (1.03)	3.21 (0.91)	-0.39	<0.001	Social relationships
22	Social support	4.29 (0.75)	3.85 (0.81)	0.44	<0.0001	Social relationships
23	Home environment	4.21 (0.72)	3.84 (0.56)	0.37	<0.0001	Environment
24	Health and social care: accessibility and quality	3.94 (0.82)	3.26 (0.85)	0.68	<0.0001	Environment
25	Transport	3.82 (0.80)	3.31 (0.95)	0.51	<0.0001	Environment
26	Negative feelings	3.67 (0.82)	3.17 (0.75)	0.50	<0.0001	Psychological

n.a. – not adequate; QOL – quality of life; SD – standard deviation

Table IV. Satisfaction of patients with stoma equipment used.

Parameter	Number	Level of satisfaction				
		1 (Unsatisfied)	2	3	4	5 (Very satisfied)
Adhesion to the skin, n (%)	711	5 (0.7)	2 (0.3)	33 (4.6)	168 (23.6)	503 (70.7)
Ease of use, n (%)	708	12 (1.7)	8 (1.1)	42 (5.9)	232 (32.8)	414 (58.5)
Persistence length, n (%)	710	10 (1.4)	10 (1.4)	71 (10.0)	203 (28.6)	416 (58.6)
Sense of security, n (%)	708	6 (0.8)	6 (0.8)	57 (8.1)	229 (32.3)	410 (57.9)
Tightness, n (%)	708	2 (0.3)	2 (0.3)	37 (5.2)	180 (25.4)	487 (68.8)
Discretion, n (%)	705	5 (0.7)	2 (0.3)	38 (5.4)	213 (30.2)	447 (63.4)

N - number

Patients with a stoma, compared to patients hospitalized in the internal medicine ward, had significantly better results for 19 of 26 WHOQOL-BREF questionnaire questions. More positively evaluated: the impact of the physical environment on health (by 1.33 pts.), thinking, learning, memory and concentration (by 1.23 pts.), freedom, physical safety and security (by 1.01 pts.), spirituality / religion / personal beliefs (by 0.97 pts.), opportunities for acquiring new information and skills (by 0.82 pts.), satisfaction with health care (by 0.68 pts.). At the same time, patients with a stoma compared to patients hospitalized in the internal medicine ward, evaluated significantly more negatively: their sexual activity (by 0.39 pts.) and mobility (by 0.23 pts.).

Satisfaction with ostomy equipment used. Patients who took part in the study of quality of life were mostly very satisfied with stoma equipment used, especially in context of: adhesion to the skin (71%), tightness (69%), discretion (63%), persistence length (59%), ease of use (59%) and a sense of security (58%, table IV). The percentage of individuals who were dissatisfied with the equipment used was low (from 0.3 to 1.7%).

DISCUSSION

Our study has shown that Polish patients with a stoma evaluate poorly their physical functioning, slightly better – mental functioning, and quite highly assess social relationships and environment conditions. Well perceived areas are: the level of social support, accessibility and quality of health care. The most problematic areas are intimate life, and reduced capacity to work.

One of strengths of our study is relatively large surveyed population (737 respondents). We estimate that this group forms about 15% of the whole population who underwent stoma performance in Poland between July 2009 and March 2010. Up till now, a substantial number of quality of life studies on stoma patients has been performed in Poland, but these were usually one-centre (11,13,17) or two-centre studies (10,14), based on limited groups of patients. The population of our study is greater than the summarized population of other eight identified studies (n=596).

Previous analyses of individuals with stoma in Poland characterized by the use of disease specific questionnaires for cancer patients such as FACT-C (16,17), FACT-G (12) and the EORTC QLQ C-30 (15). Few studies were based on created *ad hoc* and non-validated questionnaires (11,14). The second strength of our study is the use of validated and highly recognized instrument. WHOQOL-BREF questionnaire has been used in over 20 studies in Poland, but never before in a group of patients with a stoma. By using a generic questionnaire, we were able to compare quality of life of patients with a stoma with quality of life in a group of typical medical patients (hospitalized in the department of internal medicine, *Pasek* et al) (22). Contrary to expectations, stoma patients characterized by better quality of life in the majority of examined dimensions, with the exception of sexual life and mobility. The issue of limitation of the intimate life of individuals with a stoma was already noticed by other Polish authors (13,17). *Wojewoda* et al pointed out the surgery complications, the loss of physical attractiveness and a feeling of shame, as the most common reasons for avoiding sexual activity in this group of patients (13). Among other limitations of the quality of life, other authors drew attention to: the occurrence of depression and sleep disorders, feeling of inferiority, uncertainty about the future, difficulty in talking about the disease in the family circle and sadness (13,17).

There are several other limitations of our study. First, due to organizational reasons - inability to extend the survey time, we were not able to apply specific questionnaire at the same time. Simultaneous use of a generic and a specific questionnaire is the gold standard in the quality of life studies (23). Second, we lack information on underlying disease, which has led to the performance of stoma and on concomitant diseases, which may also have an impact on the quality of life perception. Third, although our results bring a new light to the current state of knowledge about the stoma patients in Poland, the ability to compare the results with other authors is partially limited, because of the use of a different measurement tool.

Through years, a unique model of care for people with a stoma, based on access to specialized medical staff, both while in the hospital (doctors, stoma nurses, psychologists) and after the discharge (stoma clinics, specialized medical supplies stores, free information telephone lines), has been developed in Poland (7). Important role play scientific organizations engaged in improving the quality of life of people with a stoma – Polskie Towarzystwo Stomijne (POL-ILKO), Polski Klub Koloproktologii (PKK) and Polskie Towarzystwo Pielęgniarek Stomijnych (PTPS). The current model of care is positively perceived by the patients who well or very well assess accessibility and quality of health care, opportunities for acquiring new information and skills and level of social support. In the future, clinicians should pay more attention to the possibility of supporting patients in restoring a satisfying intimate life and the ability to return to work. Each scheduled stoma surgery should be preceded by the determination of the optimal localization of the stoma on the skin of the abdomen in different patient positions (standing, sitting, squatting and kneeling) (7).

Further research on the quality of life in Polish patients with a stoma should be focused on a deeper

understanding of the specific stoma problems. For this purpose, it is necessary to use population specific questionnaires designed for this group of patients, for example Stoma Quality of Life Index (SQL) (24). However, such studies must be preceded by a translation, Polish cultural adaptation and psychometric validation of the questionnaire (25).

CONCLUSIONS

Quality of life in patients with a stoma, assessed at three months after the surgery, is higher when compared to typical patients hospitalized in the internal medicine ward. Identified limitations relate in particular to sexual life.

Acknowledgments: The authors would like to thank all the nurses involved in the collection of data on the quality of life in patients with stoma. The study was funded by ConvaTec Polska Sp. z o.o.

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Received: 6.03.2013
Accepted for publication: 5.07.2013

Address for correspondence:
Dominik Golicki
Department of Experimental and Clinical Pharmacology
Medical University of Warsaw
Krakowskie Przedmiescie 26/28 st.
00-927 Warsaw, Poland
Phone: +48 22 826 21 16
e-mail: dominik.golicki@gmail.com