

Acceptance of disease and the quality of life in patients with enteric stoma

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ABSTRACT:

Introduction. The main reason of the emergence of enteric stoma is colorectal cancer. Enteric stoma is a serious health, as well as life problem. In Poland, there are about 6,000 stoma surgeries yearly. It changes the functioning of patients, restricts their daily activity and influences their quality of life significantly. Therefore, in the modern treatment process, all spheres of human life and its surroundings are considered. The evaluation of the quality of life and the level of acceptance of the disease enables us to identify the regions in which patients require attention and help, as well as places to which health promotion among patients with a stoma should be directed.

The aim of the study was the evaluation of the acceptance of the disease and the quality of life in patients with colostomy.

Material and methods. The study conducted between February 2015 and February 2016 included 101 patients with enteric stoma of the Provincial Specialist Hospital in Wrocław at Kamieńskiego St. in the departments of General Surgery with the Subdivision of Traumatology and Orthopedic Surgery, Subdivision of Metabolic Surgery, Subdivision of Endocrine Surgery and Oncological Surgery. Two anonymous questionnaires, i.e., health-related quality of life (HRQoL) and acceptance of illness scale (AIS), were used. 60% (61 people) were women, and 40% (40 people) were men. The mean age was 48; the youngest respondent was 20 years old, and the oldest was 79 years old. 17% of the respondents had primary education, 25% - vocational, 33% - secondary and 26% - university-level.

Results. The most common reason for the emergence of a stoma among the respondents was colon cancer (44%), followed by: mechanical bowel obstruction (26%), intestinal damage following injuries (25%), inflammatory bowel disease (6%). The quality of life of patients with colostomy was evaluated in view of their health condition, postoperative recovery, everyday limitations, and self-evaluation. The majority of participants pointed to the deterioration of their quality of life. A higher level of acceptance of the disease was revealed in men as 75% of men, and 61% of women accepted their health status. The education level also influences the acceptance of the disease, as 41% participants with higher education, and only 6% participants with primary education did not accept their health status. We revealed some social factors influencing the quality of life and the acceptance of the disease, i.e., gender, age, education, job, and place of living.

Conclusions. Gender and education have an impact on the level of the acceptance of the disease, but they do not influence the quality of life. The acceptance of the disease is connected with the quality of life in patients with a stoma. The higher the level of acceptance of the disease, the better the quality of life. Research indicates the need to deepen patients' education regarding their functioning in society.

KEYWORDS:

stoma, quality of life; acceptance of disease

INTRODUCTION

The development of medical science has made it possible to treat diseases that were previously incurable. The most common reason for the appearance of an intestinal stoma is colorectal cancer. In many countries, including Poland, colorectal cancer is the most frequently occurring malignant neoplasm of the gastrointestinal tract and occurs mostly in the 6th and 7th decades of life. As a result of the stoma, there is a reduction or loss of the ability to store the contents of the digestive tract, as well as loss of control over excretion [1]. One's own life situation, self-esteem, self-acceptance, as well as the image of one's own body change, therefore, the assessment of only clinical symptoms and physical ailments are insufficient in effective therapy. Modern medicine approaches humans in a holistic way, uses elements of psychology, sociology and philosophy. It treats man as a whole, as a bio-psycho-social unity. The process of treatment considers all spheres of human life and his surroundings. A holistic approach speaks of illness as a change in certain conditions of everyday existence, to which a person should attempt to adapt. This can be achieved with the support

of family, friends, as well as medical staff. Chronic diseases can change the perception of the world, re-evaluate the lives of most people, change their priorities. Everyone reacts differently to the fact of illness: some people accept this condition, others do not agree with this situation. People who are able to accept the disease are more likely to undertake a fight for recovery, which causes them to experience less negative emotions. Therefore, from a psychological point of view, acceptance of a disease is an important aspect of therapy. It is treated as one of the most important determinants of adaptation to a difficult situation in life. The patient's education consists in teaching him self-care of the stoma and maintaining family, professional and social activity [2]. The nurse educates the patient in terms of taking care of the fistula, using the ostomy equipment, preventing flatulence through the use of an appropriate diet, a new lifestyle, and informs about groups of support and refund of ostomy equipment [3]. The immediate family of the patient should be included in the education process. The aim of education is to provide knowledge to the patient at such a level that the patient will gain independence and will be able to provide proper care in home conditions [4]. Therefore, both the

sick and his family should be covered by holistic care, which takes into account psychosocial aspects resulting from the fact that the stoma has emerged.

AIM OF THE PAPER

The aim of the study was to determine the degree of acceptance of the disease and to study the relationship between the sense of quality of life and acceptance of the disease among patients with a stoma.

MATERIAL AND METHODS

The study was conducted among patients with a stoma in the Provincial Specialist Hospital in Wrocław in the period from February 2015 to February 2016. Two questionnaires were used for the purpose of the study: the Acceptance of Illness Scale (AIS) and the health-related quality of life (HRQOL) questionnaire, which were anonymous, and the condition for conducting the study was voluntary patient consent [5,6,7,8].

The Acceptance of Illness Scale (AIS) allows to assess the patient's acceptance of the disease. The higher the degree of acceptance of the disease, the lower the severity of negative reactions and emotions associated with the disease and therapy. The scale contains 8 statements describing negative health consequences. Each statement contains a five-grade scale, and the patient determines his current state of health by indicating the appropriate number: 1 — I definitely agree, 2 — I agree, 3 — I do not know, 4 — I do not agree, 5 — I definitely disagree. Marking answer number 1 meant poor adaptation to the disease, while answer number 5 meant full acceptance of the disease. The sum of all points ranges from 8 to 40 and is a measure of acceptance of the disease. All persons, depending on the number of points obtained, were divided into three groups. Group 1 - lack of acceptance of the disease - brings together people who received from 8 to 18 points; group 2 - average level of acceptance of the disease - includes people who obtained from 19 to 29 points, and group 3 - acceptance of the disease at a good level - those who obtained from 30 to 40 points.

The survey to assess the quality of life of people with a stoma (HRQOL) contains 25 questions. The questions concerned personal data: gender, age, education, nature of work, residence and reasons for the emergence of a stoma and preparation for stoma self-care, the possibility of contact with professional health care staff, assessment of health after surgery, restrictions on personal contacts, performing daily activities, professional work, hobbies, external appearance, relationships of family and friends, social contacts. They also concerned economic conditions, the occurrence of anxiety, rest and entertainment after surgery and acceptance of the stoma.

The answers gave the opportunity to assess the quality of life of people affected by a stoma. The results of the measurements, which were obtained by qualitative data, were divided according to the ordinal scale. Data was divided into categories with a specific growth direction from a to e, from the worst to the best result. Each response regarding the condition of a person with a stoma was assigned a point value from 1 to 5. Each respondent could obtain from 15 to 75 points. All persons, depending on the num-

ber of points obtained, were divided into three groups. Group 1 - poor quality of life - those who scored less than 30 points; group 2 - good quality of life - includes people who received from 30 to 50 points; group 3 - very good quality of life - brings together people who obtained more than 50 points. The analysis of the quality of life of persons with a stoma included gender, age, education, type of work performed, place of residence, reasons for choosing an ostomy, preparation for self-care, the possibility of contact with health care personnel and assessment of health [9,10].

The questionnaire survey included 101 people with a stoma (61 women, 50 men). The average age of the subjects was 48 years. The youngest respondent was 20 years old, the oldest was 79 years of age. The group was diverse due to education: 17% of people declared primary education, 25% vocational, 33% average and almost 26% - higher. Physical work was carried out by 41% of the respondents, 24% performed mental work, the remaining received retirement pension (28%) or disability pension (8%). Due to the place of residence, the percentage of respondents was as follows: the village - 31%, the city below 50 thousand inhabitants - 15%, the city with the population from 50 to 100 thousand - 26%, the city with the population above 100 thousand - 29%. There were 37% of respondents living alone, people living with their spouse - 20%, living with their spouse and children - 30%, and with children and grandchildren - 14%. The most common reason for identifying the stoma in respondents was colon cancer (44%), followed by: mechanical bowel obstruction (26%), intestinal damage due to injuries (25%), inflammatory bowel disease (6%). The respondents stressed that their contact with health care workers was not the best. 41% of people indicated difficult contact, 55% of respondents indicated easy contact. There were also different statements regarding self-education: the highest number of respondents said that they received information in the hospital after surgery (52%), subsequent answers were: in a regional health center (24%), a specialist clinic (14%) and 10% said they sought information on their own.

RESULTS

Acceptance of Illness Scale (AIS)

The acceptance of illness scale was based on a standardized AIS questionnaire, which consisted of eight statements. Respondents were asked to provide information on how much they agree with the statement. The answers to the statement „I have trouble adjusting to the constraints imposed by the disease” were very diverse. Affirmative answers amounted to 44.49% and negative to only 22.77%. As many as 32.77% of respondents indicated the answer „it is difficult to say.” Over half of the respondents stated that because of their health, they were not able to do what they liked the most (56.43%). The opposite opinion was provided by a total of 24.75% of the respondents (18.81% - „I disagree”, 5.94% - „I strongly disagree”). The remaining 18.81% indicated the answer „it is difficult to say.” Most of the respondents agreed with the statement that the disease sometimes made them feel unnecessary. This opinion was expressed by a total of 50.49% of respondents, of which 18.81% indicated the answer „I definitely agree” and 31.68% - „I agree”. The opposite view was given by 29.70% of the respondents, including 4.95% who indicated „I definitely disagree” and 24.75% answered „I do not agree.” The answer „it is difficult to say” was indicated by 19.80% of respondents. Among the respondents, the most frequ-

ent opinions were that they felt more dependent on others due to their health problems: 23.8% of respondents indicated the answer „I definitely agree” and 17.8% - „I agree.” 39.6% of respondents indicated that there was no sense of dependence on others, out of which 35.6% of respondents indicated the answer „I do not agree.” 18.8% of respondents answered „it is difficult to say.” The majority of respondents agreed with the statement that the disease made them a burden to their family and friends: 39.60% of the respondents indicated an affirmative answer, as much as 33.66% were not sure and gave the answer „it is difficult to say,” and 26.73% categorically denied this statement. The disease affects the perception of oneself as a defective human being in the majority of respondents. 53.44% of respondents agreed with this statement, of which 22.77% indicated the answer „I definitely agree” and 30.69% - „I agree.” Only 19.80% of respondents thought that despite the disease, they still felt like valuable people. The respondents’ answers to the question about their faith in the return to self-sufficiency were varied. The largest group were people who agreed with the statement „I will never be self-sufficient to the extent that I would like to be”: 24.75% of respondents indicated the answer „I agree,” and 18.81% - „I definitely agree.” A total of 33.66% of the respondents indicated a negative answer: 30.69% - to the answer „I do not agree” and 2.97% - „I definitely disagree.” 22.77% of respondents answered that it was „difficult to say.” Most of the respondents felt that people staying with them were often embarrassed because of their illness. The largest part of the respondents (49.50%) indicated the affirmative answers: „I definitely agree” - 19.80%, and 29.70% „I agree.” 21.78% of respondents indicated negative answers, including 17.82% indicating the answer „I do not agree.”

Analysis of the health-related quality of life survey (HRQOL)

Another element of the study was the analysis of quality of life based on the HRQOL questionnaire. The subjects were asked to assess their health condition after the operation. The questions included in the questionnaire were divided into four groups: health condition and the method of rest after the operation, difficulties occurring after the operation, occurrence of limitations in everyday life after the operation, self-assessment of the observed changes in the appearance and the environment after surgery. Most of the respondents indicated deterioration of their health after surgery - as many as 57 people. 19.80% of respondents thought that their health had improved, and 23.76% of respondents had not noticed a clear change. People spoke similarly about the manner of resting after surgery. The frequent occurrence of physical pain after surgery was indicated by over 23% of respondents, and 52.47% experienced it sporadically. The distribution of statements about the difficulties in personal contacts and the fear of the future was similar. Only two persons responded negatively to the question about the occurrence of pain and difficulties in everyday contacts, and four to the question about the fear for the future. The respondents indicated that after the surgery, they did not enjoy any types of entertainment or did it very rarely and exceptionally - as much as 75.24%. After the procedure, the majority of subjects examined experienced limitations in their daily activities (56.43%) and in their professional work (55.44%). 21.78% of people stated that they performed everyday activities better and 12.87% that they did not feel any restrictions on their professional work. 54.45% of people indicated similar or better interest in sex and 25.74% - much worse. 18.81% of people noticed an improved appearance, 56.4% worse. 24.75% did not notice any change.

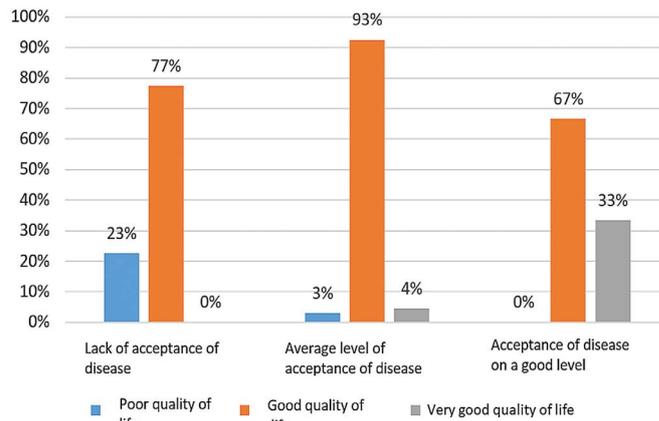


Fig. 1. Level of acceptance of disease and the quality of life after the emergence of a stoma

Nearly 41% of respondents indicated a deterioration in relations with relatives, and 19.80% experienced improvement in this field. Statements regarding friendships and social contacts are similar: their improvement was indicated by 19.80% and 16.83%, and deterioration by 46.53% and 48.5% respectively. Other people stated that no changes had occurred. Economic conditions worsened in more than 58% of people, others assessed them as unchanged (27.72%) or better (13.86%).

Acceptance of the disease, taking into account the gender of the respondents

Among the surveyed women, as many as 61% obtained an average level of acceptance of the disease. 5% of the respondents obtained acceptance of the disease at a good level. 34% of the women surveyed obtained a result indicating the lack of acceptance of the disease. Among male respondents, no one was able to accept the disease at a good level. The lack of acceptance of the disease was obtained by 25% of respondents, while as many as 75% of the men surveyed felt acceptance of the disease at a medium level. Men were a more compact group than women - the obtained scores were between 12 and 29 and women between 8 and 32. The median value indicates that half of men scored no less than 22 points, for women this value is 20. Statistical significance level $P = 0.037$. As seen, men are statistically significantly different from women in terms of health practices, and the Acceptance of Illness Scale showed that their score in this area is better.

The quality of life in respondents following ostomy taking into account gender

In the quality of life survey, 84% of female respondents obtained a good quality of life result, 11% obtained a poor quality of life, and 5% of women obtained a result of a very good quality of life. In the study of the quality of life, in males, as many as 92% of the respondents obtained a good quality of life result, 5% obtained a poor quality of life, and only 3% of men obtained a result of a very good quality of life. In the area of quality of life after performing an ostomy measured with the HRQOL quality questionnaire, it cannot be concluded that there are statistically significant differences depending on the sex ($p = 0.063$). Men, just as in the acceptance of illness survey, were a more homogeneous group than women. The difference between the highest and the lowest value obtained in men was 28 points, and in women 39. The median values are close.

Acceptance of the disease taking into account the education of the respondents

When analyzing the degree of acceptance of illness with regards to education, it can be observed that people with primary education have the best acceptance of the disease (as much as 81%). Along with the increase in education, the lack of acceptance of the disease increases. Among people with primary education, the lack of acceptance of the disease occurred in 6%, with vocational education in 27%, with secondary education in 35% and as much as 41% among people with higher education. Only 13% of people with basic education and 3% of people with higher education indicated good acceptance.

The minimum number of points scored when assessing the acceptance of the disease is characterized by people with higher education (8 points), People declaring basic education indicated a much better level of acceptance of their illness (the minimum number of points scored is 18). The maximum score is not so different. The value of $P = 0.035$ indicates that there are statistically significant differences between education and the degree of acceptance of the disease, so it can be concluded that education affects the degree of acceptance of the disease.

Quality of life of respondents following ostomy taking into account education

22% of respondents with primary education indicated a very good quality of life, only 4% of people with secondary education indicated this answer, people with higher education - 3%, while with vocational education - 0%. A good quality of life in the group with secondary education was indicated by 94% of people with higher education, 88% of people with higher education, 81% with vocational education and 78% of people with primary education. The biggest number of people with a poor quality of life occurred in the group with vocational education - 15%, then 9% with higher education, 6% with secondary education. Nobody pointed to the poor quality of life in the group of people with primary education. As many as half of people with primary education obtained not less than 41 points as a result of the quality of life survey. The median values for people from other education groups are lower: vocational -36; medium - 39; higher - 38. The value of $P = 0.059$, however, does not allow to conclude that there are statistically significant differences in the quality of life after the emergence of a stoma depending on education.

Relations between the level of disease acceptance and the quality of life after the emergence of a stoma

Of the group of respondents who do not accept the disease, a poor quality of life was indicated by 23%. A quality of life at a good level

in this group of people was marked by 77%. Nobody in this group has a very good quality of life. Among the group of respondents, whose acceptance of the disease is on the average level, up to 93% of people have a good quality of life. 3% answered that they had a poor quality of life, and 4% that they had a very good quality of life. From the group of respondents who accepted the disease at a good level, 67% pointed out that their quality of life was good. 33% answered that they had a very good quality of life. Nobody marked that their quality of life was bad. There exist statistically significant differences regarding the impact of disease acceptance on quality of life after the emergence of a stoma (Fig. 1). The results of quality of life in the absence of acceptance of the disease were in the range from 16 to 46, and the average was 35.81 points. The results obtained when the acceptance was on an average level were higher and ranged from 27 to 53, the average was 39.30. The quality of life results at a good level of acceptance were even higher - their range was 38-50, and the average was 43. These differences were statistically significant. It can therefore be said that the higher the degree of acceptance of the disease, the better the quality of life of people after the emergence of a stoma.

CONCLUSIONS

1. The majority of respondents (66.33%) accept their illness on an average level, obtaining from 19 to 29 points on the AIS scale. Lack of acceptance of the disease affects women more often (M - 10, F - 21).
2. The respondents assess their quality of life rather well (87.12%). Only 11% of women and 5% of men indicated a poor quality of life.
3. Gender affects the degree of acceptance of the disease. Men have a better degree of acceptance of the disease (75.00%) than women (60.65%) and education - along with the increase in education, the degree of acceptance of the disease decreases. The mentioned features do not differentiate the quality of life of patients.
4. The acceptance of the disease is closely related to the quality of life of stoma patients. The higher the degree of acceptance of the disease, the better the quality of life of patients.
5. The conducted research clearly indicates that in patient care, it is necessary to ensure that patients are able to accept their illness to a greater extent than they do today.
6. The level of educating patients in health care institutions should be definitely increased, so that despite the impediments in their daily functioning, they do not give up on active life, work and entertainment and can adapt them to their abilities.

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