

ORIGINAL PAPERS

QUALITY OF LIFE OF PATIENTS ON CHRONIC PARENTERAL NUTRITION BEFORE AND AFTER GASTROINTESTINAL TRACT CONTINUITY RESTORATION

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The issue of the quality of life considering patients with a temporary or permanent intestinal stoma, as well as the necessity for chronic parenteral nutrition at home remain a poorly understood problem. Daily care of the intestinal stoma and the need to comply with sterile procedures required for parenteral nutrition require such patients to commit their time, which secondarily is associated with the broad aspects of social and personal life.

The aim of the study was to analyse the quality of life considering patients with intestinal stomas subjected to chronic parenteral nutrition, before and after gastrointestinal tract continuity restoration.

Material and methods. The survey was conducted between May and July, 2014 on a group of 71 patients (33 female and 38 male) who were under the care of the Department of General Surgery and Clinical Nutrition, Warsaw Medical University, operated during the period between 2007 and July, 2014 with a present stoma (32 patients – 45%), as well as after stoma closure (39 patients – 55%). The analysed questionnaire contained 31 questions, and the SF-36 questionnaire was additionally used, determining the quality of life.

Results. Analysis of the study material showed differences in the quality of life, considering three most important determinants. Significantly worse assessment of the quality of life was reported by patients with a stoma and subject to intravenous nutrition (83.2 ± 30.5), as compared to those after stoma closure subject to normal nutrition (52.3 ± 33.8). Based on the SF-36 questionnaire differences between patients with a stoma and those without amounted to $t(69) = 2.84$ ($p = 0.006$) demonstrating that those with a stoma reported a lower quality of life. Analysis between younger and older patients, based on the SF-36 questionnaire ($t(62.87) = 2.49$; $p = 0.016$) showed that younger patients achieved lower results, considering dissatisfaction with life (61.55 ± 27.5), as compared to the elderly (80.8 ± 36.9).

Conclusions. The group of patients without a stoma seem to be more independent- the vast majority do not use the help of family members (43.6%), or friends (64.1%). Patients with a stoma more often withdraw from social life. The factor that mostly reduces the quality of life is the presence of a stoma, which impairs daily functioning a lot more than the sterile procedures associated with parenteral nutrition. All patients after stoma closure consider that their overall functioning has significantly improved.

Key words: quality of life, parenteral nutrition, stoma

The term “quality of life” taken from social sciences to the medical field resulted in extensive investigations, which enable to analyse

the influence of the disease and ensuing therapy on the physical, mental, and social functioning of the patient. Analysis of indi-

vidual quality of life parameters allows to determine important issues, from the psychosocial point of view, considering patients subjected to treatment (1, 2). Quality of life issues can also be applied to patients in whom gastrointestinal tract continuity rupture was observed with exteriorization of a temporary or permanent intestinal stoma and the need for parenteral nutrition at home. Daily care of the stoma and the need to comply with sterile procedures required for the effective and lacking complications parenteral nutrition leads to significant quality of life changes (3). Lack of literature data concerning the quality of life of patients with a stoma and subject to parenteral nutrition at home seems to be an issue requiring study analysis. The subjective feelings and opinions of patients after stoma closure allow to compare the quality of life, considering patients before and after gastrointestinal tract continuity restoration (4).

Complications after intestinal stoma exteriorization can be divided into local and systemic (5, 6). Systemic complications include psychosocial complications. The presence of an intestinal stoma is a significant psycho-emotional burden for the patient, who often cannot overcome the shame and consciously refrain from active social, family life, unwittingly placing themselves at the margin of social life in which they are fully-fledged members. Gastrointestinal tract continuity restoration is associated with the need for an additional operation, often extensive, to which the patient does not often agree, due to fear of postoperative pain and the subsequent stages of rehabilitation.

Patients with an exteriorized stoma often argument the lack of consent for another operation with the following: good organization of life with stoma presence and habituation to such a lifestyle, although difficult and to some extent limited. The need for another surgical procedure and related complications (hospitalization, postoperative pain, inability to work, poor quality of life associated with rehabilitation) are related to the fact that patients postpone surgery or abandon it altogether. An important factor determining the patients' approach to surgery (gastrointestinal tract continuity restoration) is their age, which significantly influences the perception of the quality of life and associated aspirations, future plans, or job and social opportunities,

which may be limited by the presence of a stoma. These factors are responsible for the fact that gastrointestinal tract continuity restoration procedures are positively viewed by younger patients, who find benefits influencing their quality of life. Older patients consider stoma closure procedures negatively, mentioning possible pain which they want to avoid, inherently being a consequence of gastrointestinal tract continuity restoration, and most often the probability of diarrhea, which will disorganize their lifestyle, to some extent orderly (7).

It is obvious that as a result of gastrointestinal tract continuity restoration the patients' quality of life is subject to some changes, both positive and negative depending on the subjective feelings of a given patient. Two coexisting medical problems, self-service of the intestinal stoma, and central catheter and parenteral nutrition additionally hinder the social and occupational functioning of the patient who consider their quality of life as low (8). Gastrointestinal tract continuity restoration is associated with a high chance and probability to return to everyday activities. The stoma closure procedure allows patients to gradually reduce the amount and frequency of nutritional mixtures, even discontinuation of parenteral nutrition.

The aim of the study was to analyse the quality of life of patients on chronic parenteral nutrition, before and after gastrointestinal tract continuity restoration.

MATERIAL AND METHODS

Due to the issue of the study it was considered that the research will be most meaningful when the diagnostic survey method was applied. The method is well suited to gather a large amount of research data allowing subjective opinions and point of views of the investigated group. In order to obtain study data a questionnaire was elaborated, specifically to gather required information concerning gastrointestinal tract continuity rupture and restoration, as well as parenteral nutrition. The analysed questionnaire comprised 31 questions and was divided into three parts:

- general (questions allowing to characterize each patient: gender, age, education, place

of residence, occupational situation, housing, and marital status);

- detailed (questions concerning parenteral nutrition, frequency of parenteral nutrition, its influence on everyday functioning);
- additional (comprising key questions aimed directly to patients with a stoma, and to those after stoma closure).

The questionnaire was conducted at the Department of General Surgery and Clinical Nutrition, Warsaw Medical University, during the period between May and June, 2014. The study group comprised 71 patients (33 female and 38 male) operated during the period between 2007 and June, 2014, including those with a stoma-prior to gastrointestinal tract continuity restoration (32 patients – 45%), as well as those after stoma closure (39 patients – 55%). These patients were under the care of our department, due to parenteral nutrition at home. Figures 1 and 2 presented the division of patients, based on gender and presence of stoma.

The age structure of the respondents was calculated on the basis of patient distribution into four age groups. Table 1 presented the graphic analysis of the age structure of the four patient groups.

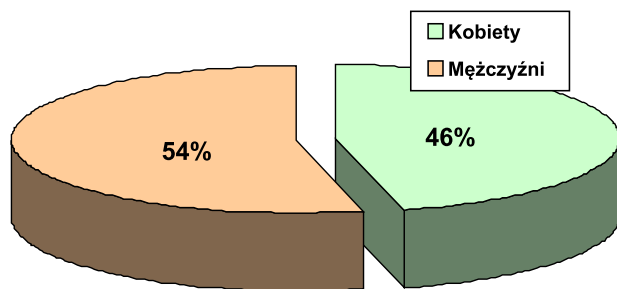


Fig. 1. Patient gender

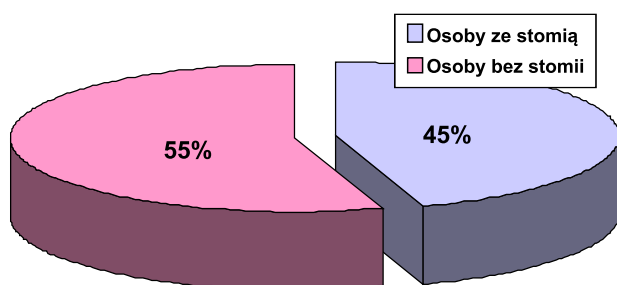


Fig. 2. Presence or absence of stoma

RESULTS

The study presented selected, most important issues concerning the quality of life of patients with stomas and chronic parenteral nutrition.

Table 2 presents cause for the implementation of chronic parenteral nutrition in the analysed group of patients with short bowel syndrome. Both in case of patients with stomas, as well as after its closure, the main cause of continued parenteral nutrition were postoperative complications.

Analysis of parenteral nutrition showed that in more than 90% of patients with stomas, the above-mentioned was conducted on an everyday basis. The percentage of patients requiring parenteral nutrition every other day is observed in those without stomas (tab. 3).

Table 1. Age structure considering the four patient groups

Age Group	n	mean	standard deviation
Young (22-43 years)	19	32,0526	6,05965
	17	52,4706	3,93887
	18	61,2222	2,18432
Older (45-57 years)	17	72,2941	5,12060
	17	72,2941	5,12060
	17	72,2941	5,12060
Middle age (58-65 years)	18	61,2222	2,18432
	18	61,2222	2,18432
	18	61,2222	2,18432
Oldest group (66-80 years)	17	72,2941	5,12060
	17	72,2941	5,12060
	17	72,2941	5,12060

Table 2. Main cause of short bowel syndrome

Cause of short bowel syndrome	Number	%
	With stoma	
inflammatory bowel diseases	3	9,4
neoplastic disease	6	18,8
postoperative complications	13	40,6
thrombosis / mesentery vessel embolism	3	9,4
road accidents	1	3,1
other	6	18,8
total	32	100
Without stoma		
inflammatory bowel diseases	3	7,7
neoplastic disease	1	2,6
postoperative complications	28	71,8
thrombosis / mesentery vessel embolism	2	5,1
road accidents	2	5,1
other	3	7,7
total	39	100

Table 3. Frequency of parenteral nutrition in patients with and without stomas

Frequency of parenteral nutrition		Frequency	%
With stoma	everyday	29	90,6
	every other day	1	3,1
	5 days a week	1	3,1
Without stoma	everyday	5	12,8
	every other day	6	15,4
	5 days a week	6	15,4

Data analysis enabled to determine the psychosocial contact with the immediate environment-family and friends, as well as the subjective opinions of the respondents concerning the support they received. Table 4 presented the opinions of the respondents concerning their contact with family members.

The presence of a stoma and intravenous nutrition shows that the vast majority of patients feel that their social contacts have changed. All respondents agreed that social

contacts did not improve, some even noticed that they deteriorated. Table 5 presented the opinion of respondents concerning their social contacts.

Result analysis allowed to determine the changes in occupational life associated with the deterioration in health-stoma and lack of gastrointestinal tract continuity. Table 6 showed that most patients were not able to continue work, which resulted in the resignation of part or the whole time required for work.

Table 7 presented the frequency of patients with stomas and after stoma closure who changed their place of residence.

Table 8 showed changes in the patients' health condition after stoma closure. 34 patients considered their condition as improved, while 5 saw no difference.

Analysis of patient opinions after gastrointestinal tract continuity restoration showed that the number of daily defecations did not exceed three. It has been proven that the earlier concerns associated with functioning in

Table 4. Family member contacts based on the opinion of patients with and without stomas

		Nothing has changed	Family has become overprotective	Family has stepped back from me	Improved contact	Worse contact	Feel that family is supporting me
With stoma	n yes	24	5	-	-	8	30
	no	8	27	32	32	24	2
Without stoma	n yes	32	3	1	2	8	35
	no	7	36	38	37	37	4

Table 5. Social contacts of patients with and without stomas

		Nothing has changed	I limited contacts	Contact only with friends	Improved contact	Worse contact	My friends have backed away from me
With stoma	n yes	10	16	12	-	19	2
	no	22	15	20	32	13	30
Without stoma	n yes	5	32	15	1	33	2
	no	33	7	24	38	6	37

Table 6. Professional activity in patients with and without stomas

		Impossible to continue work	Had to move to another workstation	I had to resign part-time	I was fired	Nothing has changed
With stoma	n yes	29	3	3	2	11
	no	3	29	29	30	21
Without stoma	n yes	35	4	4	5	23
	no	4	35	35	34	16

Table 7. Frequency of changing the place of residence and moving abroad

		Number of patients changing their place of residence	%	Number of patients moving abroad	%
With stoma	often	5	15,6	1	3,1
	sometimes	9	28,1	3	9,4
	rarely	11	34,4	7	21,9
	never	7	21,9	21	65,6
	total	32	100	32	100
Without stoma	often	2	5,1	-	-
	sometimes	12	30,8	2	5,1
	rarely	15	38,5	7	17,9
	never	10	25,6	30	76,9
	total	39	100	39	100

case of diarrhea proved unjustified. All patients (n= 39) believe that their general functioning has significantly improved (tab. 9).

Most of the respondents had to abandon work or change their workstation. Only a few were fired (tab. 10).

Table 8. General condition of patients after stoma closure

		Frequency	%
Without important stoma	improved condition	34	87,2
	nothing has changed	5	12,8
	total	39	100

Tabela 9. Liczba wypróżnień w ciągu doby u pacjentów po zamknięciu stomii

Table 9. Number of daily defecations in patients after stoma closure

		Frequency	%
Without stoma	approximately 10 daily	2	5,1
	approximately 5 daily	7	17,9
	1-3 daily	30	76,9
	total	39	100

Differences in the subjective feelings of patients concerning quality of life were based on SF-36 questionnaire results. Study analysis showed differences in the quality of life, considering the three most important determinants.

Differences in patients with and without stomas (SF-36 $t(69)=2.84$; $p=0.006$). Patients with a stoma achieved higher results considering dissatisfaction with life (83 ± 30), as compared to those without stomas (61.2 ± 33.7). Thus, the former achieved a lower quality of life.

Differences in the quality of life considering patients with a stoma and parenteral nutrition, as compared to those without stomas and on parenteral nutrition amounted to $t(51)=3.47$; $p=0.001$. Results show lower quality of life in case of patients with stomas and on intravenous nutrition (83.2 ± 30.5), as compared to those after stoma closure and on normal nutrition (52.3 ± 33.8).

Analysis showed differences between younger and older patients amounting to SF-36 $t(62,87)=2.49$; $p=0.016$. It turns out that younger patients have a better outlook on life, achieve lower results considering dissatisfac-

Table 10. Professional activity considering patients with stoma and parenteral nutrition, without stoma and with parenteral nutrition, as well as without stoma and parenteral nutrition

		Could not continue work	Had to change my workstation	Had to resign part-time	I was fired	Nothing changed
With stoma and parenteral nutrition	yes	28	3	3	2	11
	no	2	28	28	29	20
Without stoma and with parenteral nutrition	yes	15	3	1	2	10
	no	2	14	16	15	7
Without stoma and parenteral nutrition	yes	20	2	3	3	13
	no	2	21	19	19	9

tion with life (61.55 ± 27.5), as compared to older patients (80.8 ± 36.9).

DISCUSSION

The awareness of health defects and certain limitations that result from them, as well as the long-lasting mental and physical suffering indicate that patients with a stoma and on parenteral nutrition achieve lower results considering the quality of life scale. The presented study comprised 71 patients who required the implementation of parenteral nutrition, as a result of postoperative complications leading to the diagnosis of short bowel syndrome. Most of the analysed patients indicated that the negative aspects of lack of gastrointestinal tract continuity and parenteral nutrition were associated with the care of the stoma. Patients mentioned that activities associated with nutrition mixture transfers and central catheter maintenance were not as inconvenient as the maintenance of the stoma (9, 10).

Our study demonstrated that a greater impact on the negative evaluation of the quality of life was associated with presence of stoma and lack of gastrointestinal tract continuity, as compared to parenteral nutrition at home. It turned out that patients with a stoma achieved lower quality of life results, as compared to those without. The presence of the stoma is not only a health problem, but also a significant psycho-emotional burden for patients, who often are not able to overcome the shame, and consciously abandon the active, family, social and occupational life, pushing themselves to the margins of life. The presence of a stoma, based on the patients questionnaire results showed that their social contacts have negatively changed.

The study presented that patients after gastrointestinal tract continuity restoration did not exceed three defecations per day. It turned out that their previous concerns associated with functioning in case of diarrhea proved unnecessary. All patients after gastrointestinal tract continuity restoration agreed

that their overall functioning improved. It should be noted that to a very large extent the feeling of satisfaction and high quality of life are determined by patient age, marked by patient needs and goals, aspirations, and motivation. Age significantly determines the psychophysical condition of the patient, when in good physical and mental health feels greater satisfaction with life. With age, one may observe reduced general and mental condition, which negatively influences the feeling of satisfaction with life, especially in elderly patients.

With age social contact is significantly reduced- considering the oldest patient group the percentage of patients proved lowest. Negative effects of the disease on professional work were observed in the younger patient group (11). The older the group of respondents, the greater the percentage of patients who underlined that the disease changed nothing in their professional life, since they were already in retirement. Our study results were in accordance with those obtained by other authors analysing the activity of patients on chronic parenteral nutrition (12, 13).

CONCLUSIONS

Patients with stomas benefit from the help of others more often, mostly of family members. Patients without stomas seem to be more independent-in most cases do not use the help of family members (43.6%), or friends (64.1%).

Patients with stomas more often are likely to withdraw from social life. The respondents mentioned that it was not their friends that moved away from them, but they themselves limited these contacts.

The factor most significantly lowering the quality of life is the presence of a stoma, which burdens everyday functioning a lot more than parenteral nutrition.

All patients after stoma closure believed that their general functioning significantly improved.

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