

QUALITY OF LIFE ASPECTS DETERMINING THE-BIO-PSYCHO-SOCIAL FUNCTIONING OF PATIENTS IN THE-PERSPECTIVE OF A PLANNED EXTENSIVE SPHINCTER'S REPAIR PROCEDURE

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Damage to the sphincter, regardless of its pathogenesis, consists in the impossibility to control the physiology, or the so-called faecal incontinence. This implies changes in the whole bio-psychosocial functioning of the patients, and thus affects the satisfaction with their quality of life, conditioned by their health status. The problem affects around 5 to 7% of the population. Often enough, the only hope for those patients are repair procedures of the sphincter mechanism.

The aim of the study was to evaluate key aspects of quality of life which determine the psycho-social status of patients with endogenous or iatrogenic sphincter damage in the perspective of a planned extensive sphincter's repair procedure.

Material and methods. The study group consisted of 52 people, 26 women and 26 men, aged 19–72. The scale by Rockwood – Fecal Incontinency Quality of Life – was used as the basic research tool which evaluates the quality of life in four aspects: 1/behavioral (Lifestyle) 2/cognitive (Coping) 3/emotional (Depression) 4/overall self-assessment (Embarrassment). The degree of incontinence was determined based on point scales of Jorge Wexner (JW scale) and the Fecal Incontinence Severity Index (FISI scale). Structured diagnostic interview was also used in the study.

Results. The results show that lack of control over the basic physiological functions disintegrates the quality of life in all evaluated aspects related to somatic, psychological and social functioning. FIQL: Lifestyle (LS) – 1.96 pts Coping (C) – 1.67 pts Depression (D) – 2.1 pts Embarrassment (E) – 1.79 pts

Conclusions. The FIQL results presented explain the fact that among 52 patients followed, 50 decided to conduct extensive reconstructive procedures, although the results are not statistically optimistic and the risk of complications is relatively high.

Key words: faecal incontinence, sphincter complex reconstruction procedures, bio-psychosocial functioning, quality of life

Holistic health paradigm implying the recognition that every physiological change in the body is reflected in the psychosocial area of its functioning requires the adjustment of advanced surgical procedures to the multidimensional needs of the patient. Repair procedures of the damaged sphincter complex are procedures which can significantly affect the modification and the ability to exercise daily biological, psychological and social functions. Damage of this mechanism (congenital or acquired as a result of a traumatic injury) implies the “inability to hold and control the discharge

of stool in a socially acceptable way” for the patient (faecal incontinence FI) (1). Consequently, this could disintegrate all areas of their functioning. FI affects about 5 to 7% of the population, of which 30% are patients with the so-called Extreme Faecal Incontinence – EFI, in whom conservative treatment; diet, pharmaceuticals, electrical stimulation, biofeedback, cannot yield the expected results. We are currently observing increased medical interest in the impact of the disease and surgical procedures on the quality of life understood as self-evaluation of the discrepancy between

the real situation and the desired one (2). This leads therefore to a broader examination of the situation of patients with sphincter insufficiency qualified for extensive reconstructive procedures, the so-called "last step procedures".

The aim of this study was to determine the patient's psychosocial situation by analysing the essential elements of quality of life in the absence or loss of control of defecation, and before a planned repair procedure of the sphincter mechanism, based on the research and experiences of a centre where such procedures are performed.

MATERIAL AND METHODS

In the 3rd Department of General Surgery (UJCM), the study included 52 patients, 26 men and 26 women, aged 19–72, from 2001 until 2010. This group consisted of patients with end-stage sphincter insufficiency, where 10 people were patients with a complete lack of sphincter (congenital), 42 people were patients with an acquired loss of sphincter of more than 1/3 of the circumference because of mechanical damage to the anal sphincter (transportation injuries, birth defects, sexual practices) and functional failure caused by other diseases. Patient characteristics are presented in tab. 1.

In the first stage of the study, in order to objectify the evaluation degree of faecal incontinence, questionnaires were used to measure the severity of symptoms; Jorge Wexner scale – JW (3), and the FISI scale – Fecal Incontinence Scoring System (4). In order to determine the quality of psychosocial functioning conditioned by the state of health, the Rockwood scale – FIQL – Fecal Incontinency Quality of Live – was applied (4). This scale consists

of 29 questions assessing the quality of life in four aspects:

- 1) behavioural (Lifestyle, 10 questions) – concerning the lifestyle and the need to modify it, e.g. staying at home, creation of the so-called area toilet maps, avoiding travelling, withdrawal from interpersonal contacts and sexual isolation;
- 2) cognitive (Coping, 9 questions) – concerning the application of countermeasures and defence in order to maintain a positive self-image;
- 3) emotional (Depression, 7 questions) – specifying the degree of coping with negative emotions, sadness, depression;
- 4) general self-evaluation (Embarrassment, 3 questions) – concerning self-evaluation of the body, feel of shame and uneasiness.

Afterwards, a structured diagnostic interview was conducted with the patient aimed at deepening the knowledge of their psycho-social functioning in case of a planned reconstructive surgery of sphincter and the expectations with respect thereto. The questions asked in the direct conversation related to individual ways of reorganizing the lifestyle due to the symptoms of FI e.g. which spheres were mostly at risk and how; social, professional, sexual, what emotions accompany them and what the personality styles of coping with them are. There were also question about expectations related to the surgery, as well as patients' own ideas about the functioning after surgery. Elements of psychoeducation were introduced, aimed at making the expectations and needs of the patient real with regard to the possibility of reconstructive surgery.

RESULTS

The data obtained from the study questionnaire presented as follows:

- 1) In a 61-point FISI scale patients gained an average of 36 points. (with the lowest result obtained 12 and the highest 49 pts).
- 2) In a 20-point JW scale – 12 pts (with the lowest result obtained 4 and the highest 18 pts).

That meant that all patients could be qualified for the group described as patients with extreme faecal incontinence.

Table 1. Quantitative division due to the pathogenesis of anal sphincter injury

Transportation injury	Injury at birth	Sexual practices	Neurological reasons	Impaired functioning
5 people	22 people	4 people	7 people	4 people

3) In the FIQL scale measuring four psychosocial aspects of functioning in a range of 0 to 4 pts, the patients achieved the following average scores:

- Lifestyle (LS) – 1.96 pts (with the lowest result obtained 1.12 and the highest 2.70).
- Coping (C) – 1.67 (with the lowest result obtained 0.98 and the highest 2.25).
- Depression (D) – (the only scale of 0 to 6 pts) an average of 2.1 pts (with the lowest result obtained 1.40 and the highest 2.80).
- Embarrassment (E) – 1.79 pts (with the lowest result obtained 1.06 and the highest 2.45).

The results obtained are shown in fig. 1.

A comparison of these data indicates how significantly the satisfaction decreases in all categories determining the psycho-social functioning conditioned by the physiological state, i.e. quality of life (FIQL scale results), with increasing numbers in FISI and JW scales, which proves the increasing severity of incidents of "lack of control" in terms of stool/gases (fig. 2).

DISCUSSION

In a review of medical literature, there appear general data on the reduction in the quality of life of patients with FI (1, 5). However, there are no reports of patients with an extreme form of FI. Alsheik points out that due to the lack of control of defecation, patients lose their remediation capabilities (Coping), and the level of embarrassment increases (6). Our results show a significant reduction in the

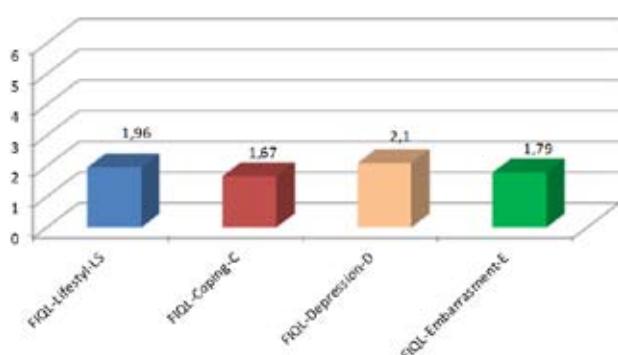


Fig. 1. Quality of life evaluation in the four aspects of psychosocial functioning on the FIQL scale: FIQL lifestyle (LS), FIQL coping (C), FIQL depression (D), FIQL embarrassment (E)

quality in all four categories. By far, the worst category that the patients evaluated was the possibility of countermeasures – Coping (1.67 pts) and the level of embarrassment (1.79 pts). This means that in terms of behavioural and cognitive coping with the problem, the personal countermeasures available (applying primers, drastic dietary restrictions or the so-called area toilet maps) are insufficient, and the patients used regressive forms of withdrawal, avoidance, isolation.

75 percent of respondents even indicated their restriction of leaving home and resignation from travelling. This is reflected in self-esteem in terms of their lifestyles (1.96pts). The consequence of these restrictions and lifestyle was a whole series of changes in social functioning. This included the whole spectrum of interpersonal relationships, withdrawal from their professional, sexual and other roles. All surveyed patients were forced to adjust their activity to the digestive function.

Meyer and Richter indicate the reduction of sexual activity in women with the FI problem in relation to the group of women not affected by this problem (7). In our study, the analysis of survey questions and conclusions from personal interviews have shown that 20 of the 26 women drastically reduced sexual contacts because of the shame and embarrassment, and the people with damaged sphincter mechanism because of their sexual practices even signalled withdrawal from sex life.

Patel et al. indicates that the restriction of sexual relations is not dependant on the gender

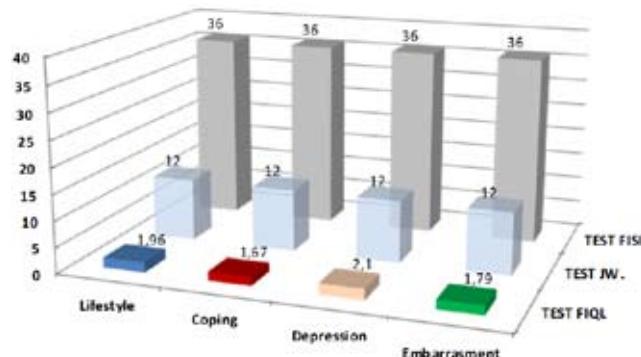


Fig. 2. The relationships between the degree of FI; The scale of Faecal Incontinence Scoring Index FISI and the scale of Jorge Wexner JW, and the quality of life as measured by the Faecal Incontinence Quality of Life – FIQL, in four categories: Lifestyle (LS), Coping (C), Depression (D), Embarrassment (E)

(8). In our group, 58% (14/24) of men and 77% (20/26) of the women with FI limited their sex life. Therefore, like Alsheikh, we find that FI restricts the sexual activity in women much more profoundly than in men (6).

Preliminary comparative data are so interesting that it seems interesting to conduct further comparative analysis of the impact of faecal incontinence disorders on the psycho-social functioning and quality of life according to gender. For example, our data shows that the impact on the professional sphere was higher in men than in women. The reports from the respondents indicate that 42% (10/24) of economically active men resigned from work after the onset of FI symptoms, whereas in women it was only about 30%. The inability to implement existing social roles, and thus deprivation and inability to meet their own needs and goals in life, caused disturbances in the emotional aspect. The dominant emotions that appeared were: anxiety, feelings of shame and embarrassment, especially in possible, anticipated situations of control loss of physiological functions (embarrassment). 30% of the patients claimed that they felt terror and shame at least once a month as a result of uncontrolled release of stool or gas, which in all patients lead to depression. The category Depression of the FIQL scale reflects to what extent patients with faecal incontinence can cope with depression. In our study it was 2.1 pts with the maximal value of 6 pts. This meant that all patient declared "occasional" significant depressed mood, 30% of them declared constant feeling of dissatisfaction and depression. 7 people in the treatment group reported suicidal thoughts in a crisis situation. This corresponds to the result by Heymen who proved in his study that patients with FI have significantly higher levels of anxiety and uneasiness (9). The results in terms FIQL, as well as an additional diagnostic survey clearly indicate the psycho-social degradation of patients with FI in terms of behavioural, mental (including emotional), cognitive and social aspects. Thus, it seems understandable that despite not the best results and the possibility of complications, the only possibility for them are the last step procedures. In the author's centre, patients with end-stage FI were qualified for the following regenerative procedures depending on the patomechanism:

1. Plastic surgery of sphincter by overlapping sphincter repair.
2. Creation of a replacement sphincter by transposing their own gracilis muscle of the thigh (graciloplasty), in some patients with additional pacemaker implantation.
3. Artificial Bowel Sphincter, i.e. implanting a hydraulic silicone prosthesis which is a mechanical valve used as an artificial sphincter.

The choice of the method used depended not only on the pathogenesis of the phenomenon, but also on the patient's age, biological state, psychological evaluation using a set of scales designed to determine the overall psycho-cognitive efficiency, taking into account the personality styles of coping with the disease and the expectations regarding the treatment.

According to Heszen-Niejodek, waiting for surgery and surgical treatment is always a stressful situation for the patient, while in the medical literature there are no reports about the specifics of the psychological situation of patients undergoing sphincter reconstruction (10). The reports of our patients showed that in the face of corrective surgery of the sphincter mechanism, the patients found themselves in situations of acute conflict related to the divergent needs and aspirations. Waiting for treatment, which was often "the last resort" and in which they had great expectations for regaining control of the physiology of their bodies, was accompanied by feelings of anxiety just before the surgery, pain, analgesia, the possibility of deterioration, postoperative complications and unpleasant diagnostic tests which violated their intimacy. In the case of dynamic graciloplasty and implanting a hydraulic prosthesis, the concerns were related to the skills of the implantable system "usage" and the ability of "rejection by the body" of an artificial implant, sphincter, or pacemaker.

Important at this stage was adequate psychoeducation aimed at providing a comprehensible knowledge about the procedure itself, its consequences and possible post-operative complications, tailored to the learning capabilities and needs of the patient, with a special rate put to their expectations for the operation itself, as the reconstruction of the sphincter does not always imply total return of previous functions. This applied especially to patients who secondarily lost the ability of "stool continence"

and expected to return to a functional state "before" injury, which cannot be guaranteed by reconstructive surgery, taking into account not the best statistical results of operations. As we know, in the case of "overlapping sphincter repair", the effectiveness does not exceed 60–65%, in the case of other procedures it is even lower, and the risk of complications reaches about 60%. In the case of dynamic graciloplasty, the need to remove or perform the reimplantation of the pacemaker due to infection or injury concerns even 42% of patients (11). For the establishment of an artificial prosthetic, the explant range varies from 15 to 58% (12, 13). We observe a similar complication rate in our study group.

In order to avoid disappointment and poor quality of life as a result of complications or failure to improve after the surgery, it is necessary to determine the real possibility of surgery in relation to patients' expectations.

As a result of multiple interviews in the presence of a surgeon and a psychologist, two patients in our study group resigned from the proposed treatment after the period of psycho-education and diagnosis due to the lack of guarantees to return to the state before the injury and regain total control of "stool continence" and fear that the operation itself can re-contribute to the deterioration of the current

situation. This concerned patients with extreme FI as a result of mechanical injury of the sphincter mechanism.

CONCLUSIONS

1. Lack of formation or damage to the sphincter in a patient implies the inability to control basic physiological functions. It is a disability that has a significant, dis-adaptive impact on all components of quality of life: behavioural – lifestyle, social, cognitive – coping and emotional.
2. The results obtained show how significantly the value of all components of the scale that measures the quality of life – FIQL is reduced with increasing results on FISI and JW scales.
3. In contrast to the data from medical literature, our research shows that not only were the aspects of coping and embarrassment significantly affected, but also the lifestyle changed and depression appeared.
4. In order to achieve the optimal effect of surgery and reduce the risk of disappointment of the patient, the importance of adequate preparation by a multidisciplinary team of preoperative diagnostic and therapy is important.

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