



Original Article

Assessment of subjective well-being and quality of life in patients with intestinal stoma



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ABSTRACT

Objective: To investigate the subjective well-being and quality of life in patients with intestinal stoma.

Method: This study was conducted at Ostomized People's Pole of Pouso Alegre. Data were collected in the period between December 2012 and May 2013, after approval by the Ethics Committee of the Universidade do Vale do Sapucaí under opinion No. 23,277. The participants were selected by a convenience non-probability sampling. The following instruments were used: a questionnaire on demographics and stoma; a Subjective Well-being Scale; and a Quality Outcome Scale.

Results: Regarding the Flanagan Quality of Life Scale, 16–22 points were obtained, indicating that these patients suffered changes in their quality of life. Regarding the scale of subjective well-being in three domains: positive affect – 43 (61.40%) individuals; negative affect – 31 (44.30%) individuals; and life satisfaction – 54 (77.10%), all subjects obtained a score of 3, characterizing a negative change in these domains. The mean Flanagan Quality of Life Scale score was 26.16, and the means for the domains included in the Subjective Well-being Scale were: positive affect: 2.51; negative affect: 2.23 and life satisfaction: 2.77, indicating that the intestinal stoma users who participated in the study had negative feelings related to their own self-esteem and to the loss of quality of life.

Conclusion: Patients with intestinal stoma who participated in this study had a change in their quality of life and in subjective well-being.

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Avaliação do Bem-estar subjetivo e da qualidade de vida nos pacientes com estoma intestinal

R E S U M O

Palavras-chave:

Estoma

Ostomizado

Qualidade de vida

Colostomia

Íleostomia

Objetivo: Avaliar o bem-estar subjetivo e qualidade de vida nos pacientes com estoma intestinal.

Método: Este estudo foi realizado no Polo dos Estomizados de Pouso Alegre. Os dados foram coletados no período compreendido entre dezembro de 2012 e maio de 2013, após aprovação pelo Comitê de Ética em Pesquisa da Universidade do Vale do Sapucaí sob parecer n° 23.277. A amostra foi selecionada de forma não probabilística, por conveniência. Foram utilizados seguintes instrumentos: questionário sobre os dados demográficos e sobre o estoma; Escala de Bem-estar subjetivo e a Escala de Qualidade de Resultados.

Resultados: Com relação à Escala de Qualidade de Vida de Flanagan, alcançou-se entre 16 a 22 pontos, revelando que esses pacientes apresentavam alteração na qualidade de vida. Com relação à escala de bem-estar subjetivo nos três domínios: afeto positivo-43 (61,40%) indivíduos; afeto negativo-31 (44,30%) indivíduos e satisfação com a vida 54 (77,10%), todos os indivíduos obtiveram pontuação 3, caracterizando alteração negativa nesses domínios. A média da Escala de Qualidade de Vida de Flanagan foi 26,16, e as médias dos domínios da Escala de Bem-estar subjetivo foram; Afeto positivo: 2,51; Afeto negativo: 2,23 e satisfação com a vida: 2,77, configurando que esses indivíduos com estoma intestinal que participaram do estudo apresentaram sentimentos negativos relacionados à própria autoestima e à queda na qualidade de vida.

Conclusão: Os pacientes com estoma intestinal que participaram deste estudo apresentaram alteração na qualidade de vida e no bem-estar subjetivo.

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Introduction

In this century, the increase in life expectancy, the globalization and the effects of urbanization mean that the Brazilian population was exposed to multiple health problems, among which cancer, trauma and chronic degenerative diseases stand out. Due to trauma or other conditions, for example, cancer and urinary tract diseases, some individuals may need an emergency surgery involving the making of some type of stoma. In some cases, there may be in order technological resources, such as the implantation of prosthetic and orthotic devices, to save the patient's life or to provide a better quality of life.¹⁻³

Ostomy, or stoma, is a word of Greek origin. The ostomy may represent limitation with respect to the person's life project, especially in the case of elderly people. In this post operatory process of adaptation, ostomized people start to give a new meaning to their condition, looking after their self-care and their new care environment. Thus, the environment is characterized by alliances and dynamic associations, convergences and estrangements, freedom, dependence and interdependence, overcoming and acceptance mechanisms, limits and potentialities.⁴⁻⁶

When receiving an intestinal stoma, the patient begins to lose control with respect to the elimination of feces and gases, as a result of stoma opening; this promotes a strong emotional impact for ostomized people, because the stoma causes body scheme, self-image and self-esteem changes, also

determining other disorders associated with these factors. Such changes cause various disorders in their lives, with which these people must live and that impair their quality of life and subjective well-being.^{7,8}

From the moment when the doctor tell to a patient that he will be submitted to a surgery for an intestinal stoma, this patient starts to suffer in advance, showing anxiety, dissatisfaction with life, and embarrassment. Furthermore, these individuals feel unhappy when faced with the necessary changes in their habits and, consequently, the significant interference in their quality of life. Often the confirmation of a stoma is an event that also affects family members and their social relations, and a great emotional and psychological impact may affect everyone involved.^{9,10}

In addition to the problems faced by those who are undergoing surgery (reported above), ostomized people are exposed to a series of social constraints, such as the possibility of outgassing and excrement leakage due to the lack of voluntary control, and also by flaws in the safety and quality of the collection bag. Thus, these people are afraid of public exposure. Typically, such problems can be understood from physical, psychological, social and spiritual dimensions.¹¹

Therefore, the nurse, as a health caregiver, must understand these changes, in order to develop an appropriate plan of care to prepare the patient for his/her new live with the ostomy. In this sense, "to take care" implies an interaction between the caregiver and the person being cared for, in an exchange of knowledge and experience. This will provide a positive outcome for the nursing care.¹²

The assessment of subjective well-being of ostomized people should be seen as a greater good to be maintained and/or restored, so that these people can live happily and in harmony in their life context. Therefore, medicine, nursing and other allied sciences, through the professionals who make up the support staff, should spare no effort so that a better quality of life for these people will be the outcome of the assistance offered throughout all stages of treatment, from preoperative phase through the postoperative period, and in the guidelines for hospital discharge and how to deal with this new reality. Thus, this study aimed to evaluate the subjective well-being and quality of life of patients with intestinal stoma.

Methods

This is a clinical, primary, descriptive, analytical, and prospective study.

This study was conducted at the Center of Ostomized People, city of Pouso Alegre. Data were collected between December 2012 and May 2013, after approval by the Ethics Committee of the Universidade do Vale do Sapucaí, under opinion No. 23,277. The participants were selected by a convenience non-probability sampling. Data collection was conducted by the authors themselves, after the signing of a free and informed consent form by all subjects. Patients aged less than 18 years with an intestinal stoma were included in this study. On the other hand, patients with dementia syndromes and other conditions that prevented them from understanding and responding to questionnaires were excluded.

Three data collection instruments for this study were used. First, a questionnaire on demographics and on stoma was applied; as a second instrument, the Subjective Well-being Scale was used; and the third one was the Flanagan Quality of Life Scale.

The Subjective Well-being Scale is divided into two subscales. The first subscale comprises components related to affective and non-affective emotions. It is composed of the items 1-47; 21 items are related to positive emotions and 26 items are related to negative emotions. For each item the respondent can assign a value from 1 (not at all), 2 (a bit), 3 (moderately), 4 (enough) to 5 (extremely). The second subscale consists of items 48-62, describing judgments related to the evaluation of satisfaction or dissatisfaction with life; these items must be answered on a scale where 1 means "completely disagree"; 2, "disagree"; 3, "do not know"; 4, "agree", and 5, "fully agree." The total score of each subscale is obtained by adding the answers of each item divided by the total number of items in the subscale. The number 3 represents the median point. With the use of the Subjective Well-being Scale, three results are obtained, and are independently assessed: positive affects, negative affects and life satisfaction. Thus, high scores of the first subscale, represented by scores >3, indicate positive affects; and scores <3, negative affects. On the other hand, in the second subscale, scores >2 represent satisfaction with life. All subscales have good internal consistency (positive affects: 0.95; negative affects: 0.95; satisfaction with life: 0.9).¹³

The Flanagan Quality of Life Scale¹⁴ conceptualizes the quality of life based on five dimensions: physical and

material well-being; relationship with others; social, community and civic activities; personal development and fulfillment; and recreation. These dimensions are measured by 15 items, where the respondent has 7 response options, ranging from "very dissatisfied" (score 1) to "very satisfied" (score 7). The maximum score achieved in assessing the quality of life proposed by Flanagan is 105 points, with 15 points being the minimum score, reflecting a low quality of life. It is worth noting that the scale is self-administered; however, some older people involved in this study received assistance from researchers in their answers to this instrument, given that these people had physical limitations as hand tremor, impaired visual and hearing acuity, and low educational level.

The Flanagan Quality of Life Scale was developed for use in the USA and has not been validated for the Brazilian culture; however, Hashimoto et al. translated the instrument into Portuguese and applied it on ostomized patients.

The scale was applied to a relatively large and heterogeneous random sample; these authors found high reliability for this instrument. Then they used the scale in a study involving elderly people,¹⁴ when a good level of reliability was found – a factor that contributed to the decision to use this instrument in this study.

In the statistical analysis, the following tests were used: the chi-squared test for socio-demographic variables and for the "related to ostomy" variable, to determine if the distribution was proportional, that is, if the same number of subjects was allocated to each variable category. Kruskal-Wallis test and Spearman correlation were also used on the scale variables of Subjective Well-being and on Flanagan Quality of Life Scale. For all statistical tests, significance levels of 5% ($p < 0.05$) were considered.

Results

Most participants were aged above 60 years old, male gender, retired, earned 1-3 minimum wages and attended support groups. Twenty-one (30%) of the respondents were illiterate and 19 (25.10%) could read and write. Thirty-eight (54.30%) of respondents were involved with support/membership groups.

Most often, the cause that led patients to acquire ostomy was a neoplasm; and permanent colostomy was the type of ostomy used. Most of the subjects were not told that they would receive a stoma. Furthermore, no stoma demarcation or irrigation was taken. Regarding the type of complication, 34 (48.60%) had dermatitis; 14 (20%) retraction and 13 (18.60%) prolapse. With respect to the diameter of the stoma, 34 (48.60%) measured 20-40 mm and 23 (32.90%), 40-60 mm.

According to Table 1, it was observed that the Flanagan Quality of Life Scale (FQLS) reached 16-22 points; this score reveals that these patients showed quality of life changes.

Table 2 shows that, with respect to the Subjective Well-being Scale, the following domains: positive affect – 43 (61.40%) subjects; negative affect – 31 (44.30%) subjects; and satisfaction with life – 54 (77.10%) subjects attained a score 3, indicating that these individuals showed a negative change in these areas.

In Table 3, it can be seen that the mean for Flanagan Quality of Life Scale (FQLS) was 26.16, and the mean for the domains

Table 1 – Results obtained with the Flanagan Quality of Life Scale total score in patients with intestinal stoma.

Total score	p	Flanagan Quality of Life Scale (FQLS)			
		N	General %	Valid %	Pooled %
16	0.037	10	14.3	14.3	14.3
17		6	8.6	8.6	22.9
18		1	1.4	1.4	24.3
19		29	14.4	14.4	65.7
20		5	7.1	7.1	72.9
21		2	2.9	2.9	75.7
22		6	8.6	8.6	84.3
31		1	1.4	1.4	85.7
37		2	2.9	2.9	88.6
55		2	2.9	2.9	91.4
59		1	1.4	1.4	92.9
84		1	1.4	1.4	94.3
85		2	2.9	2.9	97.1
99		2	2.9	2.9	100.0
Total			70	100.0	100.0

Kruskal-Wallis and Spearman tests, $p \leq 0.05$.

Table 2 – Results obtained in score for domains of Well-being Subjective Scale in intestinal stoma subjects.

Domain	p	Subjective Well-being Scale			
		N	General %	Valid %	Pooled %
<i>Positive affect</i>					
1	0.003	7	10.0	10.0	10.0
2		20	28.6	28.6	38.6
3		43	61.4	61.4	100.0
Total		70	100.0	100.0	
<i>Negative affect</i>					
1	0.057	15	21.4	21.4	21.4
2		24	34.3	34.3	55.7
3		31	44.3	44.3	100.0
Total		70	100.0	100.0	
<i>Life satisfaction</i>					
1	0.002	9	182.9	12.9	12.9
2		7	10.0	10.0	22.9
3		54	77.1	77.1	100.0
Total		70	100.0	100.0	

Kruskal-Wallis and Spearman tests, $p \leq 0.05$.

Table 3 – Results obtained in mean score of Subjective Well-being Scale and of Flanagan Quality of Life Scale in intestinal stoma subjects.

Descriptive level	Positive affect	Negative affect	Life satisfaction
<i>Subjective Well-being Scale</i>			
Mean	2.51	2.23	2.77
Median	3.00	2.00	3.00
Standard deviation	0.676	0.783	1.103
<i>Flanagan Quality of Life Scale</i>			
Mean	26.16		
Median	19.00		
Standard deviation	19.897		

Kruskal-Wallis and Spearman tests, $p \leq 0.05$.

of Subjective Well-being Scale were: positive affect: 2.51; negative affect: 2.23; and life satisfaction: 2.77, indicating that our ostomized subjects had negative feelings related to their own self-esteem and loss of quality of life.

Discussion

With regard to sociodemographic characteristics, it was found that 52 subjects (74.30%) were male and most were elderly, over 60 years, characterizing an elderly population. These findings agree with a number of studies whose subjects were male and aged over 60.¹⁵⁻¹⁹

As for marital status, the study showed that there was a prevalence among married, 34 (48.60%), followed by 22 (31.40%) widow(ers), and 14 (20.00%) separated. This result shows the importance of family involvement, especially the partner, on the recovery of an ostomized patient.

In terms of age, the most affected group was the population over 60 years. About this finding, it is important to point out that the elderly have unique biological characteristics and are more vulnerable to chronic-degenerative diseases, for instance, cancer.²⁰ In a study, the authors stated that the incidence of stoma complications is multifactorial, involving from the making of the stoma, its location, and obesity, with influence of age. Thus, when these factors are associated with the physiological changes of the aging process, a greater vulnerability of the elderly in the incidence of stoma complications is seen.²¹

As to education level, it was noted that most patients (47; 67.14%) were illiterate. This result reveals a worrisome profile in regard to citizenship and respect for rights, because it is known that the lower the educational level, the more unfavorable is the linguistic capital of the patient to question professionals about his/her health problems, the care being provided and his/her inherent rights. It is worth to point out that this situation does not affect the performance of the professionals in face of these people, because the interaction among user, service and health professionals has overcome the difficulties imposed by this variable.²¹ In reviewing the respondents' profession, it was observed that "retiree" was the professional status that stood out (50; 71.40%), followed by those working at the time (14; 20.00%). These findings are in line with data from other studies.^{18,22-26} One of the social consequences of ostomized patients is the role and social status changes in face of his/her family and society. After surgery, most often the ostomized person (which until then was working) becomes a retiree; with that, he/she stops being the family provider, thus becoming dependent in relation to his/her care.¹⁸

In this study, the investigators reported that the exteriorized bowel segments were colostomies and with respect to bowel loop externalization time, surgery was definitive. In 52 patients (74.30%), the causes for making the stoma were attributed to cancer; and most stomata measured 20-40 mm; these data coincide with the findings of other studies.²⁶⁻²⁹

It is worth noting that the time spent with the stoma will depend on the causal factor and on the clinical outcome after its making. Thus, a stoma that was initially provisional may become permanent, depending on the factors that

prevent the reconstruction of bowel transit, considering that diseases of the gastrointestinal tract lead to a radical surgery in many of these cases, resulting in a temporary or even definitive ostomy.³⁰ With regard to the type of system, 48 (68.60%) patients used two-piece devices, while in 44 (62.90%) an irrigation was not performed.

It is worth noting that when patients were asked about the completion of demarcation in the preoperative period, most of the patients told that there was no demarcation. This procedure is extremely important, given that a convenient location facilitates self-care and the rehabilitation process. Therefore, when performing the physical examination, the carer must be aware of the stoma positioning site, and the demarcation of the stoma must be made before surgery, in order to prevent or minimize possible stoma- and peristomal area complications. On that occasion, it is also important that the nurse educate the patients and their families about self-care.²⁹⁻³¹

With regard to complications, 36 (48.60%) respondents had dermatitis; 14 (20.00%) retraction and 13 (18.60%) prolapse. In addition, 48 (68.60%) patients were not told that they would have an intestinal stoma. One should also consider that some complications increase with age and with failure to perform stoma demarcation. Since the demarcation has not been done in this population, which is predominantly made up of older people, it can be said that this fact represents one of the factors that may have contributed to the occurrence of complications such as those cited, thus confirming the findings in other studies.

Usually, dermatitides are injuries resulting from improper use of collectors, more precisely by an excessive cutting of the hole of the protective barrier relative to the stoma, leaving the skin exposed to the action of effluent; or by an inadequate indication of the equipment for the type of stoma used. Collectors and adjuvant equipment available on the market must be presented to the smallest detail to ostomy patients. The equipment used in some services is recommended in accordance to the results of the assessment carried out at the time; but as time goes by, a replacement may be needed. Hence the need for continuous assessment.^{31,32}

On the other hand, the presence of prolapse and dermatitis at the same time refers to the onset of the second complication as a result from the first one; that is, depending on the degree of externalization of the intestinal loop, this may be exposing the skin to effluent and excessive secretion of mucus and, therefore, decreases the low adhesiveness of the bag, which facilitates excrement leakage.^{28,32,33}

Therefore, in view of the many aspects that involve the rehabilitation of ostomized people, nursing care of the stoma should begin at diagnosis, on the occasion of surgery indication and on the day of demarcation of the stoma. Thus, the aim is to minimize complications and sufferings in achieving self-care, and furthermore, to obtain a better adaptation. Many patients end up getting dissatisfied with life and with the difficulties to develop their daily activities, feeling afraid to perform self-care. Such feelings have the effect of modifying the quality of life.^{33,34}

When the ostomized individual starts to realize that gas or odor is coming out through the stoma, and when some complications arise (such as dermatitis, which can cause pain), a need for more than one change of the device supervenes. Such

an event makes the patient suffer biopsychosocial changes. Most patients feel shame, and in the end just do not want, or feel unable, to go on working, studying, and taking part in daily activities and leisure. This gives rise to a change in his/her quality of life and well-being – and even to dissatisfaction with their life.

All these physical changes can also cause the patient to feel that his/her life worsened and that is difficult to live with other people – and this may also result in changes in family relationship.

In the present study, the mean of the Subjective Well-being Scale domains was low (positive affect: 2.51, negative affect: 2.23, satisfaction with life: 2.77) and the mean of quality of life was 26.16, characterizing negative changes of these dimensions of Subjective Well-being Scale and a decrease in quality of life with Flanagan Quality of Life Scale.

Satisfaction is a complex and difficult-to-measure phenomenon, because it is a state of subjective well-being. It is the greatest expression of life experience with respect to the various living conditions of a person. Satisfaction with life is a cognitive judgment of a few specific areas in the individual's life, such as health, activities of everyday life, work, housing, social relationships, family relationships and leisure and autonomy; that is, a process of judgment and general assessment of life itself, according to our own discretion. The judgment of satisfaction depends on a comparison between the living circumstances of the individual and on a standard established by himself/herself. Satisfaction reflects, in part, the individual subjective well-being, that is, the way and the reasons that lead people to live their life experiences in a positive way.^{35,36}

“Subjective well-being” seeks to understand the assessment that individuals make about their own lives on the following issues: happiness, satisfaction, mood and positive affect; some authors consider this as a subjective assessment of quality of life.³⁶

In a study developed with ostomized patients, the authors concluded that the perception of these subjects with regard to the collection bag is closely intertwined with the presence of negative feelings: fear, insecurity, mutilation and suffering, as well as of self-destructive feelings. The most common changes experienced by our interviewees are related to the maintenance of their social network (work and leisure) and to their sexuality, because they feel insecure and fear rejection. It is noteworthy that these existential conflicts are generators of changes of psychological, emotional and social order. However, this study allows us to become aware of how the process of adapting this experience with the collection bag happens. Thus, it is expected that the results of this study could possibly represent a starting point for the development of a nursing care strategy centered on the client. Given this reality, we emphasize self-care. This proposal has been described as a therapeutic alternative that allows the patient to actively participate in his/her treatment, by stimulating the responsibility for continuity of care after discharge, which will contribute to the rehabilitation process and to overcoming his/her difficulties.³⁷

Of the three dimensions of subjective well-being, “life satisfaction” has greater predictive relationship with social support and with coping strategies. A study conducted by several

authors has shown that life satisfaction is higher in women, people receiving pension, people who are satisfied with the support received, people who support others, and people facing directly their problems with a positive reappraisal. On the other hand, positive affects also increase with satisfaction from the support received and with a direct and reappraising coping attitude, as well as with a decrease in avoidant coping.³⁶

In a study where intestinal stoma patients had a mean of 10.81 in the Rosenberg Self-Esteem Scale/UNIFESP-EPM, with regard to the Body Investment Scale, the mean of total score was 38.79; the mean of "body image" and "personal touch" domains was 7.74 and 21.31, respectively. These data mean that ostomized patients had low self-esteem and self-image changes in all stoma characteristics and in sociodemographic data. In other words: after acquiring the stoma, these individuals had negative feelings about their own bodies.³⁴

Negative affects decrease when social support is provided, although they increase with avoidant coping. This is another reason for not to consider the individual with acute or chronic wounds just as a passive recipient of help and understanding. The scope of their actions also contributes to their well-being and satisfaction. After all, the lesser predictive power of social support and coping styles on their positive and negative affects indicates that other variables are involved in the dimensions of subjective well-being of injured people, particularly in those issues that are directly connected to their functional autonomy.³⁸⁻⁴¹

In this study, it was shown the importance of the use, by the carer (nurse, doctor, psychologist) involved in the care of ostomy patients, of a clear, accessible and objective language, for better understanding by the client, considering that a good nursing care should begin preoperatively, with assessment, guidance and care in the necessary preparation of the client facing the surgery. On the other hand, this preparation should be continued throughout the period in which the patient remains with the ostomy – which can be permanent. The ostomized patient should be well guided, taught and trained on the skills necessary to take his/her self-care, especially regarding stoma handling, such as cleaning the peristomal skin, specifications and availability of specific equipment and aids for effluent collection.^{41,42}

Patients with intestinal stoma in this study showed changes in their quality of life and subjective well-being.

Conflicts of interest

The authors declare no conflicts of interest.

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