

Quality of life in short bowel syndrome: in a single center

Qualidade de vida na síndrome do intestino curto: em um único centro

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ABSTRACT

Model of the study: This is an exploratory and descriptive study which was executed in sector of Nutrology nursing at University Hospital, Faculty of Medicine of Ribeirão Preto, University of São Paulo (HCFMRP-USP). **Objective:** The aim of this research was to evaluate the perception of quality of life of individuals with short bowel syndrome (SBS) with the help of the Quality of Life Core - 30 Questionnaire (QLQ - C30). **Methods:** The instrument used was the EORTC- QLQ-C30 (European Organization for Research and Treatment of Cancer Quality of Life Questionnaire/ Quality of Life Core - 30 Questionnaire) version 3.0 in Portuguese. The study was conducted on six patients with SBS. **Results:** The applicability of the questionnaire was adequate and the mean score obtained for this sample (70.7) was considered to be satisfactory. **Conclusions:** The most affected domains were: Emotional Function and Symptoms: pain, insomnia, fatigue, and diarrhea. The application of the QLQ - C30 permitted us to evaluate the perception of the patient regarding his condition and quality of life, important aspects that should be considered by the team.

Key words: Quality of Life. Short Bowel Syndrome. Questionnaires. QLQ - C30 Questionnaire. Health Status.

Introduction

The different areas of medicine have always given priority to the study of disease and the way to assess its frequency and intensity.¹ Increasing concern has recently arisen not only about these aspects, but also about the measurements of the impact of diseases and their respective treatments on daily activities, and the perception of health and dysfunction or functional status.^{2,3}

In 1946, the World Health Organization (WHO) showed concern about creating a broader concept, defining health as a complete state of physical, mental and social well-being and not simply as the absence of disease (WHO, 1946 apud Fleck, 2000 p.34).³ In the 1990's, the Quality of Life Group of the World Health Organization (WHOQL Group) defined quality of life (QoL) as "*the perception of an individual of his position in life, in the context and system of values in which he lives and in relation to his objectives,*

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expectations, standards and concerns" (WHOQL GROUP, 1995 apud Fleck, 2000 p. 34).³

Nowadays, there is a consensus about the concepts for a definition of QoL, which are: Subjectivity related to the responses of the individual himself which depend on his life experience, values and culture; Multidimensionality which is characterized by the various domains that involve the evaluation of QoL, and Bipolarity, whose evaluation of QoL may vary from good to poor.^{4,5}

Improved QoL started to be one of the expected results in the sector of health promotion and of disease prevention. The information about QoL has been used as an indicator for the assessment of the efficacy and impact of determined treatments for groups of people with various diseases, and also for the comparison of procedures for the control of health problems.⁶

Short bowel syndrome (SBS) is a disabsorptive state that occurs after extensive resection of the small intestine (70 to 75%), impairing the normal process of nutrient and fluid absorption.^{7,8} The signs and symptoms observed during the immediate postoperative period are profuse watery diarrhea, weight loss, dehydration and malnutrition due to the extensive intestinal resection, especially of the ileum, with or without the presence of the colon.^{7,8,9}

Adaptive changes occur in three distinct phases. Phase I, the acute phase, occurs from the immediate postoperative period to three months after resection. Phase II, or adaptive phase, starts during the first 24 to 48 hours after resection and may last up to one or two years. And phase III, or maintenance phase, is the one during which the remaining intestine reaches its maximum adaptive capacity, of hypertrophy and hyperplasia, with the possible occurrence of total, partial or minimal adaptation.^{7,8,9}

Individuals submitted to enterectomy may depend on oral, enteral and/or parenteral nutritional therapy.¹⁰ In Brazil, treatment still involves frequent hospitalizations for parenteral and oral nutrition, with the feeding plan offered to the patient containing certain particularities and restrictions such as diet fractionation and appropriate distribution between macronutrients and fibers.¹¹ These measures require the patient to spend less time with his family and cause complaints about the treatment and diet proposed, a fact that reduces the QoL of these individuals.

The requirement of nutritional therapy is part of the daily routine, resulting in the development of other worries and necessities, especially when the

patient leaves the hospital environment and returns home. Other aspects related to the syndrome, such as the presence of pain, the constant need to consume food, the occurrence of fistulae, high-output stoma, presence of ventral venous access, and the occurrence of diarrhea may interfere directly with the self-esteem and dignity of these patients.¹⁰

It is known that the incidence of mortality among these patients is high, and the nutritional therapy is important to the maintenance of health status.¹²

Even though the home parenteral nutrition could be a good option for these patients to improve QoL, in our country, there are some limitations such as socio-economic status and conditions of home environment.¹²

Moreover, the long-term use of parenteral nutrition (PN) may result in risk of catheter complications and PN-induced liver dysfunction.¹³ Those individuals with major complications related to PN and end-stage liver failure are usually indicated to undergo small bowel transplantation.¹³ However, in Brazil, this procedure is still seldom performed.¹⁴

The Metabolic Unit Ward of our institution is a service specializing in nutritional therapy for patients with SBS. During the present follow-up period, frequent patients complaints were heard regarding QoL, mainly influenced by the disease and its treatment. In view of these problems, the objective of the present study was to assess the QoL of patients admitted at the Nutrology sector of the University Hospital, Faculty of Medicine of Ribeirão Preto, University of São Paulo (HCFMRP-USP).

Methods and Materials

This was a cross-sectional study of the exploratory and descriptive type conducted at the sector of Nutrology of HCFMRP-USP. The study was approved by the Ethics Committee of HCFMRP-USP (protocol n°9509/2010) and all patients gave written informed consent to participate.

The Nutrology sector is responsible for the follow-up of patients with a diagnosis of SBS. The referred patients have massive intestinal resections, with serigraphy corresponding to 15 minutes. During the first months of treatment the patients spend long periods in the hospital due to their fragile clinical condition. According to the evolution of each patient, follow-up can be on an outpatient basis or by means of periodic hospitalizations.

The sample consisted of patients with a diagnosis of SBS due to different causes who were selected according to the program of elective hospitalization during the period from September to November 2009. At that time, nine were the total of patients who were followed by periodic hospitalizations in the Nutrology sector. During this period, together with the administration of PN, an individualized oral diet is offered, according to the tolerance of each individual.

The instrument used for data collection was the EORTC- QLQ-C30 (European Organization for Research and Treatment of Cancer Quality of Life Questionnaire/ Quality of Life Core - 30 Questionnaire) version 3.0 in Portuguese, which was filled out by the patient himself or by means of an interview held by the investigator when the patient was unable to reply to the questionnaire in an autonomous manner due to obstacles such as being bedridden or being of low sociocultural and economic level. The remaining information, such as socioeconomic and clinical data was obtained by means of an interview and by reviewing the medical records.

The questionnaire contains 30 items consisting of scales with multiple items and measurements of a single item that reflect the multidimensionality of the instrument. The scores of the scales and of the measurements range from 0 to 100. When the score for the functional scale is high, this represents a healthy functional level, while a high score on the symptom scale represents a high level of symptomatology.⁴

The socioeconomic and clinical data and the data of the EORTC QLQ-C30 were analyzed by descriptive statistics through the calculation of the mean, standard deviation and median using the Excel Windows® 2000 software.

Results

The sample of this pilot study consisted of six patients with SBS. Mean patient age was 51 ± 17 years (range: 21-71 years). There was a predominance of female gender (66.6%) corresponding to 4 of the 6 patients. Most patients (83.3%) had a low educational level and had a mean family income of 2.6 Brazilian minimum wages, as shown in Table 1.

Mean time of disease and treatment was 51.7 ± 55.8 months (range: 2 months -141 months), as shown in Table 2.

The main causes of intestinal resection were: mesenteric thrombosis (66.6%), abdominal trauma

(16.6%) and Crohn's disease (16,6%) and the main comorbidities were arterial hypertension, aneurysm of the ascending aorta, chronic renal failure, idiopathic peripheral polyneuropathy, Sweet syndrome, renal lithiasis, pyelonephritis, chronic pancreatitis, and hypothyroidism (Table 2).

Nutritional status was evaluated on the basis of body mass index (BMI), which showed that most patients were malnourished, with a mean BMI of 18.05 ± 2.48 kg/m². Among the participants younger than 60 years, only one was found to be eutrophic according to the classification of the WHO and all subjects older than 60 were malnourished according to the classification of Lipschitz (Table 3).^{15,16}

Evaluation of the mean scores showed that there was a favorable perception of general health status and QoL (70.7) on the part of the patients although the functional scale showed low mean scores ($\leq 50,1$), except for the social subscale (64), reflecting an important sensation of limitation imposed by the

Table 1
Socioeconomic characteristics of the enterectomized patients.

Characteristic	Number	%
Age		
< 60 years	4	66.6
≥ 60 years	2	33.3
Sex		
Female	4	66.6
Male	2	33.3
Schooling		
Incomplete elementary school	5	83.3
Complete elementary school	1	16.6
Family income*		
1 to 2 minimum wages**	1	16.6
2 to 3 minimum wages	2	33.3
3 to 4 minimum wages	2	33.3
Marital status		
Single/Divorced	2	33.3
Married	4	66.6

* 1 patient did not know his family income

** 1 Brazilian minimum wage: R\$ 465.00 = US\$ 837.00

Table 2
Clinical characteristics of the enterectomized patients.

Characteristic	Number	%
Disease duration		
< 12 months	1	16.6
12 to 36 months	3	50
> 36 months	2	33.3
Motive of resection		
Mesenteric thrombosis	4	66.6
Abdominal trauma	1	16.6
Crohn's disease	1	16.6
Presence of co-morbidities		
Yes	3	50
No	3	50

Table 3
Classification of nutritional status according to body mass index (BMI)

Classification	Number	%
Nutritional Status (adults)*		
BMI > 18.5 kg/m ²	1	25
BMI < 18.5 kg/m ²	3	75
Nutritional Status (elderly subjects)**		
BMI > 22 kg/m ²	0	0
BMI < 22 kg/m ²	2	100

* BMI classification for adults according to the WHO (1998).

** BMI classification for elderly subjects according to Lipschitz (1994).

disease. The subscale with the lowest score was the emotional one, showing the importance of psychological support for these patients in order to cope with this situation (Table 4).

Analysis of the median values for each scale and respective subscales revealed wide interpersonal variation of the scores, since this is a subjective evaluation. As a function of the reduced number of participants, we calculated the median for a better understanding of the data obtained. The evaluation of gen-

eral health status and QoL was satisfactory, with a median value of 74.9 (range: 41.6- 100).

In the functional scale, the social subscale was the one with the highest median (83.4), demonstrating a good perception of this function on the part of the participants. The emotional functional subscale had the lowest median (33.7), revealing that the interviewees do not have a good emotional response to the situation (Table 5).

The other domains of the functional scale showed mean and median scores close to 50, reflecting the sensation of limitation for the execution of daily activities.

The mean and median scores for the symptoms scale and other items of the symptoms evaluated were of low significance, indicating that little value was attributed to the symptoms related to the disease. Among the symptoms most frequently cited were pain, insomnia, fatigue, and diarrhea (Tables 4 and 5).

Table 4
Mean scores of enterectomized patients on the scales of the quality of life instrument EORTC QLQ-C30.

Scales	Subscales	Mean score
Functional	- Physical Function	48.9 ± 29.1
	- Role Performance	47.4 ± 30.6
	- Emotional Function	44.6 ± 28.7
	- Cognitive Function	50.1 ± 31.6
	- Social Function	64 ± 39
Symptoms	- Pain	47.1 ± 30.6
	- Fatigue	37 ± 27
	- Nausea and Vomiting	2.7 ± 6.8
Symptoms (items)	- Dyspnea	16.6 ± 27.9
	- Insomnia	38.8 ± 38.9
	- Loss of Appetite	5.5 ± 13.6
	- Constipation	16.6 ± 27.9
	- Diarrhea	33.3 ± 29.8
	- Financial Difficulties	66.8 ± 42.1
General Health Status/QL		70.7 ± 25.1

Table 5

Median values of the scales of the quality of life instrument EORTC QLQ-C30 for the enterectomized patients.

Scales	Subscales	Median	Minimum Value	Maximum Value
Functional	- Physical Function	50.0	0	80.0
	- Role Performance	50.5	0	83.4
	- Emotional Function	33.7	16.6	91.7
	- Cognitive Function	50.0	0	83.4
	- Social Function	83.4	0	100
Symptoms	- Pain	33.3	16.6	100.0
	- Fatigue	33.3	0	77.7
	- Nausea and Vomiting	0	0	16.6
Symptoms (items)	- Dyspnea	0	0	66.6
	- Insomnia	33.3	0	100.0
	- Loss of Appetite	0	0	33.3
	- Constipation	0	0	66.6
	- Diarrhea	33.3	0	66.6
	- Financial Difficulties	83.5	0	100.0
General Health Status/QL		74.9	41.6	100.0

The median score detected for the financial aspects was 83.5, reflecting a low impact of this domain on the QoL of the patients (Table 5).

When considering variables such as time of disease and age, it can be seen that older individuals or individuals with a longer time of disease would not necessarily be those with a negative perception of their general health status or QoL, with the contrary also being possibly true.

Evaluation according to gender revealed that women had more complaints than men, most of the time having the lowest scores for the functional scale, the highest scores for the symptoms scale, and lower scores for the perception of health status and QoL.

It was also observed that 2 of the 6 patients had a low score for the emotional functional subscale and a high score for the fatigue item (symptoms subscale).

Discussion

Since the EORTC QLQ-C30 is a questionnaire applied for the evaluation of QoL in patients with cancer, a disease of a chronic and consumptive nature, this was the instrument chosen here to evaluate this group of enterectomized patients. Indeed, SBS is also a chronic and consumptive disease due to the malabsorption caused by resection and, thus far, there is no specific instrument for the evaluation of affected patients. In Brazil, the EORTC QLQ-C30 was validated by Brabo (2001 apud Santos, 2003 p.34) and used by Santos as an instrument for the evaluation of QoL in patients with colorectal cancer.^{17,4}

Among the more relevant findings, it was observed that the most affected domains were emotional function and symptoms such as pain, insomnia, fatigue, and diarrhea. Chassany et al. detected low QoL scores

when they evaluated QoL in patients with functional digestive disorders, showing that digestive disorders and correlated syndromes have a significant impact on the physical and psychological conditions of these individuals.¹⁸

In a study by Nicolussi and Sawada conducted on oncologic patients using the EORTC QLQ-C30 for QoL evaluation, the main symptoms reported were pain, fatigue and insomnia.¹⁹ Although the present sample had a different disease from that of the group evaluated by Nicolussi and Sawada, the present patients had the same complaints as the patients with colorectal cancer, also including diarrhea, since an increased number of evacuations is frequent in these patients due to the disabsorptive situation generated by the extensive resection and reduction of the absorptive surface of the intestine.^{19,20}

The literature has discussed the impact of the female perspective on the evaluation of QoL, as shown by a study conducted by Carlsson, Bosaeus and Nordgren about the QoL and concerns of patients with SBS, in which there was a predominance of female gender.¹⁰ The influence of this finding on the results was discussed since studies have shown that women have lower QoL indices related to health.

In addition, the cited study showed that the main concern of these patients is the feeling of invalidity, i.e., of becoming a burden for other persons or being dependent on others, with this feeling being interrelated with the concept of integrity of the individual, his family relations and his daily activities. It has also been reported that fatigue may be a third complaint of these patients and that the concept of fatigue is a complex one by including physical, social and psychological aspects and also by being possibly associated with depression.¹⁰

Although the mean scores for the functional scale were not satisfactory, the perception of health status and QoL by the group studied here can be considered good.

Symptoms such as nausea and vomiting, common among patients with a diagnosis of cancer, showed a low score in the present group. The loss of appetite is also another symptom with a low score since the syndrome is associated with hyperphagia due to nutrient malabsorption. Diets providing 120 to 200% of the energy and protein requirements normally compensate for these signs and symptoms.²⁰

In a study of patients with SBS, Fernández-Estívariz et al. observed that most participants underreported their energy intake. After a review of 7 day

food recordings, the mean food intake increased from 2193 ± 216 kcal per day to 2656 ± 242 kcal per day, with a variation of food consumption of 721 to 4126 kcal per day among the participants.²¹

The present study has some limitations such as a reduced number of subjects, the use of a questionnaire specifically formulated for cancer patients and the socioeconomic and educational level of the participants, facts that prevent comparisons and statistical inferences.

However, the data obtained by applying this questionnaire are interesting by pointing out the importance of the patient's view of his physical condition and of his clinical treatment, favoring a rethinking of the form of approach to treatment. It is clear that psychological support is necessary for these patients so that they may build constructs of coping with the situation.

Besides that, these instruments of QoL assessment also become useful to verify the impact of a new type of treatment, such as small bowel transplantation, on the perception of health of these patients.^{22,23} DiMartini et al. (1998) and O'Keefe et al. (2007) observed changes in QoL perception in individuals who underwent an intestinal transplantation procedure.^{22,23} DiMartini et al. (1998) found that PN dependence caused significant impairment in the QoL which were restored after the surgery.²² Likewise, O'Keefe et al. (2007) verified that the major QoL domains evaluated had an improvement following transplantation due to the nutritional autonomy and the resolution of chronic disease.²³

Few studies are available in the literature about the various aspects of SBS, especially with respect to QoL. Thus, there is a lack of validated instruments for the measurement and/or assessment of the perception of these patients regarding their physical condition and overall QoL.

It is important to point out that this instrument evaluates the QoL related to health and that an association with another more generic questionnaire would be interesting in order to consider other aspects of daily life that may influence the QoL of these patients, such as frequent hospitalizations, short permanence at home, difficulty in adhering to nutritional therapy, and social questions, among others.

Therefore, the elaboration of a specific instrument tailored to the demands of this group would be an alternative in order to perform a broader investigation of the aspects that involve the perception of health status and QoL of these patients.

Conclusion

The findings showed that the most affected domains were Emotional Function and Symptoms such as pain, insomnia, fatigue, and diarrhea. The questionnaire employed (EORTC QLQ-C30) permitted us to evaluate the perception of enterectomized patients admitted to the ward of the Metabolic Unit of HCFMRP-USP regarding their health condition and

QoL, revealing important points that should be considered by the health team. This evaluation was important for the service in order to encourage the elaboration of a new clinical approach to these patients, reducing the assistential nature that often characterizes the treatment. Other surveys should be proposed with the association of other instruments that might permit a more encompassing analysis of the aspects screened in the present study.

RESUMO

Modelo do estudo: Estudo de corte transversal do tipo descritivo e exploratório realizado na enfermaria da Unidade Metabólica do Hospital das Clínicas da Faculdade de Medicina de Ribeirão Preto, Universidade de São Paulo (HCFMRP-USP). Objetivos do estudo: Avaliar a aplicabilidade do Quality of Life Core - 30 Questionnaire (QLQ - C30), não específico para Síndrome do intestino curto (SIC) em portadores da síndrome. Metodologia: Para a coleta de dados foi utilizado como instrumento o questionário EORTC-QLQ-C30 (European Organization for Research and Treatment of Cancer Quality of Life Questionnaire/Quality of Life Core - 30 Questionnaire) versão 3.0 em português. O estudo foi realizado com 6 pacientes com SIC. Resultados: A aplicabilidade deste questionário foi adequada; o escore médio obtido nesta amostra foi considerado satisfatório (escore médio = 70,7). Conclusões: Os domínios mais afetados foram: Função Emocional e sintomas: dor, insônia, fadiga e diarreia. A aplicação do questionário QLQ - C30 possibilitou avaliar a percepção dos pacientes quanto a sua condição de saúde e qualidade de vida, revelando pontos importantes que devem ser considerados pela equipe.

Palavras-chave: Qualidade de Vida. Síndrome do Intestino Curto. Questionários. Questionário EORTC-QLQ-C30. Condições de Saúde.

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