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Original Article

Sociodemographic and clinical features and quality of life in stomized patients[☆]



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ABSTRACT

Objectives: To identify users with an intestinal ostomy concerning their sociodemographic and clinical characteristics, and to determine the scores for quality of life according to the domains of the questionnaire City of Hope.

Method: This is a household, descriptive, transversal, quantitative-approach survey, accomplished with 30 registered users at the Ostomy Association of the State of Paraíba, Brazil. A specific form for ostomy patients was applied, and data analysis was performed with the use of the software Statistical Package for Social Sciences (SPSS) version 20.0. This study was approved by CAAE No. 17224613.8.0000.5183.

Results: Most participants were over 60 years, were Catholics, with elementary education, an income up to three minimum wages, married or in a stable relationship, with almost all quality of life scores above the midpoint of the range of the variables of the domains surveyed by the questionnaire City of Hope.

Conclusion: The questionnaire led to the conclusion that the respondents with ostomy had a satisfactory quality of life.

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Características sociodemográficas e clínicas e qualidade de vida de pessoas com estomia intestinal

R E S U M O

Palavras-chave:
Qualidade de vida
Estomia
Saúde

Objetivos: Caracterizar os usuários com estomias intestinais quanto aos aspectos sociodemográficos e clínicos e determinar os escores de qualidade de vida segundo domínios do questionário City of Hope.

Método: Trata-se de inquérito domiciliar, descritivo, transversal e de abordagem quantitativa, realizado com 30 usuários cadastrados na Associação de Ostomizados do Estado da Paraíba. Utilizou-se formulário específico para estomizados e a análise dos dados foi realizada com o auxílio do programa *Statistical Package for the Social Science* (SPSS), versão 20.0. A pesquisa foi aprovada com CAAE n. 17224613.8.0000.5183.

Resultados: A maioria tinha mais de 60 anos, católicos, com ensino fundamental, renda de até três salários, casados ou em união estável, com quase todos os escores de qualidade de vida acima do ponto médio da escala para as variáveis dos domínios explorados pelo questionário City of Hope.

Conclusão: O instrumento permitiu inferir que os estomizados pesquisados possuíam qualidade de vida satisfatória.

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Introduction

The making of a stoma indicates the temporary or permanent externalization of a hollow viscus in the body. Depending on the externalized segment, the type of ostomy receives names such as colostomy, ileostomy, and urostomy, among others. This therapeutic procedure is caused by various diseases.^{1,2}

Although official information from the Ministry of Health on the situation of ostomized people in Brazil are non-existent,³ data published by the Brazilian Association of Ostomized People estimate that 33,864 people live with a stoma in our country, with 4,176 living in the Northeast Region, of which 496 are in the state of Paraíba.⁴

The biopsychosocial consequences of an ostomy procedure are associated with the surgical treatment, and influence the lives of these people and of their families. The bowel ostomy has been identified as the main change that could affect interpersonal, social, labor, sex and leisure aspects.^{5,6}

Of all the changes caused by the stoma, the physical changes stand out, not only by affecting the intestinal physiological process, but by its impact on self-image and self-esteem. On the other hand, the presence of a stoma can lead to mental and emotional imbalance, as well as interfering directly in the quality of life. The physical appearance assumes increasingly considerable dimensions when it comes to chronic wounds, given that the skin possesses an essential and almost symbolic characteristic on the lives of each individual, representing a world where body and spirit get together. Thus, the skin configures its self-wellness.⁷

The multiple transformations resulting from the colostomy deeply affect the quality of life of patients undergoing this procedure, which prompted to studies on this subject.⁸⁻¹¹ One can observe that, in order to have a good quality of life, it is critical that people feel satisfied in many ways, including maintaining

their physical integrity, which is broken during the process of making the stoma.¹²

Therefore, the knowledge of social and clinical characteristics and of aspects of quality of life of ostomy people may facilitate the planning of assistance in relief programs, considering the maintenance of a concomitant adjuvant treatment and of demands of other needs arising from the clinical condition of the bowel ostomized patient, which, after the radical change that occurred in their pattern of elimination, must relearn to live with himself and with his/her family, friends and society.

Considering the sensitivity of the subject, we consider that the investment in research seeking further clarification on the issue is highly relevant. Thus, the objectives outlined in this study were: to characterize users with an intestinal ostomy as sociodemographic and clinical characteristics, and to determine the quality of life scores according to the domains covered in the questionnaire City of Hope.

Method

This is household survey, descriptive, cross-sectional and of quantitative approach study. The initial contribution to this study came from the Ostomy Association of the State of Paraíba (AOEPB). AOEPB is considered a referral service for stomized people in that State, being linked to the outpatient department of a teaching hospital in the city of João Pessoa.

After the initial communication with the stomized patients' sector, the selection of people from the registered users' list in that service was started, considering the following inclusion criteria: people with a permanent or temporary colostomy, living in the city of Joao Pessoa or in its metropolitan area, and be of legal age. In the survey, people with urostomy, ileostomy or jejunostomy were not included. 223

people registered at AOEPB up to December 2012 were identified. At first, telephone contact attempts were made, but 92 individuals could not be reached for various reasons (non-existent phone number, or phone number not found).

Of the 131 remaining registered people, 77 individuals did not meet the inclusion criteria, i.e. they were excluded for being under legal age, by reversal of the colostomy and/or death. In addition, 24 refused a home visit, claiming that they did not feel comfortable talking about this subject. Thus, 30 individuals remained in the sample. After confirming the desire to participate, a visit was scheduled to administer the questionnaire in the participant's home.

For data collection, two instruments were used: a form consisting of sociodemographic questions and clinical data of the participants, and a questionnaire, the City of Hope – Quality of Life Questionnaire for a Patient with an Ostomy.¹³ The total score was obtained by the arithmetic mean of the 43 questions contained in the instrument (i.e., the sum of the scores of all items of the instrument, divided by 43). The arithmetic mean of all domains was obtained taking into account the number of variables in each of the domains.

In this study, a score of 5 was set as the cutoff point. Thus, means >5 indicate a good QoL, and means <5 suggest a poor QoL. The score 5 is the midpoint on the scale of assessment of the variables that make up the instrument applied.¹³ For a correct interpretation of the results, some items had their scores reversed; these items were: 1–12, 15, 18 and 19, 22–30, 32–34 and 37.¹³ The contact phase was carried out between September 2013 and February 2014. Data collection occurred from February to April 2014.

Data were compiled and analyzed using the Statistical Package for the Social Sciences (SPSS) program, version 20.0, using descriptive statistics (absolute frequency, percentage, and mean/standard deviation). The project was approved by the Research Ethics Committee under report number 370 838 and Certificate No. 17224613.8.0000.5183. All participants were informed about the purpose of the research, its secrecy, the right of withdrawal, and signing of the Free and Informed Consent form, bearing in mind the requirements of Resolution 466/12 of the National Health Council.¹⁴

Results

Participants had a mean age of 60.67 ± 11.76 years, with prevalence in the age groups 51–59 years and 59–67 years, both with 8 (26.7%) respondents. As to gender, there was equity in the distribution, since 15 (50%) were women and 15 (50%) men, constituting a coincidence of equality, because this is not a controlled variable, since ours was a non probabilistic sample.

About the occupation, five categories were cited: 20 (66.7%) retirees, 4 (13.3%) pensioners, 3 (10.0%) of domestic chores, 6 (6.7%) autonomous and 1 (3.3%) unemployed. On religion, only two categories were mentioned: Catholicism practitioners, 26 (86.7%) and Evangelical Church attendants, 4 (13.3%).

It was found that 15 (50%) participants had primary education, 16 (53%) received up to three minimum wages, were married or living in a stable union. The mean family income ranged from <1 (1) to >5 (5) times the minimum wage, with

Table 1 – Mean of scores for City of Hope Questionnaire domains. João Pessoa, Paraíba, 2015 (n = 30).

Domains	Mean	Standard-deviation
Physical well-being	7.39	2.05
Psychological well-being	7.05	1.25
Social well-being	7.06	1.56
Spiritual well-being	7.65	2.13
Global mean of quality of life	7.26	1.21

prevalence of the group from 1 to 3 salaries with 15 (50%) participants.

Clinically it was observed that most of surgeries had a therapeutic indication, for the treatment of bowel cancer (24; 80%). Of the 30 respondents, 22 (73%) had a permanent stoma, 27 (90%) showed an inadequate position of the stoma, 13 (44.8%) had a colostomy for over ten years and 24 (80%) did not present any kind of complication. With regard to BMI, 15 (50%) were overweight and 13 (43%) remained with their weight within normal limits.

Considering the structure proposed by the City of Hope questionnaire, we presented the means for each domain and for their variables, as well as the total score of QoL among the participants of the study. On the behavior of variables of “physical well-being” domain, the overall mean was 7.39, and it was observed in its variables that the lowest mean concerns to gases (5.77) and the highest mean refers to “overall physical well-being” (7.90) (Fig. 1).

For the domain “social well-being”, the overall mean was 7.06. It is evident that, for this domain, a larger number of variables stays closer to the midpoint of the scale (5); the lowest mean obtained was for “interference with the ability to travel” (5.27) and the highest mean was for “privacy at home” (in relation to the care of the stoma) (8.93) (Fig. 2).

The domain “psychological well-being” had a mean of 7.05, and was the only domain averaging <5 on one of its variables (anxiety, 4.69). “Depression” was the variable that contributed for the highest mean (8.63) (Fig. 3).

Fig. 4 depicts the mean scores of the variables that make up the domain “spiritual well-being”. The lowest mean corresponds to the “uncertainty about personal future” (5.30) and the highest mean refers to the variable “spiritual support” (8.83).

By observing the distribution of the overall means for the four domains of the questionnaire, it was found that the domain with the best scores for quality of life corresponded to “spiritual well-being” (7.65), and that the means obtained for the domains “psychological well-being” (7.05) and “social well-being” (7.05) had the lowest means. As to the standard deviation of the domains “psychological well-being” and social well-being”, a greater homogeneity among the means of the variables that make up these domains was confirmed, in comparison with other domains, which showed greater variability (Table 1).

Discussion

Analyzing the socio-demographic description, it can be inferred that, with the aging phenomenon and the normal

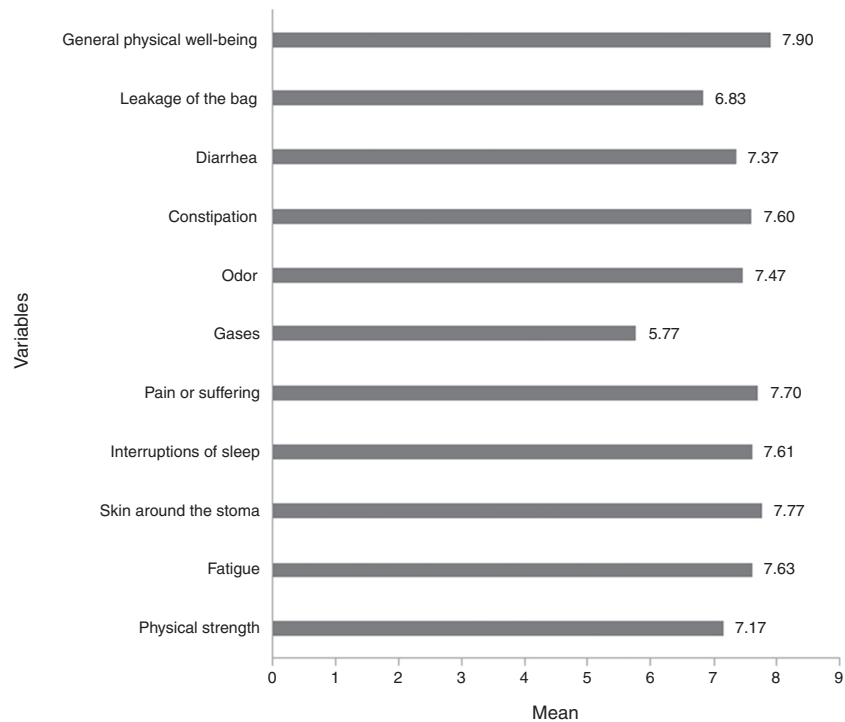


Fig. 1 – Mean scores of the variables that make up the physical well-being domain of the City of Hope questionnaire. João Pessoa, 2015, n = 30 (mean = 7.39, SD = 2.05).

physiological process of the body, illnesses or chronic conditions tend to affect people. In the case of cancer, although this disease does not result of physiological aging, it is observed that, with increasing age, there is a higher incidence of certain types of cancers, distributed between genders in a specific way. Colon and rectal cancer occurs in both genders.¹⁵

Regarding gender, the fact of being a woman or a man did not influence the fact of being a colostomized subject. In the literature, some studies show a predominance of males,¹⁶ while in others there is a female predominance.^{11,17} This fact relates to the diversity of the population and depends on the area surveyed. Although some authors^{18,19} claim that the

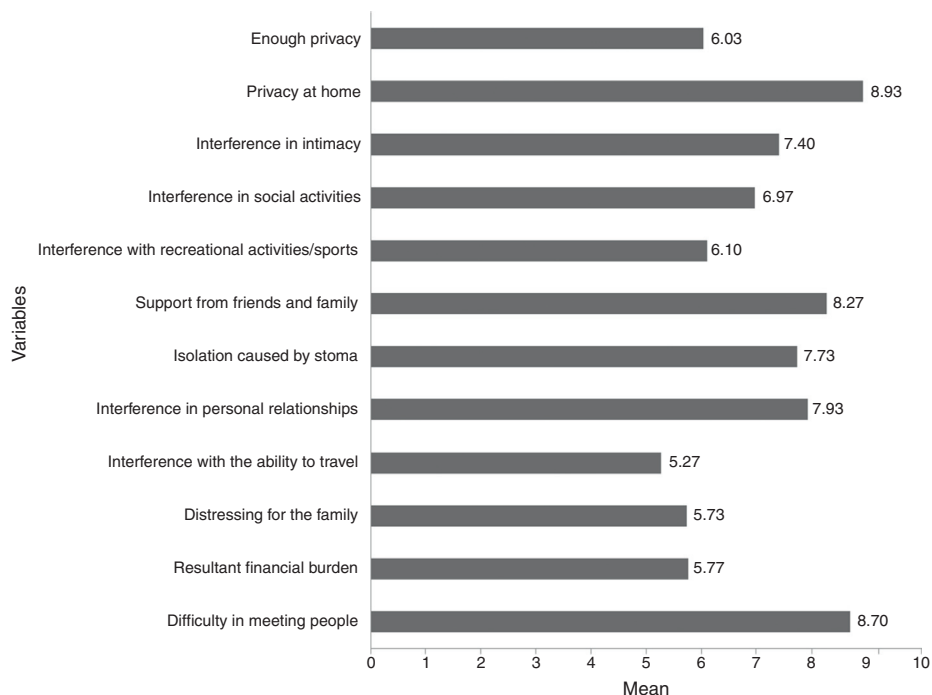


Fig. 2 – Mean scores of the variables that make up the social well-being domain of the City of Hope questionnaire. João Pessoa, 2015, n = 30 (mean = 7.06, SD = 1.56).

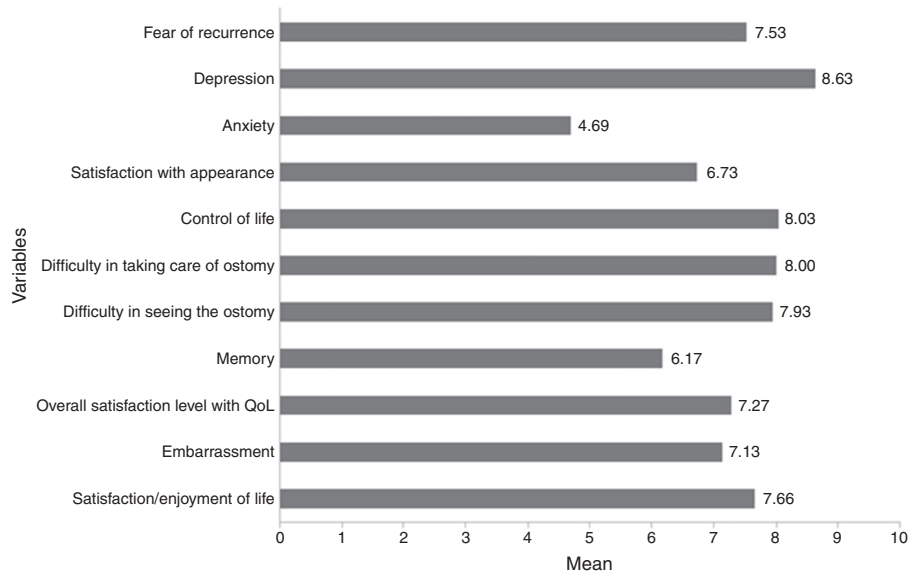


Fig. 3 – Mean scores of the variables that make up the psychological well-being domain of the City of Hope questionnaire. João Pessoa, 2015, n = 30 (mean = 7.05, SD = 1.25).

gender influences the social adaptation of the ostomized individual, emphasizing that women are more resilient and best suited to new habits.

As for working occupation, in general all workers, after contributing to Social Security, acquire the right to enjoy their labor retirement. In addition, the permanent condition of colostomy guarantees retirement to the individual affected. In this study, this relationship has not been verified. However, a similar study identified predominance of retirees in colostomized groups.²⁰

Considering the religious aspect, it is possible to ensure that this factor strengthens faith and consolidates values and beliefs that directly affect the quality of life of a stomized person, favoring his/her rehabilitation.²¹ It is believed that religion is an important factor to improve health, by providing spiritual support, regardless of which religious creed is

followed by the individual, although in the present study the majority of our sample stated to profess Catholicism (86.7%).

With regard to education, half of the sample studied only up to primary school. Schooling is a relevant aspect for understanding the guidelines for the care of the stoma, the device for waste collection, the regular monitoring of health, nutrition and hygiene, as well as the various conditions settled from the surgery.

About marital status, it is assumed that the fact that 53.4% of respondents are married or in a stable relationship can have a positive influence on the way the ostomized person deals with his/her new state of health, thanks to the emotional support offered by his/her partner. Regarding this aspect, our study confirms that many of the ostomized people are married and living with his/her spouse, but no association between resilience and marital status was proved.^{11,22}

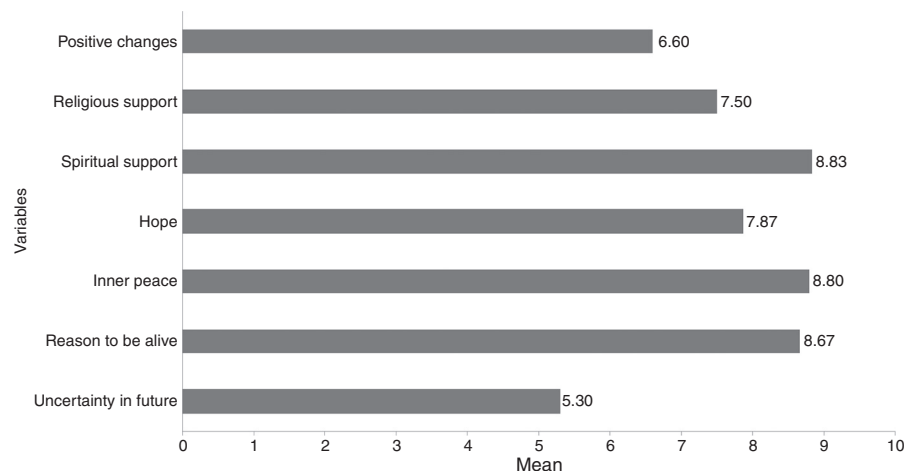


Fig. 4 – Mean scores of the variables that make up the spiritual well-being domain of the City of Hope questionnaire. João Pessoa, 2015, n = 30 (mean = 7.65, SD = 2.13).

As for monthly income, it is known that the financial situation may influence the way of living with a colostomy, because this state requires special care and the acquisition of materials that burden the family budget. As to our sample, we found that 50% live with an income of 1-3 minimum wages. The income can interfere with the acquisition of consumable materials related to ostomy care, really affecting the quality of life.¹⁰

With regard to the clinical characterization, most participants show an improper positioning of the stoma and high body mass indexes. Perhaps these two variables may be linked. However, it was not possible to say whether the inadequacy of the stoma comes from weight gain (which collaborates with an increase of abdominal circumference), or whether this inadequacy is a result of lack/inadequacy in the demarcation of the stoma during surgery. This finding only would be possible if the assessment was performed immediately after surgery and of the edema regression, commonly occurring postoperatively, or after surgical healing have been occurred.

Most of the participants did not present post-colostomy complications, and only 10% reported dermatitis. This may suggest that: the surgery was successful, the physicians conducted their guidelines efficiently, and/or the family care/self-care was adequate.

On the permanence of the stoma, 73.3% of participants claimed to have a permanent colostomy, which can be observed in other studies.^{3,23} With reference to the reason for the surgery, cancer has been the most frequently condition cited. Other studies have shown the prevalence of colostomies in association with cases of colorectal cancer.²⁴⁻²⁶

About colostomy time, most participants reported more than ten years of surgery. During the development of this study, it became clear that, over time, these individuals have found a parsimonious way to live with their current state, thanks for their religious faith, the seemingly irreversible definitive condition, or simply for the fact of being alive. This attitude seems to contribute to improving the quality of life of these individuals.

Regarding the domain "physical well-being," it is known that gases cause bloating, which can lead to viewing the prominence below the garment, or the accidental detachment of the bag. Therefore, flatulence can cause discomfort, since they are an uncontrollable phenomenon, and although the non-externalization of the odor, thanks to the closure of the device, yet the sound caused by gases may result embarrassing for ostomy patients or persons who witness this situation. Thus, it is possible that these reasons justify the smallest mean of the domain, and its closest position with respect to the midpoint of the scale for the variable "gases" (Fig. 1).

For the domain "social well-being", travels can be a form of recreation (Fig. 2). However, the colostomy implies some peculiarities, such as the need for a place and special materials for cleaning the device by the ostomized person, as well as the need for privacy to remove the collector bag, and last but not least, the nuisance caused by the curiosity of other witnesses present. Considering all that, implications can accrue for how ostomized people perceive and experience the social coexistence.

The social non-isolation is an imperative factor in the restoration of self-esteem of ostomized people. Social interaction can contribute to overcoming the feeling of mutilation,

as a network of relationships will provide distraction and moments of joy, favoring recovery and raising hopes for the continual seeking for a better quality of life.²⁷

As for the domain "psychological well-being", it is known that anxiety is part of the field of emotions, and that it may arise in new or unexpected situations. The score below the midpoint 5 indicates a negative interference in the quality of life of the participants, despite the finding of a mean of the domain above 7, which may be attributed to the value of the other variables' means, which, in three cases, was superior to 8 (Fig. 3).

On the other hand, the colostomy can be seen as a "breath of life", a hope signal, or as a new opportunity after a painful diagnosis of cancer. In this study, it is suggested that the relationship between the colostomy time and the sadness felt by the ostomized individual is inversely proportional, that is, over time, the individual can get used to the colostomy, not allowing him/herself to be depressed, and neither that it interferes with his/her quality of life.

On this subject, a study found that feelings of denial and depression were more frequent in the early stages of the new condition, because the sadness was caused by the shock of the change in body esthetics, or by the severity of the clinical picture. Over the years, there was a decrease in the frequency of reports of feelings of sadness.¹¹

Regarding the domain "spiritual well-being", it is believed that the impact caused by a negative diagnosis can lead to fear of death, frustration about upcoming plans, and doubts as to the events of life.

However, religious practices may be important resources in the process of minimization of the negative shock caused by the stoma, for helping in the subject's fidelity to treatment, reducing stress/anxiety, and in the search of a meaning for the new situation.^{28,29}

Thus, it is understandable that the group had obtained a lower mean for uncertainty in the future, thanks to the nature of the disease and its treatment; but nevertheless these people showed good means for spiritual support and inner peace, as these aspects interact with each other (Fig. 4).

The results in Table 1 indicate that, despite the means above 7, some variables evaluated in the fields presented results close to the midpoint of the range, under which the quality of life is not evaluated at a good level, which is in line with studies performed in Teresina, PI¹⁶ and Iran,³⁰ whose means and standard deviations obtained were 6.16 (SD = 2.83) and 7.48 (SD = 0.9), respectively.

Thus, a watchful eye to the aspects which can cause damage to the quality of life of stomized people is critical, because in this way new perspectives may emerge and favor the proposition of actions, be they educational or therapeutic, by different health professionals and in related fields. These dimensions would culminate in improvements in aspects that revealed more fragility in the group studied.

Conclusion

In the face of our results, it was found that the characterization of subjects follows the findings of other studies conducted in Brazil, both with respect to sociodemographic and clinical

profile, as to quality of life scores. In fact, one cannot hide the physical, social, economic and psychological disorders that involve the process of learning and living with the stoma. Therefore, it is critical to strongly emphasize the importance of health teams in all instances, in order to encourage interventions that will be converted into valuable impulses for the life of ostomized people.

We emphasize the importance of the work of the team in charge of the service in the users' care, stressing that the support and health education are unique ways in the self-acceptance process. The lack of telephone data updating in the sector researched and the difficult access through household surveys were limitations in this study. New research should be encouraged, in order to acquire a deeper understanding of the physical, psychological and spiritual conditions that function as subsidies for the establishment of more effective strategies aimed at improving the quality of life of stomized people.

Conflicts of interest

The authors declare no conflicts of interest.

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