SOCIODEMOGRAPHIC AND SANITATION AND HOUSING INDICATORS ON THE QUALITY OF LIFE OF PEOPLE WITH STOMA

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ABSTRACT

Objectives: To analyze the relationships between the quality of life (QOL) of people with stoma with sociodemographic, clinical, lifestyle, sanitation, and housing indicators. **Method:** Cross-sectional study with a sample of 106 individuals with stoma interviewed from May to December 2019. A sociodemographic and clinical questionnaire and the City of Hope Quality of Life Ostomy Questionnaire were used. **Results:** Spiritual well-being (7.71 ± 1.09) was the best performing domain. Quality of life did not differ between men and women (p = 0.372), but was associated with education (< 0.001) and family income (p = 0.025), diabetes (p = 0.008) and alcoholism (p = 0.044), drinking water conditions (p < 0.001), garbage disposal (p = 0.021), having electricity (p = 0.034), housing type (p = 0.026), number of rooms (p = 0.023), and housing coverage (p = 0.021). **Conclusion:** worse socioeconomic, sanitation, and housing indicators appear to negatively impact the QOL of people with stomata.

DESCRIPTORS: Stoma. Quality of life. Social class. Basic sanitation. Lifestyle. Enterostomal therapy.

INDICADORES SOCIODEMOGRÁFICOS E DE SANEAMENTO E MORADIA NA QUALIDADE DE VIDA DE PESSOAS COM ESTOMIA

RESUMO

Objetivo: Analisar as relações entre a qualidade de vida (QV) de pessoas com estomia com indicadores sociodemográficos, clínicos, de estilo de vida, de saneamento e moradia. **Métodos:** Estudo transversal com amostra de 106 indivíduos com estomia entrevistados de maio a dezembro de 2019. Utilizou-se um questionário sociodemográfico e clínico e o *City of Hope - Quality of Life - Ostomy Questionnary*. **Resultados:** O bem- estar espiritual (7,71±1,09) foi o domínio com melhor performance. A QV não diferiu entre homens e mulheres (p = 0,372), porém esteve associada à escolaridade (< 0,001) e renda familiar (p = 0,025), ao diabetes (p = 0,008) e etilismo (p = 0,044), às condições da água para consumo (p < 0,001), ao destino do lixo (p = 0,021), em ter energia elétrica (p = 0,034), ao tipo de moradia (p = 0,026) e ao número de cômodos (p = 0,023) e tipo de cobertura da habitação (p = 0,021). **Conclusão:** Piores indicadores socioeconômicos, de saneamento básico e moradia, parecem impactar negativamente a QV de pessoas com estomias.

DESCRITORES: Estomia. Qualidade de vida. Classe social. Saneamento básico. Estilo de vida. Estomaterapia.

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INDICADORES SOCIODEMOGRÁFICOS Y SANITARIOS Y HABITACIONALES SOBRE LA CALIDAD DE VIDA DE LAS PERSONAS OSTOMIZADAS

RESUMEN

Objetivo: Analizar las relaciones entre la calidad de vida (CV) de las personas con estoma con indicadores sociodemográficos, clínicos, de estilo de vida, saneamiento y vivienda. **Métodos:** Estudio transversal con una muestra de 106 ostomizados, entrevistados de mayo a noviembre de 2019. Se utilizó un cuestionario sociodemográfico y clínico y el Cuestionario City of Hope - Quality of Life - Ostomy. **Resultados:** El bienestar espiritual (7,71 ± 1,09) fue el dominio con mejor desempeño. La CV no difirió entre hombres y mujeres (p = 0,372), pero se asoció con la educación (< 0,001) y los ingresos familiares (p = 0,025), la diabetes (p = 0,008) y el alcoholismo (p = 0,044), con las condiciones de agua potable (p <0,001), el destino de la basura (p = 0,021), la disponibilidad de electricidad (p = 0,034), el tipo de vivienda (p = 0,026) y el número de habitaciones (p = 0,023) y tipo de cobertura de vivienda (p = 0,021). **Conclusión:** Peores indicadores socioeconómicos, saneamiento básico, vivienda, parecen impactar negativamente la calidad de vida de las personas con ostomía.

DESCRIPTORES: Ostomía; Calidad de Vida. Clase Social; Saneamiento; Estilo de Vida.

INTRODUCTION

Stoma is a word of Greek origin that means opening or mouth and its confection is performed through surgery in order to build a new cavity, temporary or permanent, in the abdominal wall whose function is to eliminate feces, waste and/or urine^{1,2}. Among the main causes for this condition are colon and rectal cancer, trauma (gunshot or stab wounds and automobile accidents) and inflammatory bowel diseases (ulcerative colitis and Crohn's disease)³.

After the surgical process, these patients go through a major reconfiguration of their anatomy and modifications in their routine and bodily functions. Evacuation and elimination of flatus occur in a completely different way, which is through an ostomy and totally uncontrolled, and they start living daily with a collecting bag attached to the abdomen to store the effluent^{4,5}.

Such situations promote a strong emotional impact for people with stoma, because this process causes alterations in self-image and self-esteem, also determining other associated disorders. This change causes various disruptions in their lives that these people have to live with and that impair their quality of life (QOL)⁶. It is believed that social determinants of health, such as sanitation and housing type, impact the QOL of this population.

Quality of life is defined as a subjective evaluation of the positive and negative aspects of life. It is considered in a broad and multidimensional concept, encompassing the notion of holistic well-being, encompassing elements concerning health and extending beyond them. And, it also includes a personal assessment about their life experiences and social well-being⁷.

Patients who need to live with stoma go through an experience that is considered one of the most difficult of their lives, even with the possibility that it is a surgical intervention that can allow increased survival in the cases of cancer patients, as well as in situations that would condition a significant improvement in QOL, as in the case of inflammatory bowel diseases. Still, the making of the stoma is a phenomenon that generates multiple psychosocial effects that directly influence QOL⁸.

Among the changes in the body, the use of the collecting equipment makes it difficult to coexist, due to the concern with the elimination of gases, odor, leakage, and physical discomfort, causing the person with stoma to adopt a posture of detachment, isolation from social coexistence and the work environment, leading him/her to retirement by disability even⁵.

In addition, complications may arise, among them parastomal hernia, stoma prolapse, stenosis, fistula, dermatitis, or peristomal abscess. Or complications at a systemic level, mainly related to hydro-electrolyte disturbances in high output stomata, anemia, pneumonia, and sepsis^{2,5}.

Therefore, studies that allow health professionals to identify the main factors that hinder the QOL of this population and generate knowledge that can serve as tools and a guiding factor in decision making are necessary, as long as they integrate new knowledge about the structure, processes, and results of the services offered to this public⁸. Thus, facilitating the understanding of the state of life of people with stoma and improving care by providing subsidies for better coping with problems and, consequently, improving QOL.

OBJECTIVE

To analyze the relationships between the QOL of people with stoma with sociodemographic, clinical, lifestyle, sanitation, and housing indicators.

MÉTODOS

This is an observational, descriptive, cross-sectional study with a quantitative approach. This study followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) strategy for observational studies9. Data collection was conducted during the period from May to December 2019. The study was developed in the outpatient service of the Hospital Universitário da Universidade Federal do Maranhão (HUUFMA), more specifically in the Outpatient Clinic of Enterostomal therapy of the Unidade Hospitalar Presidente Dutra and in the distribution center of the Programa de Órtese e Prótese do Município de São Luís, Maranhão.

The study sample was by convenience, with individuals who proved to be more approachable, collaborative, and available, depending on factors such as availability and frequency of appointments. One hundred and six users with elimination stomata on a temporary or permanent basis, who underwent evaluation at the enterostomal therapy outpatient clinic, were interviewed. Individuals were included who had elimination stoma (colostomy, ileostomy or urostomy), were 18 years old or older, and were registered with the county's orthotics and prosthetics program. Users with stoma for less than 6 months, hospitalized or with acute illnesses, and who did not undergo outpatient evaluation of stoma enterostomal therapy were excluded.

Data collection was carried out through interviews using two questionnaires with closed-ended questions. The first consisted of a structured questionnaire to assess clinical, sociodemographic, economic, housing and lifestyle data. This questionnaire, prepared by the study team, contained questions regarding age, gender, marital status, number of children, current occupation, religion, education (considered low until incomplete elementary school; medium when complete elementary and high school; and high when incomplete, complete, and post-graduate higher education), monthly income (considered low until two minimum wages; medium between three and four wages; and high when more than four minimum wages), number of residents per household, physical activity practice, and self-reported drinking and smoking. The clinical data investigated were: type of stoma, length of stay of the stoma, the cause of surgery and its respective date, presence of comorbidities, and complications presented.

The second tool used was the City of Hope Quality of Life Ostomy Questionnaire (COH-QOL-OQ), questionnaire developed by Grant and collaborators¹⁰ from another instrument by the authors themselves, in order to assess the exclusive QOL of patients with stoma¹¹. This questionnaire was translated, culturally adapted, and validated in Brazil by Gomboski¹². The COH-QOL-OQ is composed of 43 questions arranged into 4 domains: physical well-being (BEF), psychological well-being (BEP), social well-being (BES), and spiritual well-being (BEE), with answers presented on a scale of 0 to 10. Physical well-being domain: 1 to 11, psychological well-being domain: 12 to 24, social well-being domain: 25 to 36, and spiritual well-being domain: 37 to 43¹³.

The collected data were imputed into Microsoft Excel software and then imported into statistical Stata 16.0 software. The categorical variables were presented as absolute and relative frequencies, and the quantitative variables as mean and standard deviation. The normality of the continuous variables was verified by the Shapiro–Wilk test. Bivariate analysis was performed between the explanatory variables and the QOL outcome. For the dichotomous variables the student's t-test was used, for the polytomous variables one-factor analysis of variance (ANOVA one-way) was used. Pearson's linear correlation was used to analyze the continuous normal variables. Results with a p-value < 0.05 were considered statistically significant.

This study is part of a larger project entitled "Evaluation on the sexual function and quality of life of people with stomata", approved by the Ethics and Research Committee of the University Hospital of the Federal University of Maranhão, under opinion No. 3.077.936. The participants were informed about the privacy and reliability aspects of the information, being

assured of the right to withdraw from participation at any time. The Informed Consent Form (ICF) was signed by the users who agreed to participate in the research. The study is in accordance with Resolution 466/12 of the National Health Council.

RESULTS

A total of 106 people with stoma, with a mean age of 46.85 (± 15.46) years, participated in the study. Of those, 61 (57.55%) were male, 53 (50.00%) said they lived in the state capital, 70 (66.04%) said they were brown, and 41 (38.68%) were married. In addition, 56 (52.83%) had a medium level of education (complete elementary and high school). Regarding family income, 86 (81.13%) said they received less than three minimum wages, and 61 (57.55%) said they were catholic (Table 1).

Table 1. Demographic and socioeconomic characteristics of individuals with stoma and associations with quality of life (n = 106). São Luís (MA) – 2020.

Variable	Mean (± SD) or freq. (%)	p-value
Age	46.85 (15.46)*	0,388 ¹
Gender		0,372 ²
Male	61 (57.55)	
Female	45 (42.45)	
Municipality of residence		0,505³
State capital	53 (50.00)	
Metropolitan region	16 (15.09)	
Município do interior	36 (33.96)	
Other state	01 (0.94)	
Ethnicity		0,395³
Yellow	02 (01.89)	
White	21 (19.81)	
Black	13 (12.26)	
Brown	70 (66.04)	
Marital status		0,359³
Married	41 (38.68)	
Single	28 (26.42)	
Widower	02 (01.89)	
Divorced	02 (01.89)	
Separated	04 (03.77)	
Stable union	29 (27.36)	
Education		< 0,001 ³
Low	41 (38.68)	
Medium	56 (52.83)	
High	09 (08.49)	
Income		0,025 ³
Low	86 (81.13)	
Medium	10 (09.43)	
High	10 (09.43)	
Religion		0,063³
Catholic	61 (57.55)	
Spiritism	03 (02.83)	
Evangelicalism	33 (31.13)	
Jehovah's witness	01 (0.94)	
None	06 (05.66)	

SD: Standard deviation; *Mean and SD; Freq: absolute frequencies; ¹Pearson's linear correlation; ²Student's t-test for independent samples; ³One-way ANOVA.

Clinically, it was observed that the most predominant type of ostomy was colostomy, for 60 (56.60%) participants. Among the causes for the construction of the stoma, colorectal cancer with 21 (19.81%) and bowel with 18 (16.98%), and inflammatory diseases with 18 (16.98%) cases were the most cited. However, 56 (52.83%) ostomies were temporary (Table 2). Dermatitis proved to be the main complication, for 41 (38.68%) respondents. Participants had an average of 52 months of the stoma confection (Table 2).

Table 2. Clinical and lifestyle profile of individuals with ostomies and associations with quality of life (n = 106). São Luís (MA) – 2020.

Variable	Mean (± SD) or freq. (%)	p-value
Type of ostomy		0,798 ¹
Colostomy	60 (56.60)	
lleostomy	36 (33.96)	
Urostomy	09 (08.49)	
> 1 stoma	01 (0.94)	
Permanence of the ostomy		0,021 ¹
Temporary	56 (52.83)	
Definitive	40 (37.74)	
Undetermined	10 (09.43)	
Cause for making the ostomy		0,301 ¹
Colorectal cancer	21 (19.81)	
Bowel cancer	18 (16.98)	
Firearm-related trauma	15 (14.15)	
Blunt force trauma	05 (04.72)	
Inflammatory disease	18 (16.98)	
Rectovaginal fistula	01 (0.94)	
Diverticulitis	02 (01.89)	
Acute obstructive abdomen	13 (12.26)	
Other	13 (12.26)	
Hypertension		0,139 ²
Yes	20 (18.87)	
No	86 (81.13)	
Diabetes		0,008 ²
Yes	13 (12.26)	
No	93 (87.74)	
Time of confection of the ostomy	52.92 (62.95)*	0,214 ³
Receives government collectors		0,421 ²
Yes	88 (83.02)	
No	18 (16.98)	
Complications		0,990 ¹
Parastomal hernia	13 (12.26)	
Retraction	02 (01.89)	
Prolapse	11 (10.38)	
Dermatitis	41 (38.68)	
Stenosis	01 (0.94)	
Other	03 (02.83)	
More than one complication	24 (22.64)	
None	11 (10.38)	
	. ,	0,044 ²
Alcoholism		
	90 (84.91)	
No	· · · · ·	
No Yes	90 (84.91) 16 (15.09)	
No Yes Smoking	16 (15.09)	0,188 ²
No Yes Smoking No	16 (15.09) 94 (88.68)	
No Yes Smoking No Yes	16 (15.09)	0,188²
Alcoholism No Yes Smoking No Yes Physical activity None	16 (15.09) 94 (88.68) 12 (11.32)	
No Yes Smoking No Yes Physical activity None	16 (15.09) 94 (88.68) 12 (11.32) 72 (67.92)	0,188²
No Yes Smoking No Yes Physical activity	16 (15.09) 94 (88.68) 12 (11.32)	0,188²

SD: standard deviation; *Mean and SD; Freq: absolute frequencies; ¹One-way ANOVA; ²Student's t-test for independent samples; ³Pearson's linear correlation;

Of the 106 individuals, 60 (60.38%) had running water at home and 67 (63.21%) consumed filtered water daily. Public garbage collection was the main form of solid waste disposal for 90 (84.91%) individuals in the sample. Only 33 (31.13%) said they had a sewage system in their homes and 103 (97.17%) said they had electricity (Table 3).

Table 3. Sanitation and housing indicators of individuals with stomata and associations with quality of life (n = 106). São Luís (MA) - 2020.

Variable	Mean (± SD) or Freq. (%)	p value
Water supply		0,201 ¹
Well	40 (37.74)	
River	02 (01.89)	
General network	64 (60.38)	
Conditions of water use		< 0,001 ¹
Filtered	67 (63.21)	
Mineral	27 (25.47)	
Without prior care	12 (11.32)	
Garbage disposal		0,021 ²
Public collection	90 (84.91)	
Burned	16 (15.09)	
Disposal of waste		0,079 ¹
Sewer	33 (31.13)	
Black pits*	27 (25.47)	
Septic tank**	42 (39.62)	
Open sky	04 (03.77)	
Electric Power		0,034 ²
Yes	103 (97.17)	
No	03 (02.83)	
Housing type		0,026 ¹
House	97 (91.51)	
Apartment	05 (04.72)	
Room	03 (02.83)	
Others	01 (0.94)	
Housing ownership		0,478 ¹
Owner	88 (83.02)	
Rental	11 (10.38)	
Given	07 (06.60)	
Number of rooms		0,023 ¹
1 to 3	19 (17.92)	
4 to 6	66 (62.26)	
7 to 9	19 (17.92)	
> 9	02 (01.89)	
Coverage type		0,021 ¹
Tile	19 (17.92)	
Tile and liner	66 (62.26)	
Slab***	19 (17.92)	
Straw	02 (01.89)	

SD: Standard deviation; Freq: absolute frequencies; ¹One-way ANOVA; ²Student's t-test for independent samples; ³Pearson's linear correlation. *Black pits are holes with or without lining of the internal walls, in which human waste is dumped into the opening and comes into direct contact with the ground, without any kind of treatment; **These are holes with lining of the internal walls, in which human waste does not come into contact with the ground and does not contaminate the water table; ***Flat structural element, usually horizontal, represented as a concrete plate.

As for QOL, spiritual well-being (7.71 \pm 1.09) was the domain with the best rated performance, and social well-being (5.29 \pm 1.80) was the most compromised domain among people with stoma (Table 4). There was no significant difference in QOL (p = 0,372) between men and women (Fig. 1).



Figura 1. Quality of life of people with ostomies, according to gender. São Luís (MA) – 2020.

The variables analyzed that were significantly associated with the QOL of people with stomata were education, since people with higher education had higher QOL scores (p < 0.001); family income, since people with higher income had better QOL scores (p = 0,025); and predicted permanence of the ostomy, as people with definitive ostomies had higher mean scores compared to people with ostomies with undetermined prognosis (p = 0,021). Those who had comorbidities, such as diabetes (p = 0,008) and were alcoholics (p = 0,044) also had worse QOL scores.

As for sanitation and housing indicators, the results showed that those who consumed untreated water had worse QOL levels (p < 0.001). Those who did not have public garbage collection had worse QOL (p = 0,021). The worse the housing (p = 0,026) and the fewer the number of rooms (p = 0,023), the worse the QOL. Housing with electricity conferred better QOL to this public (p = 0,034). Those who lived in a house with a straw roof obtained worse levels of QOL (p = 0,021).

Variable	Mean (± SD)	Minimum-maximum
Physical well-being (0–11)	5.61 (1.93)	1.37 to 9.17
Psychological well-being (0–13)	6.72 (1.54)	2.78 to 9.75
Social well-being (0–12)	5.29 (1.80)	1.40 to 8.86
Spiritual well-being (0–7)	7.71 (1.09)	4.02 to 9.44
Total score [*] (0–10)	6.20 (1.36)	3.56 to 9.16

Table 4. Quality of life of individuals with stoma seen at a university hospital (n = 106). São Luís (MA) – 2020.

SD: standard deviation; *City of Hope Quality of Life Ostomy Questionnaire (COH-QOL-OQ).

DISCUSSION

The results showed that the majority of people with stoma were male and aged between 40 and 50 years, this finding meets the evidence of another study, showing the same prevalence of gender and age¹⁴. These results may be justified by the fact that the male population uses health services and preventive measures less frequently, leading them to seek medical care late, when they present manifestations of worsening diseases¹⁵. In addition, men have greater exposure to accidents and injuries due to external causes^{14,15}.

Regarding marital status, most were married and the self-reported skin color was brown, results that corroborate similar studies^{16,17}. Although most are married, there is a feeling of fear and insecurity regarding the partner, due to the new condition in which they find themselves physically, living with the stoma and the collecting equipment generate psychological and emotional problems, bringing feelings of shame and lack of sexual interest^{14,16}.

Regarding education and monthly family income, the results showed a situation of difficulty and social exclusion experienced by this clientele, which may make it impossible and difficult to acquire the materials needed for treatment as people with stomata, as well as basic life items, such as food, health, housing, education, leisure, and safety, which are indispensable to have QOL¹⁸. The results pointed out that people with education and high income had better QOL scores, in the same direction as a US study in which people with higher income had better QOL¹⁹.

With regard to education level, there was a predominance of low education, as in other similar studies^{14,16,20}. The low level of education is a worrisome factor when it comes to citizenship and rights, since the lower the level of knowledge, the more difficult it is to understand and learn about the health problem and the ability to assimilate guidelines for self-care²¹. However, it is important to emphasize that this variable is not an obstacle to the professional work with this population, because they have sought strategies for the translation of knowledge to this public through practical interaction and the use of a more accessible vocabulary, facilitating the compression of the treatment.

The predominantly catholic religious-spiritual bond was observed in the sample, as was the highest-scoring QOL domain. Spiritual support is extremely important in this phase of change and adaptation for people with stomata, because in it they find a source of resilience and coping with their physical and psychological problems related to the stoma²⁰.

Regarding the clinical data, the prevalent type of ostomy was colostomy, caused by intestinal cancer, and the majority was temporary. These findings were also found in previously conducted studies^{6,22}. Among the complications, the main ones cited were dermatitis and prolapse, similar to data found in other national research^{5,6,14,17}.

As for QOL, spiritual well-being was the domain with the best rated performance, and social well-being was the most compromised domain among people with stoma, in agreement with a study in the Chinese population²³. Our results did not indicate significant differences in QOL between men and women, but one study noted that women had lower scores compared to men²³. A recent systematic review pointed out that stomata negatively impact the QOL of this population, however there were no conclusive evidences that indicators such as age, gender, and length of treatment have a specific effect on the QOL of people with stomata, corroborating our findings²⁴.

The associations found between the indicators of basic sanitation and housing reflect the perception that people from lower socioeconomic conditions have about their QOL, this is due both to the low education and worse access to health services more evident in this social stratum^{14,20}, as well as may be related to the good fit of the ostomy, independent of other factors²⁵.

This study found significant associations between socioeconomic, demographic, clinical, and sanitation factors with the QOL of individuals with stomata. Having low income, low education, no sanitation services, and worse housing contributed to worse QOL scores for these individuals when compared to individuals with better income and education. This represents the need for more effective public policies that impact not only the treatment of the disease that caused the stoma, but that improve the socioeconomic conditions of the population.

From the perspective of social determinants in health, the QOL of the general population can be affected by sanitation and housing conditions, especially individuals living with stomata⁵. Factors related to living conditions, education, employment, availability of food, medicines, and access to health services are directly related to the health-disease process of this population, and indicate that socially disadvantaged people have different exposures and degrees of vulnerability to health risks.

Given this scenario, the importance of implementing public policies capable of guaranteeing minimum survival conditions and ensuring the human rights of citizenship for this population is emphasized, in view of the need

to resignify habits of life and care, requiring extra costs with medication, hygiene, proper food, transportation for treatment, and access to quality health services, in order to optimize their survival¹⁷.

Study limitations

The main limitation of the study was the convenience sample; however, studies with large samples for this public are not found in the literature, given the logistical and management difficulties of the stomata. Another limitation was the cross-sectional design, longitudinal studies with analyses of QOL before and after the stomata could bring more consistent findings.

Contributions to the field of nursing, health or public policy

Understanding the complications of stomata and demographic, clinical, and QOL factors can improve care for these users, prevent the development of complications, and help build more equitable lines of care with effective interventions aimed at reducing the negative impact of stoma on QOL.

CONCLUSION

Significant relationships were observed between the QOL of people with stomata and sociodemographic, lifestyle, sanitation, and housing indicators. Individuals with a worse social background had a worse QOL. This relationship corroborates previous studies and highlights the negative impact of stoma on key domains of QOL, such as social limitations.

AUTHOR'S CONTRIBUTION

Conceptualization: Ferreira BCS, Martins SS e Cavalcante TB; Methodology: Silva Junior JF; Research: Martins SS; Writing - First version: Ferreira BCS, Cavalcante TB e Silva Junior JF; Writing - Review & Editing: Silva Junior JF; Resources: Martins SS e Cavalcante TB; Supervision: Carneiro SCS.

AVAILABILITY OF RESEARCH DATA

All data were generated and analyzed in the present study.

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