

Epidemiological profile of people with intestinal ostomy at a referral center

Perfil epidemiológico de pessoas com estomias intestinais de um centro de referência

Perfil epidemiológico de las personas con estoma intestinal de un centro de referencia

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ABSTRACT

Objective: describe the epidemiological and clinical profile of people with intestinal ostomy. **Methods:** documentary research carried out in a reference center for people with disabilities in Northeast Brazil. Data collection was carried out from December 2018 to February 2019, by reviewing medical records. **Results:** there was a predominance of males (56.6%), mean of 56.7 years, 41.5% married, 22% had incomplete elementary school, 27.9% had an income of two to three minimum wages, 47.1% were retired and 53.4% lived in the capital. The neoplasm was the main cause for the construction of the ostomy (62.2%) and the colostomies corresponded to 84.2%, of which 38.3% were definitive. There were complications in 60.3% and 54.4% of these complications corresponded to peristomal dermatitis. **Conclusion:** people with intestinal colostomy were male, elderly, married, retired, with low education and a definitive stoma because of neoplasia. Knowing the profile is essential to plan the reception, direct the treatment and rehabilitation of people with intestinal ostomy.

DESCRIPTORS: Health Profile; Health Services; Ostomy; Epidemiology; Nursing care; Stomatherapy.

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RESUMO

Objetivo: descrever o perfil epidemiológico e clínico de pessoas com estomias intestinais. **Método:** pesquisa documental realizada em um centro de referência para pessoas com deficiência no Nordeste do Brasil. A coleta de dados foi realizada de dezembro de 2018 a fevereiro de 2019, por meio de revisão de prontuários. **Resultados:** houve predomínio do sexo masculino (56,6%), média de 56,7 anos, 41,5% casados, 22% tinham ensino fundamental incompleto, 27,9% tinham renda de dois a três salários mínimos, 47,1% eram aposentados e 53,4% residiam na capital. A neoplasia foi a principal causa de confecção da estomia (62,2%) e as colostomias corresponderam a 84,2%, das quais 38,3% eram definitivas. Houve complicações em 60,3% e 54,4% dessas complicações corresponderam à dermatite periestomal. **Conclusão:** as pessoas com colostomia intestinal eram do sexo masculino, idosas, casadas, aposentadas, com baixa escolaridade e estomia definitiva por neoplasia. Conhecer o perfil é fundamental para planejar o acolhimento, direcionar o tratamento e a reabilitação das pessoas com estomia intestinal.

DESCRITORES: Perfil de Saúde; Serviços de Saúde; Estomia; Epidemiologia; Cuidados de Enfermagem; Estomaterapia.

RESUMEN

Objetivo: describir el perfil epidemiológico y clínico de las personas con estoma intestinal. **Métodos:** investigación documental, realizada en un centro de referencia para personas con discapacidad física en el noreste de Brasil. La recopilación de datos se llevó a cabo de diciembre de 2018 a febrero de 2019, a través de una revisión de los registros médicos. **Resultados:** hubo un predominio de varones (56,6%), una media de 56,7 años, un 41,5% casados, un 22,0% de primaria incompleta, un 27,9% con unos ingresos de dos a tres salarios mínimos, un 47,1% de jubilados y un 53,4% en el capital. La neoplasia fue la principal causa de estoma (62,2%) y las colostomias correspondieron al 84,2%, de los cuales el 38,3% fueron definitivos. El 60,3% presentaba complicaciones y el 54,4% correspondieron a dermatitis periestomal. **Conclusión:** las personas con colostomía intestinal eran hombres, ancianos, casados, jubilados, con baja escolaridad y estoma definitivo debido a la neoplasia. Conocer el perfil es esencial para planificar la recepción, orientar el tratamiento y rehabilitación de personas con estoma intestinal.

DESCRIPTORES: Perfil de Salud; Servicios de Salud; Ostomía; Epidemiología; Cuidados de Enfermería; Estomaterapia.

INTRODUCTION

Accelerated urbanization combined with new consumption patterns and globalization have promoted epidemiological changes in the Brazilian population, with a decline in the birth rate and an increase in life expectancy. As a result of these changes, there was an increase in the rates of chronic noncommunicable diseases (NCDs), accidents, violence and, also, in the volume of people needing stomas¹.

Among the most frequent indications for ostomy are chronic intestinal and urinary diseases, such as colorectal and urinary bladder neoplasms, inflammatory diseases, such as Crohn's disease, ulcerative colitis and diverticulitis, abdominal trauma and congenital malformations. However, research reveals that colon and rectal neoplasms are the most frequent causes²⁻⁴.

The surgery for making the ostomy was developed as a therapy to increase the survival of individuals when it is impossible to maintain the normal function of the affected organ⁵. The name of the ostomy may vary with the place of manufacture. When made in the jejunum, ileum and colon are called jejunostomies, ileostomies and colostomies, respectively⁶.

The increase in the population of people with an ostomy and the need for specialized assistance fostered the creation of public policies to ensure the accessibility of people with an ostomy to materials, services and health professionals⁵. Thus, from the legalization, units were created to support people with ostomy throughout the country.

As it considers the relevance of knowing the sociodemographic and clinical profile of people with an ostomy to plan specific actions aimed at socialization, improving care and improving reception in health services, the present study was idealized.

OBJECTIVE

To identify the epidemiological and clinical profile of people with intestinal ostomy.

METHOD

This is a documentary research carried out in a reference center for people with disabilities in Northeast Brazil. The service is a reference for 25 municipalities and accredited

to the Unified Health System (Sistema Único de Saúde-SUS) for monitoring people with stomas.

The population consisted of 378 records of people with intestinal ostomy, aged 18 years or older, registered for follow-up at the service surveyed.

Data collection was carried out from December 2018 to February 2019, by reviewing medical records. For the collection, three nurses outside the service were trained, who during the collection were under the supervision of a stomatherapist nurse.

The spreadsheet data collection script was developed by the researchers based on information contained in the registration form adopted in the service. Thus, the script consisted of characterization data (gender, age group, marital status, education, income, occupation and place of residence) and clinical data (cause of the ostomy, type and characteristic of the ostomy in terms of length of stay and complications).

The data were analyzed using descriptive statistics, organized in Microsoft® Excel spreadsheets and transported to the Statistical Package for the Social Sciences (SPSS), version 20. The results in absolute and relative numbers were presented graphically in tables and figures

The research followed the ethical and legal aspects that regulate studies with human beings, with research approved by the Research Ethics Committee under opinion 2.562.857, in accordance with Resolution 466/12 of the National Health Council.

RESULTS

A total number of 378 people with an ostomy participated in the study, with ages ranging from 18 to 102 years old, mean of 56.7 (standard deviation 17.3), as shown in Table 1.

Table 1. Distribution of sociodemographic aspects of people with an ostomy. João Pessoa (PB), Brasil – 2019.

Gender	n (%)
Male	214 (56.6)
Female	164 (43.4)
Age range	n (%)
18 a 38	58 (15.3)
39 a 58	141 (37.3)
≥ 59	179 (47.4)

continue...

Table 1. Continuation...

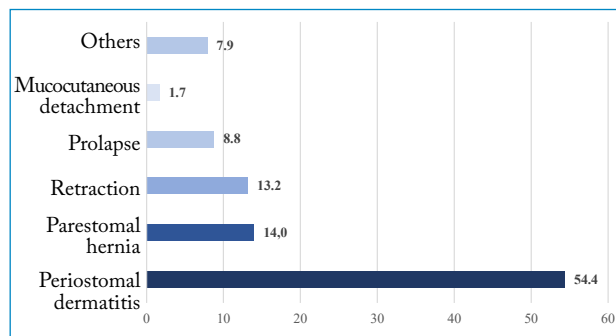
Marital status	n (%)
Married	157 (41.5)
Single	139 (36.8)
Other	69 (18.3)
No information	13 (3.4)
Education	n (%)
Not literate	26 (6.9)
Incomplete elementary school	83 (22.0)
Complete elementary school	29 (7.6)
Incomplete high school	13 (3.4)
Complete high school	29 (7.7)
Incomplete higher education	6 (1.6)
Complete higher education	11 (2.9)
No information	181 (47.9)
Income	n (%)
< 1 salary	49 (13.1)
1 minimum wage	77 (20.4)
2 to 3 minimum wages	102 (26.9)
> 3 minimum wages	44 (11.6)
No information	106 (28.0)
Occupation	n (%)
Working	110 (29.1)
Unemployed	34 (9.0)
Retired	178 (47.1)
No information	56 (14.8)
Residence	n (%)
Capital	202 (53.4)
Metropolitan region	120 (31.7)
Inlands	54 (14.3)
No information	02 (0.6)
Total	378 (100.0)

The clinical variables of people with intestinal ostomy revealed that neoplasia was the most frequent cause for the construction of the ostomy (62.2%) and the majority needed a colostomy (84.2%), as shown in Table 2.

Table 2. Distribution of clinical data related to the ostomy. João Pessoa (PB), Brasil – 2019.

Cause of ostomy	n (%)
Neoplasm	235 (62.2)
Inflammatory diseases	36 (9.5)
Trauma	31 (8.2)
Others	76 (20.1)
Type of ostomy	n (%)
Colostomy	318 (84.2)
Ileostomy	60 (15.8)
Definitive	145 (38.3)
Ostomy characteristic	n (%)
Temporary	103 (27.2)
No Information	130 (34.5)
Total	378 (100.0)

In Fig. 1, 228 people with intestinal ostomy who had a complication record in the medical record were distributed.

**Figure 1.** Distribution of complications registered in the medical records of patients with intestinal ostomy. João Pessoa (PB), Brasil – 2019.

The data revealed that peristomal dermatitis was the most frequently registered complication (54.4%) among those surveyed with complications (60.3%).

DISCUSSION

When analyzing the results of the sociodemographic aspects of people with intestinal ostomy, a predominance of males was identified. These results are similar to

those of national studies in which the percentages of males were 54.1%, 57.3% and 62.2%, respectively^{1,7-9}. This may be related to the fact that men seek less health services to prevent diseases, associated with the model of a masculinity still idealized, which consists of the idea of invulnerability, which is configured as a risky behavior^{4,10,11}.

With regard to the age group of the people studied, there was a higher frequency for the category above 59 years, which corresponded to 47.4% of the subjects. These findings are in line with studies that showed people aged between 58 to 78 years as the most affected age group for performing surgical procedures that lead to the manufacture of ostomies^{6,9,12}. This fact can be attributed to population aging, as advancing age is one of the conditions that favors illness and the oncogenesis process, leading to an increase in the number of stomas in the elderly population.

In this study, it was found that most people were married. This result is similar to the research with people with an ostomy in which most of the respondents had a partner (58.9% and 46.7%)^{1,9}. During the process of adaptation of the person with an ostomy, the support and presence of the partner is seen as an important aspect and of positive impact for the recovery of health, as it contributes to coping with the difficulties that arise with the ostomy, as well as for carrying out care and improving self-esteem¹³.

It is noticeable that the support and acceptance of the family, especially the spouse, is essential for self-acceptance and coping with the disease and the condition of living with the ostomy. However, research conducted with patients after more than six months of surgery and who did not have a partner showed that they had better self-care scores related to hygiene and the ostomy bag⁷.

Regarding education, the category with the highest frequency was that of people with incomplete elementary education, a result that is similar to studies carried out in reference centers for people with ostomy in the Northeast and Southeast of Brazil^{1,9}. The level of education can be an important factor for the non-prevention of colorectal cancer, which is one of the main causes for making stomas. In addition, the level of education positively influences learning about correct stoma care, which are essential for the development of skills for self-care, better adaptation and prevention of complications^{9,14}.

The income of two to three minimum wages was the most frequent in the studied population and was

similar to the result of a study carried out with people with an ostomy in the Southeast region of Brazil, which presented a percentage of 42.9%⁴. The low socioeconomic level of the patients makes the rehabilitation process difficult regarding the difficulty of acquiring collection bags and adjuvants, when unavailable in the public SUSn(Unified Health System) network. Thus, the disease has an even greater and more serious impact, as it enhances the situation of vulnerability and produces suffering due to the lack of access to goods and services that meet basic needs¹¹.

Regarding occupation, most people with an ostomy were retired, with 47.1%, findings that corroborate with other studies, which obtained a percentage of 46.7%, 66.7% and 78%^{9,14,15}. The data related to the occupation can be justified by the fact that the presence of an ostomy ends up limiting the performance of some activities and makes it difficult to return to the work routine. People, in general, choose to stay away from work, also giving rise to early retirements, however some people are able to continue working, requiring adjustments in access, transportation and in the work environment⁸.

People with an ostomy, in a way, have accommodation to resume their working life, feel different and fear facing the people around them, especially those who are not part of their family life. In addition, if the origin of the ostomy is related to underlying diseases such as cancer, which will require prolonged and exhausting treatment, it becomes even more difficult.

As for the place of residence of the people in this study, it was found that most of them lived in the capital and metropolitan region, that is, in an urban area. This result is similar to that obtained by the authors of a study carried out in a Center for Health Care for People with Stomas (Núcleo de Atenção à Saúde da Pessoa Estomizada), in the Southeast region of Brazil¹¹. The development of a clinical condition such as the need for an ostomy, which requires the provision of materials and supplies for self-care, seems to motivate the migration of people to urban centers. It is believed that the proximity between the place of residence and the reference services may favor the feeling of greater security in cases of complications, in addition to reducing the time and costs demanded by the need for large displacements.

Neoplasms stood out as the main cause of ostomy among the participants of this study, which corroborates

the data found by other authors who also identified cancer as a motivating factor for the making of the ostomy.^{1,8,9}. Among the reasons that may justify colorectal cancer as the main cause for making the ostomy, it is worth mentioning the vertiginous increase in the incidence of cancer over the years and the greater longevity of the population in response to the transition of the morbidity and mortality profile, in the which chronic-degenerative diseases became more frequent than infectious diseases^{1,3}.

The elimination intestinal ostomies are performed in the large intestine (colostomy) and small intestine (ileostomy), in loops that have different sizes and mobility that allow their adequate exteriorization and fixation in the abdominal wall, creating an artificial opening for the exit of feces and flatus⁶. In this study, colostomies were more prevalent than ileostomies, according to the results found by other authors^{1,8,9}.

The results related to the ostomy characteristic identified that most people had a permanent ostomy. A similar result was found in other studies in the literature, with percentages of 63.3% and 63.9%, respectively^{9,15}. In contrast to this finding, researchers found higher percentages of people with temporary stomas of 33.7 and 56.9%, respectively^{1,16}.

Although the study in question presents predominance of stomas of a definitive character, it is very common to the indefiniteness of the length of stay, as many people start the treatment of the underlying disease for subsequent reconstruction, that is, initially the ostomy has a temporary character, but during treatment, it may become definitive. Among the factors that favor the permanence of the ostomy, the fear of failure in the reconstruction of intestinal transit stands out due to the surgical risk and complications inherent to the procedure.

The construction of an ostomy is a challenge for the patient in relation to its process of acceptance and adaptation, so it is important that the health professional implements measures of care for the person with an ostomy aimed at improving the quality of life.

The occurrence of complications related to ostomy during the care process can negatively impact the patient's life. In the present study, the main complication found was peristomal dermatitis, a complication also demonstrated in previous studies^{1,15,17}. Dermatitis is the most common affection in people with ostomy and, often, its occurrence is motivated by the inappropriate use of the collection bag, because the inadequate cut of

the bag orifice or the bad installation promotes direct contact with the intestinal fluid, which irritates the skin around the ostomy^{1,13}.

Among the complications that enhance the skin contact with the effluent, the cutaneous mucus retraction and detachment, the presence of scars, folds and poor ostomy location stand out. All of these factors contribute to the need for frequent changes in the collection equipment and, consequently, the occurrence of dermatitis. It is important to highlight that dermatitis can also be related to other factors, such as the development of allergy to the materials of the bag and mechanical irritation of the skin by improperly removing the adhesive from the bag.

With this understanding, health professionals at referral centers should dedicate themselves to planning and executing health education activities, as people with intestinal ostomies need to receive information and be trained to properly manage the available resources and prevent complications.

The nurse in the service where the study was carried out is responsible for the first assistance to the person with an ostomy and for filling out the registration form, in which sociodemographic information is collected, among others. These data are important for the contact between professionals and patients in situations of absence from care, also enabling research and justifying the importance of raising nurses' awareness for the complete filling of patient data in the medical record.

CONCLUSION

The study made it possible to characterize the epidemiological and clinical profile of people with intestinal ostomy at a referral center, which consisted of elderly people with a low level of education, married and retired. Neoplasia was the reason for making permanent colostomy, with peristomal dermatitis being the most frequent complication.

The documentary survey also made it possible to identify gaps in the filling of data in the medical records, revealing a weakness in the process of monitoring people with intestinal ostomy. It is hoped that the results of this study can sensitize managers and health professionals about the importance of recording information in a complete way.

Knowing the profile of people with intestinal ostomy is essential to plan the reception, assist treatment, rehabilitation and subsidize future interventions in care, with a view to improving the health care service in Paraíba, thus assisting health teams in actions to this clientele.

AUTHORS 'CONTRIBUTION

Conceptualization: Diniz IV and Soares MJGO; Methodology: Diniz IV and Mendonça AEO; Writing - First version: Diniz IV, Soares MJGO, Oliveira SHS, Barra IP, Silva MA and Mendonça AEO; Writing - Review & Editing: Diniz IV and Mendonça AEO; Supervision: Diniz IV and Soares MJGO.

REFERENCES

1. Cerqueira LCN, Cacholi SAB, Nascimento VS, Koeppel GBO, Torres VCP, Oliveira PP. Clinical and sociodemographic characterization of ostomized patients treated at a referral center. *Rev Rene* 2020;21:e42145. <https://doi.org/10.15253/2175-6783.20202142145>
2. Ribeiro RVL, Oliveira AC, Viana LVM, Pinto AP, Carvalho ML, Elias CMV. Adaptação social do paciente colostomizado: desafios na assistência de enfermagem. *R Interd* 2016; [cited 2020 apr 27]; 9(2):216-22. Available at: <https://revistainterdisciplinar.uninovafapi.edu.br>
3. Santos MO. Estimativa 2018: incidência de câncer no Brasil. *Rev bras cancerol* 2018; [cited 2020 apr 24]; 64(1):119-20. Available at: http://www1.inca.gov.br/rbc/n_64/v01/pdf/15-resenha-estimativa-2018-incidencia-de-cancer-no-brasil.pdf
4. Maciel DBV, Santos MLSC, Oliveira NVD, Fuly PSC, Camacho ACLF, Coutinho FH. Perfil sociodemográfico de pacientes com estomia definitiva por câncer colorretal: interferência na qualidade de vida. *Nursing (São Paulo)* 2019; [cited 2020 apr 8]; 22 (258):3339-3344. Available at: <https://www.revistanursing.com.br/revistas/258/pg69.pdf>
5. Portaria n. 400 de 16 de novembro de 2009 (BR). Diretrizes nacionais para a atenção à saúde das pessoas ostomizadas no âmbito do Sistema Único de Saúde. *Diário Oficial da União* [periódico na internet], Brasília (DF). 18 de nov 2009 [cited 2020 apr 24]. Available at: https://bvsms.saude.gov.br/bvs/saudelegis/sas/2009/prt0400_16_11_2009.html
6. Nascimento MVF, Vera SO, Silva MCR, Moraes FF, Andrade EMLR, Bastos SNMAN. Perfil sociodemográfico e clínico de

- pacientes em pós-operatório de confecção de estomas intestinais de eliminação. *Cienc Enferm* 2018;24:15. <https://doi.org/10.4067/s0717-95532018000100215>
7. Andrade RS, Martins JM, Medeiros LP, Souza AJG, Torres GV, Costa IKF. Sociodemographic, clinical and self-care aspects of persons with intestinal stoma. *Rev enferm UERJ* 2017;25:e19368. <https://doi.org/10.12957/reuerj.2017.19368>
 8. Aguiar JC, Pereira APS, Galisteu KJ, Lourenção LG, Pinto MH. Clinical and sociodemographic aspects of people with a temporary intestinal stoma. *Rev Min Enferm* 2017;21:e-1013. <https://doi.org/10.5935/1415-2762.20170023>
 9. Melo MDM, Silva IP, Oliveira DMS, Medeiros ASA, Souza AJG, Costa IKF. Association of sociodemographic and clinical characteristics with the self-esteem of stomized persons. *Rev Min Enferm* 2018;22:e-1076. <https://doi.org/10.5935/1415-2762.20180006>
 10. Barbosa MR, Simon BS, Tier CG, Garcia RP, Siniak DS, Rodrigues SO. Profile of people with stomas from a municipal health service in Southern of Brazil. *ESTIMA Braz J Enterostomal Ther* 2018;16:e1318. https://doi.org/10.30886/estima.v16.465_PT
 11. Ribeiro WA, Andrade M, Fassarella BPA, Flach DMAM, Teixeira JM, Ranauro KCDSS. Patients' profile of the stomized person health care nucleus: in sociocultural and economic optics. *Nursing (São Paulo)* 2019; [cited 2020 apr 8]; 22(251):2868-74. Available at: <http://www.revistanursing.com.br/revistas/251/pg53.pdf>
 12. Moraes JT, Assunção RS, Sá FS, Lessa ER, Corrêa LS. Perfil de pessoas estomizadas de uma região de saúde mineira. *Enferm Foco* 2016;7(2):22-6. <https://doi.org/10.21675/2357-707X.2016.v7.n2.788>
 13. Kimura CA, Guilhem DB, Kamada I, Abreu BS, Fortes RC. Oncology ostomized patients' perception regarding sexual relationship as an important dimension in quality of life. *J Coloproctol* 2017;37(3):199-204. <https://doi.org/10.1016/j.jcol.2017.03.009>
 14. Miranda SM, Luz MHBA, Sonobe HM, Andrade EMLR, Moura ECC. Sociodemographic and clinic characterization of people with ostomy in Teresina. *ESTIMA Braz J Enterostomal Ther* 2016;14(1):29-35. <https://doi.org/10.5327/Z1806-3144201600010005>
 15. Ferreira EC, Barbosa MH, Sonobe HM, Barichello E. Self-esteem and health-related quality of life in ostomized patients. *Rev Bras Enferm* 2017;70(2):271-8. <https://doi.org/10.1590/0034-7167-2016-0161>
 16. Lins Neto MAF, Fernandes DOA, Didone EL. Epidemiological characterization of ostomized patients attended in referral Center from the city of Maceió, Alagoas, Brazil. *J Coloproctol* 2016;36(2):64-8. <https://doi.org/10.1016/j.jcol.2014.08.016>
 17. Oliveira IV, Silva MC, Silva EL, Freitas VF, Rodrigues FR, Caldeira LM. Care and health of ostomy patients. *Rev Bras Promoç Saúde* 2018;31(2):1-9. <https://doi.org/10.5020/18061230.2018.7223>