

Characterization of the population served by the Assistance Program for Ostomy Patients

Caracterização de população atendida em Programa de Assistência a Estomizados

How to cite this article:

Lopes MP, Correa FMB, Esmeraldo JC, Reynaldo CSB, Silva FMV, Santos ICRV. Characterization of the population served by the Assistance Program for Ostomy Patients. Rev Rene. 2020;21:e43618. DOI: https://doi.org/10.15253/2175-6783.20202143618

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Special Call 2 - Stomatherapy Nursing

ABSTRACT

Objective: to characterize the population served by the Assistance Program for Ostomy Patients. Methods: cross--sectional study, based on data from the Assistance Program for Ostomy Patients. Population of 852 registered patients. A form containing sociodemographic and clinical variables was used. Data analyzed by average comparison, using Student's 't' test and analysis of variance. Results: the age group most exposed to the investigated surgical procedure was adult/elderly (93.0%), male (52.5%). Congenital malformations and neoplasms were the main causes of ostomy for the group of children and adults/elderly, respectively. Conclusion: the age group most exposed to the studied procedure was adult/elderly, male and from the metropolitan region of the investigated state. Among children, congenital malformations required the making of a temporary ileostomy; among adults/elderly, the neoplasm corresponded to the most frequent indication of permanent colostomies. **Descriptors:** Surgical Stomas; Health Profile; Nursing Care.

RESUMO

Objetivo: caracterizar população atendida em Programa de Assistência a Estomizados. Métodos: estudo transversal, com base nos dados do Programa de Assistência a Estomizados. População de 852 pacientes cadastrados. Utilizou-se de formulário contendo variáveis sociodemográficas e clínicas. Dados analisados por comparação de médias, empregando--se o teste t de Student e a análise de variância. Resultados: a faixa etária mais exposta ao procedimento cirúrgico investigado foi a de adultos/ idosos (93,0%), do sexo masculino (52,5%). As malformações congênitas e neoplasias foram as principais causas de estomias para o grupo de crianças e adultos/idosos, respectivamente. Conclusão: a faixa etária mais exposta ao procedimento estudado foi a de adultos/ idosos, do sexo masculino e oriundos da região metropolitana do estado investigado. Entre crianças, as malformações congênitas requereram confecção de ileostomia temporária; entre adultos/idosos, a neoplasia correspondeu à indicação mais frequente de colostomias permanentes.

Descritores: Estomas Cirúrgicos; Perfil de Saúde; Cuidados de Enfermagem.

Introduction

Stoma is a word derived from two Greek terms, "os" and "tomia", which averages exteriorization of a hollow viscera, in a point other than the natural orifice, and can be performed in several organic systems, in order to supply the function of the affected organ⁽¹⁾.

When considering the life cycle, the indications for making an elimination stoma in adulthood correspond, predominantly, to malignant neoplasms, especially of the intestines. Trauma resulting from external causes also contributes significantly to the epidemiology of ostomy⁽²⁾. On the other hand, in children and adolescents, the most common indications are congenital anomalies and traumas that are successful in development, which, more frequently, are temporary⁽³⁾.

There are three main types of ostomy: colostomy (43.0%), ileostomy (37.0%) and urostomy (18.0%), according to a study conducted in eleven countries⁽²⁾, they can be temporary (transient) or definitive (permanent). The temporary ones aim to protect an intestinal anastomosis or provide pressure relief of the urinary tract, in addition, they can be reversed. Permanents are usually indicated in cases where there is no possibility of reestablishing normal intestinal or urinary transit, when abdominoperineal resection is performed, when cancer cannot be resected and or the sphincter is damaged⁽⁴⁾. Although it is a procedure performed to save lives, it is associated with significant morbidity, reaching 34.2%⁽⁵⁾.

The prevalence of ostomy is 0.12% in the world population. Approximately 500,000 people with an ostomy live in the United States and around 13,000 surgeries are performed annually in Canada, while in Europe, the estimated prevalence is 700,000⁽⁶⁾.

As with other clinical conditions, there is no updated official epidemiological information on the number of ostomy patients in Brazil. In 2010, 33,864 people living with an ostomy were registered in the Country by the Brazilian Association of Ostomy Patients, most frequently observed for the Southeast, South and Northeast Regions, respectively⁽⁷⁾. Also, there are few current studies that verify the relationships between demographic variables, such as the age structure and characteristics of the ostomy, such as diagnosis, type and character⁽⁸⁻¹¹⁾.

Thus, this study of characterization of the population submitted to procedures for the creation of intestinal and urinary stomas will help health professionals, especially nurses, since it will provide subsidies for dimensioning the subjects involved in this problem in relation to the conditions of occurrence, in order to facilitate assistance planning and decision making.

When considering the arguments presented, the objective was to characterize the population served in the Assistance Program for Ostomy Patients.

Methods

Cross-sectional study, carried out through a computerized database of the Assistance Program for Ostomy Patients, from a reference service in the city of Recife, PE, Brazil, which offers psychological, social assistance and nursing consultation, in which the nurse assesses stoma conditions, indicates the appropriate device, promotes and monitors the patient's adaptation to the indicated device.

In the research, data from patients with intestinal and urinary ostomy, registered in the Program, in 2015, the system implantation period, were considered, totaling the study population in 852 patients. The computerized database of the Program has the following variables: date of registration, age, sex, origin, profession, diagnosis, type and character of the ostomy. When considering the available variables, the data collection instrument applied by the researchers to that base was constructed.

The age variable was categorized according to the Child and Adolescent Statute. The origin was analyzed in a nominal dichotomous manner and according to the mesoregions of the State of Pernambuco, Brazil. Occupation was defined as the person's position, function, profession or occupation, being categorized according to the Brazilian Classification of Occupations⁽¹²⁾, corresponding to ten divisions, plus the category of children, students and home. For the purposes of the occupation variable, it was understood that children comprised those younger than the school age and those without schooling; the term student was applied to children with schooling and adolescents/adults, whose declared occupation status was student; and the term of the home was defined according to labor and social security law, as a woman who, regardless of marital status, carries out activities exclusively within the family, without receiving remuneration, or who is not considered habitual and principal.

The diagnosis was grouped into the following categories: neoplasms, trauma and obstructions and congenital malformations, due to the number of related pathologies found in the research.

Subsequently, tabulation and statistical analysis were performed, using the *Statistical Package for Social Science software,* version 25.0. The Shapiro-Wilk test was used to verify the normality of the data. According to the study design, descriptive statistics were used: absolute and relative frequencies, average (\overline{x}) and standard deviation (σ); and to compare the averages between the age groups, according to the diagnosis, type and character of the stoma, *Student's t* tests and analysis of variance (ANOVA) were adopted, taking 5% (p<0.05) as the level of significance for conclusions of statistical analyzes.

The study complied with the formal requirements contained in national and international regulatory standards for research involving human beings, according to opinion No. 1,266,054/2015 and Certificate of Presentation for Ethical Appreciation 48939215.2.0000.5192.

Results

Among patients enrolled in the Assistance Program for Ostomy Patients, age ranged from zero to over 64 years old (\overline{x} =52,2; σ =20.5; minimum age = 0.1 year and maximum age = 95 years), with greater frequency of adults between 19 and 64 years. The population distribution by sex showed a higher frequency of males (52.5%), with just over half of the patients (Table 1). As for the origin, there was a greater number of patients from the Metropolitan Region of Recife (66.2%). It is also noteworthy that the least frequency came from the State's Sertão Region (5.5%).

Table 1 – Demographic characteristics of patients en-rolled in the Assistance Program for Ostomy Patients.Recife, PE, Brazil, 2019

Variables	n (%)
Age group (years)	
00 - 12	46 (5.4)
13 - 18	13 (1.5)
19 - 64	532 (62.4)
> 64	261(30.6)
Gender	
Female	447(52.5)
Male	405(47.5)
Origin	
Metropolitan region of Recife	564(66.2)
Inland	288 (33.8)
Ocupation	
Military, police and military firemen	269 (31.6)
Senior members of the government, managers of publi interest organizations and companies and managers	^c 243(28.5)
Professionals of Science and Arts	122 (14.3)
Mid-level Technician	68 (8.0)
Administrative services workers	55 (6.5)
Service workers, salespeople in shops and markets	43 (5.0)
Agricultural, forestry, hunting and fishing workers	26 (3.0)
Industrial goods and service production workers	14 (1.6)
Maintenance and repair workers	10 (1.2)
Children, students and from home	2 (0.3)

Table 2 shows the comparison of the average ages of the groups of children and adolescents, as well as of adults and the elderly, by diagnosis and type of surgery. A higher average age of patients with a diagnosis of congenital malformations was found ($\overline{\chi}$ =5.92), and the difference between this average and

that corresponding to the diagnosis of trauma and intestinal obstructions was statistically significant. The same was not verified regarding the type of ostomy, that is, there was no difference between the average ages of the two age groups submitted to surgery for the making of a colostomy or ileostomy (p>0.05). Regarding the character of the stoma, patients in the group of children and adolescents (n=59) had temporary ostomy. When comparing the average ages of the groups of adults and elderly people by diagnosis, there was a higher average of patients presenting neoplasms, whose average was significantly different (p < 0.001), when compared to those diagnosed with trauma and obstructions. Also, a significant difference was identified for the averages of patients by type and character of the stoma, with a higher average corresponding to colostomies and permanent stomas, respectively.

Table 2 – Comparison of the average age of the groups of children and adolescents and adults and elderly, by diagnosis, type and character of ostomy. Recife, PE, Brazil, 2019

Variables –	Child	ren/Adolesce	nts	Adults/Seniors		
	(σ)	IC (95%)	р	Average (standard deviation)	IC (95%)	р
Diagnosis						
Congenital malformations	5.92 (7.9)	3.45 - 8.43	0.020*			
Injuries and obstructions	2.29 (4.5)	0.37 - 4.21		50.94 (17.2)	46.17 - 55.71	
Neoplasms	-	-		59.86 (14.4)	58.50 - 61.22	0.000*
Type of ostomy						
Colostomy	4.14 (6.5)	2.05 - 6.23	0.428*	61.98 (12.9)	54.24 - 57.08	0.020^{\dagger}
lleostomy	5.45 (6.5)	2.73 - 8.17		55.66 (16.7)	52.34 - 56.93	
Urostomy	-	-		54.63 (16.07)	58.42 - 65.54	
Character of the ostomy						
Permanent	-	-		62.98 (15.4)	60.89 - 65.07	0.000*
Temporary	-	-		51.73 (16.4)	50.21 - 53.25	

*Test *t* of *Student* ; [†]ANOVA; SD: standard deviation; CI: Confidence Interval

Discussion

The computerization of the registration data of patients enrolled in the Assistance Program for Ostomy Patients enabled the characterization of an expressive number of patients, however, as it is in the installation phase, it presents as a limitation the incompleteness regarding some variables, as well as lack of normalization for data filling, in order to ensure the uniformity required by the system, in addition to the integrity of the information.

However, the results of this research can contribute to the development and/or improvement of care for ostomy patients, at the three levels of complexity, since it presents the relationship between the variable age and characteristics, such as diagnosis, type and character of the ostomy, providing subsidies for the elaboration of specific strategies for each age group, according to the morbidity picture most frequently related to it.

The findings of this research, primarily, deserve attention for a higher frequency of adults and elderly people who need to have an ostomy, whose sum of the two groups corresponded to 93.0% of the studied population, a fact that is consistent with other studies on the same theme, but with small samples, but that follow the age distribution of the Brazilian population with a progressive aging trend⁽⁸⁻¹¹⁾.

Among the patients, the male gender was more likely to perform an ostomy, however, with a small

difference in relation to the female gender (not statistically significant). This may explain the variation also found in research carried out in the States of Paraná⁽¹⁰⁾ and Alagoas⁽⁸⁾, Brazil, however, with a higher frequency of female ostomy patients, however, in the latter, with little difference between the two sexes, as presented in this study.

The State of Pernambuco is divided into four mesoregions: Agreste, Zona Da Mata, Metropolitana and Sertão⁽¹³⁾, with the highest frequency of patients enrolled in the Program coming from the Metropolitan Region, which has the lowest number of municipalities, when compared to the others, followed by the Zona da Mata, located next to it.

The lower percentages of patients from the regions of Agreste (12.4%) and Sertão (5.5%) can be explained, since it was only in 2009 that the Polo de Estomizados (Center of Ostomized) in Caruarú (Agreste Pernambuco) was created, aimed at assistance for the neighboring population in these regions.

The results related to the occupation follow the national estimates for the North and Northeast Regions that presented, in the last seven years, rates of formalization of work below the national average of the last decade and that, even with continuous improvement observed, in the most recent years, Brazil still has a significant contingent of people who work informally, without a formal contract or who do not contribute to social security⁽¹⁴⁾.

The life regimen of a person living with an ostomy, with regard to consultations and treatments, often results in sick leave for health reasons. This complicates the permanence at work, which can cyclically influence the precariousness of health and quality of life.

Given this, one must consider the large number of elderly people found in this research that possibly was related to the insertion in the informal labor market or that assumed the status of retired or dependency, reinforcing the national records, in the last five years, about the decrease the number of people with a formal employment relationship, while also observing the progression of the number of people who work without a formal contract and of those who work for themselves⁽¹⁴⁾.

Regarding the value of retirement, added to the right to receive collection equipment and protection and safety adjuvants and other rights guaranteed to the person living with an ostomy, it is necessary to consider the existing contradiction between the amount received and the real needs of these people, who together with regional income inequalities, encourage these elderly people to look for informal work.

According to estimates by the United Nations, Brazil will show an increasing total dependency rate, mainly due to the increase in the dependency rate for the elderly, predicting that it will reach by 2050 a ratio of 80.6 elderly people for each group of 100 people of potentially age active⁽¹⁵⁾. In view of the growing trend of the aging of the Brazilian population and the morbidity associated with it, in which the existence with an ostomy is inscribed, it is necessary to consider the important challenges related to health care, social security and integration of these elderly people to society⁽¹³⁾.

The socioeconomic level influences access to health information, medical and hospital resources, as well as other community resources, likewise, it can interfere with the perception of the necessary requirements for self-care and the identification of complications associated with the stoma⁽¹⁶⁾.

Thus, information about the socioeconomic level of patients must be known by nurses who work in programs for assistance to ostomy patients, to develop appropriate strategies for health education, considering the impact of these variables at the regional level.

The results found regarding the indication for making intestinal stomas in the group of children and adolescents agree with another research carried out in Teresina, Brazil, to characterize children and adolescents with ostomies in health services, with a sample of 55 inpatients⁽¹⁷⁾, in which anorectal anomaly was the most frequent among children.

In pediatric surgical practice, approximately 75.0% of ostomies occur in neonates and infants. In newborns, enterostomies are indicated by diagnoses as diverse as perforating necrotizing enterocolitis, complicated intestinal atresia, volvulus, Hirschsprung's disease, meconium ileus and perforated anus⁽¹⁸⁾. In turn, the small child or adolescent will need a stoma for the treatment of Crohn's disease, clinically refractory, as part of the operative approach for ulcerative colitis, intestinal perforation, with extensive perineal contamination or ischemia (volvo, trauma, inflammatory disease intestinal), and for failure to reconstruct and manage congenital anomalies⁽¹⁸⁾.

Indications for an ostomy are dictated by the diagnosis and the desired function of the stoma. The function of an ileostomy or colostomy is usually the derivation of fecal flow, decompression of dilated or obstructed intestines, or access for irrigation and evacuation of feces or meconium⁽³⁾. The results of this research, regarding the type of ostomy, differ from a study carried out in Maranhão, Brazil, with 110 children and adolescents with intestinal stoma elimination, whose colostomies were more frequent (88.2%)⁽¹⁸⁾.

For the group of adults and the elderly, the most frequent among the total number of patients enrolled in the Program, the main indication for performing the ostomy was neoplasia, with a significant difference in relation to the diagnosis of trauma and obstructions. The major trend found for the diagnosis of neoplasia is similar to that of other studies carried out in the Brazilian states: Alagoas⁽⁸⁾, Piauí⁽⁹⁾ Paraná⁽¹⁰⁾ and Minas Gerais⁽¹¹⁾.

In Brazil, an estimated 20.520 new cases of colon and rectal cancer in men are estimated for 2020; and 20.470 in women and, without considering non--melanoma skin tumors, this type of neoplasia is the fourth most frequent in men and, in women, it is the third most incident in the North and Northeast regions⁽¹⁹⁾. The relationship with age equal to or above 50 years old can explain the average age found in this study for colostomies performed by this disease. Knowing the aging trend of the Brazilian population, health professionals must be prepared for the impact of this disease and its consequences, in terms of the increase in people living with stomas.

Often, the causes determine the type and character of the ostomy, thus, the results of this study, of higher average age related to colostomies and of a permanent character, both presenting significant statistical differences over the other types and character, reinforce the findings of studies carried out in other Brazilian states regarding type⁽⁹⁻¹¹⁾ and character⁽⁹⁾. In this context, nurses in surgical clinics and primary care should look for strategies that facilitate the understanding and practice of the activities necessary for self-care.

In view of what has been discussed, it is pertinent to highlight that the knowledge of the demographic and clinical characteristics of ostomy patients can support decision-making by both professionals and health managers, since it provides necessary information for a better provision of devices and supplies, as well as enabling health professionals' more sensitive attention to the social challenges faced by these patients, in order to employ methods for greater adherence, reducing complications, often associated with the stoma, enabling ways to improve the quality of life.

Conclusion

This study allowed to verify that the age group most exposed to the studied procedure was that of adults/elderly, male and from the Metropolitan Region of the investigated state. The main causes of ostomy among children were congenital malformations, which required the making of a temporary ileostomy; while among adults/elderly, the neoplasm corresponded to the most frequent indication of permanent colostomies.

Collaborations

Lopes MP, Correa FMB, Esmeraldo JC and Reynaldo CSB contributed to the conception, design, analysis and interpretation of study data. Silva FMV assisted in the writing of the manuscript and critical review of important intellectual content. Vieira Santos ICR collaborated with the final approval of the version to be published.

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