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# SOCIODEMOGRAPHIC AND CLINICAL CHARACTERIZATION OF CHILDREN WITH STOMA: AN EPIDEMIOLOGICAL STUDY

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## ABSTRACT

**Objective:** To characterize the epidemiological clinical profile of children with ostomies treated in the outpatient clinic of a reference public teaching hospital for children in Brazil. **Method:** Descriptive, documentary, retrospective and quantitative study, carried out by extracting sociodemographic and clinical data from electronic medical records of children with ostomies, monitored from 2014 to 2018. The data underwent descriptive statistics, and in the analysis, the data were organized in a spreadsheet in Microsoft Excel version 2010, distributed in three tables, their values represented in absolute and relative frequency. **Results:** Of the 85 children with ostomy, there was a predominance of males, aged between 1 and 4 years. Anorectal anomaly was considered the main diagnosis. There was a high number of colostomies made. Contact dermatitis was the most frequent peristomal complication. There were difficulties in the routine of families attending the outpatient clinic, and the mother as the main caregiver. **Conclusion:** The study found relevant aspects related to care planning based on the demand of each child and health education for the prevention of complications, essential actions in the provision of safe and quality nursing care, as well as favoring the operationalization of public policies related to the health of children with ostomies.

DESCRIPTORS: Enterostomal therapy. Health profile. Ostomy. Kids. Nursing care.

# CARACTERIZAÇÃO SOCIODEMOGRÁFICA E CLÍNICA DE CRIANÇAS COM ESTOMIA: UM ESTUDO EPIDEMIOLÓGICO

## RESUMO

**Objetivo:** Caracterizar o perfil clínico epidemiológico de crianças com estomia atendidas no ambulatório de um hospital público de ensino de referência na área infantil no Brasil. **Método:** Estudo descritivo, documental, retrospectivo e de natureza quantitativa, realizado por meio da extração de dados sociodemográficos e clínicos de prontuários eletrônicos de crianças com estomia, acompanhadas de 2014 a 2018. Os dados passaram por estatística descritiva e, na análise, foram organizados em uma planilha no programa Microsoft Excel versão 2010, distribuídas em três tabelas, seus valores representados em frequência absoluta e relativa. **Resultados:** Das 85 crianças com estomia, houve predominância do sexo masculino, idade entre 1 a 4 anos. Anomalia anorretal foi considerada o principal diagnóstico. Constatou-se elevado número de colostomias confeccionadas. Dermatite de contato foi a complicação periestomal mais frequente. Verificou-se a dificuldade na rotina de comparecimento das famílias ao ambulatório e constatou-se a mãe como cuidadora principal. **Conclusão:** O estudo concluiu relevantes aspectos relacionados ao planejamento do cuidado pautado na demanda de cada criança e na educação em saúde

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para a prevenção de complicações, ações indispensáveis na oferta do cuidado de enfermagem seguro e de qualidade, como também favorecer operacionalização das políticas públicas relacionadas à saúde da criança com estomias.

DESCRITORES: Estomaterapia. Perfil de saúde. Estomia. Crianças. Cuidados de enfermagem.

## CARACTERIZACIÓN SOCIODEMOGRÁFICA Y CLÍNICA DE NIÑOS CON OSTOMÍA: UN ESTUDIO EPIDEMIOLÓGICO

RESUMEN

**Objetivo:** Caracterizar el perfil clínico epidemiológico de niños con ostomías atendidos en el ambulatorio de un hospital público de enseñanza en Brasil. **Método:** Estudio descriptivo, documental, retrospectivo y cuantitativo, realizado mediante la extracción de datos sociodemográficos y clínicos de historias clínicas electrónicas de niños con ostomías, seguidos de 2014 a 2018. Los datos fueron sometidos a estadística descriptiva, y en el análisis, los datos fueron organizados en una hoja de cálculo en Microsoft Excel versión 2010, distribuidas en tres tablas, sus valores representados en frecuencia absoluta y relativa. **Resultados:** De los 85 niños con ostomía hubo predominio del sexo masculino, con edades entre 1 y 4 años. La anomalía anorrectal se consideró el diagnóstico principal. Se realizó un alto número de colostomías. Dermatitis de contacto, la complicación periestomal más frecuente. Hubo dificultades en la rutina de las familias que asisten a la consulta externa, y la madre como principal cuidadora. **Conclusión:** El estudio encontró aspectos relevantes relacionados con la planificación del cuidado con base en la demanda de cada niño y la educación en salud para la prevención de complicaciones, acciones esenciales en la prestación de cuidados de enfermería seguros y de calidad, además de favorecer la operacionalización de las políticas públicas relacionadas a la salud de los niños con ostomías.

DESCRIPTORES: Estomaterapia. Perfil de salud. Ostomía. Niños. Cuidado de enfermera.

# INTRODUCTION

An ostomy is a therapeutic surgical procedure and consists in the exteriorization of any hollow viscera of the body. When performed in childhood, it is generally related to the treatment of congenital alterations, trauma or some acute or chronic clinical situations[1,2]. They have a definitive or temporary nature, depending on the underlying disease, as well as on other factors that may influence the reconstruction of the intestinal transit[3,4].

The advance of health technology has contributed to a decrease infant mortality, has given children with physiological disorders and congenital problems a better chance of survival, and, thus, has increased the number of children dependent on health care and/or technology[5,6].

The confection of the stoma in childhood generates impacts on the body's physical integrity, on the dynamics of infant socialization, and on the alteration of the family routine. Thus, clinical follow-up is recommended throughout childhood, providing effective treatment so that the child's biological, psychological, and social growth and development are preserved[7,8].

In view of the above, the child with a stoma must receive care from a multidisciplinary team focusing on health promotion and prevention of complications. Thus, it is relevant to know the public to which the nursing care will be offered, in order to provide guidance and training to the responsible caregivers, with the purpose of making the care integralized[9].

Epidemiological data regarding the profile of the person with a stoma is still scarce in the Brazil, especially when it comes to children, making the information about this public limited. Therefore, the elaboration of this study is justified as an important instrument to guide the planning of the assistance. It provides managers and health professionals with conditions to elaborate strategies for care, with the purpose of providing specialized assistance and guidance to the responsible caregivers, providing safety to the family members in the management of child-related care[3,8,9].

Thus, the following question arose: "What is the clinical and epidemiological profile of children with ostomy assisted in Distrito Federal?" Thus, in order to answer this questioning, the objective of this study was elaborated: To characterize the clinical and epidemiological profile of children with stoma assisted in the outpatient clinic of a public teaching hospital of reference in the children's area in Brazil.

## METHODS

This is a descriptive, documental, and retrospective study of a quantitative nature. Developed in a teaching hospital, a reference hospital in the children's area for the Midwest region, exclusively for users of the public health system of Distrito Federal, Brazil.

The sample was represented by electronic medical records of children with ostomy seen at the outpatient clinic, archived in the electronic system Trakcare, of the Health Secretariat of the Distrito Federal. Determined inclusion criteria: having a stoma, noted in an outpatient follow-up chart, between the years 2014 to 2019, age zero to 11 years 11 months and 29 days. Exclusion criterion determined: children with less than two visits to the outpatient clinic.

The data was collected between the months of August and October 2019. Electronic medical records were identified using spreadsheets provided by the outpatient clinic for care of children with stoma. To guide data stratification, an instrument was built exclusively for this purpose with all the variables identified and divided into sociodemographic, clinical, and follow-up approaches.

The sociodemographic data are: location, gender, and age. The clinical data are: medical diagnosis, age at stoma confection, length of stoma duration, presence of mucous fistula, lateralization, mode of exteriorization, type of stoma, complications in the stoma and in the peristomal skin, and causative factor of the complication.

For the analysis, the data were organized in a spreadsheet in Microsoft Excel version 2010 program, distributed in three tables, whose values were represented in absolute and relative frequency.

This study followed the ethical principles of Resolution No. 466/2012, and was approved by the Research Ethics Committee of the Foundation for Teaching and Research in Health Sciences FEPECS/SES/DF under opinion No. 3,285,441. Because this is a documentary research, waiver of the Free and Informed Consent Form was requested and accepted. Since this is a secondary data study, the risks to the participants were minimal, and the confidentiality of their data was ensured throughout the study.

## RESULTS

The sociodemographic profile of the 85 children participating in the study revealed that 54 (63.5%) were male, 36 (42.4%) were between 1 and 4 years old, 67 (78.8%) lived in the Distrito Federal, 15 (17.6%) were from the state of Goiás, and 3 (3.5%) from the state of Minas Gerais (Table 1).

**Table 1.** Sociodemographic characteristics of children with stomas. Brasília, Distrito Federal, Brazil; 2020 (n = 85).

| Variables | | n | % |
|---|---|---|---|
| **Sex** | Male | 54 | 63.5 |
| | Female | 31 | 36.5 |
| **Age** | < 1 month | 6 | 7.1 |
| | > 1 month to 1 year | 29 | 34.1 |
| | > 1 to 4 years | 36 | 42.4 |
| | > 4 years | 1 (9,1) | 72.7 |
| **Location** | Distrito Federal | 67 | 78.8 |
| | Goiás | 15 | 17.6 |
| | Minas Gerais | 3 | 3.5 |

Source: Elaborated by the authors.

Six medical diagnoses were identified, among which there was a predominance of anorectal anomaly (33; 38.8%) and the diagnosis of congenital megacolon was observed as the second most frequent diagnosis (28; 32.9%). Regarding the age at which the stoma was made, 79 (92.9%) occurred in the first 6 months of life, 31 (36.5%) remained between 1 and 2 years with the stoma. Mucous fistula presented itself in 30 (35.5%) of the stomas.

Most stomas were made on the left side of the abdomen (59; 69.4%) and double-barrel stoma exteriorization predominated (63; 74.1%). As for complications, 4 (4.7%) had prolapse and 2 (2.4%) had parastomal hernia. Contact dermatitis presented in 36 (42.4%) children. Contact with effluent on the skin was found to be the main cause of the complication in the peristomal region (32; 37.6%). (Table 2).

**Table 2.** Clinical characteristics of children with stomas. Brasília, Distrito Federal, Brazil; 2020 (n = 85).

| Variables | | n | % |
|---|---|---|---|
| **Medical diagnosis** | Anorectal anomaly | 33 | 38.8 |
| | Congenital megacolon | 28 | 32.9 |
| | Necrotizing enterocolitis | 17 | 20.0 |
| | Intestinal invagination | 4 | 4.7 |
| | Intestinal perforation | 2 | 2.4 |
| | Neurogenic bladder | 1 | 1.2 |
| **Age at stoma confection** | > 6 months | 79 | 92.9 |
| | 1 year | 2 | 2.4 |
| | 2 years | 1 | 1.2 |
| | 3 years | 2 | 2.4 |
| | 4 years | 1 | 1.2 |
| **Duration of the stoma** | 1 month or less | 5 | 5.9 |
| | > 1 month to 6 months | 10 | 11.8 |
| | > 6 months to 1 year | 22 | 25.9 |
| | > 1 to 2 years | 31 | 36.5 |
| | > 2 to 3 years | 8 | 9.4 |
| | > 3 to 4 years | 4 | 4.7 |
| | > 4 to 5 years | 1 | 1.2 |
| | > 5 to 10 years | 4 | 4.7 |
| **Mucous fistula** | No | 55 | 64.7 |
| | Yes | 30 | 35.3 |
| **Laterality** | Left | 59 | 69.4 |
| | Right | 24 | 28.2 |
| **Exteriorization** | Double-barrel | 63 | 74.1 |
| | Single-barrel | 11 | 12.9 |
| **Type of ostomy** | Colostomy | 65 | 76.4 |
| | Ileostomy | 22 | 25.8 |
| | Tracheostomy | 4 | 4.7 |
| | Cystostomy | 6 | 7.0 |
| | Nephrostomy | 1 | 1.2 |
| | Vesicostomy | 1 | 1.2 |
| | Urostomy | 1 | |

**continue...**

**Tabela 2.** Continuation...

| Variables | | n | % |
|---|---|---|---|
| **Types of stoma complications** | Prolapse | 4 | 4,7 |
| | Parastomal hernia | 2 | 2,4 |
| | Necrosis | 2 | 2,4 |
| | Protrusion | 1 | 1,2 |
| | Bleeding | 1 | 1,2 |
| | Stenosis | 1 | 1,2 |
| | Without complication | 74 | 87,1 |
| **Types of complications in the peristomal skin** | Dermatitis | 36 | 42,4 |
| | Without complication | 49 | 57,6 |
| **Complication factor** | Contact with effluents | 32 | 37,6 |
| | | | 2,4 |
| | Contact with chemical agents | 2 | 1,2 |
| | Trauma | 1 | 1,1 |
| | No complicating factors | 50 | 58,8 |
| **Total** | | **85** | **100,00** |

Source: Research data organized by the authors.

Regarding outpatient visits, according to the periodicity, 11 (12.9%) gave up or abandoned the follow-up, and 72 (84.7%) had no difficulties in attending the outpatient clinic. Regarding the collecting equipment used, the most frequent was the pediatric collecting bag (75; 88.2%), 10 (11.8%) used diapers, and 85 (100%) used peristomal skin protectors for the children. Mothers were found as the primary caregiver (85; 100%) (Table 3).

**Table 3.** Distribution of children with stoma regarding follow-up and orientation at the ostomy clinic. Brasília (DF), 2020 (n = 85).

| Variables | | n | % |
|---|---|---|---|
| Outpatient periodicity | 2 months | 48 | 56.5 |
| | 4 months | 22 | 25.9 |
| | Withdrawal/abandonment | 11 | 12.9 |
| | Death | 4 | 4.7 |
| Difficulties in attending | No | 72 | 84.7 |
| | Yes | 13 | 15.3 |
| Use of collecting equipment | Pediatric bag | 75 | 88.2 |
| | Diaper | 10 | 11.8 |
| Peristomal skin protector | Yes | 85 | 100 |
| | No | 0 | 0 |
| Primary caregiver | Mother | 85 | 100 |
| **Total** | | **85** | **100** |

Source: Elaborated by the authors.

## DISCUSSION

It was evidenced that the majority of the 85 children are male. This result corroborates data from other studies, in which a higher frequency of males is commonly found among children with stoma[10]. Different age groups were observed, ranging from neonatal, preschool, and school age. The minimum age is less than six months and the maximum age is

four years. Similar data are found in other studies in which there was a predominance of the age group between 1 and 4 years[10–15]. Most are from Distrito Federal, but a number of participants from other states can be observed, from which it can be inferred that treatment is not offered in their region of origin. Corroborating a study conducted in Piauí, which obtained a high number of participants from the interior of the state[14].

The creation of a stoma in childhood is usually related to congenital causes, and the procedure is performed in the neonatal period[16]. In the sample of this study, the main diagnosis presented was anorectal anomaly, which is characterized by the absence of the anus and, in some cases, is concomitant to a defect in the genitourinary tract; in these cases, surgical interventions are performed in the first days of the child's life. This result is similar to the studies carried out in Teresina/PI[14,17]. This malformation affects males more frequently, with an incidence of 1:1,500 to 1:5,000 among live births[16]. Besides diseases of genetic origin, other comorbidities can cause the creation of a stoma, such as: necrotizing enterocolitis, inflammatory bowel diseases and trauma caused by violence or accidents[1,2,18].

In this study there was a prevalence of ostomies of the gastrointestinal tract, with colostomy standing out, which has already become evident in other investigations[10,13,15,19]. The high number of children with colostomy in the sample is justified by the predominant diagnosis of anorectal anomalies, and this is one of the common surgical treatments in these cases[20].

The surgery for creation of the stoma occurred between the first six months of life of the children in this study. They remained with stoma for 1 to 2 years of age, as found in other studies[14,15]. Generally, colostomies performed in the neonatal period are temporary, the anal fistula is performed after four to six months, for later reconstruction of the intestinal transit by a new surgical approach[21]. In this study it was not possible to identify the nature of the stoma, due to insufficient data in the medical records consulted.

The study observed a significant number of intestinal stomas created on the left side of the abdomen and a predominance of exteriorization in double-barrel stomas. Studies corroborate this result[15,22,23]. It is understood that the characteristics of the stomas, such as their location, the form of exteriorization, size, shape and protrusion may vary for different reasons, among them the surgical technique used, the exteriorized segment, the cause and the permanence of the stoma[12]. Regarding stoma complications, there was a predominance of prolapse, which is not a common complication and is usually associated with the presence of paracolostomy hernia, considered a late complication[22]. Other studies corroborate this result[14,15].

It is noteworthy that, even with the use of the skin protector, the participants were affected by contact dermatitis, this being a predominant peristomal complication in this public[14,16,24]. Peristomal dermatitis is caused by prolonged contact of effluent, be it feces, urine, or gastric contents. This injury impairs the rehabilitation process with the stoma, because it can trigger pain, inflammatory processes, disruption of the integrity of the skin and increase the cost by the need for several changes of collecting bags a day[19,21].

In this study, most participants used a pediatric device as collecting equipment, but children were observed using disposable diapers to contain the flow of effluents, a result that can also be seen in another study conducted in Brasília/DF about complications in children with stoma[15]. It should be noted that the disposable diaper is not considered a waste collection equipment and its main contraindication is the fact that it does not protect the peristomal skin and consequently causes skin complications. In addition, its continuous use during childhood can become a barrier to socialization[15].

The relevance of pediatric nursing is reinforced in maintaining a differentiated care in order to meet the specific demands of this public, prevent complications, and evaluate the conditions of the stoma and the peristomal region. In this way, pediatric nursing provides appropriate treatment and prevents possible recurrence of complications[23–25].

Most of the children attended nursing appointments at the outpatient clinic every two months, accompanied by their mothers. This periodicity was scheduled by the ostomy outpatient clinic nurse according to the child's care needs, since they also attended to purchase the collecting and adjuvant equipment. It was observed that some mothers attended the clinic accompanied by a family member: husband, grandmother, or aunt of the child, showing that the family was involved in the process of caring for the child.

Family support is very important, because in the first years of life the dependence on the mother figure is intense; however, this generates a maternal overload, both physical and emotional, especially when it comes to children with health needs[9,24].

The literature shows that there is a reduction in the physical and emotional health of family members caring for a child with an illness condition due to multiple factors, such as reduced quality of sleep and deprivation of personal activities[23,25].

The analysis of the medical records showed a lack of attendance at the appointments scheduled by the outpatient clinic staff. The family members' justifications were due to the caregiver's difficulty to be absent from work or to the difficulty of commuting because they live far from the hospital. The records show that the children/family abandoned the follow-up in the outpatient clinic, and it is inferred that the abandonment is due to the origin of the children, because they lived in distant regions of Distrito Federal. Studies conducted in Brasília/DF[12] and Belém/PA[13] obtained similar results: children who lived in municipalities distant from the capital had difficulties to attend the health service. The study carried out in Brasília/DF identified that most of the children lived in the administrative cities of Distrito Federal, but 40% came from other states, such as Goiás and Maranhão. These data probably justify the absence of reference services in ostomy in some regions of Brazil, especially in the interior of the states[12].

The adaptation period of the child with a stoma is long and requires the support of the multidisciplinary team and family, as it is essential to provide safe and efficient care. Thus, it is necessary that nurses assume their important role in preparing family members, because they are the ones who will continue to care for the child at home. In this case, health education facilitates the adaptation to the new health condition and prevents possible complications of the stoma, minimizing the difficulties found in the daily life of this family[9,26].

This research was limited by the fact that the sample did not include all types of stomas, since the characteristics of the public seen at the clinic were predominantly stomas of the gastrointestinal and urinary tracts. Another limiting factor to be considered was the failure to correctly fill out the medical records, which sometimes restricted access to all the variables.

There was restriction on the use of the data from the medical records due to insufficient completion. In addition, the sample was exclusively conducted in a reference public hospital in Distrito Federal; thus, it was not possible to identify children with stomas treated in other public and private hospitals.

However, the research seeks the improvement of the care offered by nursing to children with stomas. The results of this research offer an increase in scientific knowledge and favor the planning of nursing care and the development of actions directed at this clientele.

## CONCLUSION

The study enabled the characterization of the sociodemographic and clinical profile of children with stomas in a reference teaching hospital specialized in children's care. It consists of 85 children with stomas. It is noteworthy the high rate of lack of attendance of the child to the ostomy clinic, which is a compromising aspect for the continuity of treatment and shows the difficulties that family members experience with the demands of the child with a stoma. It is worth noting that the indiscriminate use of disposable diapers to collect the effluent can trigger complications in the peristomal region and cause future socialization problems for the child.

The scarcity of data about the profile of children with stomas can be a detrimental factor for the implementation of public health care policies related to this public. For this reason, research focused on the sociodemographic and clinical profile of children with stomas is essential to provide subsidies for assistance planning. It is necessary to value health education for the prevention of complications, early detection, and treatment, and to use this tool, health education, as a political-pedagogical strategy to support a safe and quality health work process. Hopefully, this research will subsidize future studies as well as contribute to nursing planning regarding the care of the child with a stoma.

## AUTHORS' CONTRIBUTION

**Formal Analysis:** Correia PV and Kamada I; **Conceptualization:** Correia PV and Kamada I; **Data Curation:** Correia PV and Kamada I; **Methodology:** Correia PV and Kamada I; **Writing – First Draft:** Correia PV; Melo MC, Silva AL and Kamada I; **Writing – Review & Editing:** Correia PV; Melo MC, Silva AL and Kamada I; **Supervision:** Correia PV;

Melo MC, Silva AL and Kamada I; **Validation:** Correia PV; Melo MC, Silva AL and Kamada I; **Visualization:** Correia PV; Melo MC, Silva AL and Kamada I.

## AVAILABILITY OF RESEARCH DATA

The data will be available upon request.

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