Esc Anna Nery 2024;28:e20220409

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Profile of technology-dependent children and adolescents in a referral pediatric hospital in the south of the country

Perfil de crianças e adolescentes dependentes de tecnologia em um hospital pediátrico do sul do país

Perfil de niños y adolescentes dependientes de tecnología en un hospital pediátrico de referencia del sur del país

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Submitted on 03/29/2023.
Accepted on 12/01/2023.

DOI:https://doi.org/10.1590/2177-9465-EAN-2022-0409en

Abstract

Objective: to identify the profile of technology-dependent children and adolescents at a pediatric referral hospital in southern Brazil. **Method:** a descriptive study with a quantitative approach. Data was collected by analyzing medical records between January 2016 and December 2019 and stored in a Microsoft Excel spreadsheet for descriptive statistical analysis. The project was approved by the Ethics Committee under protocol number 5.115.194. Results: The prevalence was male (50.8%), pre-school age (30.8%), from Greater Florianópolis (60.1%). The most frequent diagnoses were related to prematurity/neonatal period, congenital anomalies/genetic defects, and neurological and/or neuromuscular diseases, corresponding to 37%, 33.2%, and 18.5%. The most commonly used technological devices were gastrostomy (56.3%) and tracheostomy (36.6%). 93.4% used continuous medication and 49.2% used four or more medications. Mothers were the main caregivers (80.9%). There were 31 deaths during the period. **Conclusion and implications for practice:** this group has a high demand for care due to the main diagnosis, technological devices, medications, and possible complications. Identifying the profile of technology-dependent children and adolescents has helped to increase the visibility of a population that is constantly growing and thus provides comprehensive care according to their specific needs.

Keywords: Adolescent; Child; Nursing; Gastrostomy; Tracheostomy.

Resumo

Objetivo: identificar o perfil de crianças e adolescentes dependentes de tecnologia de um hospital de referência pediátrica do sul do país. **Método:** estudo descritivo, com abordagem quantitativa. A coleta de dados ocorreu por meio da análise de prontuários, entre janeiro de 2016 e dezembro de 2019, armazenados em planilha *Microsoft Excel* para a análise estatística descritiva. Um projeto aprovado pelo Comitê de Ética sob o parecer 5.115.194. **Resultados:** prevaleceu o sexo masculino (50,8%), em idade pré-escolar (30,8%), proveniente da Grande Florianópolis (60,1%). Os diagnósticos mais frequentes foram relacionados à prematuridade/período neonatal, anomalias congênitas/defeitos genéticos, doenças neurológicas e/ou neuromusculares, correspondendo a 37%, 33,2% e 18,5%. Os dispositivos tecnológicos mais utilizados foram gastrostomia (56,3%) e traqueostomia (36,6%). A utilização de medicamentos contínuos se deu em 93,4% e 49,2% utilizavam quatro ou mais medicamentos. As mães foram as principais cuidadoras (80,9%). Ocorreram 31 óbitos no período. **Conclusão e implicação para a prática:** este grupo apresenta grande demanda de cuidados decorrentes do diagnóstico principal, dos dispositivos tecnológicos, das medicações e das possíveis complicações. A identificação do perfil das crianças e adolescentes dependentes de tecnologia contribuiu para ampliar a visibilidade de uma população que está em constante crescimento e, assim, prestar uma assistência integral, de acordo com suas especificidades e reais necessidades.

Palavras-chave: Adolescente; Criança; Enfermagem; Gastrostomia; Traqueostomia.

Resumen

Objetivo: identificar el perfil de niños y adolescentes dependientes de tecnología atendidos en un hospital de referência pediátrica del sur del país. **Método:** estudio descriptivo con enfoque cuantitativo. La recolección de datos ocurrió através del análisis de las historias clínicas, desde enero de 2016 hasta diciembre de 2019, almacenadas en una hoja de cálculo de *Microsoft Excel* para el análisis estadístico descriptivo. El proyecto fue aprobado por el Comité de Ética bajo el parecer 5.115.194. **Resultados:** predominaron varones (50,8%), en período de desarrollo preescolar (30,8%), la región más frecuentada de la Gran Florianópolis (60,1%). Los diagnósticos más frecuentes estuvieron relacionados con prematuridad/el período neonatal, anomalías congénitas/defectos genéticos, enfermedades neurológicas y/o neuromusculares, correspondiendo al 37%, 33,2% y 18,5%, respectivamente. Los dispositivos tecnológicos más utilizados fueron la gastrostomía (56,3%) y la traqueotomía (36,6%). El uso de medicación continua ocurrió en el 93,4% y el 49,2% utilizó cuatro o más medicamentos. Las madres fueron las principales cuidadoras en 80,9% de los casos, ocurriendo 31 óbitos en el período. **Conclusión e implicación para la práctica:** este grupo tiene una alta demanda de atención debido al diagnóstico principal, dispositivos tecnológicos, medicamentos y posibles complicaciones. Identificar el perfil de niños y adolescentes dependientes de tecnología contribuye a aumentar la visibilidad de una población en constante crecimiento y, por lo tanto, calificar la asistencia, de acuerdo com sus especificidades y reales necesidades.

Palabras clave: Adolescente; Enfermería; Gastrostomía; Niño; Traqueostomía.

INTRODUCTION

In recent years, Brazil has made progress in reducing infant mortality rates, as a result of developments in the health sector, technological development, and an increase in public policies. However, death rates in the neonatal period are still high and worrying, as is the increase in survivors of perinatal complications.[1]

Pediatrics has made great strides in recent years, especially in terms of technological development and the increase in public policies to control infant mortality. This has led to an increase in the prevalence of chronic and degenerative diseases.[2]

These survivors carry the sequelae resulting from health problems, giving rise to "children with special health care needs", in Brazil known as "*Crianças com Necessidades Especiais de Saúde*" (CRIANES).[3] This definition includes children and adolescents from zero to 18 years of age, who are characterized by the need for greater attention than children and adolescents in general and are classified according to the demand for care.[1] The impairments can be physical, developmental, and behavioral, sometimes requiring the use of more sophisticated technologies to ensure their survival.[4] CRIANES who need technological artifacts are also reported in the literature as technology-dependent children and adolescents.[4]

CRIANES also require comprehensive, continuous care and present a significant demand for health services. However, families face some difficulties in providing medical care, demonstrating the fragility of the system.[5]

Thus, the care needed to de-hospitalize CRIANES is complex and routinely carried out by health professionals. In this process, families need to incorporate new skills and overcome their own fears. As such, the professionals involved need to pay attention to properly preparing this family and liaising with other health services, ensuring comprehensive and decentralized care.[6]

In Brazil, there is still no official data on this population and their invisibility has led to a lack and/or inadequacy of public policies that address their specific needs. However, a study carried out in three cities in the South and Southeast, including 35 public health units, which included 6,854 children aged zero to 11, concluded that 25.3% were considered CRIANES.[7] The scarcity of concrete data and insufficient public policies also imply a lack of specialized professionals and, consequently, fragmented care.[3]

Between 2005 and 2016, there was an increase in mortality rates in Brazil due to neurological problems in children aged between five and 14. The main causes were cerebral palsy, hydrocephalus, and other brain disorders, accounting for 67% of neurological deaths. This situation highlights the need to understand the causes and establish strategies to improve this situation.[8]

With regard to hospitalizations of individuals under the age of 18, 190,000 were recorded in the National Health Information System. Diseases of the respiratory system, neoplasms and the nervous system were the most frequent causes of hospitalization, with 13.5% of these requiring highly complex care.[9]

Given this scenario, the aim of this study was to identify the profile of technology-dependent children and adolescents treated at a pediatric referral hospital in the south of the country. Knowing the profile of a local reality can help health professionals plan comprehensive care, according to the specificities and care demands of technology-dependent children and adolescents.

METHOD

This is a quantitative, descriptive study using secondary data sources. This type of study seeks to describe what actually happens, without manipulating the data or looking for cause or effect.[10] The study was carried out in a referral hospital for pediatric care in the south of the country, which is managed by the Santa Catarina State Health Department.

The population was made up of children and adolescents who used some kind of technological device and were treated in the intermediate care outpatient clinic at the institution. The sample consisted of the medical records of the sample from 2016 to 2019. This period was established, considering the creation of this intermediate care team and the beginning of care in this outpatient specialty until the beginning of the COVID-19 pandemic, when care underwent some changes.

Initially, a survey was carried out of all consultations during the period, resulting in 1,776 consultations, which comprised 284 medical records, of which 40 were excluded because they did not belong to the specialty in question, the consultation and/or appointment to the specialty had been carried out incorrectly and/or only to carry out an independent medical request. In addition, 61 medical records were excluded for those who did not use technological devices, giving a total sample of 183 technology-dependent children and adolescents.

Data was collected from the institution's electronic medical record system, called Micromed, by reading the patients' progress. The data collected included: medical record number, age, municipality of origin, main diagnosis, comorbidities, medications used, technological devices used, type of diet, and main caregiver. Data was also collected on deaths and the removal of technological devices, but this information may be underreported, since these cases may have occurred in another hospital or at home and were not recorded in the medical records.

After collecting the data, it was stored in a Microsoft Excel spreadsheet, distributed in tables and a descriptive analysis was carried out. Categorical variables were represented by absolute and relative frequency. The age variable was represented by mean and standard deviation. The variables comorbidities and use of devices were answered with more than one response per patient.

The study was carried out in accordance with the precepts of Resolution 466/2012 of the National Health Council and approved by the Ethics Committee of the aforementioned institution, under opinion no. 5.115.194 and CAAE: 53132421.8.0000.5361.

RESULTS

183 medical records were selected, of which 90 were female and 93 male, 49.2% and 50.8% respectively, with a slight prevalence of males. The age variable was categorized according to the growth/development period: Infant (30 days to one year and 11 months), toddler (two to three years), preschool (four to five years), school (six to 11 years), adolescent (12 to 18 years) and adult (over 18 years).[11] It should be noted that this last period should not be attended to at the study hospital, but due to the bond that these families establish with the professionals, they continue to be attended to at the service.

According to Figure 1, the majority of patients were preschoolers (n: 55, 30.1%), followed by toddlers (n: 49, 26.8%), with a mean age of 6.44 years (standard deviation).

As the hospital is a reference in care for the entire state of Santa Catarina, the origin was divided by mesoregions according to the Brazilian Institute of Geography and Statistics (IBGE) in 2017:[9] Greater Florianópolis, North, South, West, Serrana and Vale do Itajaí. The Greater Florianópolis region had the highest frequency of 60.1%, with 110 technology-dependent children and adolescents; the Northern region had no cases and the region with the lowest frequency was the Western region with 5.5% of cases and one of the medical records had the state of Acre as its registered address. Figure 2 illustrates the breakdown by region.

The main diagnoses were divided according to their etiology, into cardiovascular, endocrine, gastrointestinal, neurological, and/or neuromuscular conditions, conditions related to congenital anomalies or genetic defects, prematurity and the neonatal period, renal and/or urological conditions, respiratory conditions and other complications, as shown in Figure 3.

It can be seen that conditions related to prematurity and the neonatal period were the most attended to, accounting for 66 (36.1%) of the 183 medical records, followed by congenital anomalies or genetic defects and neurological and/or neuromuscular conditions, corresponding to 57 (31.1%) and 39 (21.3%), respectively. Among the conditions related to prematurity and the neonatal period, there was a high incidence of hypoxia and/or anoxia injuries. The frequency of congenital anomalies or genetic defects was high and the neurological and/or neuromuscular conditions ranged from microcephaly due to cytomegalovirus, hydrocephalus, myelomeningocele, and neurological injuries due to different causes, such as strangulation and cranioencephalic trauma.

The technology-dependent children and adolescents developed other pathologies, whether or not they were related to the main diagnosis. Of the total, 168 had some comorbidity, the most frequent being related to the neurological system (n: 100, 54.6%) followed by the digestive system (n: 61, 33.3%) and the respiratory system (n:45, 24.5%).

As for the technological devices used, 11 used three devices simultaneously, most commonly gastrostomy, tracheostomy, and mechanical ventilation or oxygen therapy, and 56 used two devices simultaneously.

There was a high rate of gastrostomy use, with 103 children and adolescents, representing 56.3%, followed by 67 who used tracheostomy, representing 36.6%, as shown in Table 1.

With regard to the use of medication, it was observed that of the 183 technology-dependent children and adolescents, only 12 (6.6%) did not use any type of medication, with 25 (13.7%) using one medication, 27 (14.7%) two medications, 29 (15.8%) three medications and 90 (49.2%) using four or more medications continuously. Among the medications were anticonvulsants (phenobarbital), vitamin D and iron supplements, antipsychotics (chlorpromazine), and proton pump inhibitors (esomeprazole).

Concerning the main caregiver, 148 children and adolescents (80.9%) had their mother as their main caregiver, eight (4.4%) had their father as their main caregiver and ten (5.5%) had their father and mother sharing the care equally. Grandparents, siblings, and stepmothers also appeared as the main caregiver, with a small frequency of five (2.7%) of the medical records analyzed being of institutionalized CHILDREN.

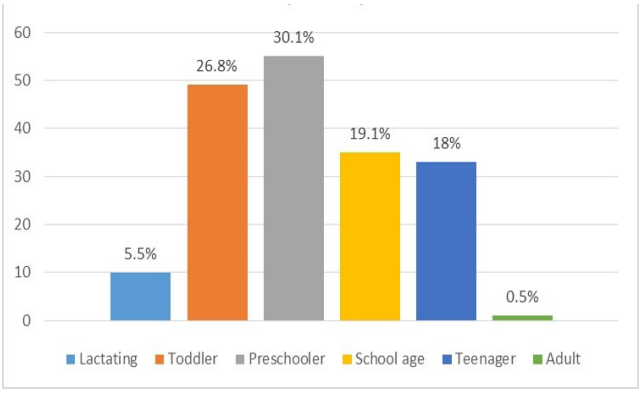

Figure 1. Developmental period. Distribution of technology-dependent children/adolescents according to developmental period (2016 - 2019). Florianópolis (SC), Brazil, 2022.

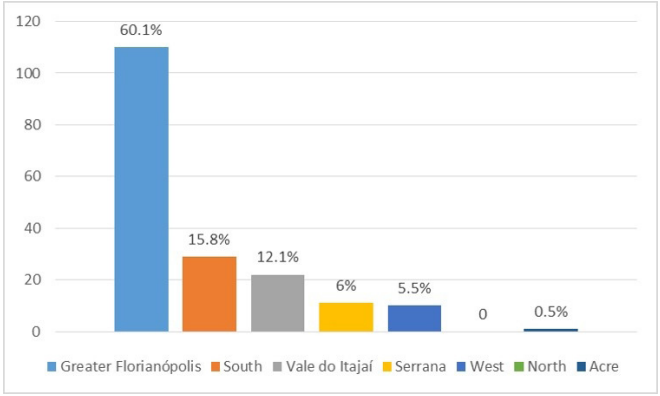

Figure 2. Region of residence. Distribution of technology-dependent children/adolescents by region of residence (2016 - 2019). Florianópolis (SC), Brazil, 2022.

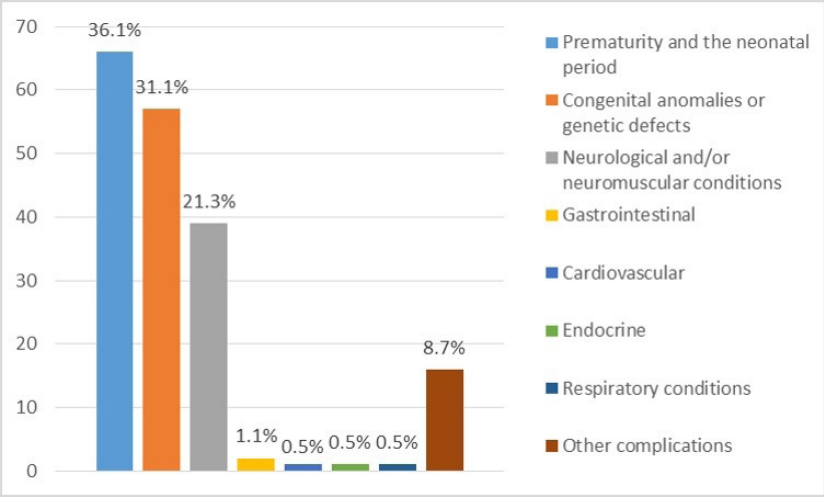

Figure 3. Distribution of technology-dependent children/adolescents according to the etiology of the main diagnosis (2016 - 2019). Florianópolis (SC), Brazil, 2022.

Table 1. Distribution according to the technological device used by children/adolescents (2016 - 2019), Florianópolis (SC), Brazil, 2022.

Patients using devices (n=183)	
Gastrostomy	103
Tracheostomy	67
Nasogastric tube	36
Oxygen therapy	17
Mechanical ventilation	14
Ventriculo-peritoneal shunt	11
Clean intermittent catheterization	5
Nasojejunal tube	3
Ileostomy	3
Colostomy	3
External ventricular shunt	1
Jejunostomy	1
Pacemaker	1

During the analysis of the medical records, it was identified that 31 of the children and adolescents (16.9%) died in the period from January 2016 to December 2019, however, it is estimated that this figure is even higher, since many occur in their municipality of residence and are not informed to the study institution.

DISCUSSION

The study showed a low prevalence of males (50.8%), as in other studies that show the susceptibility of males to chronic diseases.[1,12]

In line with other studies, there was a relationship between conditions related to the perinatal period, 66 (36.1%),[1,10] and congenital conditions and/or genetic defects, 57 (31.1%),[13] as causal factors for chronic health conditions. Prematurity is a major factor in developmental changes, and these individuals are more prone to future complications.[12]

This demonstrates the importance of quality prenatal care and assistance during labor and delivery in identifying and intervening early in preventable conditions. A national study carried out with puerperal women and newborns in 266 hospitals, with a total of 23,940 subjects in 2011 and 2012, analyzed the neonatal deaths that occurred and identified high rates of inadequate care during prenatal care and childbirth, as well as the performance of procedures that were not recommended. Although they did not find significant differences between deaths and live births, this is an important finding, given that the health conditions of live births subjected to these practices were not related in this study.[14]

The same study of puerperal women and newborns also found that 23% of all deaths were term newborns due to asphyxia during childbirth and late preterm infants, which is therefore a preventable cause.[14] Similarly, another study of 25 CRIANES found that 36% were affected by problems during pregnancy and childbirth.[1]

The medical records analyzed showed that 36.1% of the underlying diagnoses were related to prematurity and the perinatal period, reinforcing the importance of effectively implementing existing public policies and improving care for pregnant women, women in labor, and newborns. In addition to the main diagnosis, a range of subsequent diagnoses were identified, whether or not they were related to the underlying disease. A study already presented[1] identified that 25% of CRIANES, also had more than one initial diagnosis and with a significant association with chronic diseases.

The use of medication after hospital discharge was highly prevalent among technology-dependent children and adolescents, affecting 171 of them, 93.4% of the medical records analyzed, with 90 (49.2%) using four or more medications concomitantly,

with up to 11 medications prescribed. The use of a variety of medications, with a high rate of anticonvulsants, vitamins, and gastroprotectants, demonstrated the need for family members to adapt to home care, especially considering the complexity and rigor required to administer these drugs.[2,15]

A study carried out with 12 mothers of technology-dependent children showed that the mothers' experience with medication care is permeated by daily challenges, highlighting maternal overload and feelings of anxiety and depression, caused by the high demand for care for the technology-dependent child, which is enhanced by the need for continuous administration of medication.[15]

A study of 181 caregivers of CRIANES found that 83% used drug therapy and 22% were dependent on technological devices. In this study, 183 technology-dependent children and adolescents were identified, with 6% using three devices concurrently 93.4% using medication, with 49.2% using four or more medications.[16]

The complexity of caring for this population requires special attention from the multi-professional team, especially the families. The hospital discharge process requires engagement between the hospital team and the primary care team to strengthen and encourage the family to continue care at home, considering its complexity, which until then had been restricted to health professionals.[17]

In line with other studies, the mother was identified as the main caregiver, although other family members also co-participate in care, but in a more occasional and isolated way. The diagnosis of a technology-dependent child triggers a series of negative feelings, such as guilt and fear, making mothers feel the need to break down emotional barriers and incorporate new knowledge in order to ensure the maintenance and quality of life of their children.[6,18]

The findings show that a significant proportion of hospital care takes place outside the municipalities of origin of technology-dependent children and adolescents, accounting for 39.9% of care. A study carried out in two municipalities in Brazil on access to the healthcare network identified the difficulty families encounter in Primary Health Care networks and the long distances they travel to specialized care, and this reality can interfere with successful treatment.[19]

Given this scenario, there are many difficulties faced by families and in receiving care in health services. The fragmentation of care, the lack of referrals, and counter-referrals mean that many seek out the private network, urgent and emergency services, and/or tertiary services to the detriment of Primary Healthcare.[5] Although there are specific programs in the Unified Health System (UHS) for this section of the population, it is necessary to increase and strengthen public policies that guarantee agile, effective, and continuous care for CRIANES.[5,19]

Nesse sentido, as crianças e os adolescentes dependentes de tecnologia configuram-se em um desafio para os serviços de saúde, tendo em vista que os seus diagnósticos exigem cuidados intensivos, devido à complexidade e à necessidade de serem realizados continuamente.[20]

CONCLUSION AND IMPLICATIONS FOR PRACTICE

This study identified 183 technology-dependent children and adolescents, many of them in complex chronic conditions. The main diagnoses, for the most part, were related to conditions of prematurity and the neonatal period, to congenital abnormalities or to genetic and neurological and/or neuromuscular defects, in addition to having numerous correlated diagnoses.

It can be confirmed that the responsibility for care is centered on the mother's figure, demonstrating the necessary care with the workload and possible psychological changes.

By identifying and giving visibility to this population that is being assisted in the institution, knowledge is broadened and care practices are qualified. Through this study, it is expected that health professionals are attentive and seek to expand the care of technology-dependent CRIANES, encompassing the various demands, according to the specificities of each individual.

Since this is a study that was carried out in a service of only one institution, the impossibility of generalizing the results is highlighted as a limiting factor. It becomes necessary to broaden this sample in order to identify the conditions of this public in other regions of the country, so that there are changes in public policies effectively and/or to create strategies in the different sectors involved in care, with the aim of contributing to the quality of life of technology-dependent children and adolescents and their families. In addition, another limitation of this study refers to the joint presentation of the profile of children and adolescents, without specifying their peculiarities

AUTHOR'S CONTRIBUTIONS

Study design: Mariana Ceolin Tessele Sala. Jane Cristina Anders.

Data collection or production: Mariana Ceolin Tessele Sala. Jane Cristina Anders.

Data analysis: Mariana Ceolin Tessele Sala. Jane Cristina Anders. Juliana Coelho Pina. Aline Cristiane Cavicchioli Okido. Ana Izabel Jatobá de Souza.

Interpretation of the results: Mariana Ceolin Tessele Sala. Jane Cristina Anders. Juliana Coelho Pina. Aline Cristiane Cavicchioli Okido. Ana Izabel Jatobá de Souza.

Writing and critical review of the manuscript: Mariana Ceolin Tessele Sala. Jane Cristina Anders. Juliana Coelho Pina. Aline Cristiane Cavicchioli Okido. Ana Izabel Jatobá de Souza.

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