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Children and adolescents with special healthcare needs: care in home care services[a]

Crianças e adolescentes com necessidades especiais de saúde: o cuidado nos serviços de atenção domiciliar

Niños y adolescentes con necesidades especiales de salud: cuidado en los servicios de atención a domicilio

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ABSTRACT

Objective: to describe the care provided to children with special health needs in the Home Care Services of the State of Mato Grosso do Sul - Brazil. **Methods:** research, descriptive and exploratory. Study participants were professionals from home care services in Mato Grosso do Sul. Data collection took place through the application of two online forms, from 2019 to 2020, one containing descriptive data of the services and their care and the other for validation of the home care flow protocol for children. It was used for data analysis and descriptive statistics. **Results:** there was a predominance of 25 children with brain flexibility. Most classified as complex average according to the complexity and demands of care. Professionals and guidelines, procedures, assessment are responsible for training the family. The services do not have a flow protocol for the care of children. **Conclusion Implications for Practice Services** Present ability to deliver care and use the care plan and single use, advances in child care and solutions may still be presented. There is a practice of elaborating flow protocols and organization proposals that help professionals in their.

Keywords: Child Health; Child Care; Home Care Services; Nursing Care; Pediatric Nursing.

RESUMO

Objetivo: descrever o cuidado prestado às crianças com necessidades especiais de saúde nos Serviços de Atenção Domiciliar do estado de Mato Grosso do Sul. **Métodos:** pesquisa quantitativa, descritiva e exploratória. Os participantes do estudo foram profissionais dos Serviços de Atenção Domiciliar do Mato Grosso do Sul. A coleta de dados se deu com a aplicação de dois formulários on-line, no período de 2019 a 2020. Um dos formulários tinha dados descritivos dos serviços e seus atendimentos; o outro se voltava para a validação de protocolo de fluxo de atenção domiciliar às crianças. Para análise de dados, utilizou-se a estatística descritiva. **Resultados:** houve uma predominância de 25 crianças com paralisia cerebral, sendo que a maioria foi classificada como média complexidade, de acordo com a complexidade e as demandas de cuidados. Os profissionais realizam orientações, procedimentos e avaliação, além de serem responsáveis pelo treinamento da família. Os serviços não possuem protocolo de fluxo para atendimento das crianças. **Conclusão Implicações para Prática**: embora os serviços apresentem capacidade de ampliação do atendimento e utilizem o Plano Terapêutico Singular, avanços na assistência às crianças e famílias ainda se fazem necessários. Recomenda-se a elaboração de protocolos de fluxo e propostas organizativas que auxiliem os profissionais em sua prática.

Palavras-chave: Cuidado da Criança; Cuidados de Enfermagem; Enfermagem Pediátrica; Saúde da Criança; Serviços de Assistência Domiciliar.

RESUMEN

Objetivo: Descrever a atención prestada a niños con necesidades especiales de salud en los Servicios de Atención Domiciliaria del Estado de Mato Grosso do Sul. **Métodos:** investigação cuantitativa, descritiva e exploratoria. Los participantes del estudio fueron profesionales de los servicios de atención domiciliaria de Mato Grosso do Sul. La recolección de datos ocurrió a través de la aplicación de dos formularios en línea, de 2019 a 2020, uno con datos descriptivos de los servicios y su atención y el otro para la validación del protocolo para el flujo de atención domiciliaria a los niños. Se utilizó estadística descriptiva para el análisis de datos. **Resultados:** hubo un predominio de 25 niños con parálisis cerebral. La mayoría clasificó como mediana complejidad de acuerdo a la complejidad y demandas de atención. The professionals carry out lineamientos, procedures, evaluation and are responsible for training the family. Los servicios no cuentan con un protocolo de flujo para la atención de niños. **Conclusion Implications for Practice:** Although the services have the capacity to expand care and use the Singular Therapeutic Plan, advances in the care of the child and the family are still needed. The development of flow protocols and organizational proposals that help professionals in their practice are recommended**.**

Palabras clave: Atención de Enfermería; Cuidado del Niño; Enfermería Pediátrica; Salud del Niño; Servicios de Atención de Salud a Domicilio.

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INTRODUCTION

In the current Brazilian society, there is a concern for maintaining the healthy growth of children, whose responsibility for care is mainly attributed to families. Under this premise, the State has historically implemented several strategies, including the Program of Integral Assistance to Child Health, to confront adversities in the health conditions of the child population and laws such as the Statute of the Child and Adolescent (ECA). Such concern with child health, in addition to having occasioned the construction of public policies, has favored the advancement in health care technologies, which ensured greater survival of children and the search for advances, both by pediatric nursing and other health professionals.[1]

Increases in policies aimed at child health have boosted the survival rate of this public, including children who require special care. The English term Children With Special Health Care Needs (CSHCN) is used to refer to children and adolescents with clinical frailties that require continuous — and sometimes complex — health care.[2,3]

In Brazil, CSHCN are classified according to their care needs: those with developmental delays, those that require the use of technologies and medications, and those that require usual and mixed care. Care demands include psychomotor and functional rehabilitation, the use of catheters, colostomy bags, and tracheostomy, among others. Habitual needs include daily care, such as feeding and hygiene.[3,4]

Given this context in which child care becomes increasingly continuous at home, the health service had to be reorganized to meet this group's needs and demands. Hence, the Home Care Services (HCS) initiative was implemented through the *Programa Melhor em Casa* [Better at Home Program], which is organized in Brazil based on Ordinance No. 825 of April 25, 2016.[5]

This Ordinance[5] redefines Home Care (HC) within the Unified Health System (SUS) and updates the authorized teams. It presents the description of HC, which is organized into three modalities that vary according to the care needs, frequency of visits, intensity of care, and use of medications. These modalities are HC1 (low complexity), HC2 (medium complexity), and HC3 (high complexity).

In the HC1 modality, users who require care with less frequency and less need for professional intervention are eligible because it is assumed stability and satisfactory care by the caregivers. It is the responsibility of Primary Care to regularly monitor at home according to the patient's specific demands. The eligible users in HC2 are those with chronic-degenerative conditions, with parenteral treatment or rehabilitation needs that require at least weekly care; it also includes palliative care users with clinical follow-up at least once a week and premature and low-birth-weight babies who need to gain weight. In HC3, users with any situations mentioned in HC2 that require frequent visits, the use of equipment, and more complex procedures are eligible.

Both HC2 and HC3 are the responsibility of the HCS, operationalized by two types of teams: a home care multi-professional team, composed of a physician, nurse, nursing assistant or technician, physical therapist, and/or social worker, and a support multi-professional team, which, as the name implies, supports both the HCS and the Primary Health Care teams, and its composition must contain at least three of the following professions: social worker, physical therapist, speech therapist, nutritionist, dentist, psychologist, pharmacist, and occupational therapist.[5]

According to the document, the HCS is a complementary service to the care provided in Primary Care and emergency services, replacing or complementing hospitalization. Home care is a health care modality integrated into the health care network, characterized by a set of actions to prevent and treat diseases, rehabilitation, palliative care, and health promotion to guarantee continuity of care.

The objectives of the HCS include reducing the demand for hospital care, reducing the length of stay of hospitalized users, humanizing health care and user autonomy, as well as deconstitutionalizing and optimizing financial resources.[5] Since the implementation of HCS in Brazilian municipalities, the services have been structuring themselves to meet the demands of HCS and its legal objectives. Nevertheless, as this is a recent policy that has not yet been implemented in all Brazilian municipalities, and it is necessary to develop studies to better understand these services, their challenges, and potentialities. With this, it will be possible to fill the gap of knowledge that has existed about their operation and enable the development of proposals to improve the current reality.

Given the above, this study aimed to describe the care provided to Children with Special Health Care Needs (CSHCN) in Home Care Services (HCS) in Mato Grosso do Sul State (central-western Brazil).

METHOD

This is a quantitative, cross-sectional, descriptive, and exploratory study. The field of research corresponds to the HCS implemented in the municipalities of Mato Grosso do Sul State, which were identified using a Ministry of Health ordinance, freely accessible, on the website of this body. Data collection was carried out between April 2019 and September 2020.

The study participants were the HCS coordinators of Mato Grosso do Sul State, whose inclusion criterion was that they were in professional practice in the HCS at the time of data collection. Mato Grosso do Sul has eight home care services and 14 teams, which are located in the cities of Aquidauana, Coxim, Corumbá, Ponta Porã, São Gabriel do Oeste, and Campo Grande. All eight services in the state participated in the study. The eight participating coordinators belong to the following professional categories: nurses (four), physical therapists (two), physicians (one), and nutritionists (one). Three participating coordinators asked their former service coordinator to help them fill out the questionnaire since they had only taken over a few months ago. All are part of the service teams, with other professionals, such as nursing technicians, social workers, and psychologists.

An online form was created to obtain the answers from the participants. The following aspects were evaluated: identification of the service as to the type of team, documentation of the creation of the service, identification of the professional category of the participant, the quantity of children cared for, age of the children cared for, diagnoses of the children, dynamics of home visits and activities carried out, physical structure and human resources, organization of the care offered, and strategies used for the specific care of the children.

Data collection occurred through telephone and electronic contact with the participants. The first contact was made by the researchers by telephone call to the HCS, enabling us to identify the coordinators of the services and present the study. After they agreed to participate in the study, the link to the form (https://forms.gle/MBeMj3PdTeZajiDd6) and the informed consent form were sent via e-mail.

A matrix was prepared in which the information collected was grouped and organized so that its visualization and subsequent description allowed comparisons and syntheses to be established to support the analyses. Furthermore, a database in Excel version 2016 was used, and the simple and absolute frequencies, mean, and median were verified.

The quantitative data analysis was performed using descriptive statistics that, according to Polit, Beck, and Hungler,[6] is used to describe and synthesize the data, allowing them to be summarized, organized, and interpreted. The research followed Resolutions nos. 466/2012, 510/2016, and 580/218, all from the National Health Council, and the principles of bioethics, autonomy, non-maleficence, beneficence, justice, and equity. The Ethics Committee approved the study for Research with Human Beings of the Federal University of Mato Grosso do Sul (opinion no. 3.780.154) and Certificate of Ethics Appreciation Submission (no. 26555319.9.0000.0021) of December 18, 2019.

For reporting the study in article format and its publication, the recommendations of Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) were followed.[7]

RESULTS

Of the eight HCS, three were from Campo Grande, one from Corumbá, one from Coxim, one from São Gabriel do Oeste, one from Aquidauana, and one from Ponta Porã. All the services are provided in the morning and afternoon from Monday to Friday. Of those who attend at weekends, five (62.5%) do it on Saturdays and Sundays in the morning, four (50%) in the afternoon, and three (37.5%) do not perform services.

The categories that make up the Multidisciplinary Support Teams are nurses, social workers, speech therapists, psychologists, occupational therapists, pediatricians, pain specialists, physical therapists, and nutritionists.

The headquarters of three services (37.5%) are part of hospitals, two (25%) are attached to the Health Department, two (25%) to the Basic Health Units, and one (12.5%) to the Emergency Care Unit. Of the services, four (50%) have electronic medical records, three (37.5%) do not, and one (12.5%) has records only for internal communication.

As for the place of care, five (62.5%) services provide care only at home, and three (37.5%) also provide care at the headquarters. A call center with a separate telephone for caregivers is carried out by six (75%) participating services. The transportation of professionals for home visits is done with the service's car in six (75%) of the cases, with the municipality's car that is available at the time of the visit in one (12.5%) service, and with the municipality's car that requires booking in one (12.5%) service.

The HCS has a deadline to answer whether the patient will be elected and admitted after being referred by the other care network services. Such deadlines are one to two days for two services (25%), three to four days for three services (37.5%), and five to seven days for the other three services (37.5%). Table 1 lists the services that commonly refer patients to the HCS.

The number of people attended by the HCS varies due to conditions such as deaths, discharges, admissions, and seasonality. Among the HCS in this study, three (37.5%) had no children in attendance during the research period (HCAA, Corumbá, and Coxim). In the other services, considering the age from zero to 12 incomplete years, one (12.5%) had only one child in care, two (25%) with three, one (12.5%) with four, and one service (12.5%) had 14 children in care. The number of adolescents also had the same variation from one to 10 in 50% of the services, considering the ages of 12 to 18. In the other 50% of the services, no adolescents were being attended.

When a patient is admitted to the services, professionals orient families and caregivers about the care needed and how the Better at Home Program works. To reach the families' understanding of these orientations, the services adopt some strategies explained in Table 2.

As for the professional support of psychologists, psychiatrists, specialized care, and advocacy, over half (62.5%) of the services

Table 1. Quantity of services that refer to Home Care Services in Mato Grosso do Sul - Brazil - 2022.

Typology	Absolute frequency (n = 8)	Relative (%)
Public Hospitals	7	87.50
Private Hospitals	2	25.00
Emergency Care Units	3	37.50
Public Outpatient Clinics	5	62.50
Private Outpatient Clinics	3	37.50
Primary Care	7	87.50
Oncology Hospitals	5	62.50
Private network by request	1	12.50
Does not know/does not have	1	12.50

Source: The authors (2022)

Table 2. Organization of care- Brazil - 2022.

Educational resources used for family orientation	Absolute frequency (n = 8)	Relative (%)
Verbal and written guidelines	8	100
Practical demonstration of the techniques by repeating as many times as necessary	5	62.5
Use of images	3	37.5
Use of videos	1	12.5
Resources used to check understanding		
Orientation with re-evaluation as required	3	37.5
Orientation and re-evaluation according to the team's observation	4	50
Orientation and reevaluation with questions about the procedures that the caregiver should perform	3	37.5
Does not provide pediatric care	1	12.5

Source: The authors (2022)

have support for care through the health care network, one (12.5%) performs the support by the HCS, one (12.5%) offers it by the service itself — except for the advocacy, which is referenced to the public defender's office — and one (12.5%) does not offer support for the caregiver. Regarding the procedures that patients need, there are nursing care that can be performed by the family, about which some of the HCS instruct families on how to perform, such as upper airway aspiration and tracheostomy in six (75%) of the services, diet administration by nasogastric tube in seven (87%), medication administration in six (75%), intermittent bladder catheterization in four (50%), dressings in eight (100%) services, and one of them (12.5%) allows the performance of upper airway aspirations only if the caregiver has gone through training with the nurse.

As for flow protocols and standard operating protocols for specific activities, such as medication administration, probe changes, airway aspiration, diet administration, dressings, and use of orthoses and prostheses, four (50%) of the HCS do not use protocols, two (25%) use general protocols, and only one (12.5%) has specific protocols for children. When asked which protocol is used for children, this service mentioned the use of the protocols for supplying diapers and milk formulas.

Regarding the use of the special therapeutic project (STP) in the care of CSHCN, six (75%) of the HCS use it, one (12.5%) uses it occasionally, and one (12.5%) does not use it. All services have telephone assistance, which health professionals provide to clarify doubts of their patients and families.

The dispensing of the materials and medications that families and caregivers must provide care to the children is performed by six (75%) of the HCS; the others (25%) refer the patients for withdrawal in primary care. As for the provision of medical-hospital equipment (bed, mattress, wheelchair, ventilator, oxygen, aspirator, inhaler, etc.), four (50%) services have the equipment and distribute it to the families, two (25%) services do not have it — despite receiving it from the health care network — and, in two (25%) services, the family provides the equipment by its own means.

The frequency with which home visits are made for each pediatric patient was divided into weekly, more than once a week, and less than once a week, being five (62.5%), one (12.5%), and two (25%), respectively. No difference was found in the frequency of visits made to adult patients. In five (62.5%) services, all professionals perform the home visit to children; in the other three (37.5%) services, and only some professionals do it. The professionals who perform the home visits according to the patients' needs are physicians - eight (100%), nurses - eight (100%), nursing technicians - eight (100%), physical therapists - eight (87.5%), social worker - five (62.5%), psychologist - one (12.5%), and nutritionist - one (12.5%).

Among the activities performed by the professionals, which were reported by the eight (100%) participating services, are clinical assessments, professional prescriptions, procedures that are private to the health care team, and procedures that can be delegated to caregivers.

In the participating HCS that provide care to children and adolescents, 25 CSHCN with an average age of six years were in care. As for the classification of the type of HC, there were mostly 19 (76%) in HC2 (medium complexity), followed by five (20%) in HC3 (high complexity) and one (4%) in HC1 (low complexity).

Among the diagnoses, cerebral palsy stands out, with eight (32%) cases. The other diagnoses were hydrocephalus, malformation in the face Pierre-Robin sequence, hemophilia, sickle cell anemia, Dandy-Walker syndrome, unexplained genetic syndrome, congenital malformations, cerebellar ataxia, chronic non-progressive encephalopathy, short bowel syndrome, Down syndrome (cardiopathy and pneumopathy), pulmonary bronchodysplasia, degenerative neuropathy, hydrocephalus, esophageal injury from a domestic accident of caustic soda ingestion, and hyaline membrane disease.

The care that such children require varies according to their complexity. A child may need more than one type of care; therefore, the frequency listed in Table 3 may include the same child in multiple types of care and/or devices.

Regarding the demand for care and/or procedures, the most frequent ones were gastrostomy (48%), tracheostomy, ostomy, and nasoenteral tube (36%). The continuous use of drugs was present for 28%.

DISCUSSION

Most of the professionals who coordinated the teams participating in the study were nurses. Considering the centrality of the nurses' work, their fundamental role in the coordination of the care plan, and the bond they establish with patients and family members, it is tangible that they are the majority in coordinating the services. Therefore, it is the nurse's competence and part of the nursing care to train the family caregiver and distribute the demands to the other professionals.[8]

The results of a study conducted in Paraná[9] diverge from the results found in Mato Grosso do Sul regarding using the STPs. In Paraná, only 25% of the HCS used the STPs, characterized by the encompassing of behaviors built from the multidisciplinary team discussion. In Mato Grosso do Sul, most (75%) of the services use STPs, while the other 12.5% use them occasionally.

Table 3. Frequency of Care Needs of Children with Special Health Care Needs Attended in the Home Care Services in Mato Grosso do Sul – Brazil - 2022.

Procedures/care	Absolute frequency (n = 25)	Relative (%)
Gastrostomy	12	48.00
Tracheostomy	9	36.00
Oxygen Therapy	2	8.00
Ostomy	9	36.00
Hygiene and food	5	20.00
Palliative	3	12.00
Food supplements	6	24.00
Nasoenteral tube	9	36.00
Drugs	7	28.00
Nasogastric tube	1	4.00
Ventriculo-peritoneal shunt	3	12.00
Orthosis and prosthesis	1	4.00
Psychomotor Rehabilitation	3	12.00
*Catheter*S	1	4.00
Mechanical ventilation or non-invasive mechanical ventilation	1	4.00

Source: The authors (2022)

The ordinance that regulates HC[5] defines that teams must conduct home visits weekly. Because of this, our findings corroborate the study cited above,[8] which points out that most services in Paraná also perform the visits weekly, as regulated by the ordinance.

Regarding the use of Electronic Patient Record (EPR), the study identified that four (50%) of the services do not use the EPR. CIT resolution No. 007/2016 establishes the mandatory implementation of the EPR in Primary Care.[10] Implementing a system that (preferably) interacts with that of Primary Care facilitates patient follow-up. However, an internal communication record, as used by one (12.5%) of the services in the study, can also help in the organization of information and internal communication.

As considered in another study,[11] even with the risks that all technological advances bring, the benefits of EPR implementation are undeniable in terms of practicality and agility in treating information. With such advances, it is possible to provide safer and more effective care because the electronic medical record not only registers but also monitors patient treatment, avoiding errors and assisting in decisions.

When considering the classification of CSHCN,[12] the children in this study fall into the groups according to the type of care they demand, most of them being technology-dependent. Analyzing the diagnoses of the CSHCN in the study and their care demands, most originated from perinatal factors. Thus, they are mostly classified as HC2, for demanding specific care, such as using enteral tubes, gastrostomy, drugs, and catheters, among others. These results are similar to those found in Paraná.[13]

One study identified the main challenges of family caregivers[14] because the multiple, complex, and continuous care that families perform at home requires emotional and technical preparation. One of the families' main challenges is the unpreparedness to care for the child at home.

The evidence from the study[14] reinforces the importance of HCS for the families of CSHCN. When families are unassisted, the risks of hospitalization of the child because the care is not properly performed increase considerably. Appropriate guidance from a trained health professional contributes to the family's ability to provide adequate care for the child.

Convergent to the findings of Paraná[13] and similar to the data of this study, which indicate the need for organizing the flow of children in the care network, a protocol for organizing the flow of HC2 services to CSHCN was proposed. Such a flowchart is interesting for organizing strategies for scheduled hospital discharge, caregiver preparation, organized health transport, and use of the STPs.

The flow protocol can help professionals direct users and optimize the flow within the service; it can be used as a tool to systematize referrals, reduce queues, etc.[15] Thus, since the services in Mato Grosso do Sul do not have a flow protocol for CSHCN, adapting such a flow chart to the reality exposed here would allow the services to be organized.

Besides basic care (e.g., hygiene and feeding), the caregivers of the children in the study also perform procedures such as

aspiration of upper airways and tracheostomy, administration of medications, and dressings. Nevertheless, they undergo training and guidance from the team to perform such procedures. In order to check the understanding of family members about the care and procedures, the services adopt several strategies (described above). However, only three of them (37.5%) question the families about the orientations of the procedures that should be performed.

According to the methods used in the Family Intervention Program,[16] the verification of the families' understanding of the orientations or the validation of the information offered is done when there are questions about such information. When the caregiver repeats what they have understood, the professional can identify gaps in understanding and communication and correct them immediately so that care can be provided effectively.

The presence of a child with special health care needs affects family relationships, which vary depending on their degree of dependence and care. The family dynamic is complex, and there can be positive and negative aspects. For the family to meet the needs of its children, it is necessary to have caregivers who are responsible and attentive to the individual needs, offer physical protection, and are continuous in their care.[17]

However, the family system is vulnerable and influenced by physical and experiential factors. In order to cope with the care of the child, the family must have support from the support network; often, they also require professional support.[17]

Given this, the ease of access of family members to professional support, such as psychologists, psychiatrists, and specialized care, is of utmost importance. Of the services studied, more than half (62.5%) offer support through the Health Care Network, and only one (12.5%) performs such support in the HCS itself.

The dispensation of materials and the supply of medical-hospital equipment used by families in the care of the CSHCN is performed by the majority of the HCS of Mato Grosso do Sul or by the public health network, as pointed out by the results. This fact facilitates the families' access to aid, making their daily lives less complicated.

According to IBGE data,[18] Mato Grosso do Sul has 7,476 people with disabilities between the ages of 10 and 14, ranking 22nd nationally. Nevertheless, when the diagnosis of a disability is excluded, Mato Grosso do Sul ranks 15th nationally, with 309 people in home care without a disability diagnosis. It must be considered that people who need special health care are not necessarily disabled.

The largest service providing home care in Mato Grosso do Sul — considered a national reference — did not reach its goals; 120 monthly attendances were planned for the first four months of 2019. However, after the pandemic period, the service averaged 561 attendances, exceeding the goal of 450 monthly.

Due to the pandemic, dehospitalization to reduce the spread of the coronavirus was recommended by the Home Care Working Group of the Brazilian Society of Family and Community Medicine and Brazilian Association of Home Care Services.[19] Home care was presented as an effective option for three of SUS's strategic objectives in responding to the pandemic: staying at home, isolation of symptomatic patients, and agile availability of patients.

However, analyzing the data from before the pandemic, such adopted actions should be perpetuated to continue with the quick dehospitalization of patients and avoid contamination - not only by the new coronavirus but also by other nosocomial (or hospital) infections faced in non-pandemic moments.[20]

The study cited[20] argued that prolonged hospitalization is one of the problems that most affect the health system, due to the high financial cost and lower quality of care. Hospital infections can occur due to immunosuppression and the particularities that develop in this environment.

At the time of data collection, the current recommendations were not yet in place and the target had not been reached in any of the months of 2019. With the current data, it can be inferred that there were always cases eligible for rapid dehospitalization (stabilized), except for those contaminated by the new coronavirus. It can be deduced that such an emergency measure could culminate in a new culture of dehospitalizations, even after the pandemic period.

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

The care that the Home Care Service in Mato Grosso do Sul State offers to children with special health needs (CSHCN) is multidisciplinary and uses the Singular Therapeutic Plan (STP). Besides the care provided during the weekly visits to the CSHCN and their families, materials, equipment, and medications are also offered. Most of the care offered to the CSHCN is of medium complexity, classified as Home Care Type 2 (HC2). The services do not have flow protocols for the care of children.

Although the services can expand care and use the STP for the comprehensive care of their users, advances in the interaction and assistance to families are still needed. The professional approach can transcend technical care using the assumptions of Patient and Family Centered Care. Standardizing care through protocols and electronic medical records is essential to organize the care flow. Considering the coverage area and the number of children enrolled, it is essential to discuss which service the other children are using and the possible expansion of home care services in the state to better serve the population.

From the identification and characterization of the services, we verified their characteristics, the audience, their potential, and their weaknesses to contribute to the advancement of care for children and their families. Implementing flow protocols for the care of children proved to be necessary, as well as professional updating for the care of families. Moreover, a consistent proposal of health and care education should be implemented in the services so that the family feels competent and supported when assuming care practices that derive from the professionals.

One of this study's limitations is the absence of the families' perspective on the care offered by the services. Thus, it is suggested that further research be conducted to understand the family's

perspective on the functioning of the HCS. Furthermore, even though this is a quantitative study, its findings must be interpreted as a local characteristic without coverage beyond the reality studied.

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