



Development care for children with special health needs in home care at Paraná - Brazil

Cuidado desenvolvido às crianças com necessidades especiais de saúde nos serviços de atenção domiciliar no Paraná - Brasil

Cuidado desarrollado a los niños con necesidades especiales de salud en los servicios de atención domiciliar en Paraná - Brasil

Vanessa Rossetto¹

Beatriz Rosana Gonçalves de Oliveira Toso¹

Rosa Maria Rodrigues¹

Cláudia Silveira Viera¹

Eliane Tatsch Neves²

1. Universidade Estadual do Oeste do Paraná.

Cascavel, PR, Brasil.

2. Universidade Federal de Santa Maria.

Santa Maria, RS, Brasil.

ABSTRACT

Objective: To describe the development of care for children with special health needs in Paraná services of homecare. **Method:** Quantitative, descriptive, exploratory, and multiple case study was applied. Data were collected by telephone and e-mail, with professionals from the eight services of homecare of Parana, from October 2016 to January 2017. The data was treated with descriptive statistics analysis. **Results:** Among 35 children in homecare, 25.7% had cerebral palsy, 60% had a tracheostomy. The care provided by the services includes a management of tubes, administration of medication, changing dressings, caregiver guidance for tracheostomy suctioning and a management of diet. **Conclusions and implications for practice:** Services weaknesses were mainly related to low utilization of the singular therapeutic project and the counter-reference to primary care. The flow of successful practices are developed in the municipality of an isolated manner. Showing positive experiences promotes reflection and improvement of the work process of caring for children with special health needs in homecare.

Keywords: Child health; Chronic disease; Homebound Persons; Home Care services.

RESUMO

Objetivo: Descrever o cuidado desenvolvido às crianças com necessidades especiais de saúde nos serviços de atenção domiciliar do Paraná - Brasil. **Método:** Implementado pesquisa quantitativa, descritiva, exploratória, estudo de casos múltiplos. Coleta de dados por telefone e correio eletrônico, com profissionais dos oito serviços de atenção domiciliar, entre outubro de 2016 e janeiro de 2017. A análise dos dados conduzida com estatística descritiva. **Resultados:** Dentre as 35 crianças atendidas, 25,7% tem paralisia cerebral e 60% traqueostomia. Os cuidados desenvolvidos pelos serviços incluem sondagens, administração de medicamentos, curativos e orientação para aspiração e administração de dietas. **Conclusões e implicações para a prática:** As fragilidades encontradas relacionam-se principalmente à baixa utilização do projeto terapêutico singular e da contrarreferência à atenção primária. Práticas de sucesso no fluxo são desenvolvidas isoladamente nos municípios. Ao divulgar experiências positivas fomenta-se a reflexão e aprimoramento do processo de trabalho no cuidado às crianças com necessidades especiais de saúde na atenção domiciliar.

Palavras-chave: Saúde da Criança; Doença Crônica; Pacientes Domiciliares; Serviços de Assistência Domiciliária.

RESUMEN

Objetivo: Describir el cuidado desarrollado a los niños con necesidades especiales de salud en los servicios paranaenses de atención domiciliar. **Método:** Implementado una investigación cuantitativa, descriptiva, exploratoria, estudio de casos múltiples. Recolección de datos por teléfono y correo electrónico, con profesionales de los ocho servicios de atención domiciliar paranaenses, entre octubre de 2016 y enero de 2017. El tratamiento de los datos fue realizado con estadísticos descriptivos. **Resultados:** Entre los 35 niños atendidos, el 25,7% tiene parálisis cerebral, el 60% poseen traqueostomía. Los cuidados desarrollados por los servicios incluyen sondeos, administración de medicamentos, curativos y orientación para aspiración y administración de dietas. **Conclusiones e implicaciones para la práctica:** Las fragilidades encontradas se relacionan principalmente a la baja utilización del proyecto terapéutico singular y de la contrarreferencia a la atención primaria. Las prácticas de éxito en el flujo se desarrollan aisladamente en los municipios. Al divulgar experiencias positivas se fomenta la reflexión y perfeccionamiento del proceso de trabajo en el cuidado a los niños con necesidades especiales de salud en la atención domiciliar.

Palabras clave: Salud del niño; Enfermedad crónica; Personas imposibilitadas; Servicios de Atención de Salud a Domicilio.

Corresponding author:

Vanessa Rossetto.

E-mail: vanessa_rossetto@msn.com

Submitted on 03/12/2018.

Accepted on 10/23/2018.

DOI: 10.1590/2177-9465-EAN-2018-0067

INTRODUCTION

In the last years, a group of Children with Special Health Care Needs (CSHCN) emerged in Brazil due to technological development and health professionals qualification, influencing the rise of CSHCN survival rates.^{1,2}

These children are clinically fragile and need continuous care, sometimes, as a result of a chronic condition that requires special care in health services.³ A survey developed in the United States showed the following profile of CSHCN: those who were receiving care provided by family caregiver were 49.7%; the children's age ranged from 0 to 5 years represented 61.5%. The group of children that were identified as other races were 53.2% versus 48.3% of non-Hispanic white children. They also lived below poverty line (52.8%).⁴ A chronic disease were responsible for 42% of costs in health for this population.⁵

In Brazil, children with chronic condition represent 9.1% in the age group until five years old, 9.7% among school-age children between six and 13 years old and 11% among adolescents from 14 to 19 years old of the total from the population.⁶

As a strategy to meet demands of chronic conditions, full, continuous and humanized care should be prioritized. The way of Home Care (HC) is organized enables and supports care to people with chronic condition, which need continuous attention throughout time by a multi-professional team.⁷ HC modality of providing care should be an option to CSHCN, even though it is not specific to this group.

To develop HC, this modality is organized into three categories: HC1, HC2, and HC3. On HC1, Primary Care (PC) teams will assist users, with home follow up according to their needs. On HC2 and HC3 assistance will be through Home Care Service (HCS) and the differentiation among them will be defined by user's care needs, the demand for the periodicity of visits, multi-professional care intensity and equipment use.⁸

On the Health Care Network (HCN), HCS is considered a complementary service to PC and to an "emergency and substitutive services or complementary to hospital admission, responsible for the management and operation of Multi-professional Home Care Teams (MHCT) and Multi-professional Support Teams (MST)".^{8,2} HC teams "have as an attribution: to work in multi-professional team in an integrated way to HCN; to identify, guide and train the caretakers",^{8,2} involving them on by respecting limitations and potentialities; meet the complaints and doubts from users, individual family members or family caretakers; help caretakers and family members to care and exchange experience of caring; to use accessible and adequate language; to convene flows for death certificates and for admission and discharge of users in HC; and to participate in training processes and continuous education.⁸

By considering the inclusion of CSHCN in HC, we seek to prevent acute episodes and to avoid hospitalizations, it is important to identify that there are specific strategies to care for CSHCN, in home care services of Paraná and how to offer care for them. It starts from the presumption that the organization of specific care to children with special health care needs is still not clearly defined and/or implemented in existing services.

So, the objective was to describe the care provided to children in home care services in Paraná, Brazil.

METHOD

Quantitative, descriptive and exploratory study multiple cases study type, which participated eight professionals from HCN in the study of Paraná, which are presented in the municipalities: Cambé, Cascavel, Curitiba, Guarapuava, Londrina, Palotina, Paranaíba, and Santa Terezinha do Itaipu.

To contextualize the research scenery, the state of Paraná is constituted by 399 municipalities and presents an esteemed population of 11,163,018 inhabitants in 2015.⁹ On Box 1, we present data of each city of the state of Paraná.

We contacted the coordinator of each HCS, inviting him to participate or to indicate a professional that could answer to research questions. This way, we achieved one participant from each HCS, constituting an intentional sample of eight participants. We adopted as a selection criteria that participants who were working at HCS during the data collection. All existing services were included.

The researcher applied an instrument of data collection, which was tested previously. Questions in an open format approached the identification of the service, about its structure, relation to the health care network, the organization of consults, the quantity of patients and age group, ages and diagnosis of children condition, as well as their health needs and devices in use. The instrument also searched for activities related to care, information given to caretakers and the existence of not of specific protocols to care for those children. Data collection occurred through electronic mail, answered by the participant and given back to the researcher through electronic mail on time agreement.

Subsequently, the researcher contacted the participants through telephone to confirm data and clarify doubts and approach information that was not clear, when needed, having as an average of ten minutes per call. Data collection was developed between October 2016 and January 2017.

Information collected was gathered and organized in a way that enabled visualization and description enabling comparisons and synthesis, which could subsidize analysis. To analyze data, they were organized in the Excel software, with a double check procedure, the data were treated and presented as an absolute and relative frequency,

Box 1. Home care services in the state of Paraná, 2017.

City	Region	Population/number of inhabitants	Number of services	Information Source
Cambé	Norte	96,733	1 MHCT 1 MST	IBGE/Cidades/Cambé
Cascavel	Oeste	312,778	3 MHCT 1 MST	IBGE/Cidades/Cascavel
Curitiba	Leste (capital)	1,879,355	10 MHCT 3 MST	IBGE/Cidades/Curitiba
Guarapuava	Centro	178,126	1 MHCT 1 MST	IBGE/Cidades/Guarapuava
Londrina	Norte	548,249	1 MHCT 1 MST	IBGE/Cidades/Londrina
Palotina	Oeste	30,859	1 MHCT 1 MST	IBGE/Cidades/Palotina
Paranavaí	Noroeste	86,773	1 MHCT	IBGE/Cidades/Paranavaí
Santa Terezinha de Itaipu	Oeste	22,570	1 MHCT	IBGE/Cidades/Santa Terezinha de Itaipu

Source: IBGE. Instituto Brasileiro de Geografia e Estatística. Available in: <<http://cidades.ibge.gov.br/xtras/perfil.php?lang=&codmun=410370&search=|infor%r%E1ficos:-informa%E7%F5es-completas>>. Access in May 31st 2016.

We followed all ethical standards and a research was approved by an institutional ethic research committee under the feedback number 1.741.820. After accepting to participate in the research and before initiating the data collection, we obtained the Free Consent Form through electronic mail.

RESULTS AND DISCUSSION

On Table 1, we present the characterization data of children assisted on the HCS in Paraná, contemplating data referred to their ages, diagnosis, and devices used.

The number of people assisted on HCS is variable, due to new admissions, discharges, and deaths of each period. Even though the high complexity of most of them, children represent the minority (5.3%). Among eight HCS, one did not present children in follow up in the moment of the research. In the rest of them, the number of children per HCS varied from one to ten. We considered children, individuals from zero to 12 incomplete years old. On most of them, 23 (65.7%) children were comprehended as the age group until six incomplete years old.

Among the main diagnosis of CSHCN, we highlight brain paralysis, with nine cases (25.7%), hydrocephalus, with five

Table 1. Children with Special Health Care Needs in Home Care Services in Paraná, Brazil. 2017.

Characteristic		N	%
Children's age groups	Until incomplete six years old	23	65.7
	Six to 12 years old	12	34.3
Children's diagnosis	Brain paralysis, hydrocephalus, prematurity, or degenerative diseases	20	57.1
	Others	15	42.9
Use of tracheostomy	Yes	21	60
	No	14	40
Gastrostomy use	Yes	20	57.1
	No	15	42.9
Other devices	Yes	51	146*

Source: Researcher's database. * One child can use more than one device.

(14.3%), prematurity in three children (8.6%) and degenerative diseases in three (8.6%). In the set of diagnoses, 50% are considered perinatal causes.

The special health care needs of these children make them dependent of some devices and daily special care, as 91% of them are dependent of some type of technology. Most of those children use tracheostomy (60%) and/or gastrostomy (57.1%). In the group of others, there are: oxygen therapy (n=11; 31.4%), airways suctioning (n=10; 28.6%), mechanic ventilation (n=6; 17.1%), rehabilitation (n=5; 14.3%), medication dependency (n=5, 14.3%), a continuous use of diapers (n=4; 11.4%), nasoenteral tube (n=3; 8.6%), food supplements (n=3; 8.6%), daily special care (n=3; 8.6%), and totally implanted catheter (n=1; 2.9%).

Considering diagnosis and special health care needs of cited children, we can classify them in HC2 and HC3.⁸ Among them, 29 (82.9%) are classified as HC2, for presenting acute condition or chronic condition (with potential to acute episodes), that required intensified and sequential care (such as parenteral treatments, including totally implanted catheter and rehabilitation), chronic degenerative condition, palliative care need and prematurity post-effects, beyond using tracheotomy, gastrostomy, oxygen therapy, airways suctioning or nasoenteral tube and other care. Six (17.1%) of them were classified as HC3 because they need more frequent multi-professional care due to mechanic ventilation.

Among several daily challenges on caring for CSHCN, caretakers face the need to apprehend knowledge and practices that were not part of their daily life and the difficulty of access to health services to continue these children's treatments. To overcome these challenges, it is needed to develop an assistance that has the family in focus, using education in health to promote empowerment of CSHCN's caretakers to care for these children and, enable their access to health services.¹⁰

For such, family-centered care, preparing the caretakers to the transition from the hospital to home and reorganization of a health network to decrease hospital dependency is imprescriptible, as well as contributing to amplifying the social network of CSHCN.¹¹

Even though most HCS assist children with special health care needs, including some with high complexity devices, no services have a specific assistance protocol for this group, as observed in the following data.

On Table 2, we present the characterization of services, as HCS work process.

Most of respondents (75%) were nurses, which also in the same proportion coordinate home care teams. The nurse has an important role in HC, for coordinating the plan of care at home and through the bond that establishes with users and caretakers;

for this to be, most of the times, who realize counseling to caretakers and family members.¹²

Exclusively, compete to the nurse who works on HC " to dimension the nursing team; to plan, organize, coordinate, supervise and evaluate nursing care; organize and coordinate environmental conditions, equipments and needed material to the production of competent, solve and safety care; acting in a continuous education of the nursing team; and executing high complexity nursing care and demand the need to immediate decisions".^{13:2-3} Their actions must be executed in a nursing assistance systematization context, guided by norms, routines, validated and frequently revised protocols, through the process of nursing care.¹³

To develop health care, however, a multi-professional teamwork is essential. Among eight Paraná municipalities that have HCS three have MHCT, while five have Multi-professional Support Teams (MST), knowing that MHCT is required to constitute an HCS, not being able to implement an MST without previous experience from MHCT.⁸

To compose the MHCT, beyond the physician, nurse, nursing technician, and nursing auxiliary, there is a need to add social worker and physical therapist.⁸ Among the services that have only MHCT (37.5%), one of them has a physical therapist, another has a social worker, while the other disposes of two professionals on MHCT. On MHCT's structure, it is also possible to adequate them according to needs identified by HCS. Among the services that have MHCT (62.5%), all have social worker and dietist three of them have pharmacists, three have a psychologist, and one has a dentist and another speech therapist.

Those municipalities that already have a MHCT in course "type 1 or type 2, will enable a MHCT, being possible to implement one MHCT each 3 (three) MST implemented".^{8:8} Considering the three services that informed to not have MHCT could request habilitation of teams, aiming to strengthen the interdisciplinary and multi-professional work team, knowing the presence of MHCT favors experience exchange and the construction of strategies as a team.

In addition, according to the governance that regulates the best program at home,⁸ the accreditation of an HCS is conditioned to the existence of a population of a minimum of 20 thousand inhabitants. Considering the quantitative of state inhabitants, so that all population from Paraná to have access to this service must exist approximately 522 HCS in Paraná, however, there are only eight accredited services in the entire state.

Still, even though all HCS use Home Visits (HV) as an instrument of work, different are the ways, which they are organized. In two HCS, the work hours are inferior to the one

Table 2. Characterization of Home Care Services in Paraná. Cascavel/PR, Brazil. 2017.

Characteristic		N	%
Interviewed Professional	Nurse	6	75.0
	Other professional	2	25.0
Team	Only MHCT*	3	37.5
	MHCT and MST**	5	62.5
Work Hours	Day	6	75.0
	Day and Night	2	25.0
Weekend Work Hours	Yes	7	87.5
	No	1	12.5
Service Headquarters	Owned	3	37.5
	Attached to another service	5	62.5
Electronic interconnected records	Yes	3	37.5
	No	5	62.5
Sanitary transportation	Shared	7	87.5
	Owned	1	12.5
Formal responsibility of the caregiver	Yes	4	50.0
	No	4	50.0
Caregiver's preparation routine	At home	7	87.5
	In the hospital	1	12.5
Utilization of printed material to counseling	Yes	4	50.0
	No	4	50.0
Owned telephone on HCS***	Yes	8	100.0
	No	0	0.0
Singular Therapeutic Project	No	6	75.0
	Yes	2	25.0

Source: Researcher's database. 2017. * Multiprofessional Home Care Teams; ** Multiprofessional Support Team; *** Home Care Service.

indicated, eight hours in one and ten in another. And in two others, the period of assistance was extended to more than the indicated minimum, to 15 and 24 hours per day, meeting the needs identified by the services themselves, drug administration and palliative care. One of the services does not work on the weekends.

According to work hours, daytime (75%) predominated, which varied between 12 working hours per day (in four services) to eight working hours with a lunch break (in one service). Beyond this, the majority of them (87.5%) are available also on weekends.

According to the regulatory authority, HCS must offer, at least 12 working hours a day, every day, including weekends and holidays, so there is not a disruption on health services offer.⁸ On duty, the regime can be used in specific situations. MST should support MHCT in working days if activities on a special scale for weekends and holidays are needed.⁸

The fact that half of the services that participated in the study are attached to other services, including hospitals and Emergency Rooms (ER), favors the articulation of HCS in the healthcare network, considering that HC composes a care network to emergencies.⁸

Related to the digital integration of services, we found that three (37.5%) of them have electronic interconnected records. Beyond that, using e-mail to receive follow-ups is not yet the predominant way, coexisting with other ways that take more time like express mail.

Electronic records aggregate higher quality to assistance and public management. When used it can reduce the number of archived papers, lower conduct error occurrence; data can be stored longer; it avoids the redundancy of procedures; it raises service productivity and user satisfaction and eases intercommunication in care settings.¹⁴

However, the same author considers that there could be hindrances for its utilization, such as the implementation cost and the need for professional training. However, the benefits generate would overcome difficulties in implementation of electronic records. On HCS, digital tools for management could be created to receive follow-ups, on the admission process and service discharge to interconnect, in general, with the other network settings.¹⁴

All HCS use a car to move to the residency of cared people, and five (62.5%) of them have their own car. In all services, MSHC and MST make HV. Visiting routine is established according to the needs, however minimum frequency in seven (87.5%) of HCS is weekly, and in one (12.5%) is every two weeks. However, home visits regulatory authority⁸ defines that HV should be done at least once a week for each patient.

National Policy of Primary Health Care, responsible for HC1, establishes HV to develop care by the health team, to those individuals and families that cannot access the services.¹⁵ This way, HV is considered a strategy that enables access to users and families without going to health units¹⁵ and, HC needs to be organized to meet individual's needs about their care, without harm for being out of a hospital and meeting determinations required by law.

To transport patients, one of the HCS has a simple own transport vehicle that makes the moving to the domicile, with technical follow-up in nursing and the rest use de city vehicle for such. It is necessary to reflect about effectiveness of each flux, analyzing which is the service that makes this transportation; who is the professional that follows up; if the ambulance and the professionals are prepared to assist patients that will be moved; in which situations and to what ends such service will be used; which flow to drive the transport; and how primary care interacts in these situations; considering the HCS must be inserted in the HCN to assure the transit and removal flux of the user in both situations of urgency and on elective situations indicated by the HCS.⁸

The practice of accountability and self-care was evidenced by half of the researched HCS, which occurs in the moment of admission when the caretaker assumes formally the responsibility for caring to the person, signing a document for this end, called consent form, responsibility forms or contract in this services. So that the admission to HCS occurs, individual and his caretaker previous agreement with the signature of the free consent form is necessary.⁸

The caretaker is "the person(s) with or without family bond with the user, capable to assist him in his needs and daily life activities, that depending on the functional and clinical condition of the user, must be present on home care".^{8:2} Responsibility assumptions of subjects for their self-care is indicated on

chronic conditions management, or in the case of HC, supported self-care.¹⁶

In this sense, HCS must be aware to promote accountability and self-care, through practices that promote one's independence and fluidity in health services network.¹⁶ In one of the services, preparing the caretakers, regarding the execution of new care the child will require at home, happens still in the hospital. In this HCS, caretakers preparation is developed by the hospital team, in others, this training happens at home after discharge, except another HCS, which the training happens in the hospital by the HC professional, in cases, the child will need suctioning of the airways.

It is recommended to demonstrate to the caretaker the practice of procedures with devices such as: "intermittent bladder catheterization, tracheotomy, and colostomy care, long-stay urinary catheter, enteral diet, and dressing",^{17:27} still before the user inclusion in HCS, so one acquires abilities to manage these devices. Being in the own HCS, through using mannequins to simulation, for example, or during hospital admission, when it is the case.¹⁷ A strategy with great potential consists on preparing the caretaker still in the hospital, when possible, by hospital and home care teams, as unification mar of practices and care transference.

Considering that the caretaker is an essential part of the HC,⁷ mainly for being the executor of daily care, assistance capacity and procedure execution must be evaluated, as well as having one's consent to begin the home care. In one of HCS, this practice is routine, having an evaluation in the admission moment and resumed in the follow-ups.

Considering that the moment to return home, many times after a long time of hospitalization, is a moment invaded by anxiety and, frequently but the fear to a new reality, some information is not totally absorbed by the caretaker. To complement and assist on fixation of counseling, four (50%) of services use printed information as instruments to assist in the counseling process of caretakers. The use of educational materials contribute to the work team, as a way to reinforce information and counseling developed in an oral way and it serves as a guide in situations of doubts from the user.¹⁸

Even if the process of counseling of caretaker presents a total use, still new situations can emerge and, then new instructions will be needed. This requires clear flows to be envisaged foreseeing such situations, such as a telephone.

Even though all services have their own telephone number, it is not a health professional that answers it. Nursing technician is available 24 hours a day to answer any caretakers demands, to develop counseling has had positive repercussions in one of the HCS, as well as the possibility of Users to enter in contact directly by the team's cell telephone, in other services.

These are important strategies to ease the caretaker access to solving information, considering that normally on HC, due to professionals' displacement, it becomes more difficult the contact with them in HCS headquarters. In urgency and emergency cases, family members and caretakers of all HCS are advised to call urgency and emergency services.

In the research of HCS, we identified the utilization of Singular Therapeutic Project (STP) in two (25%), of services being this the condition to be debated, once it is recognized that this strategy can qualify assistance developed by HC teams. STP is characterized for involving conducts/actions/measures, of clinical competence or not, proposals to assist individual health needs, constructed from the discussion of a multi-professional team.¹⁹

The aim of STP is producing individual autonomy and appropriation of one's process of care, characterizing as an instrument that answers to objective and subjective demands from people.¹⁹ This way, the construction of a STP must, always that possible and needed, to be developed with PC team members, when the person in HC remains in his coverage area, enabling his enrichment through information that results from a cross-sectional follow-up in the PC and seeking to understand the subject in his context and define proposals of actions. Beyond that, this contact also favors the bond and care shared among teams, favoring the process of "transference to HC1".¹⁹

Regarding the assistance provided to subjects in these HCS, it is possible to prove that each service establishes its own routines for caring and the procedures, such as medication administration, catheters replacement, suctioning of airways, respiratory therapies, dietary management, dressing and counseling on using prostheses and orthoses, as exposed on Table 3.

Three services indicated that they developed medication management until twice a day, however, for the procedure to be developed in this frequency, that is every 12 hours, it is necessary that the work hours are superior to 12 hours a day. The exchange of gastrostomy tubes is not common in all services, but in one of them is exchanged every six months or more.

For dressings, an HCS informed that its frequency is daily if necessary and in another, when the team identifies a more frequent follow-up need, it is required support to the family health unit. In one of them, this service is offered as a priority for children and people that have a chronic pulmonary obstructive disease.

For the use of prostheses and orthoses, in one of the HCS, even if the service itself develop usage guidelines, prostheses and orthoses supply is developed by the rehabilitation centers from the teaching institutions, after medical reference, and in another, the person in rehabilitation is forwarded to the municipality program for prostheses and orthoses.

Among the procedures that are always developed by family members is the airways suctioning and dietary management, which are delegated care to the family caretakers, after being prepared by the team. A study demonstrates that family members of children with a chronic condition create strategies to develop care at home, which involve dividing care tasks throughout the day, reconciling the care with other life activities, to adapt the house's environmental, to involve the child in his own car, to seek support resources, to seek assistance in another city and to perform a physical activity to become strong and reduce stress.²⁰

Many of the procedures and care developed by HCS are not organized by protocols, however, this standardization is needed, on seeking safety and an expected result. According to the Federal Council of Nursing,¹³ nursing HC must be developed based on valid norms, routines, and frequently revisited protocols. Beyond that, divergence on how procedures are organized show that there is no standardization among HCS.

On Table 4, characteristics of a process for admission patients in services are presented, considering professionals that reference to service, the deadline to provide eligibility evaluation, the professional responsible by this evaluation and the process of counter-reference to the health units.

Reference sources for HCS patients comprehended hospitals, emergency room units, ambulatories, specialty centers and in one of the services, there is always the spontaneous demand reference.

The type of reference to home care also presents the variation among the researched municipalities, being possible to use e-mail, express mail, fax, telephone and the caretaker himself who takes the reference letter created by the service to HCS, remembering that in the same service, there could be more than one of these ways.

The eligibility evaluation deadline varies between one and seven days. Legally, these variations don't represent issues, considering that there are not indications related to the issue in the HC regulatory law.⁸ Standardization of this time could raise services' credibility to support them when pressured by the referral service.

An important advance related to the physician decentralization of reference letters and eligibility evaluation were perceived. However, to define eligibility in HC, fundamentally criteria indicated by law should be considered.⁸

HC has an essential role in de-hospitalization and optimization in hospital beds,⁹ however it is necessary that the process of transferring care to home be clearly organized. Eligibility evaluation deadline must be established, considering time need for identification of the caretaker, evaluation on his capacity to develop procedures needed at home, the caretaker accept on home follow up, home evaluation if indicated, and the organization of patient removal.

Table 3. Procedures developed by Home Care Services in Paraná. Cascavel/PR, 2017.

Characteristics		N	%
Parenteral drug administration	Once to twice a day	5	62.5
	As needed	3	37.5
Nasoenteral tube replacement	As needed	6	75.0
	Every three months	2	25.0
Exchanging bladder catheter	As needed	5	62.5
	Between 21 and 30 days	3	37.5
Exchange of gastrostomy tubes	As needed	7	87.5
	Every six months	1	12.5
Dressings	Once a week or more	6	75.0
	As needed	2	25.0
Airways suctioning	By family members	8	100.0
	Only by the team	0	0.0
Respiratory therapy	By family members	4	50.0
	Only by the physiotherapist	4	50.0
Dietary administration	By family members	8	100.0
	Only by the team	0	0.0
Counseling on using prostheses and orthoses	By HCS professionals	7	87.5
	Only by a specialized service	1	12.5

Source: Researcher's database. 2017.

Table 4. Patient admission to Home Care Services in Paraná, Brazil. 2017.

Characteristics		N	%*
Units for reference	Hospitals	7	87.5
	Emergency Care Units	6	75.0
	Other Services	4	50.0
Professionals for reference	Only physicians	2	25.0
	Physicians, nurses and social assistance	6	75.0
Evaluation deadline	From one to three days	4	50.0
	Until seven days	4	50.0
HCS professional that evaluates the patient eligibility	Only the physician	2	25.0
	Also other professionals	6	75.0
Counter-reference	Only on the process of evaluation, discharge, and death	6	75.0
	During the whole follow up	2	25.0

Source: Researcher's database. * The percentage is higher than 100% because one HCS can receive references from more than one kind of service.

Considering the singularity of the process returning home of a child will require specific care, the caretakers will need interventions that go through technical training. It is essential to develop this care, that family members of CSHCN constitute trust bonds with the HC team.¹²

There are limitations when considering the HCS communication with other healthcare settings. On most researched services, communication of health units happens only to inform the user's admission in the program or its disconnection, knowing that after admission, HCS rarely sends or receive information from the respective unit.

PC units must work in Cinergy with HCS and maintain its responsibility with users being assisted also by the HCS.⁷ This way, the exchange of information must continue, in order to favor integral and continuous care by the HC and PC.

On half of the services, there is a formal moment for transferring care, when the patient is discharged from HCS to HC1. In these services, HCS services find themselves, in the health unit, with PC professionals. This looks like a good strategy to guarantee continuity of care after disconnecting from HCS.

Health services must be developed in networks. Networks overcome usual pyramidal conformation to polyarchical arrangements among different actors who have a certain autonomy and represent a system that seeks, deliberately, in its institutional plan, to deepen and establish stable patterns for inter-relations.²¹

HC involves all health care settings and seeks to overcome the care model centered on hospital care, recognizing that it is necessary for specific situations.⁸

Mobile Care Service to Urgencies (SAMU, Portuguese acronym for *Serviço de Atendimento Médico de Emergência*) coverage is considered an HCS habilitation, in a way that all HCS have this service's support to urgent situations.⁸ For these urgency or emergency transportation, it is important to agree with the service a specific flux for HCS, in order no delay for the difficulty of flux among services to harm or put at risk the patient's life.¹⁶

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

Homecare has great potential in caring for the CSHCN, considering a longitudinal and multi-professional approach. Health demands presented by the CSHCN assisted on home care services from Paraná are meaningful, oscillating from the management of acute conditions until conducting conditions that involve high technology devices, such as invasive mechanic ventilation. Facing demands evidenced, services organized themselves to assist them the best way however, these services still can advance on caring for the CSHCN in HC, organizing and standardizing it through the utilization of protocols.

In this perspective, this study subsidizes data to reflect and improve the work process in HC, as well as markets successful practices already developed, that involve singular therapeutic project, working in networks, properly preparing the caretaker, organized sanitary transportation, and counseling through the telephone in an organized way.

However, this study also presents limitations, considering it is restricted to professionals' perspectives, without considering users' perspectives. Thus, new studies that approach the users' perspectives about home care are suggested.

REFERENCES

1. Cabral IE, Moraes JRMM. Familiares cuidadores articulando rede social de criança com necessidades especiais de saúde. *Rev Bras Enferm* [Internet]. 2015; [cited 2017 May 20]; 68(6):769-76. Available from: <http://www.scielo.br/pdf/reben/v68n6/0034-7167-reben-68-06-1078.pdf>
2. McPherson MG, Arango P, Fox H, Lauver C, McManus M, Newacheck PW, et al. A new definition of children with special health care needs. *Pediatrics* [Internet]. 1998 Jul; 102(1 Pt 1):137-40. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/9714637>
3. Zamberlan KC, Neves ET, Severo VRG, Santos RP. O cuidado à criança com doença crônica ou incapacitante no contexto hospitalar. *J Res Fundam Care* [Internet]. 2014 Jul/Sep; [cited 2017 Feb 23]; 6(3):1288-301. Available from: <http://www.seer.unirio.br/index.php/cuidadofundamental/article/view/3098>
4. Romley JA, Shah AK, Chung PJ, Elliott MN, Vestal KD, Schuster MA. Family-provided health care for children with special health care needs. *Pediatrics* [Internet]. 2017; [cited 2018 Jun 25]; 139(1):e20161287. Available from: <http://pediatrics.aappublications.org/content/pediatrics/139/1/e20161287.full.pdf>
5. Ferro MA, Boyle MH. The impact of chronic physical illness, maternal depressive symptoms, family functioning, and self-esteem on symptoms of anxiety and depression in children. *J Abnorm Child Psychol* [Internet]. 2015 Jan; 43(1):177-87. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/24938212>
6. Ministério do Planejamento, Orçamento e Gestão (BR). Instituto Brasileiro de Geografia e Estatística - IBGE. Pesquisa Nacional por Amostra de Domicílios: um Panorama da Saúde no Brasil. Acesso e Utilização dos Serviços, Condições de Saúde e Fatores de Risco e Proteção à Saúde. Rio de Janeiro (RJ): IBGE; 2010.
7. Oliveira Neto AVO, Dias MB. Atenção domiciliar no Sistema Único de Saúde (SUS): o que representou o Programa Melhor em Casa? *Divulg Saúde Debate* [Internet]. 2014; 51:58-71. Available from: <http://bases.bireme.br/cgi-bin/wxislind.exe/iah/online/?IsisScript=iah/iah.xis&src=google&base=LILACS&lang=p&nextAction=lnk&exprSearch=771499&indexSearch=ID>
8. Ministério da Saúde (BR). Portaria Nº 825 de 2016. Redefine a Atenção Domiciliar no âmbito do Sistema Único de Saúde (SUS) e atualiza as equipes habilitadas. Brasília (DF): Ministério da Saúde; 2016.
9. Ministério do Planejamento, Orçamento e Gestão (BR). Instituto Brasileiro de Geografia e Estatística - IBGE. Estados - Paraná [Internet]. [cited 2016 May 28]. Available from: <http://www.ibge.gov.br/estadosat/perfil.php?sigla=pr>
10. Neves ET, Silveira A. Desafios para os cuidadores familiares de crianças com necessidades especiais de saúde: contribuições da enfermagem. *Rev Enferm UFPE On Line* [Internet]. 2013 May; 7(5):1458-62. Available from: <http://pesquisa.bvsalud.org/enfermagem/resource/pt/bde-34025>
11. Ramos LDC, Moraes JRMM, Silva LF, Goés FGB. Maternal care at home for children with special needs. *Invest Educ Enferm* [Internet]. 2015 Sep/Dec; 33(3):492-9. Available from: http://www.scielo.org.co/scielo.php?script=sci_arttext&pid=S0120-53072015000300013
12. Andrade AM, Silva KL, Seixas CT, Braga PP. Nursing practice in home care: an integrative literature review. *Rev Bras Enferm* [Internet]. 2017 Jan/Feb; 70(1):210-9. Available from: http://www.scielo.br/scielo.php?pid=S0034-71672017000100210&script=sci_arttext&tlng=en
13. Conselho Federal de Enfermagem - COFEN (BR). Resolução Nº 0464/2014. Normatiza a Atuação da Equipe de Enfermagem na Atenção Domiciliar. Brasília (DF): COFEN; 2014.
14. Gonçalves JPP, Batista LR, Carvalho LM, Oliveira MP, Moreira KS, Leite MTS. Prontuário Eletrônico: uma ferramenta que pode contribuir para a integração das Redes de Atenção à Saúde. *Saúde Debate* [Internet]. 2013 Jan/Mar; 37(96):43-50. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0103-11042013000100006
15. Ministério da Saúde (BR). Política Nacional de Atenção Básica - PNAB. Brasília (DF): Ministério da Saúde; 2017.

16. Morais HCC, Gonzaga NC, Aquino PS, Araújo TL. Strategies for self-management support by patients with stroke: integrative review. *Rev Esc Enferm USP* [Internet]. 2015 Feb; [cited 2018 Jun 25]; 49(1):136-43. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0080-62342015000100136&lng=en. <http://dx.doi.org/10.1590/S0080-623420150000100018>
17. Ministério da Saúde (BR). Secretaria de Atenção à Saúde. Departamento de Atenção Hospitalar e de Urgência. *Segurança do paciente no domicílio*. Brasília (DF): Ministério da Saúde; 2016 [Internet]. [cited 2017 Mar 20]. Available from: http://bvsm.s.saude.gov.br/bvs/publicacoes/seguranca_paciente_domicilio.pdf
18. Pimentel PP, Toldrá RC. Desenvolvimento de manual para orientações básicas do dia a dia para pessoas com esclerose múltipla. *Cad Ter Ocup UFSCar (São Carlos)* [Internet]. 2017;25(1):67-74. Available from: <http://www.cadernosdeterapiaocupacional.ufscar.br/index.php/cadernos/article/view/1483>
19. Lima CVC, Moura MSR, Cavalcante MVS. Projeto Terapêutico Singular como Abordagem Multiprofissional no Hospital. *Saúde Sociedade* [Internet]. 2017; [cited 2018 Jun 25]; 2(2):472-82. Available from: <http://www.seer.ufal.br/index.php/nuspfamed/article/view/3018>
20. Salvador MS, Gomes GC, Oliveira PK, Gomes VLO, Busanello J, Xavier DM. Strategies of families in the care of children with chronic diseases. *Texto Contexto Enferm* [Internet]. 2015 Jul/Sep; [cited 2018 Jun 25]; 24(3):662-9. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-07072015000300662&lng=en. <http://dx.doi.org/10.1590/0104-07072015000300014>
21. Mendes EV. As redes de atenção à saúde. *Ciênc Saúde Coletiva* [Internet]. 2010 Aug; [cited 2014 Aug 30]; 15(5):2297-305. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1413-81232010000500005