

## Therapeutic itinerary of children with special health care needs: analysis guided by care systems

*Itinerário terapêutico de crianças com necessidades especiais de saúde: análise guiada por sistemas de cuidado*

*Itinerario terapéutico de niños con necesidades especiales de salud: análisis guiado por los sistemas de atención*

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### ABSTRACT

**Objective:** To understand the therapeutic itinerary taken by families in search of attention to their child's special health care needs in a Brazilian border town.

**Method:** Qualitative research based on dialectical hermeneutics and on the Health Care Systems model. Interviews and Talking Maps (Dynamics of Creativity and Sensitivity) were carried out with 19 caregivers of children with special health care needs, attended at care institutions in Foz do Iguaçu, Paraná, in 2020. For data analysis, thematic analysis was used.

**Results:** The fragilities of the Health Care System were highlighted, permeated by: difficulties in accessing the diagnosis and consultations; overload for care; (dis)organization of the care itinerary; and deconstruction of the bond, due to failures in communication and reception. Conclusion: The deconstruction of the therapeutic itinerary of children with special health care needs involved, above all, the professional context in the Health Care System, leading to the search for care in private services and in care institutions.

**Keywords:** Child health. Child care. Border health. Health services accessibility. Disabled children.

### RESUMO

**Objetivo:** Compreender o itinerário terapêutico percorrido pelas famílias em busca de atenção às necessidades especiais de saúde do filho em um município brasileiro de fronteira.

**Método:** Pesquisa qualitativa fundamentada na hermenêutica dialética e no modelo de Sistemas de Cuidado à Saúde. Foram realizadas entrevistas e Mapas Falantes (Dinâmica de Criatividade e Sensibilidade) com 19 cuidadores de crianças com necessidades especiais, atendidas em instituições assistenciais em Foz do Iguaçu, Paraná, em 2020. Para análise dos dados, utilizou-se análise temática.

**Resultados:** Destacou-se a fragilidade do Sistema de Cuidados à Saúde, permeada por: dificuldades para acesso ao diagnóstico e consultas; sobrecarga para o cuidado; (des)organização do itinerário de cuidado; e desconstrução do vínculo, por falhas na comunicação e acolhimento.

**Conclusão:** A desconstrução do itinerário terapêutico de crianças com necessidades especiais envolveu, sobretudo, o contexto profissional no Sistema de Cuidado à Saúde, levando à busca por atenção em serviços privados e em instituições assistenciais.

**Palavras-chave:** Saúde da criança. Cuidado da criança. Saúde na fronteira. Acesso aos serviços de saúde. Criança com deficiência.

### RESUMEN

**Objetivo:** Comprender el itinerario terapéutico que recorren las familias en busca de atención a las necesidades especiales de salud de sus hijos en una ciudad fronteriza brasileña.

**Método:** Investigación cualitativa basada en la hermenéutica dialéctica y el modelo de sistemas de salud. Se realizaron entrevistas y *Talking Maps* (Dinámicas de Creatividad y Sensibilidad) con 19 cuidadores de niños con necesidades especiales, atendidos en instituciones de cuidado en Foz do Iguaçu, Paraná, en 2020. Para el análisis de datos se utilizó análisis temático.

**Resultados:** Se destacó la fragilidad del Sistema de Salud, permeado por: dificultades para acceder al diagnóstico y consultas; sobrecarga de cuidados; (des)organización del itinerario asistencial; y desconstrucción del vínculo, por fallas en la comunicación y recepción.

**Conclusión:** La desconstrucción del itinerario terapéutico de los niños con necesidades especiales involucró, sobre todo, el contexto profesional en el Sistema de Salud, conduciendo a la búsqueda de atención en los servicios privados y en las instituciones de atención.

**Palabras clave:** Salud del niño. Cuidado del niño. Salud fronteriza. Accesibilidad a los servicios de salud. Niños con discapacidad.

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## ■ INTRODUCTION

Better living and health conditions motivated by technological advances, good environmental and nutritional conditions and the implementation of Primary Health Care (PHC) programs considerably reduce infant mortality, but, on the other hand, can cause changes in the population's epidemiological profile, with an increase in chronic health conditions, including in the child population<sup>(1)</sup>.

Children with Special Health Care Needs (CSHCN) require complex care because they present demands for attention beyond children of the same age, namely: developmental, technological, drug and modified habitual<sup>(2)</sup>. These are children who need intensive, temporary or permanent care and who end up going a long way in an attempt to get a diagnosis and a solution to their health problems<sup>(3)</sup>.

This trajectory, called Therapeutic Itinerary (TI), includes not only the planning of actions to deal with the disease and to promote health<sup>(4)</sup>, but also seeks socially significant explanations and psychosocial treatments to achieve the well-being and/or the cure<sup>(5)</sup>.

The health-disease process requires multifactorial interactions related to the biological, psychological and social levels, as in the Health Care Systems model<sup>(6)</sup>, represented by the cultural method and governed by the systems: folk (non-professional healing specialists, religious groups), popular (family context of care and illness, social and community networks) and professional (professional of medicine and indigenous cures).

Therefore, the decision of where and when to seek help is characterized by the popular system and involves expectations, functions, relationships and healing processes<sup>(6)</sup>, considering that the relationships of projects in the way of being human, with ways of understanding themselves and their world, in addition to their ways of acting and interacting, are constantly experienced in the health area to refer to care<sup>(5)</sup>.

National and international consolidated data indicate that PHC has been recognized as a central strategy to improve child health, especially for CSHCN<sup>(1-2,7)</sup>, however gaps related to the actions offered by the Health Care Networks are still observed (HCN)<sup>(8)</sup>, mainly in vulnerable regions such as border areas. A study showed that care in these regions is disjointed and disorganized<sup>(9)</sup>, generating insecurity for the community and for health professionals. Thus, it is essential to invest in a more effective flow and preventive practices that ease the overload on the health system and expand access to services, achieving resolution and reducing inequities<sup>(8,10)</sup>.

Vulnerability in border areas, setting of the present study, refers to a situation of interdependence between countries, with spaces shared between the cross-border population

and with a complex, cross-cultural population and health dynamics that predispose people to illness, further aggravating their health condition<sup>(11)</sup>. In addition, the lack of intercountry communication and the difficulties in the referral and counter-referral system generate delays and lack of assistance<sup>(11)</sup>.

By considering that CSHCN demand complex, individualized care, directed to their special needs and in a quantity greater than those required by children in general, a disarticulated PHC can intensify their fragilities and demands for care<sup>(7)</sup>.

In this context, the following question was highlighted to guide this study: what is the TI taken by families in search for care and cure for CSHCN in border regions? The understanding of the trajectory taken by families to take care of their children allows us to assess the effectiveness of the service and identify the needs of educational programs in health, professional training, and adequacy of care flows.

This article aimed to understand the TI taken by families in search of attention to their child's special health care needs in a Brazilian border town.

## ■ METHODS

Qualitative research with exploratory analysis, conducted by the theoretical-methodological framework of hermeneutics-dialectics. Hermeneutics seeks to interpret and understand the context of falling ill in the daily search for well-living. This incessant understanding acts through the question and answer dialectic, not in an attempt to seek the weak point of what was said, but in finding its true strength and discussing perspectives of the search itinerary for the care of CSHCN from the perspective of their caregivers<sup>(12)</sup>.

This investigation began in three philanthropic care institutions for CSHCN in the city of Foz do Iguaçu, Paraná (PR), southern Brazil, which borders Cidade do Leste (Paraguay) and Porto Iguaçu (Argentina). These are entities that provide care for people with multiple disabilities, in the areas of special education, health and social assistance. Among the five institutions existing in the city, only the three selected host children under the age of six, the object of this study.

For the selection of participants, the entities made available a list of all assisted children and their service hours. Thus, the search was made by gathering cases rich in information that would contribute to the deepening of the phenomenon studied, considering children under the age of six years and with at least two demands for care (continuous use of medications, modified habitual, of development and/or behavior, use of technological device and/or mixed)<sup>(8)</sup>. Thus, 19 caregivers of CSHCN, over 18 years of age, participated in the research.

Due to the COVID-19 pandemic, the interviews took place in the philanthropic entities, without the possibility of conducting them at home, as initially proposed in the research project. Participants were approached in person, as they arrived for their children's care, and invited to participate in the study. There was no refusal of the approaches. Caregivers who did not attend the institutions at the scheduled times for their children's care were excluded.

The search for data took place from October/2020 to February/2021, conducted by the first author, who has professional experience in the field of child health. The researcher also received prior training, with two pilot interviews, which were not considered for the organization of this study.

The institutions provided a private room for data collection, in which there was only a researcher and researched. All were informed about the research objectives and, upon accepting, signed the Free and Informed Consent Form (FICF) in duplicate, ensuring confidentiality and anonymity.

The meetings were held individually, starting with the Dynamics of Creativity and Sensitivity (DCS) – Talking Map (TM), developed based on the Sensitive Creative Method<sup>(13)</sup>, and followed by an in-depth interview. The following question was used as a generator of the debate: Tell me how the paths taken with the child to meet their health needs have been?

It is noteworthy that DCS is epistemologically based on the critical-reflective of participant research, on the group dynamics of social psychology and on the artistic creation of the research<sup>(13)</sup>. The TM tool allows an in-depth reading of reality from its multiple dimensions, bringing the relationship between the researcher and the researched closer<sup>(8)</sup>.

The researcher provided blank paper and colored pencils for the production of the TM and these were individually constructed by the participants, at the time reserved for the interview. After the construction of the TM, caregivers were encouraged to explain the path represented and, thus, the in-depth interview began, using a guiding script as an instrument, which addressed: access to health care services; reception and listening offered in the PHC; continuity of care; the offer of specialized professionals and medium-complexity exams; the follow-up in child care and the resoluteness of services.

It was decided to conduct the TM followed by an interview to offer a dialogic space to the participant, so that he/she could reflect and go deeper into the issue addressed. The meetings were audio-recorded, lasting between five to nine minutes for the production and explanation of the TM and 11 to 35 minutes for the interviews. The recordings

were made available at the end so that participants could agree on their content.

For data analysis, thematic analysis was elected<sup>(14)</sup>. Initially, it was carried out the transcription of the recorded interviews and the organization of the collected material. To contemplate the data exploration phase, in-depth and repeated readings of the material were conducted, making an interrogative relationship between the theoretical framework and the proposed objectives.

The statements were divided, a priori, into pre-categories, organized in the Health Care Systems model<sup>(6)</sup>. This model is based on the impact of culture on disease and cure, which involves external (social, political, economic, historical, epidemiological and technological) and internal (psychophysiological, behavioral and communicational) factors, structuring itself into three domains: folk, popular and professional. The final step made it possible to obtain thematic categories.

In order to maintain the anonymity of the participants, they were identified by alphanumeric codes, using the letters CC – Caregiver of CSHCN, followed by numbers according to the order of the interviews, that is, CC1, CC2 and so on. The development of the study met the standards of the Research Ethics Committee (REC) of NN [eliminated for the purposes of peer review], being approved by Opinion No.4,300,226, in accordance with Resolution 466/2012 of the National Health and Research Council involving human beings.

## ■ RESULTS AND DISCUSSION

Fourteen mothers, two grandmothers and three fathers participated in the research, totaling 19 caregivers, aged between 22 and 54 years. The children were aged between two and five years old and had a pair of twins. The 20 children involved had at least two care demands, namely: development and/or behavior and modified habitual care. Among them, 11 children had additional demand for medication and four needed technological care (gastrostomy and/or wheelchair).

Data analysis focused on the Fragility of the health care system, disease and cure in the care of CSHCN, anchored by four thematic axes, namely: Functional barriers: challenges for the access of children with special needs to health care services; Physical, social and emotional overload generating fragilities in the search for care; (Dis)organization of the Therapeutic Itinerary as a reflection of a fragmented service; (De)constructing the bond between professional, community and family networks.

## Functional barriers: challenges for the access of children with special needs to health care services

The practice of care can be learned from the reflection of language and the understanding of the human reality<sup>(12)</sup> and has as a challenge the (dis)encounters between users, services and professionals. Within the context of the professional system, the reports of the participants were about the existence of obstacles to accessing health care services, added to the lack of reception and unpreparedness of professionals in face of the care demands presented by the CSHCN.

*There were some [professionals] that you would come in, try to talk about some situation, but change the conversation and leave. (CC7)*

*I took it to the pediatrician who referred me to the neuropediatrician. I was in a giant queue, it was five hundred and something, I went to the Public Ministry [PM], they gave me a paper to take to the Health Department. The lady who answered me called on the cell phone of the [manager of the Basic Health Unit – BHU] and she advanced my appointment, sent me to the [specialty center of the municipality] and started the therapies, even without the medical report. Soon I went to the neuropediatrician, in a week. (CC17)*

However, international research has shown that by guaranteeing and expanding access, regardless of the number of times or the service that the user needs, the responses to the health needs of CSHCN and their families can be optimized<sup>(2)</sup>.

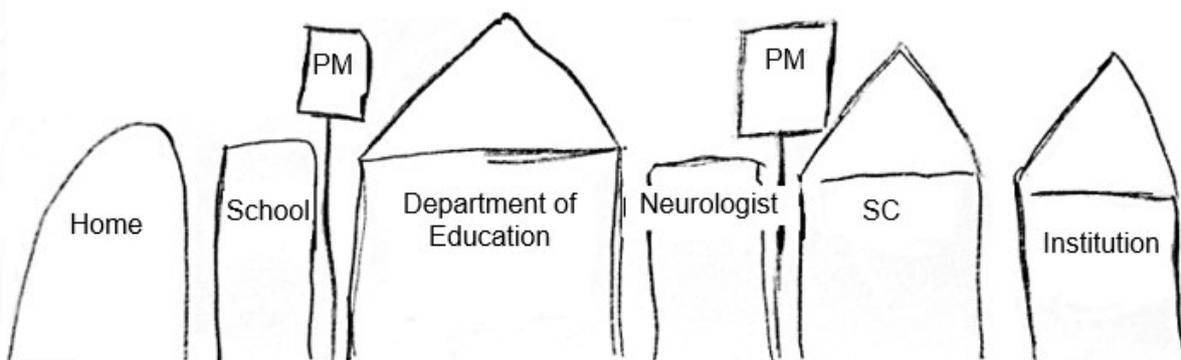
The barriers reported in this trajectory led family members to seek public agencies to demand the rights of CSHCN, as represented in the TM in Figure 1.

As care coordinator and organizer of the network of services to the population, the PHC should offer services without restriction of access, addressing a range of health care needs of the population through the prevention of diseases and injuries, promotion, assistance and rehabilitation<sup>(1)</sup>. However, the lack of reception and qualified listening reported by caregivers and the neglect in the care of CSHCN families, present throughout the process of seeking the diagnosis, were characterized as functional barriers and interfered in the provision of services in a timely manner and, consequently, in the progress of the neuropsychomotor skills of the CSHCN<sup>(8)</sup>.

*I got the report from the National Institute of Social Security [Instituto Nacional do Seguro Social – INSS] when I was five [years old], a short time now. (CC5)*

*The doctor [from BHU] referred the neurologist who had the MRI done. When the result came, he said: “mom, you are very neurotic” and I said: “no doctor, he has something different, that when he was one year and six”. [...] I found another pediatrician and he said: “mother, the [son] doesn’t interact, doesn’t have eye contact, nothing? He had to be investigated” [sigh of relief and tears in her eyes]. He referred me to another neurologist who also said he has nothing. The pediatrician asked if I could go in private [...], I got a private appointment and found out his diagnosis, that’s when everything resolved. (CC12)*

The care demands of children, as well as their needs for injuries prevention, should be recognized even in basic health



**Figure 1** – Talking map produced by CC18; Foz do Iguaçu, PR, 2020

Legend: PM – Public Ministry. SC – Specialty Center of the municipality.

Source: Researcher data.

activities, followed by guidance and monitoring of the child and their families, as demonstrated in a recent study<sup>(15-16)</sup>. But according to the participants, the precariousness of care made decision-making difficult and boosted the search for other services that meet the demands of care required by CSHCN, including secondary and tertiary health care levels.

*When he started to shake, he kept rolling his eyes, I took him to the Emergency Care Unit (ECU), then he started to be treated with medicine. (CC5)*

*I don't even go to the health center, I only use the 24 hours [ECU], then they send them straight to the hospital to do the tests. (CC14)*

On the path in search of resoluteness and attention to the needs of their children, families of CSHCN needed to resort to private health services, converging with recent research<sup>(4)</sup>.

*We needed a report from a doctor from the Unified Health System – SUS, but it is not very easy to get, because the SUS does not offer the tests and we had to pay for everything, so the SUS doctor could give the report. (CC1)*

*[...] it was very complicated to be depending only on the SUS to get tests, therapies, treatment, so we were practically forced to do the [health insurance plan] so that she could have care as soon as possible. (CC8)*

*If you don't pay for a health insurance plan, you lose time to undergo therapies, your child can't do the treatment*

*he needs at the right time, which is fundamental for the development of people with special needs. (CC8)*

*I made a health insurance plan for him, [...] in the SUS it's been over a year since I've done anything, because there isn't even a pediatrician. (CC15)*

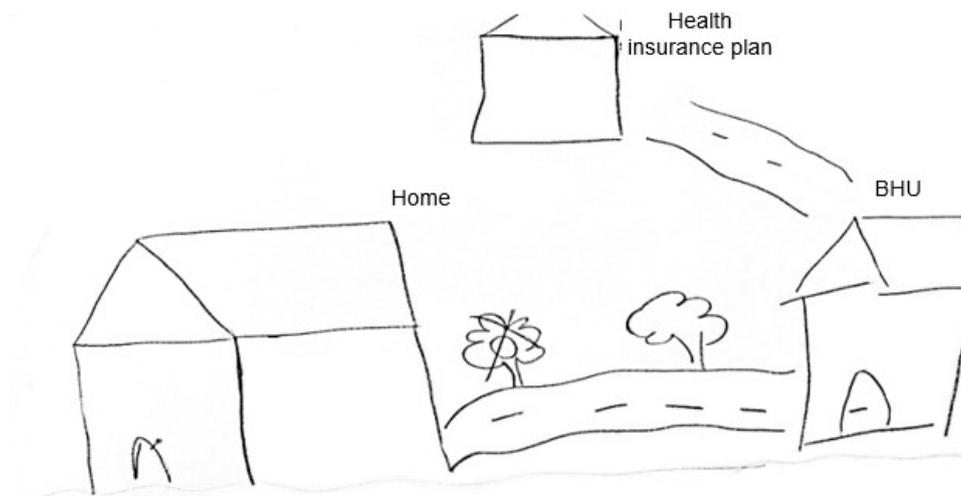
In the hermeneutic perspective, this movement corresponds to the search for solutions to overcome the illness process, symbolized by the daily search for good living<sup>(12)</sup>. And to exemplify this trajectory, the TM presented in Figure 2 shows that after being neglected by the health unit, the mother went to the private sector and that, according to her, “there were no flowers on this path”.

The expression now given by the participant reinforces that this search for health insurance plans and private care takes place even in the face of financial difficulties, intensifying the obstacles encountered by family members.

The unpreparedness of professionals, the lack of reception and the precariousness of health care services constitute a barrier to access, which weakens the families of CSHCN and hinders the construction of TI.

### Physical, social and emotional overload generating fragilities in the search for care

The high demand for care required by CSHCN is associated with the various challenges reported by their families, including the constant search for resolving services. National and



**Figure 2** – Talking map produced by CC1; Foz do Iguaçu, PR, 2020

Legend: BHU – Basic Health Unit.

Source: Researcher data.

international studies indicate that the exclusive dedication to care of child makes that caregivers do not find space to care for themselves, their health and their social life within the community, which, according to the participants, generates physical, social and emotional overload<sup>(3,17-18)</sup>.

*I can't count on anyone, it overloads me a lot [...]. These days I just wanted to cry, so I went to the health center and said I needed an appointment, she [nurse] told me to come back in 15 days for us to make an appointment. I got crazy, [...] I have a problem today and I want an appointment today, [...] she fit me into the appointment and the doctor gave me an antidepressant. (CC15)*

*[...] I wanted a psychologist for me, I put my name in the queue in 2019 and so far they haven't called me. (CC17)*

*[...] my family does not accept [the child], the mother's psychological condition is racing. When you arrive at the appointment, you expect a hug from the professionals, the therapists, but if you don't have anything, you just see a darkness, it seems that it will never get better. I hope doctors have more empathy. (CC17)*

It is important to highlight that the decision of where and when to seek help is part of the family system, according to the Health Care Systems model, and is composed of social and community networks<sup>(6)</sup>.

The scientific literature highlights that actions aimed at strengthening support networks reduce the strain faced by family members when looking for care for their child with special health care needs and enable child care, improving the community context in which they live<sup>(3,19)</sup>.

In these circumstances, empathy, coexistence and interaction are known to be important for self-care<sup>(12)</sup>, as the involvement of the community in the process of caring for CSHCN led families to feel more welcomed and able to follow the intense routine of care that their children require<sup>(17,19)</sup>.

*There is a group in Curitiba, that any child born with Down Syndrome, they go to the house to be welcomed. There, he went to a school that provided all the support he needed [...], but here there are difficulties, here in Foz they are light years late, here you can't get anything. (CC15)*

Furthermore, the interaction between subjects (professionals and caregivers), promoted by the sharing of technical-scientific-practical knowledge, expands the individual's space as an active subject of their health, enabling the overcoming of adversities and the construction of other views about reality<sup>(3,12)</sup>.

Dialogical relationships involved in the professional-user encounter, through the fusion of horizons and practiced by listening, interest and building bonds of trust, should be encouraged, but this was not the reality found in this study.

*It would be interesting to have a psychologist for the parents, it would be very good if they offered it, because we would not need to travel to other places, such as the Psychosocial Care Center – CAPS. (CC18)*

*[...] groups of parents help a lot, I learned lots of things, there are groups that are more for outburst. (CC18)*

According to the discourses, the intensive care of children with complex health demands overloads the main caregiver, usually the mother, and disrupts family relationships. In this scenario, studies reinforce the need to produce family rearrangements to face this new reality<sup>(4,20)</sup>.

*We don't have help because we can't afford it financially. My wife works, I work. But since I work from home, I stay with him. (CC4)*

*My 12-year-old son helps me. I used to work before, now I had to stop because she has appointment every day, so I have to go out with her straight away and I prioritized my daughter. (CC13)*

The absence of a father figure was another factor reported by the participants and which converges with the researches with regard to their little participation in the life and treatment of children with chronic health diseases<sup>(3,8)</sup>.

*[When asked if he has help to take care of the child] No, just me. (CC5)*

*I'm alone, their father didn't even see him born. (CC17)*

Therefore, the scarcity of support networks and the lack of attention directed to families generates an overload for caregivers, hindering the construction of care and coping with adversities.

### **(Dis)organization of the Therapeutic Itinerary as a reflection of a fragmented service**

The obstacles found for access to consultations, tests and specialized care, added to the lack of structure and qualified professionals resulted in disconnected care, reflecting in long waiting periods and increased vulnerabilities of CSHCN. As an example, the delay in diagnosis hindered TI planning and early access to treatments, as shown by the reports of the participants.

He left the nutrition center when he was seven months old [...] we already knew he had a delay. As he was already referred to a neurologist, he was in the queue for six months [...], when he completed one year and a month, he went to the neurologist for the first time. (CC2)

[He stayed] two months in the hospital [...] and went home with a gastro [gastric] tube. They gave me a lot of paper, which I had to start all from the health unit. I was in queue for three months to get a position with a neurologist. Go back to the health unit again, give what the doctor asked and go back in queue again. It takes time, sometimes it doesn't even call. (CC10)

The individual view of the world delimits their choice and the way in which the care and healing itinerary is constructed. Therefore, parents, with little or no guidance, should not be expected to face a variety of aspects and obstacles that limit their children's access to health care services in a solitary way<sup>(11,16)</sup>. It is necessary to be by the side of the families, offering a regular source of care based on a relationship of mutual trust<sup>(12)</sup>.

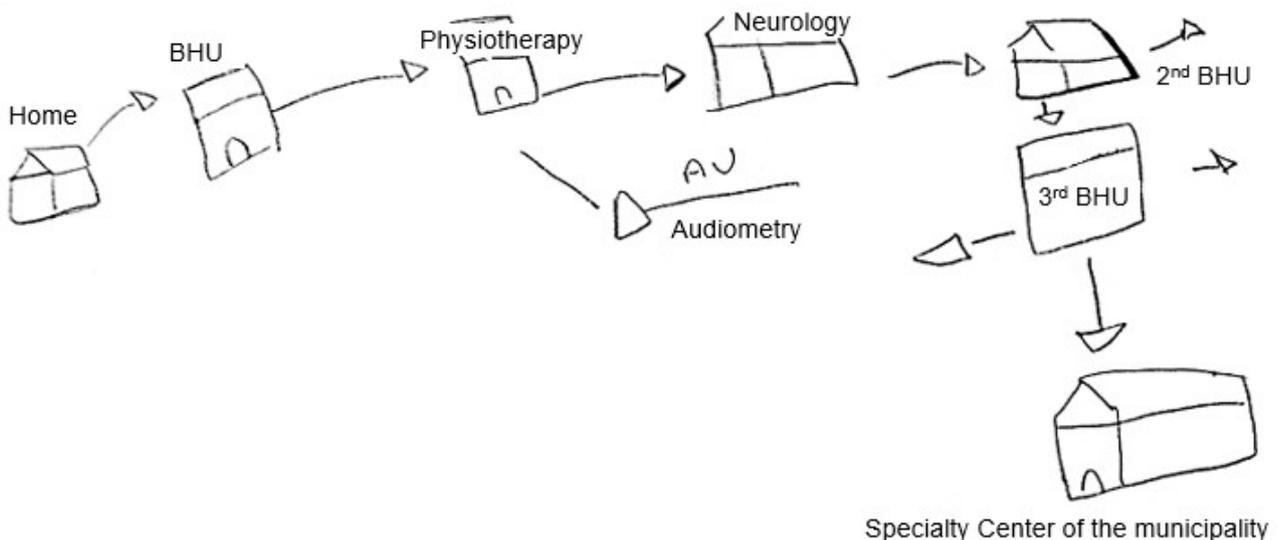
A research conducted in Foz do Iguaçu, PR, showed that the support networks for children are fragile and fragmented<sup>(9)</sup>, and that, in order to guarantee comprehensive care, it is essential that the care flows are well defined and planned, offering a service resolute and in a timely manner<sup>(3)</sup>. This fragility was evidenced in the TM in Figure 3 and reinforced by the participant's speech.

At the health center, we couldn't do it. Even then, for us to be able to do that newborn screening test, it was a lot, it still is, but it was worse before, it was very messy. You couldn't get assistance, so we always ended giving up. (CC6)

Another study conducted in the same municipality<sup>(11)</sup> found a trajectory marked by disarticulation and slowness, where users are referred without rigor, that is, from one side to the other, not only during the first access, but also in the continuity of care, corroborating the reports of caregivers.

My son didn't speak, I went to the health center and after three months the consultation with the speech therapist came out. [...] the same doctor who sent me to the clinic, sent me to a neurologist [it took four months] and the neurologist referred me to a speech therapist, occupational therapist (OT) and psychologist. That's when I started looking, I went to the [second BHU] there wasn't, I went to the [third BHU] there wasn't, I went to the [specialty center of the municipality], there wasn't any either. Then I went back to my health center and there wasn't either. Then I got in queue for the [name of institution] and spent two years waiting for a place. (CC6)

He [physician] sent him to the nutrition center to gain weight and I'm waiting for his surgery, [...] It's been three years. There's an exam that that you don't do here in the city, and I have to go to Pato Branco. You have to go after it yourself, nobody helps you to go after the surgery. (CC7)



**Figure 3** – Talking map produced by CC6; Foz do Iguaçu, PR, 2020  
 Legend: BHU – Basic Health Unit.  
 Source: Researcher data.

*The [exam] of heart I have to do in Cascavel or Curitiba, so that's something to be desired because it's hard to go out with the child, we see the mothers always going out to take them in Curitiba, every month or every six months. (CC13)*

It is noteworthy that international border regions have spaces shared by the cross-border population and that the overload generated by the high demand of foreigners to Brazilian health services hinders access to specialized care and medium and high complexity exams, as observed in the statements and corroborated by the literature<sup>(11)</sup>.

In addition, the distance from large reference centers and the lack of specialized professionals, characteristics that are quite common in border regions, were identified by families as responsible in the search for care in cities far from their homes, converging with local research<sup>(11)</sup>.

*Foz do Iguaçu has a very big gap with professionals, she needs, for example, to follow up with a pediatric ophthalmologist, we have to go to Cascavel because there isn't one here. We already had to go to Curitiba, because in Cascavel there was no schedule. (CC8)*

*I got it [report] in Curitiba, when she was born there was no neurologist, then she got sick again, I went to the Hospital [...] and I said: "Doctor, I still haven't got the diagnosis of [daughter] because there is no neurologist, there was only the pediatrician, and she is no longer in the network." Then he gave me a referral and sent me to Curitiba, then it was easy. (CC10)*

Although the necessary referrals are conducted by professionals, the speeches were about the lack of adequate guidance for the direction of these children and their families.

*We went there [BHU], he consulted him [son] and the nurse said he had to go and enroll in other entities and*

*also in the [specialty center of the municipality], [...] so we waited. As here [institution] has the five things he has to do and there wasn't, I started there [specialty center] then when it came here, I left and enrolled here. (CC4)*

This come and go of families in search of care refers once again to the professional system, considering that the disarticulation between the services in the municipality weakens the TI and makes the care of CSHCN even more complex<sup>(17)</sup>. That said, studies confirm that disorganized services affect family dynamics, identities and roles and lead to a disorderly itinerary, with low coverage, difficult access and discontinuity of care<sup>(3,20)</sup>.

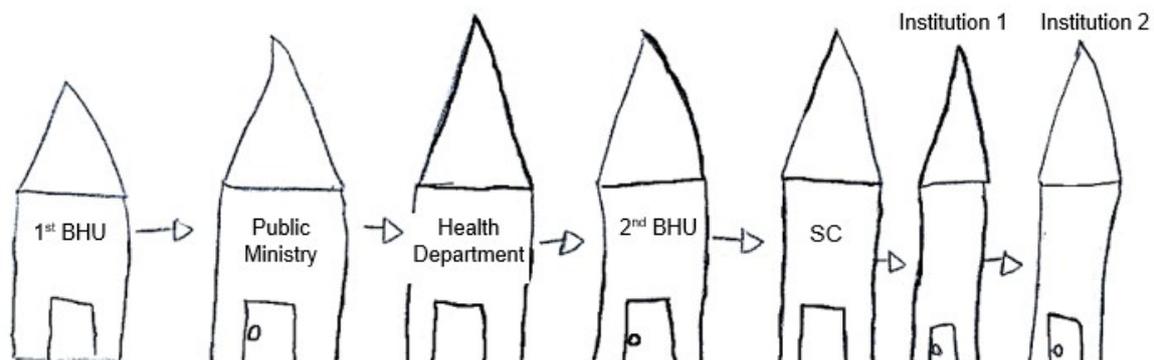
*The pediatrician at the nutrition center referred me to a neurologist and had only two appointments. Then she stopped consulting by SUS. (CC2)*

However, specialized services for long-term treatment proved to be incipient in this region, with their overload, delays, and lack of assistance of the population.

*The doctor who took care of him since day one, I didn't even need a waiting list. As for the other treatments, I am until today. There is treatment that [son] needs and that he hasn't even consulted. Every year I have to update the reports to get in line and I never get called. (CC2)*

*It took a long time to get it [at the institution], I had to keep charging, charging, because there was no place, it's a very big demand, waiting list, because there isn't for everyone. There were even people who said they were dismissed because there was no way to attend everyone. (CC15)*

For this reason, the families visited different institutions in the hope of finding a place for their children (Figure 4).



**Figure 4** – Talking map produced by CC17; Foz do Iguaçu, PR, 2020

Legend: BHU – Basic Health Unit. SC – Specialty Center of the municipality.  
Source: Researcher data.

*She [private doctor] gave us the report and instructed us how to do it, we ended up at [institution A]. I came here to [institution B] which was considered to have the most assistance, but there is a long waiting queue, so I left her name here and went looking for other assistance. At [institution A] I found consultations with a speech therapist and music class, until I was called at the [specialty center of the municipality], where she had only a psychologist, which is very annoying because we have to choose. (CC3)*

*The teacher at the CMEI (Municipal Child Education Center) referred me to a psychologist at the Department of Education who referred me to the neurologist and already referred me to therapies, [...] it took about three months or more, but it didn't have everything. For me to get her therapies I had to go to the PM, then I was referred to the [specialty center of the municipality] and to get here she spent a year waiting in queue. (CC18)*

Researches claim that this constant movement reported by families in search of resoluteness and continuity of care undermines the relationship between professionals and family members and compromises the bond – a fundamental element for the quality of care<sup>(19–20)</sup>.

Therefore, a fragmented and disorganized service makes it difficult for families to interact with professionals, impairs the TI organization and leads to discontinuation of care.

**(De)constructing the bond between professional, community and family networks**

Communication and listening are fundamental elements to establish a dialogical relationship, with mutual trust between families and health professionals<sup>(12,18)</sup>, however, the speeches dealt with the lack of qualified listening and

difficulty in creating bonds with the professionals of the PHC units, diverging from the scientific literature.

*[...] outside of here [institution], at the health center and at the [specialty center of the municipality] it is very precarious, in talking to you, in speaking, in explaining to you. They don't have patience, they are ignorant, they don't know how to talk to people. (CC12)*

The bond established with the health team could facilitate the articulation between the referral and counter-referral systems<sup>(4,16)</sup>, but the caregivers' speeches emerged in the opposite direction, since the children who migrated to private services returned to the health care unit only in search of vaccines; and children referred to philanthropic institutions and to the specialty center occasionally used the health units (Figure 5).

*I take to the nutrition center, but sometimes to the health center. (CC13)*

*[Questioned if they use the BHU] No, part of the plan, part here at the institution, because my health insurance plan doesn't cover everything, right. (CC16)*

It is important to point out that in hermeneutic thinking, the fusion of horizons established between professionals and users, from the exchange of different knowledge, with respect to identities, values and experiences, as well as the dialogue centered on care, greatly contribute to the transformation of practices into health and for the construction of happiness projects<sup>(12)</sup>.

This interaction was present in socioeconomically more vulnerable children, as the reports pointed to a continuous monitoring conducted by community health agents, facilitating care and bonding with families.



**Figure 5** – Talking map produced by CC2; Foz do Iguaçu, PR, 2020  
 Legend: SC – Specialty Center of the municipality.  
 Source: Researcher data.

*There is the woman who visit homes [community health agent], she always goes there to see, visit and ask if she is okay. (CC9)*

*The health agent goes home, schedules tests so I don't have to go to the health center. (CC10)*

It should be highlighted that coordinated and longitudinal services are essential to ensure adequate care for chronic conditions<sup>(1,3)</sup>, in addition to strengthening the construction of the TI.

The folk system<sup>(6)</sup>, which integrates the Health Care Systems model, is another fundamental element for care, however it was not reported by the participants in this study. This result converged with a recent meta-analysis, which found few citations about this system in the literature<sup>(5)</sup>. However, a research conducted in Foz do Iguaçu, PR, the setting for the present study, stated that there is a search for social and religious groups during the healing process<sup>(11)</sup>.

And finally, other actions have been shown to be beneficial for the care of complexities presented by children, but families reported lack of knowledge of complementary therapies to establish this comprehensive care for the child.

*The SUS does not offer it, but there should be complementary therapies, [...] hydrotherapy, music therapy, at home I do some things like that and she likes it a lot. (CC18)*

The use of complementary therapies associated with clinical treatment allows for greater interaction between professionals, children and families, which could bring relief from symptoms, facilitate other treatments and strengthen the bond between family and professional networks.

Thereby, the functional barriers faced by the families of CSHCN to access health care services were evident in the border context, which led to an increase in parental overload and disarticulation of the TI, making it time-consuming and unresolvable. In addition, the lack of listening and reception made it difficult to build the bond, an essential element to ensure continuity of care.

## ■ FINAL CONSIDERATIONS

For the families of CSHCN, health care services are fragile, uncoordinated and unresolvable. The TI presented evidenced that the CSHCN caregivers faced difficulties related to the search for the diagnosis, consultations with specialized professionals, failures in communication, reception and care provided to children and their own families in PHC units.

The search for health care was predominantly constituted by caregivers, in addition to being permeated by comings

and goings to several health institutions, showing the incipience of the professional context in the CSHCN Care System. Situations found in border regions, such as demographic and technological incompatibility, diplomatic and public health problems, and the distance from major reference centers intensify the problems, leading these families to look for assistance in private services, philanthropic institutions, and cities far from their residence.

The TM instrument was an important ally for understanding the paths taken in the search for health care, as it urged the participants to reflect on the path lived by them since the discovery of their children's diagnosis. This process is marked by insecurity, with fears and anxieties about when and where to seek assistance.

To establish a well-defined and resolute TI, it is necessary that the continuous demands for children and their families be attended, with relevance to the improvement of nursing skills to act assertively in the monitoring of CSHCN, as well as in the implementation of policies aimed at them. It is essential to respect and integrate cultural and family systems, so that children's rights be achieved and, above all, with empathy for the intense path that these families take every day in search of a dignified and quality life for their children.

The study has as a limitation the conduct of interviews in care institutions and entering the home environment could show in greater depth the vulnerabilities of CSHCN and their families to meet the demands of care. To broaden the understanding of the results found, more studies are needed aimed at the HCN and at the Specialty Center of the municipality.

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