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Perceptions of caregivers about the continuity of care for children with special health needs

Percepções de cuidadoras acerca da continuidade do cuidado às crianças com necessidades especiais de saúde

Percepciones de cuidadoras sobre la continuidad del cuidado de los niños con necesidades especiales de salud

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Objective: to know the perceptions of caregivers about the continuity of care for children with special health needs. **Methods:** qualitative research carried out in a municipality in the *sertão* of the state of Ceará, Brazil, with caregivers of children with special health needs, from June to August 2020 through semi-structured interviews, and the data were subjected to thematic content analysis. **Results:** 11 caregivers participated, with an average age of 33.3 years, average income of R$1,360.00, most of them married, and who did not finish high school. In the occupation, 10 caregivers reported that their main task was to take care of the child and carry out domestic obligations. Two categories were constructed: "*we are always struggling… since the time he was born, this is his routine: caregivers' experiences and perceptions about the care path*"; and "*I'll wherever I must, I'll do whatever it takes. Feelings of hope and faith that strengthen caregivers*". Caregivers face challenges with constant displacements and waiting times at health services, aggravated by the COVID-19 pandemic. Hope and faith was configured as sources of support. **Conclusion:** the challenges and obstacles faced for the continuity of care by the caregivers interfere with the evolution of the child's clinical condition, make the care provided more laborious, manifesting even more the social vulnerability of this public.
Descriptors: Continuity of patient care; Health vulnerability; Child health services.

Objetivo: conhecer as percepções de cuidadoras acerca da continuidade do cuidado às crianças com necessidades especiais de saúde. **Método**: pesquisa qualitativa realizada em um município do sertão do estado do Ceará, Brasil, com cuidadoras de crianças com necessidades especiais de saúde, de junho a agosto de 2020 por meio de entrevistas semiestruturadas, e os dados foram submetidos à análise de conteúdo temática. **Resultados**: participaram 11 cuidadoras com média de idade de 33,3 anos, renda média de R$ 1.360,00, maioria casadas, e não chegaram a concluir o ensino médio. Na ocupação, 10 cuidadoras informaram que tinham como principal tarefa a de cuidar da criança e a realização das obrigações domésticas. Duas categorias foram construídas: *"A gente sempre está na batalha... desde a época que ele nasceu que a rotina dele é essa: vivências e percepções das cuidadoras acerca do percurso de cuidado"*; e *"Eu corro atrás para onde for, eu faço tudo e vou. Sentimentos de esperança e fé que fortalecem as cuidadoras".* As cuidadoras enfrentam desafios com os constantes deslocamentos e tempo de espera nos serviços de saúde, agravados pela pandemia de COVID-19. A esperança aliada à fé se configurou como fontes de suporte. **Conclusão:** os desafios e obstáculos enfrentados para a continuidade do cuidado pelas cuidadoras interfere na evolução do quadro clínico da criança, torna o cuidado prestado mais laborioso, manifestando ainda mais a vulnerabilidade social desse público.
Descritores: Continuidade da assistência ao paciente; Vulnerabilidade em saúde; Serviços de saúde da criança.

Objetivo: conocer las percepciones de cuidadoras sobre la continuidad del cuidado de los niños con necesidades especiales de salud. **Método:** investigación cualitativa realizada en un municipio del interior del estado de Ceará, Brasil, con cuidadoras de niños con necesidades especiales de salud, entre junio y agosto de 2020 a través de entrevistas semiestructuradas, y los datos fueron sometidos a análisis de contenido temático. **Resultados:** Participaron 11 cuidadoras con una edad media de 33,3 años, la renta media fue de R$ 1.360,00, la mayoría de ellas estaban casadas y no terminaron la escuela secundaria. En cuanto a la ocupación, 10 cuidadoras informaron de que su principal tarea era cuidar del niño y realizar las tareas domésticas. Se construyeron dos categorías: *"Siempre estamos en la batalla... desde que nació esta es su rutina: experiencias y percepciones de cuidadoras sobre el proceso del cuidado"; y "Voy hasta donde sea necesario, hago todo y voy. Sentimientos de esperanza y fe que fortalecen a las cuidadoras*". Las cuidadoras se enfrentan a desafíos con los constantes desplazamientos y el tiempo de espera en los servicios de salud, agravados por la pandemia de COVID-19. La esperanza unida a la fe se configuraron como fuentes de apoyo. **Conclusión:** los desafíos y obstáculos a los que se enfrenta la continuidad del cuidado por parte de las cuidadoras interfieren en la evolución del cuadro clínico del niño, haciendo que el cuidado prestado sea más laborioso, manifestando aún más la vulnerabilidad social de este público.
Descriptores: Continuidad de la atención al paciente; Vulnerabilidad en salud; Servicios de salud del niño.

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INTRODUCTION

The change in the epidemiological profile of child health problems associated with technological development and the qualification of health professionals resulted in an increase in the rates of children who survive with some special health need[1-2]. This public, known as children with special health needs (CSHCN), are those who have or are at increased risk of developing a physical, developmental, behavioral or emotional condition, and who require health services in greater quantities than those required by children in general[3].

In 2016, a study on the Global Burden of Disease estimated that, globally, 52.9 million children under 5 years of age have developmental disabilities[4]. Special health needs have been identified in 18.5% of children in the United States, representing more than 40% of all child care costs[5]. In Brazil, a study carried out in Southern and Southeastern Brazil estimated a prevalence of 25.3% of CSHCN in the child population[6].

Given this scenario, the CSHCN need a network of specialized health services, as such conditions require differentiated care. These are children who generally present demands for continuous care (temporary or permanent), in addition to specialized, individual and personalized technical care, such as technologies, services, exams and high-cost medications[7-8].

Therefore, the continuity of care represents a fundamental condition in the lives of these children and their families, with a view to offering care in a continuous and coordinated way, formulated to guarantee the integration of practices and care continuity[9]. In addition, there needs to be an empathetic, longitudinal and comprehensive bond between health professionals and these families[10].

Assuming that caregivers face challenges to ensure the continuity of health care for these children, some questions arose: *What are the main difficulties faced by caregivers of CSHCN for the continuity of care? What are the strengths and weaknesses of the Health Care Network (HCN) to achieve continuity of care for CSHCN?* Thus, the present study aims to know the perceptions of caregivers about the continuity of care for children with special health needs.

METHODS

Research with a qualitative approach with an exploratory character. The qualitative method focuses on the study of relationships, representations, opinions and perceptions of human interpretive production on how to establish their way of life, thus proving to be adequate for the object of this research[11].

The study was carried out in a municipality located in the *sertão* of the state of Ceará, Brazil, 273 kilometers from the state capital Fortaleza, with a population of about 26,469 thousand inhabitants, with the rural population estimated at 10,763 (40.7%) and the urban population at 15,706 inhabitants (59.3%)[12]. It has 11 Family Health Teams included in the National Register of Health Establishments, a small hospital that meets the spontaneous and referenced demand for low and medium complexity hospitalizations, a Psychosocial Care Center - CAPS I and a Multidisciplinary Health Center[13].

Caregivers of CSHCN recruited from the physiotherapy clinic in the municipality participated. Inclusion criteria were: being one of the main caretakers responsible for monitoring the child in health services and at home; who have been followed up by the HCN for at least six months; caregivers of children up to 12 years of age, according to the Brazilian Child and Adolescent Statute[14]. As an exclusion criterion, caregivers with communication problems that prevented them from answering the interview questions.

Data collection took place from June to August 2020 in the participants' homes, through a semi-structured interview script. The interviews took an average of 30 minutes. The instrument's guiding questions were: "*Tell me about the monitoring of your child by the health services*" and "*Tell me about the difficulties faced in seeking care for your child in the health services of the health care network*". These guiding questions were followed by auxiliary questions in order to guide and deepen the information.

Due to data collection taking place during the COVID-19 pandemic, all sanitary measures and precautions were taken (such as the use of a mask, face shield, availability of hand sanitizer and physical distancing) for safe data collection and aiming at preserve the health of those involved, according to the guidelines of the Brazilian Ministry of Health and the National Research Ethics Committee (CONEP).

The data collected in the interviews were transcribed in full and soon after submitted to thematic content analysis[15]. To structure the analysis, after exhaustive reading of the transcripts of the interviews (pre-analysis), analytical tables were used in which the clippings of the participants' speeches were organized according to the identified themes (exploration of the material); from this, the thematic categories were established (treatment of results). Subsequently, the inference and interpretation occurred with the use of updated works related to the theme.

This study complied with all ethical precepts for research involving human beings in accordance with Resolution No. 466/12 of the National Health Council. To ensure anonymity, caregivers were identified with the name of flowers. The study was approved by the Research

Ethics Committee of the Universidade Estadual do Ceará (UECE) under opinion number: 3,829,101.

RESULTS

Eleven caregivers of CSHCN from the urban and rural areas of the municipality participated in this research. Nine were mothers and two grandmothers. They had a mean age of 33.3 years, ranging from 18 to 53 years. Their average family income was R$ 1,360.00. As for marital status, seven caregivers were married, two were single, one was separated and one was widowed, and most did not finish High School. In terms of occupation, 10 caregivers reported that their main task was to take care of the child and carry out domestic obligations (Chart 1).

Chart 1. CSHCN caregivers regarding sociodemographic data. Ceará, 2020.

Participant	Age (years)	Marital status	Educational level	Occupation	Residence	Income (R$)
Camellia (CSHCN 1)	40	Widow	Incomplete High School	Housework and child care	Urban area	1,500.00
Daisy (CSHCN 2)	18	Married	Incomplete Elementary Education	Housework and child care	Rural area	1,400.00
Hydrangea (CSHCN 3)	32	Married	Complete High School	Kitchen assistance	Urban area	2,300.00
Jasmine (CSHCN 4)	45	Married	Incomplete Elementary Education	Housework and child care	Urban area	1,045.00
Tulip (CSHCN 5)	30	Single	Incomplete Elementary Education	Housework and child care	Urban area	1,045.00
Amaryllis (CSHCN 6)	23	Single	Complete High School	Housework and child care	Urban area	1,545.00
Iris (CSHCN 7)	25	Married	Complete High School	Housework and child care	Rural area	1,300.00
Azalea (CSHCN 8)	56	Separated	Complete Higher Education	Housework and grandchild care	Rural area	2,230.00
Melissa (CSHCN 9)	22	Married	Incomplete Elementary Education	Housework and child care	Rural area	1,045.00
Violet (CSHCN 10)	38	Married	Incomplete Elementary Education	Housework and grandchild care	Urban area	1,045.00
Azucena (CSHCN 11)	38	Married	Incomplete Elementary Education	Housework and child care	Rural area	500.00

After analyzing the data, two thematic categories emerged: "*we are always struggling... since the time he was born, this is his routine: caregivers' experiences and perceptions about the* *care path*"; and "*I'll wherever I must, I'll do whatever it takes. Feelings of hope and faith that strengthen caregivers*"..

we are always struggling... since the time he was born, this is his routine: caregivers' experiences and perceptions about the care path

CSHCN routinely demand multiple services to maintain care for their health needs. Caregivers need uninterrupted support from health professionals and services to provide the necessary health care for their children.

In the interviews, the caregivers were asked to talk about the challenges they have faced regarding the child's health treatment.

[...] *we are always struggling, from here to Fortaleza, since the time he was born, this is his routine* [...] *it was difficult to face the struggle of having a follow-up for transport, like, sometimes, even the trips when we go from here to there.* (Jasmine)

[...] *right when I took him in, I would go, sometimes, three times a week to Fortaleza, it was very difficult, because there are already the other little ones.* (Violet)

[...] *The public system for me here in* (city of study) *is very scarce, all she needs is in Fortaleza, and until today I haven't had any problems, she goes, takes exams, so I don't have what to complain about, just the distance, and the fact that she has to travel all the time* [...] *she gets very tired and irritated, every trip is a process.* (Iris)

These statements share the same challenges: the difficulties of constant travel to other municipalities in the health network – mainly to the state capital, Fortaleza, in addition to the physical and mental fatigue for the child and the caregiver.

All participants in this research revealed challenges with the constant displacements between the cities of the health network. In these routes, they can travel more than 600 kilometers, considering the round trip. Given this scenario, it is necessary to integrate health services to minimize travel difficulties, with the aim of ensuring that children with chronic conditions can receive care as close as possible to their homes.

The COVID-19 pandemic brought additional challenges to this daily care, translated by the fear of contracting the disease and the cancellation of some appointments in some services:

I'm very afraid of going with him, because he gets tired very easily, I don't know if it's because of his lungs, I know that any choking, any issue with him, he gets very tired and from then on we were very scared, of him having any contact in the hospitals. (Azalea)

I missed some blood tests, it was right at the beginning of the pandemic, they said I couldn't go out, I was restricted, I couldn't mix special needs children with other people. She also missed some appointments, because the hospitals were left without care, due to the pandemic. (Melissa)

We had a lot of complications, because I canceled two of his appointments in Fortaleza because I was afraid to take him. (Violet)

Describing the path these mothers and grandmothers take in search of care for their children is essential to understand their desires and minimize possible obstacles and difficulties in this journey. Each interviewee approaches care in a unique way, based on their ways of seeing the world:

[…] *there were weeks when I went three times* [to Fortaleza]*, leaving here at midnight and arriving, sometimes, at midnight the next day. It's very difficult* [...] *I spent the day at the hospital outside, it was very tiring to him, my God, he got angry, he cried. We were robbed once on the bus.* (Violet)

[…] *now I have to take that chair there, I can barely take that. Whenever I go, I carry her in my arm* [child]*, and she is already too big for me to carry in my arms. And she doesn't really like being on the bus, she gets very agitated* [...] *I leave at dawn and arrive late* [...] *it's a five hour trip. The last time I went I arrived here at* (city of study) *it was after midnight.* (Melissa)

We always go by city hall car, then, sometimes, because we get there very early, especially in Fortaleza, which is further away, and usually his appointments are in the morning, then we're coming back by bus [private]*, because then it's less exhausting, because you spend the whole day with a child without taking a bath, sitting down, sometimes, with that heat, it's not easy.* (Hydrangea)

The greatest difficulties and challenges faced by caregivers on this journey are inherent to the departure and arrival times of health transport, waiting time at health services, inadequate transport for the children's special conditions, in addition to geographical distance:

[...] *the biggest difficult, like, is him going there in the chair, that's the only difficulty, and also when he gets a consultation, we leave at dawn.* (Azalea)

We used to go to Quixadá [...] *to occupational therapy, physiotherapy and to the speech therapist. I liked it, the only problem was the trip from here to there* […] *I used to take the hemodialysis minibus, so I had to wait for everyone to be done. There was a whole process of waiting for us to come home.* (Amaryllis)

[…] *we suffer a lot of humiliation, like, a SUS issue, because our baby needs a car to travel to Fortaleza, to Quixadá, to undergo treatment, and sometimes there isn't one, so they want to take the child to go on the bus, a special needs child to go on the bus and come back is very difficult, because there is a risk, a very high risk, because they have a very low immunity, I think this is negligence.* (Daisy)

There are important gaps in the care of CSHCN by the health system, as it does not visualize their singularities. It is necessary to look carefully at these children, as they need and have the right to a health service that meets their demands, since the quality of care can influence their growth and development.

Anxiety is pointed out for the qualification of continuity of care, aiming to reduce the constant displacements between the HCN points. In the speeches, there is dissatisfaction with the municipality not offering the necessary consultations, exams and follow-ups:

[…] *what I miss is a doctor, a pediatrician who monitors him more, because it is only when we go there in Fortaleza. A pediatrician here in town.* (Azalea)

[…] *here in* (city of study)*, it was supposed to have more of those that we look for in Fortaleza,* [specialist doctors] *because here we only have a pediatrician, now, you know, it's here now, and the physiotherapy, then neurologist and cardiologist, no yes, if there was, it would be better, because there was no way we could go from here to Fortaleza, it's very tiring.* (Violet)

[...] *I miss here from* (city of study)*, which could have a lot of things and doesn't have* [...] *for example, a direct pediatrician, like in* [city 60 km away]*, every day there is both in the public and private hospitals, not in* (city of study)*, it is once a week, once a month. A child doesn't get sick once a week, once a month, it's not like that.* (Iris)

I'll wherever I must, I'll do whatever it takes. Feelings of hope and faith that strengthen caregivers

Despite the difficulties faced in daily care and the constant wanderings through the HCN, the caregivers recognize that every effort is valid and emphasize the importance of treatment for the child's development:

[…] *he arrived here, he didn't even weigh three kilos and the city had almost no equipment for him, there was no treatment, it was very difficult* […] *he didn't even have an appointment scheduled,* […] *because his mother didn't care , it was very difficult for me to get everything back in Fortaleza, he wasn't taking any medication, he was taking nothing, then thank God it worked.* (Violet)

[…] *since the day* (CSHCN 1) *was born, my God, I'll wherever I must* […] *I'll do whatever it takes.* (Camellia)

Thank God, God gives me the strength to face everything, everything, to be able to take care of him. It's tiring? It's a lot, but you have to go, you have to take care of it so that it gets better and better. (Tulip)

The hope in the improvement of the clinical condition strengthens the caregivers to continue the search for therapeutic solutions for CSHCN, as well as faith. In the course of this investigation, some caregivers, even though they were not questioned, stated that the care they provided and the challenges they faced were rewarded by small achievements in the development and quality of life of the children. Regardless of the child's prognosis, the desire to see the child better drives the caregiver to seek treatments and continue their care journey back and forth through the health network.:

[...] *I really wanted* (CSHCN 8) *to have a treatment to see if he could walk* [...] *but then I don't know, if there will still be that chance in the hospitals where he is* [...] *but also if not If it's meant to be, it won't stop us taking care of it, liking it. It is very satisfying for me to take care of him.* (Azalea)

[...] *I particularly like going to consultations, routine exams to see if he's better* [...] *Today, at four years old, he's already much better than when he was born and what I could run after for him, I ran and I don't hide from anyone, what I could do for him is as he is today, I did.* (Amaryllis)

DISCUSSION

The findings of this study reinforce a problem that is still little discussed in public health policies for children: the invisibility of CSHCN. These children have been on the margins of the health system, becoming more socially vulnerable.

A study carried out in Maringá, Paraná, Brazil, with 68 caregivers of children with special needs for multiple, complex and continuous care, identified that all families presented individual vulnerability due to the clinical fragility of the child, social vulnerability due to exclusion, and programmatic vulnerability related to the precariousness of access to health services[16].

Faced with care requirements, they seek out different professionals and health services throughout the RAS to provide for the needs of CSHCN. A study carried out in João Pessoa, Paraíba, Brazil, observed that chronic illness in childhood drives the family to seek help from the health network equipment. The caregiver responsible for this mission accepts the diagnosis and treatments offered, which depend on the organization, coordination and continuity of care, sometimes considered complex and difficult to be incorporated into the daily lives of families[17].

The CSHCN require multiple health services, such as consultations, exams and surgeries, which are almost always offered in larger municipalities or central municipalities, making the caregivers have to travel great geographical distances in search of the resolution of the health condition of the child. A recent qualitative investigation, carried out in the state of Rio Grande do Sul, showed that CSHCN families do not have a consolidated referral and counter-referral flow in the HCS and face constant pilgrimages in search of health services[18].

The issue of geographic distance is also experienced by CSHCN caregivers at a university hospital in Southern Brazil, where it was found that the care network is dispersed by the geographic distance from the home to the multiple health services, since sometimes the caregiver needs to travel to another city, covering different itineraries for each type of care the child needs[19].

Research carried out in Porto Alegre, Rio Grande do Sul, Brazil, with family members of children with chronic diseases, found that access to health services is an element that makes them vulnerable, as families are forced to travel from cities in the interior of the state to a reference center in the capital for treatment, often traveling long distances, in inadequate means of transport, on poorly maintained roads, exposing themselves to a series of discomforts and risks. Families reported frustrations of not having health institutions in their cities qualified to provide them with treatment, or, at least, support, direction, adequate referral[20].

An additional challenge for caregivers in 2020 was the COVID-19 pandemic, which increased obstacles to the continuity of care for CSHCN. A recent investigation carried out in Foz do Iguaçu, Paraná, Brazil, with mothers of premature children, showed that the pandemic brought uncertainties and concerns related to the impact of the disease on children, and increased the vulnerabilities and weaknesses in the follow-up of the health of this public, such as gaps in communication, lack of guidance, vaccine delay and interruption of care demands[21].

In research that aimed to analyze children's vulnerabilities in accessing primary care care during the COVID-19 pandemic in Brazil and Portugal, it was shown that longitudinality was affected by reduced access to child health promotion, determining greater vulnerability programmatic. It was also observed that the vulnerability of children with specific health needs and greater exposure to diseases and hospitalizations sensitive to primary care increased[22].

The search for health care for CSHCN has represented an additional challenge for caregivers, especially in times of a pandemic[23], making it vital that health professionals and managers can develop strategies to mitigate the suffering of this public and improve continued access to health services.

A study carried out with health professionals and managers on the challenges faced by children and adolescents with chronic diseases found that, for care to become comprehensive and integrated, improvements are needed in the management of the health needs of this population. Network support and logistics systems need to be strengthened to ensure continuity of care[24].

The purpose of integrating health services and systems is to ensure continuous and comprehensive care, improving adherence to treatment and preventing the emergence of health problems and adverse events. The HCN has been shown to be a strategy for the integration of health services, providing an indispensable condition for the qualification and continuity of care[25].

The statements reflect gaps in comprehensiveness and accessibility to health services. In this sense, qualitative research, carried out with seventeen family members of CSHCN, confirms the results by stating that the difficulties experienced are directly related to the integrality and accessibility to health services and actions, which should be made available by the Unified Health System (SUS), since health is a citizen's right and a duty of the State[26].

In this investigation, the day-to-day care of a child with special health needs is an arduous task that requires patience and dedication. The statements reflect the weight of the challenges faced daily in the care of their children. However, the caregivers remain steadfast in wanting the child to evolve in their clinical condition, clinging to hope and the spiritual dimension.

In this perspective, research carried out in the state of Paraíba found that families of children with chronic diseases face a care process permeated by a trajectory of confrontations, changes, conflicts, impact, concerns, insecurity and fear, arising challenges inherent to illness and subjection to services of health during the course of diagnosis and treatment[17].

With regard to the caregivers' hope and faith in the child's rehabilitation, another study corroborates the findings presented here, by showing that CSHCN families undergo changes in their daily routine, experience adverse feelings and seek nurturing in the spiritual dimension to the adversities encountered[27].

CONCLUSION

The perception of caregivers about the continuity of care for children with special health needs is that it is marked by challenges, with emphasis on the need for constant displacements to guarantee access to different points of the HCN.

The findings of this study showed that, since the birth of the child, caregivers seek strategies to guarantee the necessary care, tracing a tortuous path full of challenges. This journey involves constant travel, inadequate transport, and long journeys. The caregivers yearn for an improvement in the continuity of care in order to mitigate the constant geographical displacements between the points of the HCN.

The challenges and barriers faced for the continuity of care interfere with the evolution of the child's clinical condition, make the care provided more laborious, manifesting even more the social vulnerability of this public. The COVID-19 pandemic added to these challenges the fear of contamination by the coronavirus and the cancellation of some health services.

Thus, facilitating the continuity of care in the HCN should be a priority in health policies with a view to improving access in favor of comprehensive care and quality of life for these children and their caregivers. The structuring of guidelines and lines of care aimed at CSHCN is an important path to be followed, aiming to improve access to the health system.

One of the limitations of the present study is the fact that the caregivers of CSHCN who were attending the physiotherapy clinic are the ones who were using the HCN services more routinely and, therefore, are the ones who reported the greatest difficulties with the continuity of care. Another limitation was the fact that the health system is facing the COVID-19 pandemic, which has substantially changed the care for these children. In this way, it is believed that further research can be carried out with more representative samples of this reality so that we can improve understanding and improve health care for this public.

On the other hand, the investigation presented here shows a scenario that needs to be reviewed in the search for support for women caregivers of CSHCN, in order to requalify both these special children and this caregiver.

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