Repercussions of COVID-19 on the care of children with special health needs
Repercussões da COVID-19 no cuidado às crianças com necessidades de saúde especiais
Repercusiones del COVID-19 en el cuidado de infantes con necesidades de salud especiales

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Abstract

Objective: Understanding the repercussions of the COVID-19 pandemic on the care of children with special health needs.

Methods: Exploratory, qualitative research, anchored in the conceptual framework of health vulnerability in the individual, social and institutional dimensions. Interviews were carried out from October 2020 to February 2021 (pre-vaccination against COVID-19) with 19 family caregivers, 11 professionals from education, social protection and health institutions and 15 primary health care nurses in a Brazilian city on the Brazil-Argentina-Paraguay border. Reflective thematic analysis was applied.

Results: Discontinuity in care, low scope of social protection and unstable institutional context marked the attention of children with special health needs. Individual vulnerabilities were highlighted as a result of vaccination delays, fear of contagion and changes in development; institutional vulnerability due to restrictions on home visits, waiting lists, lack of professionals and absence of group activities; and social vulnerability related to difficulties in social assistance and the closure of land borders. Elements related to the telehealth strategy and mechanisms that assume professional responsibility expressed strengths for the care of children with special health needs.

Conclusion: The restrictive measures adopted at the beginning of the COVID-19 pandemic had a negative impact on the care of children with special health needs, intensifying their individual and social vulnerabilities. Strengthening family and community contexts and expanding dialogue between sectors of primary health care indicate avoiding a mismatch between professional support and the pressing needs of these children, ensuring continuity of care.

Key words: Health vulnerability; Disabled children; COVID-19; Coronavirus infections; Continuity of patient care; Child health.

Descritores: Vulnerabilidade em saúde; Crianças com deficiência; COVID-19; Infecções por coronavírus; Continuidade da assistência ao paciente; Saúde da criança.

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Resumo

Objetivo: Compreender as repercussões da pandemia COVID-19 no cuidado de crianças com necessidades de saúde especiais.

Métodos: Pesquisa exploratória, qualitativa, ancorada no quadro conceitual de vulnerabilidade em saúde nos dimensões individual, social e institucional. Foram realizadas entrevistas, no período de outubro de 2020 a fevereiro de 2021 (pré-vacinação contra COVID-19) com 19 cuidadores familiares, 11 profissionais de educação, proteção social e saúde e 15 enfermeiros de atenção primária à saúde em um município brasileiro na fronteira Brasil-Argentina-Paraguai. Foi aplicada análise temática reflexiva.

Resultados: Descontinuidade no cuidado, baixo alcance da proteção social e contexto institucional instável marcaram a atenção de crianças com necessidades de saúde especiais. Destacaram-se vulnerabilidades individuais em decorrência de atraso vacinal, medo de contágio e mudanças no desenvolvimento;

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Repercussions of COVID-19 on the care of children with special health needs

The Sars-CoV-2 virus emerged at the end of 2019 and infected more than 630 million people worldwide.\(^1\) Due to its high contagion power and high mortality rate, prevention and control measures were implemented to prevent its spread.\(^2\) The closure of non-essential services and physical distancing required as preventive measures have had significant effects on health, social relations and the economy.\(^2\) The context of the COVID-19 pandemic generated stressful situations for families, substantially interfering in care relationships,\(^5\) Such elements can aggravate the vulnerability of CSHCN, harming their growth and development, if added to the gaps in health monitoring.\(^12\)\(^-\)14\)

Therefore, the objective of this study was to understand the repercussions of the COVID-19 pandemic on the care of CSHCN.

**Methods**

Exploratory research, with a qualitative approach, anchored in the conceptual framework of health vulnerability,\(^12\) involving individual, social and...
institutional dimensions with a focus on child health. (13)

This study was carried out in Foz do Iguaçu (PR; Brazil-Argentina-Paraguay triple border region), in philanthropic education, social protection and health institutions that serve children with multiple disabilities, and Primary Health Care (PHC) units close to the areas where CSHCN reside.

The investigation was carried out from October/2020 to February/2021 with interviews conducted by the first author, who has professional experience in the field of child health and received prior training to conduct interviews.

The inclusion criteria were the following: being the main caregiver of children under six years old (with at least two health care demands and being followed up in institutions), working professionals (for at least one year in the area of social work, psychology and pedagogical coordination), nurses from PHC units (North, Northeast, South, East and West regions). The exclusion criteria were: being a caregiver for children who only had hearing impairment.

A convenience sample was created and data collection began after scheduling a time through telephone with all professionals in social care, psychology and pedagogical coordinations of the institutions. Based on a list made available by the institutions containing the names of 38 children (under six years old) and the opening hours, the caregivers were approached personally and invited to participate in the study while they waited for their children to be seen. In relation to nurses, the sample consisted of 17 nurses, working in the 11 units mentioned by the caregivers. For this group, prior appointments were made (by telephone), and the interviews took place in the units themselves during consultation breaks. Two nurses refused due to work overload.

Participants were identified using the letters CC (caregiver of CSHCN), HP (health professional) and PI (professional from another institution), followed by interview numbers. The writing of the manuscript was guided by the Consolidated criteria for reporting qualitative research (COREQ). (15)

No prior sample calculation was carried out, as the emphasis was on the quality of the data and the interconnections necessary to understand the object of study. The search was ended when the researcher found the internal logic of the study. (16)

The interviews were carried out in person in private rooms, respecting sanitary measures (physical distancing of 2 meters, ventilated room, use of mask and alcohol gel for hand hygiene), with an average duration of 30 minutes, being recorded in audio and transcribed in full by the first author. The interview began with the guiding question: “How has the care been and the paths taken by families to meet the child's health needs?” A script was followed focused on the first contact with PHC, referrals, quality of listening, reception, guidance given by professionals, completeness of care and continuity of care.

Two pilot interviews were carried out and were disregarded for data analysis. The recording was made available at the end of each interview so that the participant could consent to the content.

Reflective thematic analysis (17,18) was used to understand the participants’ perceptions. First, the transcriptions were read repeatedly to become more familiar with the collected material. A systematic coding was then carried out, with the identification of some patterns in the segments of the collected discourses. Thus, these segments were grouped into horizontal maps. Afterwards, the themes were created and revised for greater clarity and proximity to the adopted framework, (12,13) avoiding passive channels and without context with the participants’ responses. (17,18)

The investigation was approved by the Research Ethics Committee (number 4,300,226) in accordance with the recommendations of Resolution 466/12 (Certificate of Presentation of Ethical Appreciation: 37530620.8.0000.0107).

Results

The research involved 45 participants: 19 family caregivers of CSHCN (14 mothers, three fathers and two grandmothers), Brazilian, aged 22-54; 11 professionals from education, social protection and health institutions, aged 22-67 (five pedagogical coordinators, four social workers and two psychologists); and
15 PHC nurses (11 Family Health Units and four Basic Health Units) aged 22-46 years old. The results emerged from the systematization of data, allowing us to understand the repercussions of the COVID-19 pandemic on the care of CSHCN. Table 1 shows the thematic units, dimensions and codes.

Table 1. Presentation of thematic units, dimensions and codes related to the care and health needs of children with special health needs (CSHCN)

<table>
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<th>Thematic units</th>
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Health needs and fragility of comprehensive care
This theme shows care for CSHCN in the context that the pandemic brought to their daily lives, considering their needs and implications for comprehensive care. During the COVID-19 pandemic, attention to children’s needs was recognized as being fragile, especially regarding prevention and health promotion actions.

“This year, mothers didn’t want to take their children to care because of COVID” (HP7)

“Mothers get in touch by phone because they are afraid to bring their children” (HP6)

Children’s care was highlighted by aspects linked to their development, highlighting the difficulties in their daily lives.

“My son had evolved a lot, but with that thing [mask] on his face all the time, it makes it difficult” (CC7)

“At the beginning of the year everything was wonderful; Then the pandemic came and ended everything; he [son] started having nightmares and laughing at the walls, symptoms he didn’t have before” (CC6)

“We are trying to adapt to the pandemic, but it is not easy. I have to keep her [daughter] at home and we are suffering a lot” (CC3)

Obstacles included sometimes monitoring child growth and development, and sometimes dialogue with family caregivers.

Barriers to achieving health protection and meeting special care needs
This theme expresses the scope of protection for children in the dimension “access to education, social protection and health institutions” given the circumstances of the COVID-19 pandemic. Practices involving exchange of experiences, reception, guidance and resolution of doubts were interrupted. Group activities have been suspended due to physical distancing.

“This year, we did not do any group action due to the pandemic” (PI1)

“There was a support group that addressed different situations and that was positive: they supported each other, but since March the recommendation has been not to form a group” (HP2)
Home visits were also interrupted although there was demand for care.

“The ACS [Community Health Agent] is not making home visits; only active search due to the pandemic” (HP3)

“During the pandemic, we don’t have routine home visits, but we have demand” (HP14)

Considering Brazilian care services for CSHCN who live on the triple border (Brazil-Argentina-Paraguay), the closure of land borders prevented access to children.

“With the border closed, there is no demand for care” (PI3)

“Paraguay was closed, so we had no contact with them [children and families]” (PI2)

The socioeconomic peculiarities of the families were also highlighted by the professionals, highlighting the situation of social vulnerability in which they found themselves.

“During the pandemic, families looked for us more. Even those who had a very good financial condition, they needed social assistance” (PI2)

“During the pandemic, we provided basic food baskets to several families, including those who didn’t need them before” (PI11)

Restrictions on access to health practices and the social support network limited the opportunities to reach health care and meet the special attention needs of CSHCN.

**Discontinuity in monitoring CSHCN**

This theme addresses the institutional context (in the dimension of programmatic actions) and its immediate and longitudinal commitments. The high number of serious cases of COVID-19 infection and hospitalizations led to the implementation of new flows and protocols to reorganize health services. Professionals from primary care units were reallocated to combat COVID-19, leaving the units devoid of human resources.

“We referred to the unit’s pediatrician, who came once a week and cared for high-risk children. But with the pandemic, he stopped answering” (HP9)

“Due to the pandemic, we were limited, with a reduction in the team” (HP15)

This transfer of health professionals to other sectors changed the monitoring of children.

“Now, during the pandemic, they [families of CRIANES] have sought out the Emergency Care Unit (UPA) because it is easier and faster” (HP15)

“Now, I’m taking my son to the UPA” (CC6)

In the management of health services and care institutions, there was a reduction in the supply of care, which already presented difficulties in responding to demands.

“We were supposed to call most of the children who were on the waiting list, but with the pandemic, this delayed a year” (PI2)

“The waiting list is very long; especially now during the pandemic” (CC11)

“Our demand here is very high: we have two doctors due to the pandemic, and the schedule is full for two months” (HP11)

Complementary strategies used to facilitate the flow of care were implemented, but insufficiently.

“At this time of pandemic, we provide telephone support: it’s not much, but it’s still done” (PI2)

Other sectors were also affected, but they sought to provide care for CSHCN.
“Here [philanthropic institution], they organized quickly, and we didn’t have assistance for a short time” (CC3)

“During the pandemic, public funding and donations [to philanthropic institutions] were suspended. In order not to leave anyone without assistance, we took on this responsibility. We serve, but we don’t get paid for the service” (PI5)

Although health institutions have reorganized actions trying to meet the demands presented by CSHCN, these were not enough to ensure continuity of care.

**Discussion**

This study showed that the COVID-19 pandemic, including the restriction measures adopted to contain the spread of the virus, had a negative impact on the health care of CSHCN. The results exposed the weaknesses and insecurity experienced by family caregivers, with individual vulnerabilities due to delayed vaccinations, fear of contagion and changes in child development. Little coverage of child health protection was observed, with institutional vulnerabilities due to restrictions on home visits and waiting lists, including lack of professionals and absence of group activities. The circumstances described also show social vulnerability due to difficulties in social assistance and the closure of land borders. Thus, the repercussions of the COVID-19 pandemic on the health care of CSHCN are expressed as a set of vulnerabilities, including discontinuity in care, low scope of social protection and unstable institutional context.

Actions such as physical distancing and closure of services designated as non-essential deprived children of longitudinal health monitoring, as described in other studies. (9,19) The fear of possible contamination by COVID-19 was also evidenced, causing a reduction in demand for services, both in PHC and specialized care. (4,7,19,20)

The removal of CSHCN from care and health services intensified their vulnerabilities, especially in the individual component, leading them to present behaviors that were different from usual, in agreement with other investigations. (9,21) Maintaining actions to promote and stimulate growth and development could ensure early detection of correctable situations and continuity of care for CSHCN. (22)

The delay in the vaccination schedule, resulting from gaps in longitudinal follow-up, increased the vulnerabilities of CSHCN at the interface between individual and institutional vulnerability. It is worth highlighting the reappearance of serious diseases in Brazil, such as measles, unlike what happened in Portugal, where vaccination was encouraged. (22)

Considering the individual vulnerabilities and behavioral changes observed in CSHCN, our findings were similar to those described in another study carried out in six countries, which showed an increase in hyperactivity and children’s difficulties in controlling their emotions and acquiring new skills during the pandemic. (13)

In terms of social vulnerability, the vulnerable situations of CSHCN families became more evident, being also characterized as economic recession. (4,9,12) The present study also agrees with another research carried out during the pandemic in 35 countries, showing that two-thirds of families with children lost part of their monthly income. (23) The insufficient distribution of emergency aid from the Brazilian government in the face of socioeconomic difficulties differs from that of some countries that took more immediate actions for the less favored population. (23,24)

The interruption in support networks (with little dialogue between families of CSHCN and education, social protection and health services) generated a mismatch between children’s needs and professional support, showing institutional vulnerability. Such dialogue is essential to reduce stress, motivate families and bring hope in the face of difficulties. (25)

The fragility of the link between families of CSHCN and health units led families to seek other services, such as UPA and the private network. In this scenario, the CHA could identify situations of individual and/or collective vulnerability and direct families to appropriate services to meet their needs and health care. (26-28)
As this study was carried out in an international border region, with interdependence related to work, leisure, health and education, the closure of land borders also prevented access for Brazilians residing in neighboring countries, thus characterizing their social vulnerability. These aspects were reflected in the interruption of care for CSHCN, in agreement with a study carried out in the initial phase of the pandemic.\(^{(29)}\)

Furthermore, the increase in hospital demand and the precariousness of structural and managerial resources to overcome a situation of vulnerability of this magnitude led health professionals to intensive services, leaving PHC units devoid of professionals.\(^{(4,6,7,12,20,24,29)}\)

Efforts to maintain continuity and management of health care for people with special needs, such as telehealth, were highlighted in the present study as a strength, as reported in the literature.\(^{(22,30,31)}\)

As a limitation of this study, the interviews with family caregivers in care institutions during specialized care for children stand out, which ended up restricting the interaction time between the participant and the researcher.

This study contributed to better understanding the implications between health measures adopted during the pandemic and the continuity of care for CSHCN. Understanding that CSHCN are more vulnerable in times of health emergencies can help in planning specific actions, ensuring access, continuity of care and coordination with families, thus responding to their special care needs.

To maintain adequate organizations in a public health emergency situation, especially those aimed at more vulnerable groups, with the right to health and social protection, it is essential to strengthen intersectoral actions, with social income and employment policies, maintenance of essential services and scientifically validated information and published in a timely manner.

**Conclusion**

We learned the repercussions of the COVID-19 pandemic on the health care of children with special care needs through the components of individual, social and institutional vulnerability in an international border context. Difficulties in caring for children with special health needs point to individual vulnerabilities (delayed vaccinations, fear of contagion and changes in development), institutional vulnerabilities (absence of group activity, restrictions on home visits, waiting lists and lack of professionals) and social vulnerabilities. (difficulties in social assistance and closure of border crossings). The elements related to the telehealth strategy and the mechanisms that assume professional responsibility showed strength in care.

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**Collaborations**

Casacio GDM, Mello DF, Zilly A e Silva RMM have contributed to the design of the project, analysis and interpretation of data, they also wrote the article, critically reviewed the relevant intellectual content and approved the final version to be published.

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