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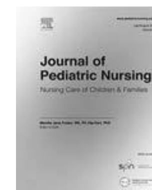
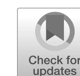


# The experiences of mothers in caring for children with complex health conditions during hospitalization in Brazil: a grounded theory analysis



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A R T I C L E I N F O

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A B S T R A C T

*Purpose:* Children with Complex Health Conditions (CCHC) require prolonged, specialized, and multidisciplinary care, often demanding prolonged hospitalizations. In this context, mothers generally assume the role of primary caregivers, facing emotional, physical and social overload. However, their experiences during hospitalization remain little explored. This study aimed to understand the experiences and needs of mothers caring for CCHC during hospitalization.
*Design and methods:* This qualitative study used an inductive approach based on the Straussian Grounded Theory principles. Data collection took place between September 2024 and March 2025, through individual, in-person, semi-structured interviews, conducted with mothers of CCHC admitted to a Brazilian university hospital. Data analysis followed the constant comparison method, occurring simultaneously with collection, enabling the construction of categories and conceptual refinement.
*Results:* Sixteen mothers aged between 23 and 46 years ($34.75 \pm 7.55$) were recruited. Data analysis generated the core category "Care experiences: balancing between light and shadow" around which three categories are anchored: 1) Dealing with the complexity of the disease and hospitalization; 2) Barriers to care dynamics during hospitalization; and 3) Enablers of care for children with complex health conditions.
*Conclusions:* The analysis of maternal experiences highlights the urgent need for care practices based on family-centered care models that recognize mothers as protagonists in the care process.
*Practice implications:* Findings support the implementation of institutional protocols that ensure effective communication, continuous support and qualification of professionals to promote a welcoming, safe and humanized environment, reducing the emotional and structural vulnerabilities faced by mothers who care for CCHC.

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## List of abbreviations

| | |
|---|---|
| CCHC | Children with Complex Health Conditions |

## Background

Advances in science and medical technologies have been decisive in reducing infant mortality and, consequently, have driven a change in the pediatric healthcare model, which now includes the care of Children with Complex Health Conditions (CCHC), previously overlooked (Cassidy et al., 2023; Muñiz, 2021). This reality has increased the number of CCHC, which constitute a pediatric population characterized by involving "one or more chronic condition(s), regardless of type(s), whose trajectories are dynamic, requiring services across settings and/or sectors, taking into account severity/intensity of conditions and CCHC's developmental age whilst being unique to each child and family's context, often resulting in a lower quality of life" (Azar et al., 2020). These conditions may or may not be associated with specific diagnoses and vary in severity over time, significantly affecting the quality of life of the child and their family (Brenner et al., 2018; Cassidy et al., 2023; Loura et al., 2024).

The diagnosis of CCHC signifies a health-illness transition for children and their parents, indicating a prolonged revolution that results in increased vulnerability. Understanding the attributes of this process

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is crucial for facilitating secure transitions for CCHC and their parents (Loura et al., 2024). Due to the complexity of the conditions affecting these children, hospitalizations tend to be longer and more frequent, which has a significant impact on both children's health and the routine and well-being of their families (Araújo et al., 2020; Souza et al., 2025). Studies show that hospital stays are longer (Mattiello et al., 2022; Mery et al., 2017), hospital costs are higher, and mortality rates are much higher when compared to children without complex conditions (Kuo et al., 2016; Demetriou et al., 2023; Pérez-Ardanaz et al., 2024).

In a retrospective North American study (Bjur et al., 2019), found that over a 15-year period (1999–2014), the adjusted prevalence of CCHC increased from 1200 to 1948 per 100,000 children, and the adjusted incidence increased from 256 to 335 per 100,000 children-years. Additionally, the same study revealed relevant social disparities, where children with a lower socioeconomic level and belonging to ethnic minorities had a higher prevalence of complex conditions.

Given this scenario, improving clinical outcomes while developing strategies to reduce costs has become a global priority for research agendas (Bell et al., 2020; Lacerda et al., 2019; Pérez-Ardanaz et al., 2024). Another significant challenge is hospital ableism, understood as discrimination and exclusion based on the child's disability or health condition, resulting in stigmatization, difficulties in accessing adequate care and lack of support for families (Oslin et al., 2025). This situation is aggravated by the emotional overload of mothers who assume a central role in caring for and defending the rights of their hospitalized children (Chaudhry et al., 2023; Panicker & Ramesh, 2019; Rathee et al., 2019). The impact of this reality is not limited to individual experience but reflects systemic failures in promoting equitable, humanized care centered on the needs of children and their families. In this vein, the theoretical framework based on Anne Casey's (1995) care partnership model is noteworthy, as it proposes the centrality of the family in assisting hospitalized children. According to this approach, mutual respect and dignity, active participation of parents in care, effective communication between staff and family members and co-responsibility for therapeutic planning are essential elements to ensure safe and humanized care (Arabiat et al., 2018; Casey, 1995). The application of this model in CCHC hospitalizations enables the promotion of a more welcoming environment, reducing parental anxiety and strengthening family caregiving skills as well as satisfaction with care (Loureiro et al., 2021; Sheehan et al., 2024; Terp et al., 2021).

Parents often experience stress, anxiety, distress, and worry when their children are hospitalized (Mackay et al., 2025; McLorie et al., 2023). They also report feelings of isolation from their regular community because of the high needs of their hospitalized CCHC (Oulton et al., 2018). Long-distance travel and other conflicting family duties, such as running the household and looking after siblings, were additional sources of parental exhaustion during extended hospital stays (Hagvall et al., 2016). Parents manage stress by relying on supporting connections, deriving meaning, normalizing experiences, sustaining hope, and seeking mental respite (Mackay et al., 2025). If they receive adequate professional support, parents shift from feeling overwhelmed by their child's care responsibilities to confidence in their role as a parent and advocate (Mimmo et al., 2019). Notably, previous studies underscore the significance of negotiating care roles, engaging in shared decision-making, establishing common goals, fostering positive relationships, facilitating effective communication, exchanging knowledge, and of the hospital environment itself (Atout et al., 2017; Dewan et al., 2024; Lin et al., 2020; Madrigal et al., 2012).

While international evidence has already addressed essential tenets of the hospitalization of CCHC, there is still a significant gap regarding the experience of families in this scenario, especially in middle-income countries like Brazil, where the institutional, social, and organizational specificities of care remain poorly explored. Given the increasing prevalence of CCHC, this configures an emerging public health concern in Brazil (Oliveira et al., 2023). Therefore, more studies are needed to investigate maternal experiences and institutional challenges that can contribute to the formulation of more effective and humanized strategies to serve this population (Sahoo et al., 2021; Willis & Godbold, 2023). Expanding the debate on this topic is essential to support practices and policies that guarantee comprehensive and equitable care for CCHC. Therefore, this study aimed to understand the experiences and needs of mothers caring for CCHC during hospitalization. From this perspective, this research seeks to answer the following research question: How do mothers with CCHC perceive and deal with the challenges of care during their children's hospitalization? By creating a space for analyzing mothers' experiences in relation to the hospital stay, this study contributes to the construction of guidelines that favor the humanization of hospital care, and the implementation of best practices based on the care partnership model.

## Materials and methods

### *Study design*

This qualitative study employed a grounded theory approach as theorized by Corbin and Strauss (2014). This is an inductive-deductive method that seeks to understand a given situation within the paradigm of symbolic interactionism (Hewitt et al., 2022), whereby phenomena are constructed and developed through social interactions. This approach is especially useful for studying topic areas that are difficult to access using orthodox (i.e., positivistic) methods. Grounded theory aims to produce substantive theories that are beneficial in clinical practice (Corbin & Strauss, 2008; Corbin & Strauss, 2015), making it appropriate for our study, as this methodology has been underutilized in CCHC research. In parallel, this approach emphasizes the constant interaction of data and analysis, allowing a continuous process of comparison and theoretical refinement that goes beyond superficial description, exploring the mechanisms that give rise to social phenomena (Corbin & Strauss, 2008).

The study followed the recommendations of COREQ checklist (COnsolidated criteria for REporting Qualitative research) (Tong et al., 2007) (Supplementary Table S1).

### *Setting, participants and recruitment*

The study scenario consisted of a pediatric clinic and an intensive care unit (ICU) of a University Hospital in the state of Paraná (Brazil). This institution is accredited by the Brazilian Unified Health System with formal services to treat CCHC and serves 30 municipalities in one of the health regions of Paraná.

To constitute the sample group, a purpose sampling technique was undertaken. The inclusion criteria were (1) being a mother of CCHC aged between 0 and 12 years (because children aged 12 years and older are more inclined and encouraged to assume greater responsibility for their own healthcare); (2) being over 18 years of age; (3) being the primary caregiver of the child during hospitalization; and (4) understanding and speaking Portuguese. Mothers who were not primary caregivers and who lacked the capacity to participate in the study were excluded.

Mothers of different ages, marital statuses, with one or more children, and with different care trajectories were recruited to maximize the diversity of experiences. The total number of participants was not defined previously but determined throughout the study using deliberate and theoretical sampling. Thus, the first twelve participants were chosen using the purposive sampling method. The initial analysis of these interviews revealed categories related to maternal experiences during hospitalization, especially regarding interactions with the healthcare team, decision-making about care, and coping strategies adopted in the institutional context. Based on these analytical categories, the continuation of data collection was guided by the analytical process (Corbin & Strauss, 2015), directing the inclusion of new participants whose care trajectories and family contexts allowed for a deeper

understanding and refinement of these categories. Subsequently, four additional mothers were incorporated through theoretical sampling (totaling sixteen mothers with CCHC), achieving theoretical saturation through conceptual densification (Rahimi & Khatooni, 2024).

*Data collection*

Data collection took place between September 2024 and March 2025. The nurse manager of each pediatric ward assisted in finding eligible mothers with pertinent study information and brokering trust between participants and researchers. Interested participants received a letter with instructions on how participants could contact the research team. After approaching the study team, mothers were contacted and filled the consent form, and an interview was scheduled. In-depth, semi-structured, face-to-face interviews were conducted, lasting an average of 45 min (ranging from 30 to 60 min), and took place in a hospital office prepared for this purpose. A welcoming environment was created, conducive to dialogue and emotional expression. All interviews were conducted by a white female registered nurse (CH) with experience in the prevention, rehabilitation, and treatment of children with complex needs, who underwent interview training and was unfamiliar with the participants before the study.

A semi-structured interview topic guide was constructed by two researchers (Supplementary Table S2), based on their professional experiences and available evidence (Baker & Claridge, 2022). It includes the following topics: views on met and unmet needs regarding the received care, communication with the healthcare team, information and support obtained, care partnership and team preparation. A pilot interview was conducted with two mothers with CCHC, leading to minor adjustments and allowing for the incorporation of the pilot interview data.

A guiding question opened the interview: "What is your experience of hospitalization with your child?". Subsequent questions emerged from the insights gained during the preliminary interviews and the developing conceptual framework. The interviewer engaged attentively and posed pertinent follow-up and probing questions as appropriate (e.g. Can you provide examples?; Please, tell me more about this issue; How do you deal with it?; What do you feel?). The participants were encouraged to express their experiences and impressions candidly.

As the interviews progressed, the questions were modified to improve clarity and understanding of the phenomenon under study. In accordance with grounded theory recommendations, field notes were collected at different stages of the interviews – before, during and after they were conducted – and memos with the researcher's reflections were developed to support the analysis and development of the study (Corbin & Strauss, 2008; Chun Tie et al., 2019). To minimize response biases and increase rapport with participants, communication techniques were used (such as open questions, reformulation, synthesis, active listening, non-judgmental attitude and use of silences) so that participants could express themselves genuinely. All interviews were audio-recorded and transcribed in full in the order in which they were conducted, and alphanumeric codes were assigned (M1-M16).

*Data analysis*

The data analysis comprised three phases: open, axial, and selective coding, as delineated by Corbin and Strauss (2015). In practice, these were largely interconnected. A concomitant data collection and analysis favored the continuous formulation of concepts and the deepening of ideas throughout the process. Initially, open coding was performed, and the analysis was done incident by incident, with preliminary codes being assigned individually. As the process progressed, these substantive codes were compared to identify similarities and differences, which enabled the creation of conceptual codes. Axial coding was carried out at the same time as open coding, with the purpose of reorganizing the initially fragmented data, and establishing relationships between categories and subcategories to obtain a more precise and comprehensive understanding of the phenomenon studied. Finally, selective coding was performed by organizing the categories around a central explanatory concept that constituted the link between the categories and revealed the essence and magnitude of the experience (Strauss & Corbin, 2015). Coding was induced and led by one researcher (CH) with frequent discussions with the research team (peer questioning) to optimize reliability. Given the qualitative design of the study, no inferential statistical analyses were performed for analytical or comparative purposes. The quantitative data presented were exclusively descriptive, with the intention of characterizing the sample.

MaxQDA® software (version 24.7.0) was used to organize and explore qualitative data, especially in the initial and more targeted stages of coding.

*Study rigor*

The grounded theory approach of Corbin and Strauss (2014) ensures methodological rigor by using criteria that promote reliability, validity and quality of research. One of the main criteria is adherence to the data, which requires that the theoretical categories be deeply anchored in the information collected, thereby ensuring that the emerging theory faithfully represents the phenomenon investigated. The constant comparison technique is also essential, as it ensures consistency and logic in the analysis by continually comparing new data with already established categories, thereby contributing to the study's internal validity. Theoretical saturation, in turn, is achieved when there is no new information relevant to the categories under development emerges, indicating that the theory is sufficiently comprehensive (Hall & Callery, 2011; Saunders et al., 2018). Furthermore, auditability is guaranteed by the detailed documentation of the entire research process, allowing understanding and possible replication by other researchers. Finally, the researcher's reflexivity is considered fundamental, as it involves the recognition and critical consideration of theoretical and personal influences throughout the analysis, thus reducing biases and strengthening the credibility of the study (Cooney, 2011; Rahimi & Khatooni, 2024). The first author (CH) was a nursing student at the time of data collection and with prior experience with CCHC. The second author (CL) is a nursing faculty member with extensive experience in guiding and developing grounded theory studies. He supervised all stages of the research process. ALL is a female registered nurse who works on mental health issues in childhood. She has also accompanied parents of ill children and recently began to work with qualitative methods. The other three authors (IH; AEJ and MP) are associate professors in nursing with prior experience in conducting qualitative studies and analyzing qualitative data. Throughout the research process, authors discussed how their biases, assumptions, and identities might influence their interpretations of the findings (researcher triangulation).

*Ethics*

The study was approved by the Research Ethics Committee of the State University of Maringá (UEM), under approval number 6.041.704, and followed all the guidelines of the Declaration of Helsinki. Participants signed an informed consent form prior to the interviews, authorizing audio recording, and were informed that they could leave the study at any time. All participants also consented to the use of anonymized excerpts from their testimonies for scientific publication purposes. To preserve the identity of the participants, an alphanumeric code was used, according to the order of the interview (M1; M2;…). The audio files and transcripts were stored in a secure, password-protected digital environment with access restricted to the researchers involved in the study, ensuring the confidentiality and integrity of the data. Participants received no financial incentive for participation. Psychological support was also provided to address possible discomfort during the interviews or if requested by the participants.

## Results

*Participants background*

The sample consisted of 16 mothers with CCHC, aged between 23 and 46 years (34,75 ± 7,55), mostly non-white, single and unemployed. Occupations varied between self-employed, housewives and formal workers. The children have different diagnoses, such as genetic syndromes, neurological disorders, metabolic diseases and congenital malformations. The number of hospitalizations during the last year ranged from 2 to 15, with hospitalization periods ranging from one week to continuous hospitalization since childbirth. A sample description is provided in Table 1 to support contextualization of findings rather than comparison or generalization.

*Findings from interviews*

Based on the analysis of interviews a core category was generated, "Care experiences: balancing between light and shadow", around which three categories are anchored: 1) Dealing with the complexity of the disease and hospitalization; 2) Barriers to care dynamics during hospitalization; and 3) Enablers of care for children with complex health conditions. The overarching categories were divided into nine subcategories displayed in Fig. 1.

*Dealing with the complexity of the disease and hospitalization*

The narratives highlight the mothers' emotional and psychological experiences, including the prolonged impact of the disease, the burden generated by hospitalization, and the coping strategies adopted to deal with the challenges of care.

a) Experiences of suffering and vulnerability.

CCHC mothers experience permanent suffering, characterized by emotional fatigue, isolation, fear and a feeling of helplessness when facing the worsening clinical condition of their children and the exhausting hospital routine. When hospitalization becomes part of the participants' daily lives, it creates a rupture with family life outside the hospital.

> "(…) raising a child is already difficult, even more so a child with special needs, he is a part of me, so it hurts when a mother sees the child she loves sick. It hurts a lot when we see our child suffering and we can't do anything. There comes a time when we get nervous, angry and that is really damaging." (M2).

> "I try to be strong, because I know they depend on me, but there are days when it is very difficult. There are days when everything seems too heavy, but then I remember that I can't give up." (M14).

> "At first, I was afraid of losing her (daughter), then came the fear of not knowing how to take care of her. She was an active child and from one day to the next she became bedridden. She doesn't answer anything. My fear was not knowing how to recognize when she needed help." (M4).

> "Well, it's difficult because I have to leave the rest of the family at home, and stay with him (son) here. He always feels pain when he is hospitalized, because the nurses puncture him a lot, and it is not easy." (M11).

b) Prolonged impact of illness and hospitalization.

Frequent and prolonged hospitalizations generate a cycle of exhaustion that goes beyond physical fatigue. For many mothers, the hospital becomes an extension of their home, and the routine of care puts their mental health at risk. The experience of the child's illness leaves psychological scars on mothers that worsen over time.

> "At the time, when they said it, I felt really bad. Then one hospitalization followed another. I've lost count of how many times he (son) has been hospitalized, there have been several. I just cried, until I had to have sessions with a psychologist and take medicine." (M11).

> "My son was hospitalized his entire life […] he was intubated in the ICU for a long time and went through so many difficulties. He was discharged and came to pediatrics, but because he got worse he had to go back to the ICU." (M8).

*Barriers to care dynamics during hospitalization*

The findings highlight a set of barriers in interactions between mothers and the healthcare team, highlighting the lack of support and feelings of abandonment, difficulties in communication and challenges in building bonds.

a) Lack of support and feeling of abandonment.

Some participants highlighted the difficulties arising from the lack of professional support and the overload associated with care. Often, preparation for discharge and the subsequent return home generate insecurity and determine the need to seek knowledge by one's own initiative, often without adequate support.

> "Next week, he (son) goes home. I have been doing everything on my own to learn and prepare to go home safely, because the team doesn't talk about it much and I still feel afraid to do some things." (M6).

**Table 1**
Sociodemographic characterization of mothers and clinical conditions of children.

| Mothers | Age | Race/Color | Marital Status | Professional Status | Child Diagnosis | Number of Hospitalizations in the last year | Time of hospitalization |
|---|---|---|---|---|---|---|---|
| M1 | 26 | Non-white | Married | Employed | Nemaline myopathy type 2 | 10 | 20 days |
| M2 | 38 | Non-white | Single | Unemployed | Phenylketonuria and Severe Intellectual Disability | 4 | 30 days |
| M3 | 46 | Non-white | Divorced | Employed | ADHD, Bipolar Disorder and Epilepsy | 5 | 10 days |
| M4 | 29 | White | Single | Unemployed | Epilepsy and Down Syndrome | 3 | 52 days |
| M5 | 46 | Non-white | Single | Unemployed | Down Syndrome | 2 | 7 days |
| M6 | 34 | Non-white | Married | Unemployed | Congenital hypothyroidism and Noonan syndrome | 11 | 7 months |
| M7 | 41 | White | Single | Unemployed | Rasmussen syndrome | 6 | 15 days |
| M8 | 44 | Non-white | Married | Unemployed | Congenital heart disease; Fryns syndrome; Congenital Cataract. | Hospitalized since birth | 1 year and 10 months |
| M9 | 34 | Non-white | Married | Employed | Sickle Cell Anemia | 3 | 16 days |
| M10 | 24 | Non-white | Single | Unemployed | Hemophilia and Congenital Cerebral Malformation | 8 | 15 days |
| M11 | 32 | Non-white | Married | Unemployed | Cornelia de Lange syndrome | 11 | 20 days |
| M12 | 23 | Non-white | Married | Employed | Congenital heart disease | 3 | 30 days |
| M13 | 29 | Non-white | Single | Unemployed | Severe Epilepsy | 3 | 9 days |
| M14 | 42 | Non-white | Married | Unemployed | Congenital heart disease and Down syndrome | 3 | 11 days |
| M15 | 36 | White | Married | Unemployed | Down syndrome | 2 | 27 days |
| M16 | 32 | White | Single | Unemployed | Duchenne muscular dystrophy | 15 | 2 months |

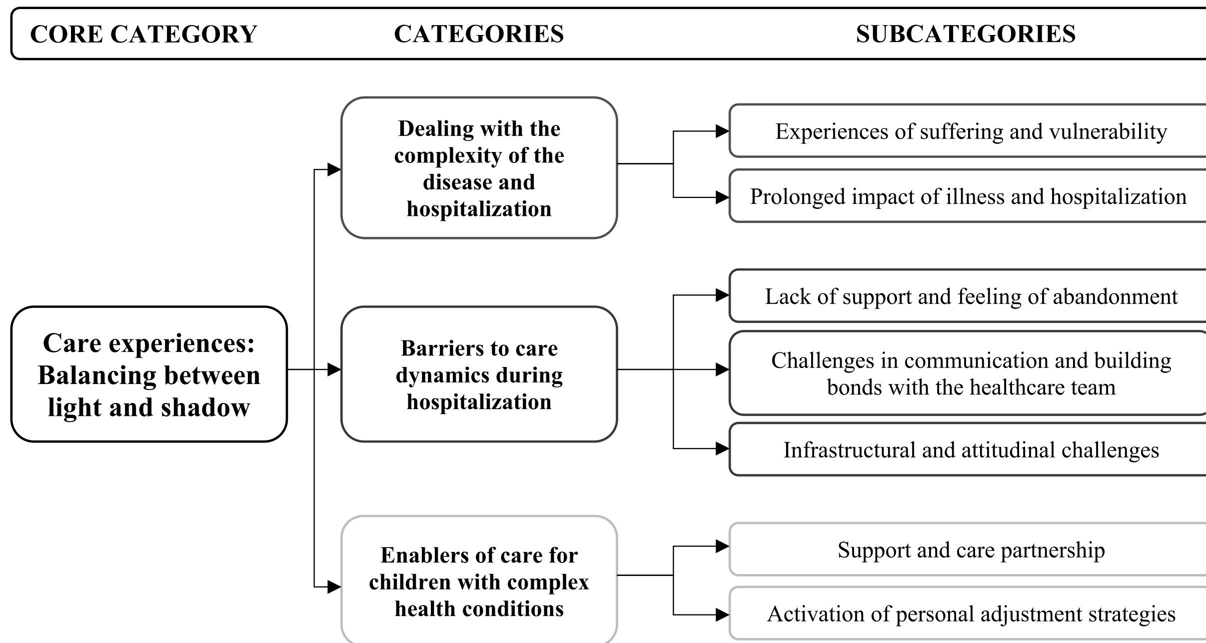


**Fig. 1.** The core category, four categories and related subcategories.

"I learned everything on my own, by googling, watching videos. Sometimes the hospital gives instructions on how to do it, how to perform the aspiration, but I prefer not to risk doing it myself, I'm afraid of doing it wrong and making the situation worse. It scares me to think that the responsibility is all mine, but I can't afford to make mistakes, so I study, ask questions and do my best for when we get back home." (M5).

"If I'm not careful at home and she (daughter) turns over, the gastrostomy tube could come out. I was afraid of leaving the hospital, because I wasn't sure what to do." (M4).

Furthermore, some mothers reported discrepancies in the quality of care between different teams, which generates ambivalence and frustration. The variation in the level of care provided at different times of the day negatively impacts one's experience during hospitalization. One of the challenges highlighted was the lack of continuity in the exchange of information between professionals, which contributes to emotional overload.

"My daughter is very sensitive to noise. I have to keep alerting the professionals, because they don't pass on the information to each other. It's exhausting having to talk every time, because I end up being the annoying mother." (M12).

"The daytime staff are easygoing, super good, but the nighttime staff are a little more difficult. We call and they don't come, you call two, three, four times and then they come to see what's going on." (M3).

"It is important for us to feel that we are being well taken care of, as the situation is already quite stressful and difficult. I had problems mainly at night, when the number of professionals is smaller, because when we call, it takes a long time to be seen, and some nurses do not give the necessary attention and this makes me feel insecure, mainly because we know that, at night, because there are fewer people available, the risk is greater." (M13).

b) Challenges in communication and building bonds with the healthcare team.

The difficulty in accessing information about the health status of children was also an obstacle to the active participation of mothers who are caregivers. The lack of transparency and the reactive nature of communication require constant effort by participants to obtain information, contributing to feelings of exclusion in the care process.

"I think it's very important that we don't stay locked in the room without knowing what's going on, what they're talking about her (daughter). We have to keep asking all the time and that's annoying." (M2).

"I know I can trust the team, but I like to be informed so I know what to do if needed. So, I'm not ashamed to ask questions, to clear up doubts, but doctors don't see me in time." (M5).

"So they said that she could have been stillborn, that she would last a few hours or days and they ended the speech with that and every time it was like that, I arrived in the room and they said the same thing." (M10).

The perception of neglect and devaluation of the mother's role as a caregiver directly impacts the relationship with the healthcare team.

"Sometimes they treat us with disdain, and if we don't demand it, we don't receive care." (M2).

"It seems like we are asking for a favor, I even left there crying, feeling humiliated." (M10).

"There are times when they don't listen to what we say, it seems like they don't believe what we're saying. For example, he was on oxygen at home, but the nurse didn't want to put it on." (M1).

"[…] It is frustrating when professionals do not realize that parents know their children and know when something is not right." (M16).

c) Infrastructural and attitudinal challenges.

There are several situations in which participants consider that the individuality of CCHC is threatened, whether for structural and/or attitudinal reasons. Barriers such as the lack of individual rooms or the lack of televisions in rooms to provide distraction and comfort to children during prolonged hospitalizations were highlighted.

> "I just think they could have a TV in the rooms. Sometimes they get bored, and a TV would help distract them, it would make them calmer." (M1).

> "I think he should have a room just for him, because he can't eat right now… and having to be around children who don't have dietary restrictions makes him a bit anxious." (M12).

In addition to the physical structure, the reports reveal experiences marked by a lack of acceptance and judgmental and discriminatory attitudes, bordering on a prejudiced and ableist view.

> "It's different because he should receive the same care as the others […] professionals should be more capable and efficient in their service." (M11).

> "[…] people who do not work in the health sector sometimes have a devaluing attitude." (M6).

> "It was always very annoying […] sometimes they said things and didn't care about how I felt […] and I looked at my daughter and thought that at any moment she could stop breathing." (M5).

The mothers' reports reveal a certain lack of technical and relational preparation of the nursing team, which generates insecurity, emotional exhaustion and a feeling of helplessness. Thus, the participants reinforce the need for healthcare institutions to invest in the continuous qualification of teams, not only in the technical domain, but also in the dimensions of communication, empathy and respect for families, essential elements for humanized and person-centered care.

> "It is also difficult when professionals treat us coldly or ignore our concerns, we feel helpless. We need them to be patient and willing to explain things as many times as necessary because I am not a healthcare professional, but I am there 24 hours a day taking care of my son." (M11).

> "What I find most tiring, even before I get to the room, is thinking about who I'm going to have to deal with." (M6).

> "We had bad situations in my old city, it was the lack of knowledge of the professionals." (M9).

> "I think training could be provided for professionals." (M15).

*Enablers of care for children with complex health conditions*

The findings highlight a set of facilitators, including support and care partnership and the activation of personal adjustment strategies to deal with the complexity of the disease.

a) Support and care partnership.

The shared care experience reflects both the support offered by professionals and the active participation of mothers in the care process. Interaction with the nursing team stands out as a catalyst capable of strengthening the feeling of trust and security. The mothers' involvement in daily care is facilitated by clear communication from professionals, who provide information about procedures and treatments.

> "Nurses always explain everything. I ask about the medicines, what they are for, how they work, and they always answer. I like to understand what is happening, what they are doing to him, because that gives me security." (M5).

> "Here I feel like they really care about my son. They reassure me, give me information and I feel like I am participating in his recovery, and that is very important to me." (M15).

The support offered by the team is essential for mothers to adapt to the care routine, with learning occurring both through clarifying doubts and through observing professional practices.

> "I believe that the choice to always take care of him is mine. In the ICU, I had all the support, training from the staff and everything. I spent many months there, and they told me to rest. But, I stayed there the entire time, and when someone came, I would spend the weekend at home to try to get some sleep. It was more than seven months, and they always gave me support. Here in pediatrics, we are going through a process of returning home." (M12).

> "At first, it was very difficult to accept the difficult news and using the aspirator with my son for the first time. The nurse was very attentive and helped me overcome my fear. After I got it, everything became easier." (M1).

Finally, the care partnership strengthens the bond and the perception of belonging to the care process, even under the guidance of professionals. However, this participation is not always fully assumed, either for fear of disrupting the team's work or due to insecurity regarding technical practices.

> "Like, we help each other. They were the ones who gave the bath in the ICU. Then he came to pediatrics, and I started to be the one who gave him baths. But the employees came to make the bed, leave everything ready." (M8).

> "I feel part of the care, I feel that they listen to me and that helps me trust them." (M5).

> "I stay close by, watching everything, and help when I can, but I know it's better to let them do their job properly. We end up working together, each one doing their part." (M3).

> "(…) most of the time I prefer to let the nurse take care of him, because I don't want to get in the way of their work. They always ask me if I want to help, like giving him a bath, and I even like it, but I think they know what they are doing and I don't want to bother them." (M12).

> "I also do the inhalation when he needs it, but I don't know how to do the aspiration, I'm afraid of hurting him, so I leave it to the nurse." (M5).

To reinforce the culture of partnership in care, some mothers point out the need for support groups that encourage contact with other mothers in similar situations, highlighting the therapeutic potential of sharing experiences.

> "I think that this part of the pediatrics department down here could have, I don't know, a meeting […] for mothers with hospitalized children. Like: Today, at such and such a time, we'll have a meeting there. If you want to go there and share your experience here, let off some steam." (M14).

> "A mother listens to another's story […] there are times when we think we are suffering, but there is someone who is suffering more […] I think that would be interesting." (M5).

b) Activation of personal adjustment strategies.

Although the chronic nature of the disease weakens the psychological state of mothers, they develop coping strategies that allow them to reframe the experience. Faith emerges as a source of emotional support, functioning as a coping strategy to maintain hope in the face of adversity.

"God gives strength. I believe in God a lot, and that is what sustains me. There are days when I just want to cry, but then I remember that I need to be strong for him and for my other children." (M16).

"My daily struggle, but we move forward with faith. I always try to think positively, I know that everything has a purpose and that God is taking care of everything." (M7).

"Before, I felt very sad, I cried every day, and after praying a lot and asking God to perform a miracle, he answered me because he managed to get better." (M9).

Another strategy involves reorganizing the domestic routine and the physical space of the house to facilitate ongoing care. However, more than logistical adaptations, the emphasis was on changes in life and time management capable of responding to the priority needs of CCHC. At this point, M13 mentioned: "At home, each space was adapted to facilitate care. But the biggest change was in my life, in my time, which is now all focused on him."

## Discussion

To the best of our knowledge, this is one of the first Brazilian qualitative studies to explore the maternal experience in caring for CCHC during hospitalization. Only mothers were included in the study, considering their central role as main caregivers, especially with CCHC (Difazio et al., 2023; Willis & Godbold, 2023; Van de Riet et al., 2023). The findings highlight that the care process is permeated by feelings of insecurity, emotional overload and structural barriers, reflecting the challenges faced by mothers in constructing care that is effectively shared, informed and sensitive to their realities. This approach presupposes the recognition of mothers as an essential part of the therapeutic process and must incorporate practices that favor their active and continuous involvement (Cohn et al., 2020; Haspels et al., 2023; Murdoch & Chang, 2022; Oulton et al., 2024; Ronan et al., 2020). According to a recent study (Chow et al., 2024), family-centered interventions for CCHC have greater impact when they are based on clear communication, active participation of caregivers and facilitated access to services. This is fundamental to promoting more positive and effective care experiences.

In line with the literature, the transition from hospital to home in CCHC care is described as a time of high vulnerability, both for children and their families. Parents and caregivers often report feelings of insecurity, anxiety, and emotional overload when faced with the responsibility of taking on complex care at home, often without adequate preparation and support (Haspels et al., 2023; Ronan et al., 2020). The absence of structured discharge plans, failures in communication between services and the shortage of trained professionals in home care compromise the continuity of care and increase the risk of readmissions (Breneol et al., 2017; Ronan et al., 2020). The feeling of emotional overload due to the full responsibility for care after hospital discharge highlights the importance of care models that include discharge planning and ongoing education for caregivers. It is essential for healthcare professionals to design holistic, family-centered interventions to reduce this burden (Shattnawi et al., 2023). Another highlighted point was the inconsistency in communication between health professionals, which has a direct impact on the confidence and well-being of mothers. This fragmentation of care is discussed in the literature, especially in highly complex contexts, where coordination of the multidisciplinary team is essential to reduce failures and promote safety (Müller et al., 2018; Raeisi et al., 2019).

The experience of ableism was reported through attitudes of contempt, judgment and denial of maternal knowledge. Recent studies demonstrate that ableism in hospital contexts directly affects the quality of care and the relationship between professionals and family members, especially in the case of CCHC (Oslin et al., 2025). Such experiences not only generate suffering but also impact the quality of shared care.

The mothers' narratives also reported chronic emotional suffering, which intensifies with recurrent hospitalizations and the unpredictability of clinical conditions. The literature indicates that caregivers of CCHCs are at greater risk of physical and mental exhaustion, especially when they do not have adequate institutional support (Bjur et al., 2019). Given this scenario, the hospital ceases to be a transitory space and begins to be experienced as an extension of the home, which poses challenges to the emotional health of caring mothers (Cioga et al., 2025).

Despite the numerous challenges faced in caring for CCHCs, mothers demonstrated that they developed personal coping strategies that helped them adapt to the hospital routine and long-term care. Among these strategies are the use of hope and spirituality, the reorganization of daily activities and the search for social support among peers (Laranjeira & Querido, 2022; Laranjeira & Querido, 2023). Such resources are fundamental for managing stress and emotional overload: religious coping, family support and emotional self-management recognized are key elements in reducing the psychological impact on mothers of children with special needs (Asa et al., 2021; Wang et al., 2023). When faced with high-stress situations, mothers may activate support networks as predominant coping strategies (Alós et al., 2022; Cioga et al., 2024). However, the absence of institutional spaces for listening and sharing still represents an important gap, revealing the unpreparedness of humanization policies to fully embrace the emotional dimensions of care.

### *Strengths and limitations*

The study's strengths include the analytical depth guaranteed by rigorous coding, adherence to data and the use of rigor, such as theoretical saturation, auditability and reflexivity. Conducting interviews was essential to understanding the mothers' experiences of CCHC, although the fact that coding was conducted by a single researcher may have introduced some bias. To minimize this risk, the team adopted a rigorous methodological approach, with ongoing discussions about interpretations and possible prior assumptions about the topic. The option to exclusively recruit participants from a specific location was made for practical reasons, but this decision limits the transferability of the findings to different cultural and geographical contexts. Still, the reported experiences may reflect similar realities in other regions of the country. Furthermore, there is a lack of information regarding additional events that may affect responses, such as the childhood stage of the illness trajectory, prior caregiving interactions, or varying family dynamics. The participants in this study shared similar sociodemographic characteristics, which may not represent the full diversity of experiences of caregiver mothers, and thus may be perceived as limiting the generalizability of interpretations. In this vein, additional investigation should recruit mothers based on CCHC age and maternal age to enhance the theory's robustness and applicability. Further studies should also investigate the perspective of male parents, which remains underrepresented and, in some ways, is different and contrasts with the female perspective. Future research should also consider variables such as support network and degree of dependence of the child, factors that directly influence the ability to care. Lastly, future study should incorporate the perspectives of children and healthcare professionals to enhance comprehensiveness. Despite these limitations, this study provides valuable insights about the experiences and needs of mothers caring for CCHC during hospitalization.

### *Implications for practice*

Considering the essential role that mothers play in CCHC care during hospitalization, it is necessary to strengthen institutional practices that promote their active inclusion in the care process. The partnership with the healthcare team should be encouraged not only as a humanization strategy, but also as a central component of safety and continuity of

care. The creation of institutional protocols based on co-responsibility, clear communication and active listening can contribute to reducing maternal emotional overload and improving the hospitalization experience.

Furthermore, the research revealed flaws in professional qualifications and episodes of dehumanization and ableism in the hospital environment, which reinforces the need for continued training of health professionals, especially those working in pediatrics and in long-term care settings. Training must go beyond technique, including content on empathic communication, family diversity and the rights of people with disabilities (Collet et al., 2022; Marjadi et al., 2023; Wilkinson et al., 2021). Creating formal spaces for emotional support for mothers during hospitalization that encourage the sharing of experiences and the strengthening of the support network, such as conversation circles and therapeutic groups, is also recommended (Bird et al., 2022).

Another important measure concerns the hospital structure and the organization of services, which must consider the specific needs of the CCHC. The inclusion of simple resources, such as televisions in bedrooms or adapted play areas, can improve children's well-being and reduce mothers' stress (Samal et al., 2021). Furthermore, hospitals must review care practices that reinforce inequalities and should ensure, for example, respect for priority and differentiated care according to the child's clinical condition.

Finally, the adoption of technological and telehealth strategies can represent an advance in supporting families, both during hospitalization and in the discharge process. Telehealth can be used to reinforce mothers' training in complex care, provide remote psychological support, and keep referral staff accessible after hospital discharge (Brenner et al., 2015). However, for this to be effective, it is necessary to consider inequalities in digital access and promote inclusion and technological literacy actions aimed at caregivers, as already indicated in other research in the area (Pope et al., 2025; Van Cleave et al., 2022). Future research should explore how the use of technologies can improve mothers' preparedness and positively impact their quality of life and emotional well-being during and after hospitalization.

## Conclusions

The findings provide a context-specific theoretical understanding of mothers' experiences of CCHC during hospitalization, structured around the central category “Care experiences: balancing between light and shadow”. Participating mothers reported intensive experiences marked by emotional distress, caregiving overload, and feelings of vulnerability, which intensify in the face of the continuous demands imposed by the child's health condition. Barriers to the dynamics of care emerged significantly in the maternal accounts, especially those related to communication failures with the health team, lack of institutional support, ableist practices, and difficulties in building bonds. These barriers weaken interactions between mothers and professionals, intensify feelings of abandonment and insecurity, and limit the effectiveness of family-centered care in the hospital setting. On the other hand, mothers highlighted the importance of active listening, acceptance, recognition of their knowledge, and partnership with healthcare professionals as facilitators of care, capable of strengthening relationships, reducing insecurity, and promoting more positive experiences during hospitalization. The presence of these facilitators proved fundamental in mitigating the impacts of the disease complexity and promoting more shared and humanized care. Aligned with Casey's Model of Nursing, the findings reinforce that family-centered practices, with qualified teams that are sensitive to the specificities of caring for CCHC, are essential to ensure more integrated, safe and shared care. These findings provide valuable support for the reformulation of institutional policies and practices aimed at humanizing pediatric hospital care. Lastly, and because current indicators frequently neglect the holistic, family-centered, and developmental dimensions critical to CCHC care, it is imperative to establish a comprehensive and standardized set of nursing-sensitive indicators that address their particular needs.

## Human ethics and consent to participate

The study was approved by the Research Ethics Committee of the State University of Maringá (UEM), under approval number 6.041.704, following all the guidelines of the Declaration of Helsinki. Written informed consent to participate was obtained from the parents or legal guardians of people who are under 16 years of age.

## Declaration of generative AI use

No Generative AI was used in the preparation of this manuscript.

## CRediT authorship contribution statement

**Camila Harmuch:** Writing – review & editing, Writing – original draft, Validation, Software, Resources, Project administration, Investigation, Formal analysis, Data curation, Conceptualization. **Carlos Laranjeira:** Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Software, Resources, Project administration, Methodology, Funding acquisition, Conceptualization. **Ana Luísa Serrano Lima:** Resources, Methodology, Investigation, Data curation, Conceptualization. **Ieda Harumi Higarashi:** Visualization, Methodology, Investigation. **André Estevam Jaques:** Visualization, Methodology, Investigation. **Marcelle Paiano:** Writing – review & editing, Writing – original draft, Visualization, Supervision, Project administration, Methodology, Conceptualization.

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## Declaration of competing interest

The authors declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.pedn.2026.03.014.

## Data availability

The raw data supporting the conclusions of this article will be made available by the authors upon request.

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