

RESEARCH ARTICLE (ORIGINAL) 8

Situations of vulnerability experienced by family members during the hospitalization of chronically ill children

Situações de vulnerabilidade vivenciadas por familiares na hospitalização de crianças com condição crónica

Situaciones de vulnerabilidad vividas por los familiares en la hospitalización de niños con enfermedades crónicas

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Abstract

Background: Vulnerability is classified as a triad consisting of individual, social and programmatic elements.

Objective: To understand the situations of individual, social, and programmatic vulnerabilities experienced by family members during the hospitalization of their chronically ill children.

Methodology: This is a qualitative research study using thematic analysis and conducted with ten family members of hospitalized chronically ill children. Data were collected between June and August 2018 through simple observation, semi-structured interviews, and a field diary.

Results: This study identified family members' caregiver burden as the individual vulnerability, family members' accommodations as the social vulnerability, and the geographic distance between families' homes and the hospital as the programmatic vulnerability. Health care services and health professionals' care delivery were identified as conditions minimizing vulnerabilities.

Conclusion: Understanding the situations of vulnerability experienced by families allows implementing more inclusive and efficient care strategies to expand access to health services and professionals, respond to families' needs, encourage family participation, and create support networks.

Keywords: child; chronic disease; family; pediatric nursing; health vulnerability

Resumo

Enquadramento: A vulnerabilidade é classificada como uma tríade de elementos individual, social e programático.

Objetivo: Conhecer situações de vulnerabilidade individual, social e programática vivenciadas por familiares durante a hospitalização de crianças com condição crónica.

Metodologia: Pesquisa qualitativa desenvolvida com 10 familiares de crianças com condição crónica que estiveram hospitalizadas, utilizando-se análise temática. As informações foram colhidas de junho a agosto de 2018, por meio de observação simples, entrevista semiestruturada e diário de campo.

Resultados: Identificou-se como vulnerabilidades individual, a sobrecarga do familiar; social, a acomodação dos familiares; e programática, a distância geográfica de seu domicílio do hospital. Como condições que minimizaram as vulnerabilidades evidenciou-se o atendimento dos serviços de saúde e os cuidados que receberam dos profissionais.

Conclusão: Conhecer as situações de vulnerabilidade vivenciadas pelas famílias possibilita implementar estratégias de cuidado mais inclusivas e efetivas, visando ampliar o acesso aos serviços de saúde e aos profissionais, oferecer acolhimento às necessidades e incentivar a participação da família e a criação de redes de apoio.

Palavras-chave: criança; doença crónica; família; enfermagem pediátrica; vulnerabilidade em saúde

Resumen

Marco contextual: La vulnerabilidad se clasifica como una tríada de elementos individuales, sociales y programáticos.

Objetivo: Conocer las situaciones de vulnerabilidad individual, social y programática que viven los familiares durante la hospitalización de los niños con enfermedades crónicas.

Metodología: Investigación cualitativa desarrollada con 10 familiares de niños con enfermedades crónicas que estuvieron hospitalizados, para lo cual se utilizó el análisis temático. La información se recopiló de junio a agosto de 2018, a través de la observación simple, la entrevista semiestructurada y el diario de campo.

Resultados: La vulnerabilidad individual se identificó como la sobrecarga del familiar; la vulnerabilidad social como el alojamiento de los familiares, y la vulnerabilidad programática como la distancia geográfica del hogar al hospital. Como condiciones que minimizaron las vulnerabilidades, se constataron los servicios sanitarios y la atención recibida por parte de los profesionales.

Conclusión: Conocer las situaciones de vulnerabilidad que viven las familias permite poner en marcha estrategias de atención más inclusivas y eficaces, con el fin de aumentar el acceso a los servicios y a los profesionales sanitarios, satisfacer las necesidades y fomentar la participación de las familias y la creación de redes de apoyo.

Palabras clave: niño; enfermedad crónica; familia; enfermería pediátrica; vulnerabilidad en salud



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Introduction

Experiencing a child's illness is a complex process, with a more significant impact when associated with a chronic condition. Living with a chronic illness demands constant care and (sometimes) recurrent hospitalizations. This arouses multiple feelings in the children and their families, who need to (re)organize themselves to provide care. Becoming ill during childhood is not expected, as this period is usually a phase of growth and development (Lise et al., 2019). Thus, families need to manage illness as something new and different. Chronically ill children are in the group of children with special health care needs (CSHCN). CSHCN present combined or isolated, multiple, complex, and continuous care demands, and family members are responsible for delivering care at home (Dias et al., 2017).

Becoming ill and living with a chronic condition causes biological changes in individuals and alters their affective and relational world, primarily impacting their interiority and how they see and are in the world. Looking at the illness process from this existential perspective is to overcome the biomedical perspective and understand that becoming ill during childhood causes existential changes in the children and people who have an emotional relationship with them. To be a child and to experience illness is to go against the expected normativity of the social role of childhood. It is to see little human beings experiencing the ontological vulnerability of their existence and having the possibilities of their human accomplishments limited and their freedom restricted (Roselló, 2009).

The existential facticity of a child's illness can make them and their family experience the anguish of understanding themselves as finite and, thus, vulnerable. From this perspective, it is during illness that individuals become aware of their vulnerability and develop forms of protection (Roselló, 2009). Thus, to care for chronically ill children and their families, it is vital to understand the situations of vulnerability they experience. Understanding these vulnerabilities involves a set of aspects that are not only individual but also collective and contextual (Ayres et al., 2018).

Therefore, knowing the situations of vulnerability that affect chronically ill children and their families allows developing more efficient strategies to cope with the difficulties experienced. Also, health services and the professionals working in them must be prepared to provide care support to promote these children's growth and development and support their and their caregivers' physical and mental health. Thus, it is crucial to expand the knowledge about the vulnerabilities experienced by these children and their families. This study aims to identify the situations of individual, social, and programmatic vulnerabilities experienced by family members during the hospitalization of chronically ill children.

Background

Vulnerability is intrinsically related to human individuals as these are fragile beings exposed to the dangers of illness,

failure, aggression, and death (Roselló, 2009). Thus, the more fragile a person is, the greater their vulnerability. As developing beings, children are even more fragile and vulnerable, as they are not aware of their vulnerability and cannot find ways to face it like an adult can. Also, when one has a chronic illness during childhood, vulnerability is further increased. Chronic illnesses start gradually and have an uncertain prognosis and long duration. These conditions may present moments of aggravation and cause disabilities during their course, leading to several hospitalizations and requiring continuous care (Silva et al., 2018). Therefore, those responsible for delivering care to chronically ill children often experience several vulnerabilities in meeting the needs caused by chronic conditions.

Vulnerability can include individual, collective, and contextual factors predisposing people to become ill. The conceptual framework of vulnerability classifies situations according to a triad of elements: individual, referring to people's values, beliefs, and emotional relationships and the access to resources that allow implementing safe or healthy behaviors; social, including the living and working conditions, culture, environment, social and economic conditions and the access to information and the ability to apply it in practical changes in life; and programmatic, referring to the elements that structure and qualify Health Systems, the prevention, control, and assistance during periods of health aggravation, and the continuity and sustainability of public actions and policies (Ayres et al., 2018).

It is worth noting that the illness and worsening of clinical conditions in chronically ill children are further aggravated when access to health services is precarious, and health professionals do not recognize the vulnerabilities experienced by these children and their families (Dias et al., 2017). Therefore, each health care service must become a comprehensive and integral support reference in the care delivered to these children and their families (Silva et al., 2018). Children's hospitalizations impact families by breaking their routines and activities and demanding all family members' mobilization to adapt to the "new" reality and readjust the family's functioning, both at the hospital and at home (Morais et al., 2018). From this perspective, when chronically ill children and their families experience hospitalization, either to confirm a diagnosis or due to the worsening of the clinical condition, they experience various situations of vulnerability.

Research question

Which situations of individual, social, and programmatic vulnerability do family members experience during the hospitalization of chronically ill children?

Methodology

This is an exploratory, descriptive research study using a qualitative approach and conducted in a municipality

in southern Brazil. This study followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) to ensure reliability and validity (Souza et al., 2021). This study used Ricardo Ayres' conceptual framework of "vulnerability" (Ayres et al., 2018) to clarify the role of individual, social and programmatic vulnerabilities in the construction of multidisciplinary and interdisciplinary care strategies.

Participants were selected based on the database of the Brazilian Research Project "*Vulnerabilidades da criança e do adolescente com doença crônica: cuidado em rede de atenção à saúde*" (Vulnerabilities of chronically ill children and adolescents: care in the health care network). Thus, all chronically ill children hospitalized in pediatric units in the municipality were included, excluding those in palliative care or critical life situations. The choice of the study participants was intentional, as the children's chronic condition was considered in the selection to diversify the experiences in the data collected.

The collection of information was limited by saturation. First, the interviews were transcribed, and the initial codes were extracted. Next, the codes were categorized according to prevalence and type. Then each code was identified and analyzed to determine if it had sufficient depth and complexity to allow understanding the issue studied. In this study, saturation was reached with ten interviews, considering that the data provided sufficient depth and complexity to understand the phenomenon (Hennink et al., 2017). This study's inclusion criterion was being a family member responsible for delivering care to a chronically ill child who experienced hospitalization. Seven family members of children in palliative care or critical life situations, children continuing their treatment in another municipality, children who died, and family members under 18 were excluded.

The information was collected between June and August 2018 using the semi-structured interview method complemented by the researcher's simple observation. The interviews followed a previously developed script consisting of questions on the participants' sociodemographic characterization (age, education, employment, marital status) and guiding questions. These questions focused on how they received the child's chronic illness diagnosis, the health care spaces used for diagnosis and treatment, and the positive and negative aspects encountered in child health care during hospitalization and post-hospitalization. The method of simple observation was used at the participants' homes, paying attention to housing conditions (lighting, ventilation, and type of construction, among others) and the family member's verbal and non-verbal language (facial expression, tone of voice, and gestures). The field diary was also used to record the researcher's observations/perceptions. The data resulting from observation and the field diary were manually recorded in a file after each visit.

The study took place in the participants' homes and workplaces and the health service, covering the municipality where the children were hospitalized and/or their municipality of residence. The interviews were individual and conducted in a private place, with an approximate

duration of 40 minutes. A voice recorder was used to record the statements that later were manually transcribed in full. These transcriptions were double-checked.

The participants' identity was preserved using codes, namely "FM" for "Family Mother," "FF" for "Family Father," "FGM" for "Family Grandmother," and "FGF" for "Family Grandfather," followed by a sequential number, according to the order of the interviews, for example, "FM1". The data collected was submitted and organized deductively, adopting the thematic analysis method (Braun et al., 2019). This method uses an existing reference framework to guide the initial coding and the relationship between the codes. The reference for this study was the organization into situations of individual, social and programmatic vulnerabilities described by Ayres (Ayres et al., 2018). The analysis process was conducted according to six phases: (1) familiarization with the data; (2) coding the data; (3) generating initial themes; (4) reviewing and developing the thematic map; (5) refining, defining, and naming themes; and (6) producing the report. The data were analyzed and categorized based on this referential and the predetermined codes.

This study followed the ethical guidelines recommended by Resolution 466/12 of the Brazilian National Council of the Ministry of Health (Ministério da Saúde, 2012). It was submitted to and approved by the Research Ethics Committee under opinion number 2,736,019, CAAE: 90904418.3.0000.5316. To comply with Resolution 466/12, an Informed Consent Form was prepared and signed by the participants after being read.

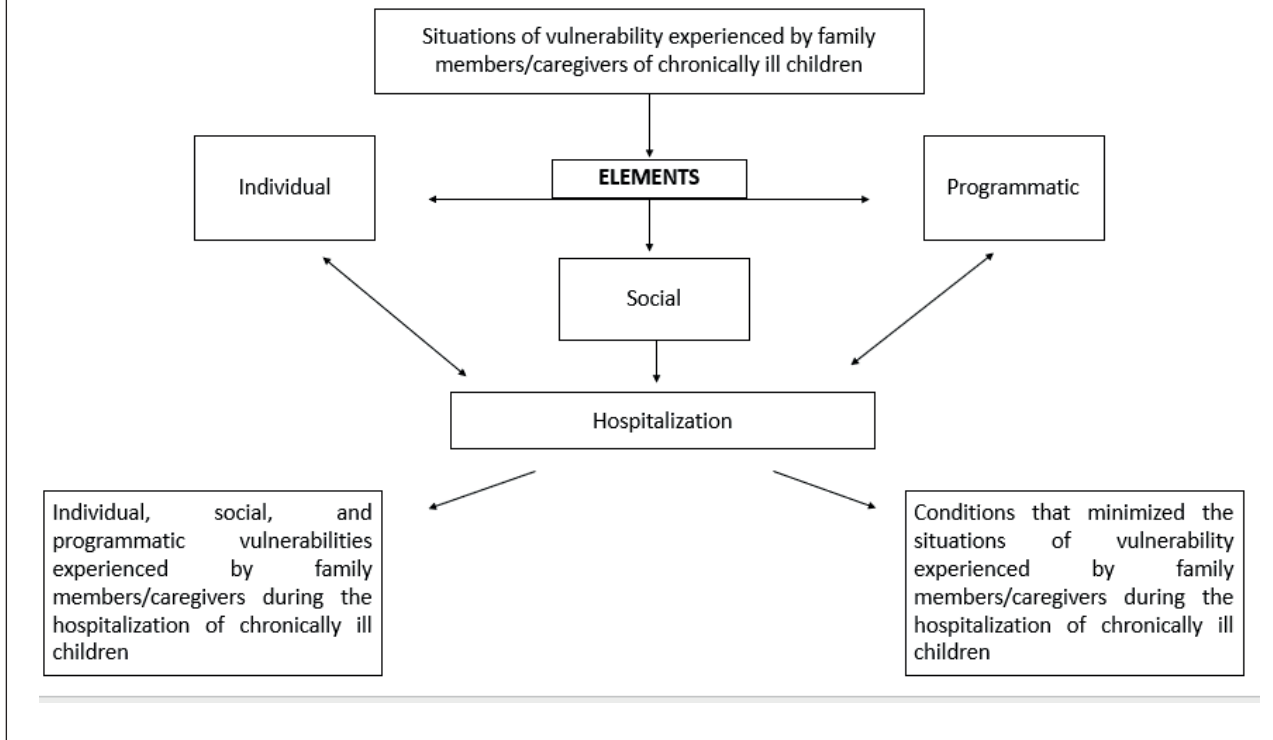
Results

Ten family members of chronically ill children participated in this study: seven mothers, one father, one grandfather, and one grandmother. Their ages ranged from 27 to 58 years. The participants' education levels included incomplete primary education (6/10), complete secondary education (3/10), and complete higher education (1/10). The participants' income varied between R\$ 290.00 and R\$ 2,000.00 (with the minimum wage at the time of the study being R\$ 954.00). The children were between 5 and 9 years old, most of them attending primary education and one in pre-school education. Asthma, diabetes mellitus, epilepsy, nephrotic syndrome, Crohn's disease, Hirschsprung disease, hyperactivity, and schizophrenia were among the diagnoses of chronic illnesses. In two cases, the children had more than one associated chronic condition.

After analyzing the results, two themes emerged regarding situations of individual, social and programmatic vulnerabilities. They were "Individual, social, and programmatic vulnerabilities experienced by family members during the hospitalization of chronically ill children" and "Conditions that minimized the situations of vulnerability experienced by family members during the hospitalization of chronically ill children". Figure 1 presents the thematic map of analysis based on the conceptual framework that guided its construction:

Figure 1

Thematic Map of Analysis: Construction of the themes and sub-themes according to the individual, social, and programmatic elements presented in the results



Theme 1: Individual, social, and programmatic vulnerabilities experienced by family members during the hospitalization of chronically ill children

Faced with the child's hospitalization, family members become aware of the individual dimension of the vulnerability they experience by understanding they are vulnerable and finite.

Regarding their child's hospitalization, the participants reported:

I felt the greatest difficulty, I stayed there for almost a week straight. I stayed there every night. Having to stay there was the least of it, my problem was falling asleep, and I should not sleep . . . Sleep was the real problem until, at one point, I could not stay awake anymore. (FM1; June 2018)

"The difficulty is that we stay there [in the hospital] and we cannot take a proper bath, it is all that stuff" (FM2; June 2018).

I was the only one that stayed there with him. My husband even stayed there with me when we were in the [name of the hospital]. However, after I went to the [name of the other hospital], I was the only one there. (FM5; July 2018)

The only bad thing is fatigue because you get tired of always being there. Sometimes, I would stay there for a month with her, which was exhausting. Even though I could sleep after she went to her room, it was exhausting. (FM7; August 2018)

These statements allow observing that the family member's caregiver burden and fatigue increase when there is no one with whom to share the everyday tasks. The lack of more

comfortable conditions, which allow family members to sleep or take a proper bath, is also recognized as a negative aspect of hospitalization. Mothers' stress caused by the mother's/ caregiver burden was also observed due to the children's preference to stay with their mother: "When her father came to stay, she would say: no, I will stay with mom" (FM6; July 2018).

Although they sometimes felt overwhelmed with taking care of their children during hospitalization, mothers reported they would not leave their children's side even if they could. Moreover, they mentioned they would go through the process more often if necessary. According to them, their care is vital for their children's improvement, apart from being their responsibility as mothers:

Because I must be the one who takes care of her, not someone else. It is my responsibility, my obligation . . . if she is feeling unwell, I will miss work and stay with her . . . I will not leave her with anyone else. (FM1; June 2018)

"We must fight for our children, that is why I do not complain . . . for a child, we do everything" (FM4; July; 2018).

I do not point out the burden as a difficulty, no . . . because I do it with pleasure... she will never say: "my mother abandoned me when I needed her." Because for me, in a certain way, it is abandonment. If I left her there, even if I went home and came back, for her, it would be abandonment . . . I may not have everything to give her, but I can say that she will never complain because I took care of her, I stayed with her, and I was happy to stay . . . because I wanted to stay. (FM6; July 2018)

Mothers' statements demonstrate that they feel responsible for care delivery to their children, having difficulty delegating care to somebody else. They end up giving up other obligations, such as their job, to stay with their children. Thus, mothers choose to be the primary caregivers, which overloads them even more:

"We spend much time there, and we feel stressed out, [with] the environment and all that stuff." (FM2; June 2018).

"Because I live for him. He is hyperactive and studies only in the afternoon, so I cannot work full-time." (FM4; July 2018).

"So, the thing was I would eat at dawn when she was sleeping. Or when she could eat and at the time she would eat" (FM6; July 2018).

Elements of social vulnerability were also identified in the participants' statements as, in addition to fatigue, caregiver burden, and sleep deprivation, they also faced the difficulties of accommodation, food, and logistics for the accompanying person:

The first night was his surgery, after he got out of surgery, we stayed in a little inn across the street from the emergency room. They did not let me stay in the ICU because he was still sedated ... (FM5; July 2018)

Participants also report having difficulties communicating with the health team during their children's hospitalization:

"The physician from the [name of the hospital] told them to start antibiotics, which they should have already started. They continue to wait and wait for the girl to get worse to then think about an exam" (FM1; June 2018).

The physicians themselves are not very aware ... They started to measure every hour, if it is above 200mg/dl [glycemia], they must do it. I said not really, do it when she eats, do not do insulin now. Only when she eats, not now. They would leave and call the endocrinologist, and the endocrinologist would say, "the mother is right, she will do the insulin when she has to do it." One day a nurse came, and I felt sorry for him. At midnight, he measured [the glycemia], and it was 344... he said, "we will do it," and I said, "if we give her insulin now at night. She will not eat anything now, [and] she will be hypoglycemic by dawn". (FM6; July 2018)

The lack of support and communication from professionals is described as an element of family members' social vulnerability. Thus, families seeking care are exposed to several adversities, such as health professionals' lack of preparation and fear of caring for chronically ill children. Considering programmatic vulnerability, participants highlight the geographical distance from home as one of the difficulties in caring for their children during hospitalization because most of them were from cities neighboring the hospitalization unit.

"In the 15 days he was hospitalized there, I came home one day" (FM2; June 2018).

"Far from home, only an aunt of mine and my daughter live in Pelotas, but they worked, studied, and did not

have time. So, it was just me, and I had to take care of him 24 hours a day, without being able to leave." (FM3; June 2018).

"When I left here, I took a few changes of clothes, and I only returned once to São Lourenço, to get more clothes for myself, and it worked out." (FM4; July 2018).

"The difficulty I faced was that there was no one there. Because I lived inside the hospital. Because I had nowhere to go, I did not know anyone... Apart from the distance, I had no difficulties." (FM5; July 2018)

"Another difficulty was the distance, and I spent a whole week without seeing him [the other son who stayed at home]" (FM6; July 2018).

Families consider distance difficult due to the lack of resources (such as clothes), the lack of contact with family support, and the separation from other children who stay at home being cared for by others. This causes mothers to feel twice as worried and more vulnerable, as they cannot meet all their families' care needs in the way they want to.

Theme 2: Conditions that minimized the situations of vulnerability experienced by family members during the hospitalization of chronically ill children

Despite the burden and the distance from home during their children's hospitalization, participants reported that some aspects of the process minimized the situations of individual, social, and programmatic vulnerabilities they experienced:

Look, there in the ER [emergency room], everything was very accessible. There was a social worker because I had no cell phone, did not bring anything, and did not know anyone's number by heart. So, I went there, and she helped me. . . there in the [name of the hospital], everything was very good, very good. We arrived there, and they were already making the beds, changing the sheets and everything. (FM1; June 2018)

"The positive aspect is that you are among physicians if you need something, you go there, and they take care of you." (FM2; June 2018).

Family members pointed out that easy access to professionals during their children's hospitalization is essential. Participants also mentioned that the care delivered by health care professionals to children and their caregivers minimized the vulnerabilities experienced.

"The nurse patiently washed her nose, and there was a playroom, which was a good thing. Because children always want to go to the playroom... The child's attitude immediately changes" (FM1; June 2018).

"Ah, the positive aspect was that the service was good, I was very well taken care of" (FM3; June 2018).

The positive aspect was the service, and everything was very easy there, everything was very good. . . especially the night nurses came there and gave me money and said: "Mother, go get something to eat because I know you have not eaten today." (FM5; July 2018)

"I cannot deny that she was well cared for...very well cared for . . . the nurses are angels. Because nurses are the ones we see there the most . . ." (FM6; July 2018).

“They all took good care of us. We had a very good team there. Everybody helped us” (FF1; July 2018).

Because every time we went, they always treated her well, exceptionally well. She likes it when she stays there, she stays there and does not even complain... we were well taken care of, really well, when I was there in the ER [emergency room], I was completely broke. I did not know that they gave us those snacks, some people give them, right? . . . Down there, I thought that I would not get any meals, but no, like she had [her meals], I had mine too. So, it is something they do that helps both of us. . . The welcoming there is really good. (FM7; August 2018)

“I have nothing to say [about] the good service, it was great there. The nursing staff, the medical staff too, everything was always good” (FGF1, August 2018).

“Everything was always good . . . it was agile and fast, it was very good” (FGM1, August 2018).

For family members, the care provided to families by health services and professionals who accompany their children’s hospitalization contributed to solving and minimizing the situations of individual, social and programmatic vulnerabilities experienced.

Also, participants describe good care delivery as explaining to parents what is happening to their children. “I liked their service very much, there in Pelotas. Very good, the physician who treated him was very good. She explained everything, everything I asked, she explained” (FM4; July 2018).

Discussion

This study has demonstrated that the situations of vulnerability, as they interfere with the children’s health, cannot be handled separately and should be connected to allow understanding the situation in which the person is. This is observed in the theme referring to the conditions that minimize vulnerabilities, which intersect the situations of individual, social, and programmatic vulnerabilities. Also, it is necessary to reflect on the term “vulnerability,” which is not measurable and requires the consideration of its meaning to visualize the protagonist of a story who is inserted in a particular environment (Ayes et al., 2018). Having a chronic illness causes both the child and family to go into a state of vulnerability as they are forced to experience a new world of impositions, doubts, questions, and uncertainties (Silveira & Neves, 2012).

The negative aspects experienced while caring for their children and mentioned by families are the fatigue caused by the poorly slept nights, the lack of conditions to carry out their hygiene and feed properly, and being in a non-familiar environment, which increased the stress experienced during the hospitalization process. Sleep is a basic human need, but family members accompanying their children’s hospitalization process cannot rest comfortably. A study indicated that the hospital environment is unknown, and the facilities can be inadequate, not offering comfort, privacy, and rest (Bazzan et al., 2020).

Apart from the poor conditions of hospital facilities for family members’ rest, the lack of caregivers’ rotation amplifies the burden and fatigue. A study confirmed that mothers of chronically ill children presented a multifaceted stress condition associated with the daily care of their children, the management of illness situations, the high level of responsibility and commitment, the care provided, and the fear of losing their children (Cruz et al., 2017). Another study conducted with mothers of children with cerebral palsy also highlighted mothers’ burden. They were described as their children’s primary caregivers in all contexts of their lives, which resulted in the mothers’ constant fatigue (Freitag et al., 2020).

Children become distressed when they are not with their mothers and feel helpless. In the case of chronic conditions, maternal attachment takes on more significant proportions because mothers experience the constant fear of their children’s health conditions worsening. The mothers of chronically ill children often cannot delegate their children’s care because they believe their care is the best and feel safer by their children’s side (Freitag et al., 2017). Moreover, women see themselves as having an obligation to care for their children. Even though certain taboos were broken, society still imposes on women/mothers the primary responsibility for their children. At the same time, fathers do not have as many duties and obligations (Mapelli et al., 2018). Women’s role as family caregivers is socioculturally determined. When a woman becomes a mother, she takes on the role of her child’s primary caregiver, dedicating herself entirely to care as a legacy determined by moral obligation (Freitag et al., 2020).

Most mothers have magical thoughts that their presence protects their child from any event, even death, and their physical presence prevents their children from suffering any harm. Thus, mothers are like “guardian angels,” who act as protective shields (Caligiuri, 2018). This situation describes both the individual and the social vulnerability of these mothers/primary caregivers. In the hospital, children and their mothers feel safer when they are together, which is why mothers should have suitable accommodations. These would allow mothers to rest without leaving the hospital while their children are with their fathers, grandmothers, or family members who can care for them. The father’s full-time participation and permanence in the hospital environment is a new way of organizing support for hospitalized children. Family-centered care is an approach that recognizes the family’s importance as a client of care, ensuring their participation in action planning (Rodrigues et al., 2019). It is up to health institutions and professionals to reflect on the adoption of the joint mother-child hospitalization system, making it a reality in the whole pediatric unit, which will lead to improvements in the mothers’ accommodation.

When children are hospitalized, they require more frequent care, which may jeopardize the care parents need to provide to their other children due to the time they need to be away from home to treat the sick child. The separation from other members that make up the family nucleus reflects the family’s social and programmatic vulnerabilities.

The social component of vulnerability is characterized by the difficulties of access felt by families and children and the type of information made available to them. The scenarios promoting social vulnerability range from restricted access to material goods to situations that violate human rights. The programmatic component of vulnerability refers to the evaluation of the resources allocated to individuals and health programs for illness control, the degree and quality of commitment of institutions, resources, and managers, and the monitoring of programs in different settings (Ayres et al., 2018).

The care process demands that health professionals promote supportive relationships and understand individuals' unique needs. Thus, families and children consider that health professionals must be accessible and care for them effectively. In this sense, pediatrics considers the family as a unit of care. Family-centered care delivers care to the child considering the family as a unit and recognizing all members as the focus of care planning and delivery and not only the child.

The care of hospitalized children is necessary to encompass the family, understanding the child as a being that is constituted in this world, a being of relationships. In this sense, it means being in the world with others, and for children, others are, in most cases, their family (Roselló, 2009). Within this perspective, it is crucial to know the existential (re)organizations that each family has experienced or experiences daily to be able to care for their hospitalized chronically ill child. Therefore, family-centered care aims to promote the health and well-being of individuals and their families, promoting their dignity (Rodrigues et al., 2019).

This study's participants also highlighted the difficulties in communicating with health professionals, particularly regarding the medications administered to children, which constitute a social vulnerability that they experienced. In this context, it is essential to facilitate the communication process, contemplating the family members' knowledge and doubts about the care provided. It is worth noting that when the family can understand the situation experienced and why their child is submitted to a particular procedure or needs medication, it is possible to reduce this situation of vulnerability, facilitating the family's care delivery to the child. Hospitalization interferes with the child's daily life, behavior, and mood. In this context, the possibility to play helps minimize the negative factors of hospitalization because, as mentioned by mothers, "the child's attitude immediately changes". Playing helps hospitalized children's mental health, and playful activities can accelerate their clinical recovery process, thus reducing hospitalization time (Alves et al., 2019).

Nurses consciously use emotions in their daily practice to provide and improve the care delivered to children and their families. This way, they create bonds within the hospital environment based on the genuine intention to provide care, develop an empathic relationship, and recognize the unique experience of being a patient and having a chronic condition (Santos et al., 2018). From this perspective, this study considers that the way health care services welcome families can minimize the situations

of individual, social, and programmatic vulnerabilities experienced during their children's hospitalization.

This study is limited because it primarily interviewed only one family member, making transferability difficult. Nevertheless, the results obtained can help develop care strategies for families experiencing similar situations. Two external researchers audited this study's results. They confirmed that the listed themes adequately related the participants' statements to the three vulnerability axes (individual, social and programmatic) that guided the analysis.

Conclusion

This study's results allow identifying the situations of individual, social, and programmatic vulnerabilities experienced by families and children with chronic conditions. Individual vulnerability was characterized by lifestyle changes, which required family members to adapt to the hospital environment. These changes were related to the need to improve the children's symptoms, in their new family routine, and include the family members' concern for their children's chronic condition.

Social vulnerability included the conditions of the hospital environment and the social and economic conditions of the family nucleus, as well as the access that family members had during the hospitalization to food, the accompanying person's accommodation, the correct and necessary information about their children's chronic condition, among others.

Programmatic vulnerability was observed in social resources and the commitment of the Union, States, and Municipalities to providing and implementing health services to the population. This study identified that the access to health services implied the need to move to another municipality.

This study contributes to education by showing the need to qualify nurses' education, addressing and discussing, from a comprehensive perspective, the issue of health care delivery to chronically ill children and their families. Nursing care must include the experiences of these families and their children so that professionals can identify the situations of vulnerability they experience and develop strategies to support care and minimize the difficulties faced. Moreover, this study shows the need to expand access to health services and professionals by offering chronically ill children's family members a more welcoming approach to their needs and encouraging the creation of bonds and support networks, thus contributing to their empowerment.

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