Vulnerabilities experienced by family members/caregivers of children with chronic conditions

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Abstract: The objective was to know the vulnerabilities experienced by family members/caregivers of children with a chronic. Qualitative research supported by the theoretical framework of the French philosopher Roselló Un which 15 family members/caregivers of children with chronic conditions participated in the study. The information was collected in the years 2018 and 2019 and submitted to thematic analysis. The results are presented in three themes: The disease as an expression of the vulnerability of being a child; The child's chronic illness as a condition of vulnerability of the family member/caregiver; The support of support networks: potentialities and vulnerabilities in the daily life of children with chronic conditions and family members/caregivers. Knowing the components of vulnerability experienced by the families of children with chronic conditions is complex, as it requires analyzing and reflecting on the situations these families face, considering their peculiarities, feelings, family organization and the accessibility they have to health services. Therefore, knowledge about the context in which these families are inserted is essential to establish an adequate planning of health actions aimed at promoting their well-being.

➤ **Keywords:** Child. Chronic disease. Family. Child's health.

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Introduction

Added to the diagnosis of a chronic condition, illness in childhood imposes on children a life different from the one imagined/idealized, as living with this condition generates a series of extremely complex feelings and situations, both for children and for their family members/caregivers (BELLATO *et al.*, 2015). Over time, chronic diseases in childhood cause sequelae that impose limitations on children, requiring special care skills and competencies from their family members/caregivers (XAVIER *et al.*, 2020). A family member/caregiver is considered to be any person with a strong personal connection with the child, such as a close relative, such as parents. Caregivers provide extensive assistance in all aspects of everyday life, performing direct care (ADASHEK; SUBBIAH, 2020).

These family members/caregivers experience what Roselló (2009) calls existential vulnerability when they realize the ontological vulnerability, in this case of the child as a human, finite and vulnerable being. Consequently, this distress arises from the perception of the child as exposed to existential facticities, vulnerable to suffering and illness.

Suffering is enhanced when family members/caregivers realize that the child's disease is incurable, when living with uncertainties, insecurities and continuous needs for the reorganization of everyday life, in order to meet the care demands (BROCK *et al.*, 2018). Therefore, regardless of the chronic condition, a change in life is assumed, which is not only related to the somatic structure of the human being, but also to its integrity, associated with suffering. Each family interprets illness through their own perceptions, culturally incorporated in and influenced by their way of being in the world and by the affective relationships established with and among its members (ROSELLÓ, 2009).

Coping with a chronic condition causes transformations in the life of the children and their family, requiring intense emotional involvement, from the impact of the diagnosis to the implications of the disease throughout life. Thus, health care becomes complex, requiring accountability from the family members/caregivers, which can go beyond the competencies inherent to caring for a child (PIMENTA *et al.*, 2020).

Thus, including these family members/caregivers in the care provided by health professionals does not mean a resolution of the painful experience faced, but the possibility of helping them bear this experience, overcoming it in the physical, emotional, moral, social and spiritual senses (ROSELLÓ, 2009).

Despite all the limitations imposed by vulnerability, their experience can become something positive, impelling human beings to seek recovery of their autonomy, threatened by the human existential condition. The experience of vulnerability can occur in different axes: Ontological (constitution of the being that is limited, dependent and determined by its finitude); Ethical (it is related to the moral duty to protect the weakest individuals), Social (possibility of the human being who is an object for violence in the social environment); Natural (the environmental setting affects the life of the human being and vice versa): and Cultural (ignorance about the different knowledge orders, rendering the individual manipulable and unprotected from power abuse by others). Four of these vulnerabilities were identified in this research, namely: Ontological, Ethical, Social and Cultural (ROSELLÓ, 2009).

Considering that vulnerability has varied permanence and intensity, it is important to understand the spheres that produce human vulnerability in the health field. In this way, health professionals and services will be able to offer autonomy to the children and their families, in order to manage the experience of living with the chronic condition.

Based on the above, and in order to contribute to the discussion on this theme, the following research question was established: Which are the vulnerabilities experienced by family members/caregivers of children with chronic conditions? The objective was to know the vulnerabilities experienced by family members/caregivers of children with chronic conditions.

Methodology

A qualitative research study supported by Roselló's theoretical framework (2009), which describes vulnerability as an experience intimately rooted in the human condition. Thus, human beings are exposed to the danger of getting sick, being attacked, failing and dying, living in vulnerability. The study was conducted and structured according to the Consolidation Criteria for Reporting Qualitative Research (COREQ) (SOUZA, 2021).

This study is part of a multicenter research study developed in four municipalities from Rio Grande do Sul (Porto Alegre, Santa Maria, Palmeira das Missões and

Pelotas) and in one from Santa Catarina (Chapecó), entitled “Vulnerabilities of children and adolescents with chronic diseases: Assistance in a health care network”. The data presented in this manuscript refer to the information collected in Pelotas.

The information was collected in 2018 and 2019 by the research group members, previously trained to do so. The study participants were the family members/ caregivers of children with chronic conditions (admitted to Pediatrics units of public hospitals in the municipality in question), with the following inclusion criterion: being a family member/caregiver of a child aged from six to 12 years old with a chronic condition. Family members/caregivers of children on palliative care or under critical life situations were excluded.

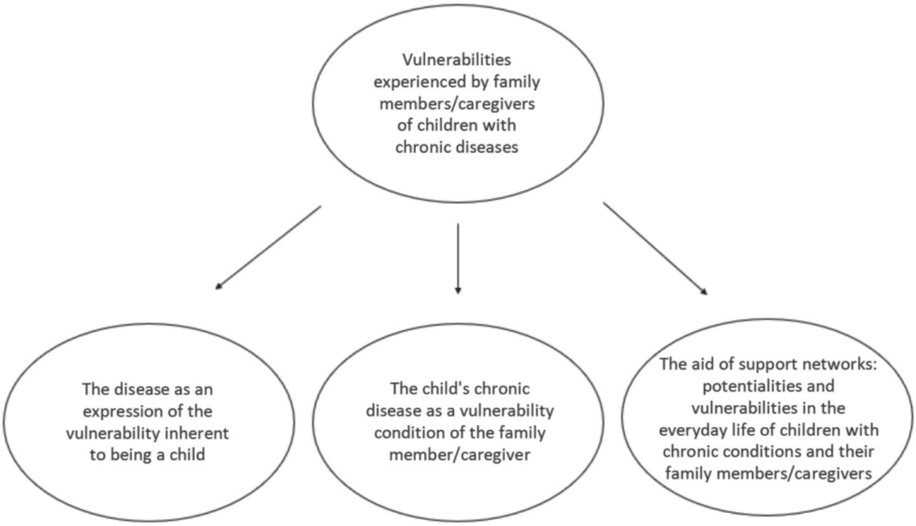
For data collection, semi-structured interviews were used, with open and closed questions about the perspective of the family members/caregivers about the experience of the child's chronic condition. The place where the interviews were conducted was the house of the family members/caregivers, and the meetings were previously scheduled. The interviews lasted a mean of 60 minutes, were recorded on a cell phone and manually transcribed in full (with double checking). A total of 15 family members/caregivers took part in the study: ten mothers, three fathers and two grandmothers. The information reached saturation when no new element was found in the new participants' speeches, not needing to add new information to understand the phenomenon studied (HENNINK; KAISER; MARCONI, 2017).

The ethical precepts set forth in Resolution No. 466/12 were respected (BRAZIL, 2012). To this end, before conducting the research, the project was submitted to and approved by the Research Ethics Committee under CAEE 54517016.6.1001.5327, and opinion number 1,523,198. The participants' identity was preserved by naming them with the consonant “F” (Family member), followed by an increasing numeral according to the order of the interviews (F1, F2, ...). The information was analyzed in an inductive way, using thematic analysis and following six stages: (1) Familiarization of the researcher with the data (reading and re-reading of the data with note-taking of initial ideas); (2) Generation of initial codes (coding of the pertinent characteristics of all data in a systematic way, as well as collection of important data for each code); (3) Search for the topics (compilation of the codes into possible topics, joining the important data for each potential topic); (4) Creation of the thematic map (it is verified whether the topics work in the coded extracts and in the integral dataset, originating a thematic map of the analysis); (5)

Refinement of the topics (the analysis is deepened to improve the particularities of each topic); and (6) Preparation of the final report (final examination of the extracts selected, association between analyses, research question and scientific bibliography to prepare the analysis report) (BRAUN *et al*., 2019).

The thematic map prepared is presented below (Figure 1).

Figure 1. Thematic map corresponding to organization of the results



Source: The authors, 2021

Results and Discussions

It was found that the family members/caregivers experience situations of ontological, ethical, cultural and social vulnerability, which are closely interconnected, influencing each other. It is not possible to treat them separately, and the entire situation in which the person is should be understood, as these conditions interfere with the child's health and the care provided by the family member/caregiver.

The disease as an expression of the vulnerability inherent to being a child

This topic presents the reports of family members/caregivers about their perspectives on the vulnerabilities experienced by children with chronic conditions. The participants cited as a care difficulty the limitations that affect both speech and locomotion, as well as agitation of the child, thus reaching its ontological constitution.

> Then everything becomes more difficult, because the child doesn't walk or speaks [...]. (F6)
>
> Ah, it's difficult because the child's very agitated, [...] any kind of noise he gets very agitated [...]. (F9)
>
> That some days he's very agitated, [...] others he's calmer. (F14)

Another issue evidenced with the ontological vulnerability inherent to human beings was the difficulty faced by children not accepting the restrictions imposed by the conditions and/or treatments. Diabetes, for example, implies changes and restrictions in habits, especially in terms of food. Children do not understand severity of the disease and the consequences it can generate, as caregiver F11 needs to always be “quarreling”, because the child does not understand the reason for not being able to do things that other children do, evidencing social vulnerability.

> [...] so the child goes to a little party, for example, she has to take care of what she eats [...] we have to take care of what she eats, because otherwise she messes around, easily gets to eat a candy. [...]. [...] so we take care of that [...] but it's control [...] sometimes it becomes a difficulty [...]. (F7)
>
> He's not mature enough to understand his disease, he’s always angry, always quarreling [...] he already has the rebellion of his age, right, he already has this aggravating factor and generating this lot of things. He can nothing, nothing I allow, because I don't trust him because he's lied to me several times, his lie is to say that he can when I'm not with him and he can't eat or take anything. [...]. Always this rebellion of wanting to do something that can't be done [...]. (F11)

F11's speech also allows noticing the mother's overprotection to the child, who can only do something if she's with him, limiting and restricting the child in socialization with other children, thus increasing his social vulnerability.

Living with a chronic condition gains a higher proportion when it affects a pre-adolescent. This scenario is characterized as ontological vulnerability, due to not understanding the new existential condition. As chronic diseases in childhood and adolescence are unexpected and unwanted by the family, many difficulties to be faced arise (FREITAG *et al*., 2020).

These children experience many changes in their everyday lives, such as changes in their diet, physical exercise, blood glucose monitoring and insulin application, which are oftentimes performed by the pre-adolescents themselves. Therefore, self-care regarding hemoglycotest (HGT) and insulin application can be perceived negatively, as it generates pain and discomfort, demotivating and causing depressive symptoms. However, the pre-adolescents' autonomy generates positive feelings, such as the ability to take care of themselves and be self-responsible. Independence also increases adherence to the treatment, contributing positive results (BERTOLDO *et al*., 2020).

It is difficult for a child to accept the treatment, which is initially frightening; it evidences ontological vulnerability due to the fear of being injured, as well as cultural vulnerability due to not understanding the chronic condition, as observed in F7's report about the child's fear of needles.

> It was the initial acceptance [...]. The fear of needles all the time, that the child was panicking about it. (F7)

Chronicity exposes children to invasive procedures, which involve painful and frightening experiences. In an attempt to reduce these negative experiences, it is necessary to prepare the child, and resorting to therapeutic toys is an excellent tool. Playing assists in children's healthy development, offering broad physical, emotional, cognitive and social benefits; in addition, it allows then to develop their motor skills and to simulate scenarios and their consequences in a safe and engaging way, reducing stress and preparing them for the procedures to be performed (NIJHOF *et al*., 2018).

It is believed that, when experiencing a disease, human beings recognize their own vulnerability, the unpleasant and frail character of the human body. A sick person realizes the constitutive frailty of their own being and, then, knows themselves better (ROSELLÓ, 2009).

Humans are potentially sick beings, as they can fall ill at any time precisely because of their intrinsic vulnerability; thus, the disease and the process of becoming ill are evident and touching forms of human vulnerability. This human capacity to get sick can be understood as the hallmark of human vulnerability (ROSELLÓ, 2009). However, there are conditions that favor the care of children with chronic conditions, such as their acceptance and understanding of the disease and treatment:

> It was easier at home, we explained it to the child and she understood better [...] since she was very young she already controls her own insulin, already measures it and everything, she does everything. (F7)

Thus, when children understand their condition and the limitations they are exposed to, they minimize their vulnerabilities.

The child's chronic disease as a vulnerability condition of the family member/caregiver

The participants outlined their ontological vulnerabilities as human beings who care for children that experience illness and a chronic condition. The initial shock of the chronicity diagnosis and the questions about whether or not there was some failure in their care, added to the feeling of guilt or blame for onset of the disease, also evidence the ethical vulnerabilities, as the people responsible for the child's care.

> [...] it wasn't negligence because what we hear most is condemnation, what did you do? Why didn't you take care? What did this kid eat? [...] they all think it's the mother's negligence. [...] I keep blaming myself. (F11)
>
> [...] everyone blames me, they tell me that I had to go further, that it was necessary to demand. But no matter how much you demand, you're not in charge [...]. I just ran doing everything I could from side to side several times, but [...] I don't see it advancing [...]. Just me alone is no use. (F13)

The chronic condition causes changes in family dynamics; the family members seek strategies to face and adapt to this reality, aiming to provide the most appropriate care (GOMES *et al.*, 2017). Roselló (2009) brings up the reflection that human beings' vulnerability is closely linked to the disease, as this supposes a change in the person's life, which does not only refer to the somatic structure of human beings, but also to their integrality.

Faced with the child's chronic condition, vulnerability is directly linked to care, as well as the idea of responsibility. Referring to the child's illness, the blame that falls on the caregiver generates distress, and the condition is identified as negligence. In this sense, it is noticed that, many times, support is lacking for these caregivers, adding to the ethical vulnerability they experience, as they understand themselves with the moral duty to protect children (ROSELLÓ, 2009).

The reports present feelings triggered in the family members/caregivers facing the diagnosis of the child's chronic condition, mainly fear of losing the child or that some complication resulting from the chronic condition will leave sequelae. Thus, ontological vulnerability is characterized as a caring human being, which is perceived in view of the possibility of the child's finitude. In addition to that, ethical vulnerability is also perceived, referring to the need to protect a child against their frailty:

> [...] he has no idea of the severity of the disease. He's already been hospitalized nine times in these three years and has been to the ICU (Intensive Care Unit) four times. I thought I was going to lose him that last time he was hospitalized, it was very difficult, I've never seen him so bad [...] we know that a lot of things happen, it's amputation, it's the organs that stop little by little and then I'm already terrified that he's only thirteen years old and has already been hospitalized so many times [...]. Then the doctor tells me that I'm overestimating it, but I think it's fear. (F11)

> If it was no use [...] they would take it and remove it, amputate it, which was to avoid the risk of going up because it goes up, it becomes general [...]. I sleep, I wake up every day thinking terrified, how must it be [...], but who can sleep peacefully, can lay their head on the pillow peacefully knowing everything that can happen [...]. (F13)

In these reports, the constant concern of the family member/caregiver with the hospitalizations and the complications inherent to the pathology are evidenced, potentially traumatic situations, even affecting sleep due to concern. In addition to that, F11's speech reflects overprotection of the child, evidencing his ethical vulnerability, as the people responsible for dealing with his frailty.

The family members/caregivers faced with the diagnosis of the chronic condition encounter doubts, fears and uncertainties, but time is too short to understand and organize these feelings, get to know the disease, provide resources and adapt to the reality imposed. Therefore, ontological/ethical vulnerability oftentimes goes unnoticed, may increase over time and not be resolved (DIAS *et al*., 2020).

Seeing the child's suffering revolts family members/caregivers, as they recognize themselves as incapable of managing, organizing and submitting it to logic. Pain erupts into human existence without a prologue, it appears on the stage of individual life and alters the dimensions of being (ROSELLÓ, 2009). The parents experience several feelings after the diagnosis of a chronic disease in their children, such as anguish, fear, guilt, hopelessness, impotence and insecurity. These feelings deserve attention from health professionals, as understanding the experience of patients and their families is fundamental to provide care according to their needs and identify better strategies according to their unique experiences (HAWKINS *et al*., 2020)

Through the reports, the anguish suffered by the family members/caregivers is perceived; F11's speech shows that, at times, the child states that they are fine in order to be able to remain strong in the face of the adversities experienced but, in fact, they feel physically and emotionally overloaded:

> And we understand that it's difficult, the child’s side is not easy either. But we have to be a little tougher, because if we let it fade, it's worse. We have to be strong. (F11)

The participants report the feeling of helplessness when they do not notice any improvement in their children, since, even doing their best so that the children do not suffer or feel pain, they sometimes cannot solve the difficulties and do not know who to turn to. Thus, ethical vulnerability intensifies:

> Pulled the information and I didn't even know what to do [...] the least from a mother, I think, is to take care and always stay on top watching things over [...] and it's not for lack of care, because I'm always on top of him [...] I don't miss any consultation. (F11)
>
> [...] he was with a fever, he was in pain and he (doctor) said that all of this was normal, that it would pass with time, that there was nothing else to do. [...] they know that I'm going to stomp my feet, if I have to go to the prosecution again I will, like I did a report on television when they were denying assistance to him [...] this is something that hurts, because you know it's your child who needs it [...] you have nowhere to run. [...] they say they've already tried to do everything and that they don't know what they're going to do now [...]. (F13)

For being responsible for the child's care, when the diagnosis of the chronic condition appears, the main caregivers feel guilty, assuming responsibility for the disease, believing that they did not do everything possible to avoid it or that they did something wrong. The feeling of guilt arises with onset of the pathology due to the negative meaning of this experience. It is precisely this feeling of guilt that causes parents/caregivers to overdo care, overprotecting (PIMENTEL *et al.*, 2017). Witnessing a child's suffering and pain generates feelings of anguish, fear and, above all, impotence in parents, as they are unable to do anything to stop their child's pain/suffering (FAIRFAX *et al.*, 2019; MEDEIROS *et al.*, 2020).

Human beings are frail because they are finite, and they only live safely when they identify their own vulnerability and the others', learning to deal with it in order to live with it. Thus, their greatest vulnerability to finite existence is revealed, and its only certainty is death (ROSELLÓ, 2009).

In F2's report, it is possible to perceive the vulnerabilities faced due to the visual limitation. When the school staff calls warning about any complications with the child, the child needs the help of the other daughter to be able to commute to school:

> There's no way I'm going alone to fetch the child, where I leave my girl would go with me, because I'm alone so I can walk, like this the holes I can twist my foot. Or when walking like this I can stumble, I may fall. [...] because of the sight difficulty. (F2)

Complementarily, other conditions inherent to the caregiver also bring about weaknesses to the care of a child with a chronic condition, as in the case of F1: when she was pregnant, she had to stop her daughter's treatment, as she was unable to accompany the child:

> [...] there was even a time when she stopped doing it because I couldn't bring her anymore, because I was pregnant and then we slept both in the same [...] hospital bed, or in that armchair there and I was at the end of my pregnancy, so everything was very uncomfortable and then she stopped going, that's when we went to the blood center again. (F1)

Another important aspect that contributes to care discontinuity and to difficulties during hospitalization is the family member/caregiver having a job and/or other children.

> The only difficulty I had was because I work [...] I had to go out to work [...] and I left the other two at home, because I have another two children and I went to stay with her [...] all the time with her, she was afraid to be alone. (F5)
>
> My difficulty, as I have three children, of staying with her all the time, I can't, I have the other two, so I even can't manage [...] be always in my role, and my husband is always working. (F15)

The parents' presence during children's hospitalization generates several concerns, as it is necessary to understand that most of them are not able to stay all the time with the hospitalized children due to unfavorable socioeconomic conditions that do not allow their absence at work or even in the care of the other children, having no one to leave them with.

It is generally the mother who gives up her job to take care of a hospitalized child; in many cases, the workplace does not accept the child's medical certificate. In addition to that, the other children also undergo changes in their everyday lives, ceasing to attend school and being cared for by family members and friends, even outside their homes (MELLO; FRIZZO, 2017).

The aid of support networks: potentialities and vulnerabilities in the everyday life of children with chronic conditions and their family members/caregivers

The family members/caregivers point to the support networks as minimizing the vulnerabilities they face. Most often, these networks are made up of family members, godmothers, colleagues and friends:

> It's just me and my husband and my mother-in-law who send the little pump, there's no one else. (F2)
>
> [...] staying with my mother, my mother-in-law. (F3)

> Only my family". (F4)
>
> I have my family [...] there are seven of us. (F5)
>
> There is the godmother who's always here, she's always attentive too [...] she's very careful [...]. (F8)
>
> It's quiet, in the role like this at home [...] everyone I think has become used to the role of taking care of her. So each one takes care a little bit. (F10)
>
> It was all very natural, very correct, everyone helped, friends, family members, everyone helps, the colleagues are an example, they're always helping. (F12)
>
> His father, I myself, sometimes my neighbors [...] and my mother and my father. (F13)
>
> It's me, his father, and his eight-year-old sister. It's the four of us. (F11)
>
> No, it's just me and his father. (F14)
>
> My husband [...] helps me with her, who stays with them so I don't have to leave the service. Staying with her, staying with the other one, so I can be with her. [...] there are my sisters-in-law, my sisters-in-law work. [...] they'd like to help more. (F15)

The child's chronic condition generates in the families the need to overcome ontological vulnerability, imposing transformations and struggles, with obstacles that need to be overcome. In addition to that, when they gradually realize their vulnerability, human beings can seek shelter against it, empowering themselves with their rights and thus reducing their vulnerabilities. Thus, when identifying their weaknesses and difficulties, family members/caregivers look for support networks in order to minimize the situations of vulnerability they experience (ROSELLÓ, 2009). Social support is important for the family in coping with the chronic condition (SILVA *et al.*, 2017).

In its very essence, the care process implies the virtue of responsibility. Caring for a frail or vulnerable human being is exercising a form of social responsibility (ROSELLÓ, 2009). For the families of children with chronic conditions, the social support network is the one that helps them face this condition (GOMES *et al.*, 2019).

In addition to family members and friends, health professionals and religion are also seen as a support network:

> Nutritionist, endocrine surgeons, doctors. (F12)
>
> And I have a second family, because we're Jehovah's Witnesses, right, and we're a family, so when one is need the other is always there. (F5)
>
> I read a lot of Spiritist books and it's still some support [...]. (F15)

It is observed that religiousness or spirituality are important and constitute a support network for these families, representing a source of hope in coping with the difficulties. In addition to that, they contribute to minimizing the pain and anguish that mark the everyday life of the family member/caregiver, relieving the fears arising from the disease (NEVES *et al.*, 2017).

Lack of bonding and support by the health services to these families enhances the social vulnerability faced, weakening them even more. The family members/caregivers report not using Basic Health Units (BHUs) for several reasons: not having a specialist physician (pediatrician), not being resolute or not having enough records, thus, they end up resorting to the Emergency Departments (ERs) when they need care, especially when the chronic condition is exacerbated.

> She hardly goes to the health center, that when [...] I feel that she's sick, that she has something wrong I already take her straight to the ER [...] there they always treat her, the pediatricians already know the case and everything. (F6)
>
> What makes it difficult is what sometimes you think you can consult on a small health center and then sometimes there's no doctor, it's difficult now. [...] sometimes you have to take out a record and there are three, four records, and there's no way, then the resource is the ER itself [...]. (F8)
>
> There's no pediatrician. And the information here by the health center is much more difficult [...] we tried, but I had a problem when collecting, because they collected it wrong [...]. Then I gave up from this function in the health center [...] I think that then it's the thing of not having a pediatrician, right, in the center, with no way for you to do any follow-up. [...] then either you take it to the ER [...] to be treated by a pediatrician or you pay. (F10)

BHUs should be the gateway to the health service, but what happens is the great demand for medium- and high-complexity services. Such demand can be considered by the low resoluteness of Primary Care, professionals without specific training for care, insufficient devices and materials, with migration of users to urgency and emergency services (FREIRE *et al.*, 2020).

In addition to that, when there is a link with a specific health professional, people search for the service where they work. This is often only established after a pilgrimage through multiple health services.

> [...] then we returned and she continued undergoing treatment with [...] (name of the physician) who's the one treating her to this day. We always consult in the medical school [...] there was a time that I went to [...] (name of the health service), then she started to do the transfusions in the blood center, then she stopped doing it in the blood center and started

> to hospitalize because in the blood center there were no more doctors, the doctor had left. Then she stayed [...] a year and a little I think with the hospitalizations at [...] (name of hospital) every month and now we managed to move to the blood center again. (F1)

In this sense, health professionals should articulate support networks so that family members/caregivers do not feel helpless. Nursing may contribute with diverse information on pathology, treatment, care and prevention of future complications, also paying attention to the caregivers, who suffer together with the children (GOMES *et al.*, 2016).

It is noticed that many families do not have any health service and/or professional as a support network and that, without due support for care and continuous monitoring of the child, they seek the emergency care service when the disease is exacerbated, or try to circumvent the situation with their own knowledge:

> [...] he does the treatment at home, now these days he used the little pump for not needing to take him [...] to the hospital, because if I take him [...] he'll end up hospitalized [...]. (F2)

> When it's like this, something lighter [...] then we give predsim, there's nasonex also, which he uses and that I have it prescribed. So we control [...] what you can control at home [...], but sometimes, when you see that you can't [...] you have to take him straight to the ER, when things can't wait. (F8)

The mothers provide care to their children based on the knowledge they have, use medications that are part of the home pharmacy as a way to complement the treatment and mitigate the acute symptoms: in addition, they are influenced by the health professionals' behavior, and it is indispensable that they provide them with the necessary support (NEVES *et al.*, 2017).

As a potentiality in the support network is the tertiary-level care that is sought for the trust in the help it provides:

> It was easy for the doctors, the most specialized one for her has already arrived [...] the doctor already knowing her condition, bronchitis [...]. Pulmonologist, right? And then I find this practicality [...]. So I think it's good, I'm always assisted, I feel like that there. (F15)

Another facilitating aspect mentioned by the caregivers is the good care provided by the professionals, which strengthens the bond, increasing the potential to face the vulnerabilities experienced.

> [...] we were very well treated there, the child's tests didn't take long, the results were very fast, and we had follow-up. Several types of follow-up for her to be entertained, from the nurses, even from the dentist who went there to visit her. So, there I really enjoyed the care provided [...]. (F5)

> The practicality was the care they provided there, which was good, it was quite well-oriented. (F12)
>
> Of course that there in the hospital, anywhere we went we were very well received, really very good care the girls, it was huge affection with her [...]. (F1)

The health team should be a support reference for these family members/caregivers, through effective strategies and health actions aimed at the needs of the child and family (KALANTAR-ZADEH *et al.*, 2021).

When asked about health services as effective support networks, the family members/caregivers point out that, although they resort to urgency and emergency services (ERs) these places do not constitute support networks, as the environment is usually not appropriate for children, in addition to the delay of care in these places.

> [...] one difficulty is the environment [...] the hospital environment is bad for a child [...] it's not a cool environment. How much we see. Apart from the contamination risk, as the child's immunity is already low and there's also the delay. (F1)
>
> In the ER it's more difficult, because, [...] going through those corridors there, it's bad [...]. You see everything there, right? And the x-ray that takes a lot of time [...]. And she sees certain things that I think are bad, [...] she already comes home terrified [...]. She had horrible moments to see, even more for her [...]. (F15)

It is important to emphasize that the ER environment can be frightening for family members and especially for children, as the physical space, organization of the materials, observation room, invasive procedures performed, noises and even excessive luminosity can cause discomfort. In addition to that, whether pediatric or adult, the patients are exposed to common areas, a context characterized as a frightening place, with situations that a child has never experienced (LIMA *et al.*, 2018).

The family members/caregivers pointed out that, as they do not have a support network in health services, they face difficulties treating their children, such as access to medications, physical therapy or surgical procedures. Many times, lawsuits are required to access services, medications and devices:

> And in this drainage, they did a biopsy and I didn't even know about it. Then over time that I went to the prosecutor's office, in the child's health care council and then I got them to do the child's treatment [...] fighting because no one wanted to assist. [...] the difficulty that we find the most is to get things [...] there's a lot of legal stuff [...]. There's a lot that there's a month that sometimes doesn't come so it's always a problem [...] something from the State, the Municipality, you go to the pharmacies and things are so always missing [...] you have to always be running after [...] the physiotherapist also entered the justice, I got it too. (F3)

In this speech, the cultural vulnerability experienced by F13 is made evident, unaware of the biopsy to which the child was subjected. In addition to that, the access limit to the health services is configured as a social vulnerability, as care is not linked to any health network in many cases. Therefore, the family needs to undertake this path independently and, if it lacks resources, the child may have his/her health condition worsened, with the possibility of dying without receiving the necessary care (ROSELLÓ, 2009).

In some cases, the treatment involves surgical procedures that are sometimes not performed because there is no anesthesiologist in the Unified Health System (*Sistema Único de Saúde*, SUS) service:

> She had to have the surgery. There's a big adenoid [...] but there's the anesthesiologist. [...] OK, but how much is the anesthesiologist? [...] that was just four thousand for the anesthesiologist. No way for me to do this. (F15)

Absence of professionals who assist through the SUS is common, increasing the vulnerability of families and children with chronic conditions. The SUS physician advised the family to seek a private doctor to provide care to the child, which was unfeasible, leaving the child without care. This is related to the social vulnerability experienced by the families of children with chronic conditions, linked to the scarcity of resources that are indispensable for the effective prevention and treatment of diseases. The social dimension seeks to show how services can improve the life of the population, through public policies for the care and autonomy of people, not attended to in these cases (AYRES, 2009).

In this sense, considering that health services are the spaces where the family members/caregivers of these children seek care, diagnosis and treatment for the chronic conditions, and that these loci cannot meet their health needs, the social vulnerability situations of these families are amplified, as collective coping practices and adversities, such as unavailability of resources and access to them, are social components.

Final considerations

Seeking to know the components of the vulnerability experienced by the families of children with chronic conditions is complex, as it requires analyzing and reflecting on the situations faced, in view of the peculiarities, feelings, family organization and accessibility to health services.

It was found that vulnerability is something intrinsic to human beings, experienced by everyone to a lesser or greater degree. For the children's families, the vulnerabilities were accentuated after the children's illness, exposing them to difficult periods. In this context, it is considered that, through welcoming in health services, it is possible to minimize the ontological, ethical, cultural and social vulnerability situations experienced by family members/caregivers and children.

The study limitations are the fact that it was not possible to interview other members of the family nucleus and the difficulty finding the families, as many of them lived in rural areas.

It is believed that, through the knowledge of the components of the vulnerabilities experienced by these families and children, health professionals can act, plan and evaluate ways to minimize these situations, offering tools for the family members/caregivers to develop their empowerment and, thus, be able to recognize, confront and minimize them.[1]

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References

ADASHEK, J.; SUBBIAH, I. Caring for the caregiver: a systematic review characterizing the experience of caregivers of older adults with advanced cancers. *Esmo Open*, v. 5, n. 5, p. e000862, 2020. Doi: 10.1136/esmoopen-2020-000862

AYRES, J. R. de C. M. Organização das ações de atenção à saúde: modelos e práticas. *Saúde e Sociedade*, v. 18, n. 2, p. 11-23, 2009.

BERTOLDO, C. S. *et al*. Perspectiva de adolescentes que vivem com diabetes mellitus sobre autocuidado. *Pesquisa qualitativa em saúde: avanços e desafios,* v. 3, p. 347-358, 2020. Doi: 10.36367/ntqr.3.2020.347-358

BRASIL. Conselho Nacional de Saúde. Resolução CNS nº 466, de 12 de dezembro de 2012: diretrizes e normas regulamentadoras de pesquisas envolvendo seres humanos. Brasília; 2012.

BRAUN, V.; CLARKE, V.; HAYFIELD, N.; TERRY, G. Thematic Analysis. In: LIAMPUTTONG, P. (edit.). *Handbook of Research in Health Social Sciences*. Australia: Springer, 2019. p. 843-860.

BROCK, K. E.; WOLFE, J.; ULLRICH, C. From the child's word to clinical intervention: novel, new, and innovative approaches to symptoms in pediatric palliative care. *Children (Basel)*, v. 5, n. 4, p. E45, 2018. Doi:10.3390/children5040045

DIAS, B. C. *et al*. Dinâmica familiar e rede social de famílias de crianças com necessidades especiais de cuidados complexos/contínuos. *Revista Gaúcha de Enfermagem*, v. 41, p. e20190178, 2020. Doi: 10.1590/1983-1447.2020.20190178

FAIRFAXA. *et al*. A systematic review of the association between coping strategies and quality of life among caregivers of children with chronic illness and/or disability. *BMC Pediatr.,* v. 19, n. 215, 2019. Doi: https://doi.org/10.1186/s12887-019-1587-3

FREIRE, A. P. F. B. *et al*. Percepção de pacientes em um serviço de Pronto Atendimento: Os limites da Dor e a busca por cuidados. *Braz. J. of Develop.,* v. 6, n. 3, p. 11306-18, 2020.

FREITAG, V. L.; MILBRATH, V. M.; MOTTA, M. G. C. Tornar-se mãe de uma criança com paralisia cerebral: sentimentos vivenciados. *Psicologia em Estudo*, v. 25, p. e41608, 2020. Doi: 10.4025/psicolestud.v25i0.41608

GOMES, G. C. *et al*. Chronic Disease in children: Family experience in diagnostic reception. *Revista de Enfermagem UFPE online*, v. 10, supl. 6, p. 4837-4844, 2016.

GOMES, G. C. *et al*. (Des)preparo do familiar para o cuidado à criança com doença crônica. *Revista de Enfermagem da UFPI*, v. 6, n. 1, p. 47-53, 2017. Doi: 10.26694/reufpi.v6i1.5737

GOMES, G. C. *et al*. Social support network of the Family for the care of children with cerebral palsy. *Revista Enfermagem UERJ,* v. 27, n. e40274, p. 1-6, 2019.

HAWKINS, L. M. *et al*. Patient and family experience with chronic transfusion therapy for sickle cell diasease: A qualitative study. *BMC Pediatra*, v. 20, n. 1, p. 172, 2020. Doi: 10.1186/s12887-020-02078-x

HENNINK, M. M.; KAISER, B. K.; MARCONI, V. C. Code Saturation Versus Meaning Saturation: How Many Interviews Are Enough? *Qualitative Health Research*, v. 27, n. 4, p. 591-608, 2017.

KALANTAR-ZADEH, K. *et al*. Living well with kidney disease by patient and care-partner empowerment: kidney health for everyone everywhere. *Clin. Exp. Nephrol.*, v. 25, n. 6, p. 567-573, 2021. Doi: 10.1007/s10157-021-02044-5

LIMA, D. A. *et al*. Children’s satisfaction and dissatisfaction with pain management in a Pediatric Emergency Department. *Rev Esc Enferm USP*, n. 52, p. e03373, 2018. Doi: 10.1590/S1980-220X2017044503373

MEDEIROS, J. O.; BEZERRA, A. L. D.; SOUSA, M. N. A. Expectations, sentiments and living of parents of children with severe hematological problems. *Revista de Enfermagem da UFPI,* v. 9, n. 1, p. 27-34, 2020. Doi: 10.26694/2238-7234.9127-34

MELLO, D. S.; FRIZZO, G. B. Depressão, ansiedade e suporte familiar para mães na primeira hospitalização do filho. *Psicologia, Saúde & Doenças*, v. 18, n. 3, p. 814-827, 2017. Doi: 10.15309/17psd180315

NEVES, E. T. *et al*. Rede de apoio de familiares de crianças em pronto atendimento pediátrico. *Revista Pesquisa Qualitativa*, v. 5, n. 7, p. 53-65, 2017. Disponível em: <https://editora.sepq.org.br/rpq/article/view/74/63> Acesso em: 13 ago. 2021

NIJHOF S.L. *et al*. Healthy play, better coping: The importance of play for the development of children in health and disease. *Neurosci Biobehav Rev.*, v. 95, p. 421-429. Doi: 10.1016/j.neubiorev.2018.09.024.PIMENTA, E.A.G. *et al*. Cuidar de crianças com necessidades especiais de saúde: Do diagnóstico às demandas de cuidados no domicílio. *Braz J of Develop*, v. 6, n. 8, p. 58506-58521, 2020. Doi:10.34117/bjdv6n8-311

PIMENTEL, R. R. S.; TARGA, T.; SCARDOELLI, M. G. C. From diagnosis to the unknown: perceptions of parents of children and adolescents with diabetes mellitus. *Revista de Enfermagem UFPE online*, v. 11, n. 3, p. 1118-1126, 2017. Doi: 10.5205/1981-8963-v11i3a13486p1118-1126-2017

ROSELLÓ, F. T. *Antropologia do Cuidar*. 1.ed. Petrópolis: Vozes, 2009.

SILVA, M. E. A. *et al*. Network and social support in children with chronic diseases: understanding the child's perception. *Texto Contexto Enfermagem*, v. 26, n. 1, p. e6980015, 2017. Doi: 10.1590/0104-07072017006980015

SOUZA, V. R. *et al*. Tradução e validação para a língua portuguesa e avaliação do guia COREQ. *Acta Paul Enferm.*, n. 34, p. eAPE02631, 2021.

XAVIER, D. M.; GOMES, G. C.; CEZAR-VAZ. Meanings assigned by families about children's chronic disease diagnosis. *Rev Bras. Enferm.*, v. 73, n. 2, p.e20180742, 2020. Doi:10.1590/0034-7167-2018-0742

Note

[1] V. M. Milbrath, R. I. B. Gabatz, J. C. Vaz and T. D. Hense: Design, data analysis and interpretation; writing of the article and critical review of the content; final approval of the version to be published; responsibility for all aspects of the paper in ensuring accuracy and integrity related to any of its parts.

Abstract

Vulnerabilidades vivenciadas por familiares/cuidadores de crianças com condição crônica

Objetivou-se conhecer as vulnerabilidades vivenciadas pelos familiares/cuidadores de crianças com condição crônica. Pesquisa qualitativa sustentada pelo referencial teórico do filósofo francês Roselló, da qual participaram 15 familiares/cuidadores de crianças com condições crônicas. As informações foram coletadas nos anos de 2018 e 2019 e submetidas à análise temática. Os resultados são apresentados em três temas: A doença como expressão da vulnerabilidade do ser criança; A doença crônica da criança como condição de vulnerabilidade do familiar/cuidador; O suporte das redes de apoio: potencialidades e vulnerabilidades no cotidiano da criança com condição crônica e do familiar/cuidador. Conhecer os componentes da vulnerabilidade vivenciados pelas famílias das crianças com condição crônica é algo complexo, pois exige refletir sobre as situações que essas famílias enfrentam, tendo em vista suas peculiaridades, sentimentos, organização familiar e acessibilidade aos serviços de saúde. Portanto, o conhecimento acerca do contexto em que essas famílias estão inseridas é fundamental para que se possa estabelecer um planejamento adequado das ações de saúde voltadas à promoção de seu bem-estar.

➤ **Palavras-chave:** Criança. Doença crônica. Família. Saúde da criança.