PSICOLOGIA EM ESTUDO

ARTICLE 10.4025/psicolestud.v30i0.60868

EXPERIENCES OF FAMILY MEMBERS IN CARING FOR CHILDREN HOSPITALIZED WITH COMPLEX CHRONIC CONDITIONS[1]

Luana Rodrigues de Oliveira Tosta[2] [3], Orcid: https://orcid.org/0000-0002-6033-2299
Conceição Aparecida Serralha[1] [4], Orcid: https://orcid.org/0000-0003-4916-7410

ABSTRACT: Complex chronic conditions in childhood are characterized by irreversible clinical conditions, technological dependence for survival, prolonged hospitalization, and severe physical and/or cognitive limitations. This study aimed to understand the experiences of family members, the primary caregivers, in providing daily care to hospitalized children with complex chronic conditions. To this end, qualitative research was conducted in the hospital rooms of children who had lived there since birth, with no contact with the outside world. Nine family members of these children were interviewed using a semi-structured interview guide, and thematic analysis and the Winnicottian framework were used to analyze the data and discuss the results. Aspects that comprise and characterize the care relationship between family members and their children were identified. Environment and time were decisive factors in the experience of caring for the child in these families' daily hospital routine. To broaden the perspective beyond the technologies, techniques, and diagnoses that surround them, the subjective aspects of family members, which permeate the complex dimension of childcare, must be considered.

Keywords: Hospitalization; child; chronic disease.

A VIVÊNCIA DOS FAMILIARES NO CUIDADO DE CRIANÇAS HOSPITALIZADAS EM CONDIÇÕES CRÔNICAS COMPLEXAS

RESUMO: As Condições Crônicas Complexas na infância são caracterizadas por um quadro clínico irreversível, dependência tecnológica para garantia de sobrevida, hospitalização prolongada e limitações severas a nível físico e/ou cognitivo. O objetivo deste estudo é compreender as experiências dos familiares, cuidadores principais, no cotidiano de cuidados destinados às crianças hospitalizadas em Condições Crônicas Complexas. Nesse sentido, desenvolveu-se uma pesquisa qualitativa no cenário de um quarto hospitalar, onde essas crianças estão residentes desde o nascimento, sem nenhum contato com o meio externo. Foram realizadas entrevistas semiestruturadas com nove familiares dessas crianças e utilizou-se a análise temática e o referencial winnicottiano para a análise dos dados e discussão dos resultados, sendo identificados aspectos que compõem e caracterizam a relação de cuidado estabelecida entre os familiares e seus filhos. Observou-se que os fatores ambiente e tempo foram determinantes na experiência de cuidado com a criança, no cotidiano hospitalar dessas famílias. Destaca-se a importância de se considerarem os aspectos subjetivos dos familiares, que perpassam a dimensão do cuidado complexo com os filhos, na direção de se ampliar o olhar para além das tecnologias, técnicas e diagnósticos que os cercam.

---

[1] Setion editor: Letícia Cavalieri Beiser de Melo

[2] Universidade Federal do Triângulo Mineiro, Uberaba-MG, Brazil.

[3] E-mail: luana.ro.tosta@hotmail.com

[4] E-mail: serralhac@hotmail.com

Palavras-chave: Hospitalização; criança; doença crônica.

LA EXPERIENCIA DE LOS FAMILIARES EN EL CUIDADO DE NIÑOS HOSPITALIZADOS COM CONDICIONES CRÓNICAS COMPLEJAS

RESUMEN: Las enfermedades crónicas complejas en la infancia se caracterizan por un cuadro clínico irreversible, dependencia tecnológica para asegurar la supervivencia, hospitalización prolongada y limitaciones severas a nivel físico y/o cognitivo. El objetivo de este estudio es conocer las experiencias de los familiares, cuidadores principales, en el cuidado diario de los niños hospitalizados en Condiciones Crónicas Complejas. En este sentido, se desarrolló una investigación cualitativa en el escenario de una habitación de hospital, donde estos niños residen desde su nacimiento, sin ningún contacto con el entorno exterior. Se realizaron entrevistas semiestructuradas a nueve familiares de estos niños y se utilizó el Análisis Temático y el referencial winnicottiano para el análisis de los datos y la discusión de los resultados, identificando los aspectos que componen y caracterizan la relación de cuidado que se establece entre los familiares y sus hijos. Se observó que los factores entorno y tiempo fueron decisivos en la experiencia de los cuidados con el niño, en la vida diaria hospitalaria de estas familias. Cabe destacar la importancia de considerar los aspectos subjetivos de los familiares, que atraviesan la dimensión de la atención compleja con sus hijos, en la dirección de ampliar la mirada más allá de las tecnologías, técnicas y diagnósticos que los rodean.

Palabras clave: Hospitalización; niño; enfermedad crónica.

Introduction

Recent pediatric studies have revealed a shift in the epidemiological profile of children in the context of a modern capitalist landscape. Technological advancements ensure the survival of babies and children who would have otherwise not developed (Carvalho et al., 2019; Pinto et al., 2019). Consequently, the number of children with chronic diseases is growing, necessitating research that contributes to care consistent with the specific needs imposed by such health conditions (Moreira et al., 2017; Silva & Moreira, 2021).

This study highlights the reality of children with complex chronic conditions (CCC) and their families, mothers, and fathers who provide primary care. CCCs are predominantly irreversible and refer to a group of children with severe functional limitations who depend on technology to survive. CCCs include different diagnoses and clinical presentations, but they are united by similarities, such as technological dependence, a history of long or recurrent hospitalizations, the need for specialized and continuous care from different health services, whether in hospital or home settings, and the presence of multisystemic diseases associated with the clinical condition (Carvalho et al., 2019; Castro & Moreira, 2018; Moreira et al., 2017).

Family members' accounts of their experience accompanying and caring for children with CCC involve aspects of loneliness, fear, anxiety, pressure, and social isolation, health and sleep impairment, and emotional and physical exhaustion (Woodgate et al., 2015). They spend a large part of their time in the hospital, facing emotional vulnerabilities, stress, and economic and social changes (Moreira et al., 2017; Ribeiro & Calado, 2017).

Considering the topicality of the theme and the social isolation to which these children are subjected, it is noted that “[...] Complex chronic health conditions in childhood, due to their novelty, still do not have a place in the social imagination" (Paez & Moreira, 2019, p. 11). Furthermore, contact with malformed bodies and unnatural technologies that guarantee the survival of these children causes an initial sense of strangeness, demanding constant approaches and adaptations that facilitate possible care (Paez; Moreira, 2016).

Studies in this area are recent and still scarce, and although it is an emerging theme in public health policy, many issues are undervalued, such as the psychological and behavioral aspects experienced by children and their families (Carvalho et al., 2019; Moreira et al., 2017). Therefore, the objective of this study was to understand the experiences of family members, the primary caregivers, in providing daily care to hospitalized children with complex chronic conditions (CCC).

Method

This was a qualitative research study conducted in a pediatric hospital ward. The space consists of six beds where children with CCC who cannot be discharged or have contact with the outside world are placed. Most of these patients were initially hospitalized for several years in the Neonatal Intensive Care Unit (NICU) before being transferred to the pediatric ward to improve the quality of life for the children and their caregivers.

All family members accompanying and caring for children with CCC were invited by telephone to participate in the study. Out of eleven invited, three fathers and six mothers were interviewed, with two fathers declining. The mothers' ages ranged from 22 to 47 years, while the fathers' ages ranged from 25 to 54 years. Family income ranged from one to two and a half minimum wages. Three of the mothers quit their jobs to care for their children, and three of them had stable jobs, as did all of the interviewed fathers. Three participants had more than one child in addition to the hospitalized child. Family members spent between two and ten hours per day inside the hospital.

The children's ages ranged from two to eight years old, and their length of stay ranged from one to seven years. Most required the use of technology, such as mechanical ventilation, tracheostomy, gastrostomy, and thermal blankets for body temperature regulation. Despite the severity of their condition, the children presented clinical stability, with most being in a vegetative, unconscious, or semi-conscious state. Only one child had preserved cognitive function but severe physical, motor, and language impairments. Hydrocephalus and progressive spinal muscular atrophy (SMA type I) were confirmed diagnoses, though three family members could not determine their child's diagnosis, and one stated that the diagnosis was undefined.

Data were collected in 2020, at the beginning of the COVID-19 pandemic, when hospital restrictions affected the methodology of this research. Initially, two stages were planned: an analysis of medical records and an observation of family members and children in the hospital environment, but these had to be suspended. Initially, the researcher administered a socioeconomic questionnaire. Then, individual face-to-face interviews were conducted using a semi-structured guide. These interviews were audio-recorded and transcribed in full. Initial contact was made with the mothers, which facilitated communication with the fathers. The fathers were also invited to participate in the study. The researcher adapted to the participants' needs, traveling to their homes when necessary. Most participants opted to conduct the interviews in a room at the university near the hospital.

Thematic analysis, which focuses on identifying thematic patterns, was used to identify, organize, describe, and analyze the data (Braun et al., 2019; Souza, 2019). Following the authors' guidelines, after a skimming reading of the interviews and familiarization with the data, we organized the analysis using tables in three stages. We revisited and reorganized the data throughout the process. The results were organized into two main thematic categories with subdivisions. Then, the results were interpreted and discussed in relation to studies from the reviewed literature on the context of CCC, in dialogue with D. W. Winnicott's theory of maturational processes.

The presentation and organization of the data were carefully constructed to preserve the identity of the family members and their children. They were presented as 'Family Member 1' (F1), 'Family Member 2' (F2), and so on, in sequential order. This research was approved by a research ethics committee under registration number CAAE: 30155320.6.0000.5154, and all requirements for research involving human subjects were met. All participants signed an informed consent form as required by resolutions No. 466 of December 12, 2012, and No. 510 of April 7, 2016.

Results and Discussion

The possible daily routine: the reality of family members caring for hospitalized children with CCC

The results showed that the hospital routine for family members, the primary caregivers of children with CCC, is intense, with physical and emotional burden predominantly assumed by the maternal figure, which is in line with scientific literature on the subject (Alves & Bueno, 2018; Alves & Fleischer, 2018; Fleischer & Franch, 2015; Martins et al., 2018; Paez & Moreira, 2021; Woodgate et al., 2015). Family members indicated difficulty naming and describing their experience caring for their children. They repeatedly stated that it was an unimaginable and inexplicable reality understood only by those who experience it.

> It is an experience that cannot be described, and it is pointless for anyone to try. The only mothers who can understand me are [cites the names of some mothers of children with CCC], and even then, maybe not! Sometimes, what's a negative point for me is a positive point for her, and vice versa. I consider those who go through it [...] for six months […] over a year in, so they can really see what it's like (F3).

In this account, it becomes evident how the experience of a family member and primary caregiver of a child with CCC is complex and very specific. Even though family members are in the same context and deal with similar conditions with their children, they have very particular ways of facing and perceiving reality, as F3 stated. Therefore, an analysis must consider the length of stay, the difference in the children's diagnoses, the psycho-emotional, social, and cultural conditions, and the personal maturation of each individual (Moreira, 2019).

The interviewees' difficulty in defining their experience can be associated with the traumatic dimension. The condition of complex chronic illness is not a matter of choice or imagination for family members. The diagnosis suddenly and forcefully enters their lives, requiring them to adapt to this condition (Moreira, 2019). Due to the social invisibility that these children experience, as well as the fact that they challenge what is expected within an order of *normality*, the participants had difficulty expressing their experiences. According to Paez and Moreira (2016), this difficulty seems to reflect something traumatic and violent in their lives. "Because, for me, this is very difficult [...] It's been four years, but [...] [crying]. I never get used to it. I try to live like this one day at a time, you know?" (F1).

> I was very upset, because I never thought I would go through this [...] At first [...] Oh no! I didn't understand, I didn't accept it, and [...] it went on like that [...] and sometimes I accept it, sometimes I don't, I'm not going to tell you that I accept it [...] (F6).

Family members expressed the pain of an unavoidable daily routine to which they cannot adjust, even though they must adapt. Their responses converge on the difficulty of being separated from their children daily. They are subject to hospital rules that limit the time they can spend with their children in the institution. For this reason, they experience the daily pain of being separated from their children, who, although clinically stable, have severe conditions and a certain degree of instability. This causes insecurity, anxiety, and guilt when parents cannot be present for personal reasons or when the institution restricts their presence.

At the same time, reports were common, mainly from parents of children with longer hospital stays, indicating the appropriation of daily care for their children, demonstrating a movement toward autonomy and independence: "We never let anyone bathe our daughter either, no, because we don't accept it [laughs], I take responsibility [...]" (F2). "The girls [nursing technicians] help me bathe him [...] I bathe him, I change his diaper, do the suctioning, I just don't give him medicine or his diet, they do that [...]" (F6).

Similar to what Simonato et al. (2019) found, it is observed that routine childcare represents the most important dimension of daily life for family members and children. From a Winnicottian perspective, this care refers to *holding*, a term that encompasses all the provision of environmental care that guarantees the survival and continuity of being of the individual dependent on the care of another (Winnicott, 1983).

Perhaps for this reason, the importance of this care was so emphasized in the interviews, as it is the way parents can express and feel love for their children, given that the children have severe limitations in interacting with them. Through listening to these families, parents were creating new ways of caring and gradually building confidence in their own ability to care. Life can recover after traumatic and catastrophic events through the everyday and simple things (Paez & Moreira, 2021; Simonato et al., 2019).

Winnicott (1966/2020) highlighted, in reference to the baby, that it is the repetition of care that subtly establishes its capacity to feel real. According to the author, it is the interaction with caregivers and the predictability of care that establishes the contours of a body and a psyche for the baby, developing its capacity to feel real and alive. Transposing this idea to children with CCC who are severely physically and psychologically dependent and considering their families' emotional vulnerability and fragility, it can be deduced that the repetition of physical and subjective care contributes to these children feeling as real as possible, given their diagnoses.

Although it is impossible to know exactly how children with CCC feel, their place and perspective within the family cannot be overlooked, contributing to an experience of vitality for the child (proprioceptive reactions), albeit in an incipient way. Family members may also feel real in their parental roles, resume the maturation process, and redefine the trauma of hospitalization through their relationships with their children.

Changes in family life after the child's hospitalization

Regarding the changes that occurred in the family after the child's diagnosis and hospitalization, some mothers stopped working to take on caregiving responsibilities at the hospital. Most of those interviewed reported avoiding travel and situations that would require them to be away from the child and the hospital for extended periods; thus, the caregiving routine also began to interfere with their social and leisure activities.

Furthermore, family members described a constant state of worry about the child. They felt torn between providing hospital care, caring for their other children, and working for those who had a paid profession. “We feel a bit divided [...] if I’m there [at the hospital], I’m worried about the [children] here, if I’m here [at home], I’m worried about her 24 hours a day” (F1). “Now it’s more worrying than before, because before he was there with me [at home], [...] now I’m leaving and the worry is much greater [...] Because we don’t know what tomorrow will bring” (F6).

As parents reported, their attention became entirely focused on caring for their children, and issues related to self-care became secondary needs, since their children were the priority. It is important to highlight that these children live in the hospital, which is different from most cases found in the reviewed studies regarding long hospitalizations. In those cases, preparation was made for discharge from the hospital and for home care. In the present study, however, family members reported an overload in relation to the care required but also defended their autonomy in providing it. This seems to be a way of guaranteeing and sustaining the role of the father and mother in an environment that often proves to be invasive and delegitimizes the role of the family caregiver.

There were also mentions of changes in the way they felt love for their child, which seemed to intensify in the face of daily distance and separation, when they returned home and left their children in the hospital.

> What I feel for him is inexplicable [...] Now, right? Because before [...] We say *mother’s love and all that*, but it’s because the child is close by, right? And after he’s far away [...] I think it’s more, you know? The love is much greater because it changes a lot (F6, emphasis added).

According to Novaes (2018), mothers of children with rare diseases have unique experiences and challenges, as well as a unique sense of love. They must cope with the reality of urgency and the possibility of losing their child at any moment. The concept of caring for these children has many meanings, and because these diseases are incurable, the chronic condition will always be present. This demands constant adjustments and rearrangements from parents as they learn to live with the illness, but also despite and beyond it (Fleischer & Franch, 2015).

Given these reflections, it is important to consider the implications of changes in the mental health of family members. Some of them addressed this issue in the interviews, considering risk and protective factors for coping with possible illnesses.

> After [child’s name] came here, I was out of work for almost two years. I’m already a quiet person, you know? So, after the experience of being in the hospital, I decided to go back to work before something happened [...] because we could get depressed [...] or experience something other than depression, you know? (F6).

It is worth noting that, during the data collection period, the pediatric ward was without a psychologist or occupational therapist because the reference professionals had retired, and their positions had not been filled. Only one mother received psychological support within the hospital, as she requested it from the psychology department. Most of the other family members interviewed expressed doubts about accepting or not accepting psychological care due to time constraints or strained relationships with hospital staff. This made it difficult for them to have confidence in the care provided. According to some interviewees, this ultimately led them to *sense* a state of mental illness, as in the account of F6.

Thus, it was noted that many of them sought ways to defend themselves from anguish or the possibility of depression, whether through work or religion. However, this dynamic must be carefully evaluated, because, according to Winnicott (2021), this movement can characterize a "[...] flight toward sanity [...]", which "[...] is not synonymous with health" (p. 14). For this author, a defensive and non-spontaneous movement can be observed, in which the wounded and traumatized individuals present a *façade*, a false *self* whose unconscious function is to protect the true *self* from further suffering.

According to the author, the organization of a false *self* is usually easily accepted in society, and, in a hospital context, the institution may, in a way, demand and sustain this dynamic of a false *self*, considering that the valued family members are those who appear *well-behaved*, independent, strong, and patient. This possibility corroborates the need for studies on the hospital environment to understand its influence on the development of parenthood in the context of CCC.

Implications of the pandemic on family care for children with CCC

The COVID-19 pandemic was a factor that interfered with the data collection process for this study. It is important to contextualize that, since the room is small and has six beds, the coexistence of children with family members and staff constitutes crowding, which is a risk factor for the spread of the virus, and required the institution to implement some regulations. In the interviews, participants did not report significant changes regarding the procedures required by the child's condition; they only pointed to the intensification of hygiene care, aiming at preventing contagion.

Nevertheless, family members were unanimously uncomfortable with the hospital's decision to limit the presence of the father or another family member who provided additional care for the child to 30 minutes. Thus, only the primary caregiver, usually the mother, had unrestricted access to the institution.

> The schedule is what makes it difficult now, right? Because I get there and I want to spend more time with her [...] you know? And what happens? Twenty [...] twenty-five minutes go by, and I start looking at the clock [...] I would like to spend more time with her (F5).

The study by Martins et al. (2018) addresses the issue of balancing mothers' autonomy in their relationships with their children with the risk of placing an excessive burden of care on them, particularly those with a history of long hospital stays, which represents a social problem. Although limiting one family member in the room was a restrictive and difficult action, it is important to note that the sanitary measures adopted during the pandemic were crucial for containing the virus and reducing the number of deaths.

In this sense, given the restrictive reality, one couple interviewed stood out, as both assumed primary care in a rotating schedule, creating a strategy of alternating every other day to care for their daughter, to ensure that neither of them had to distance themselves from the child's care and routine. Several international studies have highlighted the importance of this alternating dynamic for mothers, fathers, and children (Smith et al., 2015; Woodgate et al., 2015). However, this is not an option for most working fathers, which excludes them from childcare and overburdens mothers.

Family members whose children had been hospitalized for longer periods reported greater emotional involvement with their children and fear of separation from the hospital during the pandemic, as many of the interviewees identified their roles in caring for the child.

> I can't imagine myself without this routine, and the pandemic scared me a lot at first! I was very worried because they banned her father from entering the hospital, and I was thinking, *Oh my god, I can't be without her, she can't be without me* [...] I warned my family that I could move to the hospital at any moment (F4, emphasis added).

Conversely, families with shorter hospital stays, recently arrived in the pediatric ward – one couple had transitioned from the neonatal ICU during the pandemic – were interviewed, and in these cases, it was observed that mothers and fathers distanced themselves from their children, becoming less involved in their care. It is noteworthy that the hospital did not prevent them from touching the children. However, one couple made the joint decision to avoid touching their child as a way to protect them during the pandemic. This decision may reflect the couple's insecurity in handling and caring for the child, as they relied on the rules to justify their personal difficulties. On the other hand, it may indicate a lack of dialogue and mediation from staff regarding the caregiving relationship between these parents and their child, especially during the pandemic, when there were several changes to the hospital setting.

It can be concluded that the pandemic context frightened and caused insecurity among these family members, who had been developing a relationship with the child and becoming involved in their care. It is worth remembering that, although interviewees F7, F8, and F9 had already been accompanying their children in the ICU for a year, the transition to the pediatric infirmary was recent in relation to the data collection period. This led to new adaptations and changes in their relationships with their children. Thus, the environment and time proved to be preponderant factors in the quality of care and in the family members' perception and understanding of their child's condition and the hospital reality, as other studies have pointed out (Alves & Fleischer, 2018; Fleischer & Franch, 2015; Torquato et al., 2020).

Influences of the environment and length of stay on the care relationship between family members and children with CCC

The influences of the environment on the care relationship

In this category, the ICU was perceived as a safe space by family members, staffed by a large team with doctors on call 24 hours a day, trained to handle the most serious and urgent cases. However, considering the chronic nature of these children's illnesses and the preparedness of the intensive care team to handle acute cases, especially premature newborns, some conflicts began to emerge over the course of the children's stays in the ICU. Most interviewees expressed negative views about spending a prolonged period of time with their children in the ICU since the team assumed most of the children's care and did not encourage family members to become involved or take ownership of these tasks.

> There in the ICU, I didn't have that bond. I would just sit down, and they would put her on my lap. I couldn't suction, I couldn't change diapers [...] they wouldn't let me do anything! I could only sit and look at her [...] (F4).

It was observed that the ICU played an important role in the initial hospitalization of children with CCC. However, considering the chronic stability over time, the ICU came to represent an environment that did not meet the needs of the children and their families, precisely because of the sector's restrictions, which hindered contact and autonomy for parents in caring for their children. For this reason, the pediatric ward was viewed positively in the interviews because it allowed parents to have more experiences with their children, giving them more intimacy and autonomy.

> After my daughter was transferred to the pediatric ward, her condition improved significantly! Being able to hold her, do whatever I want, bathe her, take care of her, dress her up, dress her up however I want, is already good! In the ICU, I couldn't even bathe her! Sometimes I could barely hold her [...] I would watch the others take care of my daughter and I [...] Wow! (F1).

In dialogue with Winnicottian theory, the more dependent an individual is, the more influence the environment has on their maturation. More than mechanical predictability is necessary for an individual to constitute themselves as a person: it is fundamental that there be essentially human care. Thus, parents must have the opportunity to discover their role, being sensitive to their children's needs, to trust in the unique care they can provide, even in the face of their imperfections, which makes care something personal (Winnicott, 2020).

Before the pandemic, the pediatric ward emerged as an environment that favored the presence and participation of men in childcare, which eased the burden on mothers since family visits were restricted in the ICU. Due to greater freedom and autonomy in care, mothers requested help handling and manipulating their children, especially when the child was older and heavier, encouraging the participation and involvement of fathers in the process. Furthermore, family members could experience more natural and typical aspects of parenthood, such as bathing and dressing the child, celebrating birthdays, receiving visitors, and providing playful activities.

The birth of a child leads parents to experience new situations that surpass their sense of omnipotence. In this sense, family members depend on an affective environment that supports them and adapts to their needs so they can experience the process of becoming parents more naturally (Serralha, 2018). For children with CCC, the pediatric ward is a significant space for mediation, allowing parents to discover motherhood and fatherhood amidst their children's complex conditions.

> In the pediatric ward, it was totally different! I loved it, because now I'll be a mother! A different kind of mother! I thought it would be good for me to be that different kind of mother, because she'll feel more at ease with me and I'll pass that peace on to her (F4).

> In the ICU, we know we're mothers, but, on the one hand, you lose a little bit of the right to have contact with your child, and I think that's even why the children get so sick, because my daughter was always having a fit, and in the pediatric ward, she doesn't because I think she feels our care more, from me and her father (F1).

According to Serralha (2018), parenthood is a processual construction that changes with the objective presence of the baby, as parents assimilate reality and align their expectations and fantasies based on it. In F4's statement, the pediatric ward favored the possibility of experiencing a different and complex motherhood, built on interaction and intimacy with the child. F1 added that her and her husband's care was a health factor for their daughter compared to her pattern of illness in the ICU when she was deprived of affective contact and emotional closeness with her parents. This statement indicates the mother's greater confidence in her and her husband's ability to care for the child.

When addressing the origins of the individual, Winnicott (1966/2020) argues that a baby can only survive if it has an environment that provides the necessary conditions. In this sense, the author points out that, in states of greater physical and emotional dependence, as is the reality of a baby, the care received is an integral part of the individual to whom it is linked. Similarly, the care provided by family members to children with CCC is a factor of health even within the context of illness, as stated by F1, these children can survive thanks to technology, but they can only thrive in a human way through human attention and care. In this direction, the interviewees reported that their children significantly exceeded the life expectancy range defined by doctors and the scientific literature on their diagnoses. This demonstrates the quality of care that the children have received.

Regarding the transition process between the two sectors, negative aspects were observed, whose evaluation should include the emotional state of each family member to deal with this process, and how the teams conducted it. Some family members associated the transition to the pediatric sector with the child's discharge home, which was particularly evident in the accounts of family members newly arrived at the ward, who were still assimilating the reality experienced in that room where the patients live. A pattern of fear was also observed in the mothers' accounts, stemming from the sector transfer process, as they heard negative aspects from ICU professionals about the work done in the pediatric ward, which fueled their fears and insecurities and caused them to suffer unnecessarily.

There were recurring complaints among family members, such as the lack of comfort and privacy to feel more at ease and spend more time with the child. The space was shared with others, and there were not enough activities to diversify the children's reality, such as going outside and getting some sun.

> I used to stay in a room alone [before the transition between sectors [...] it was me, her, and our time [voice breaking]. And then there were five more different families, five more sets of thoughts, five mothers, five routines plus yours, you understand? And [...] you don't have privacy with your child. Like, sometimes I lie there with my daughter, cover our heads, so we can feel more comfortable, because there's no other way (F3).

Most of those interviewed reported that these environmental difficulties are what wear them down, as they do not feel that caring for the child is tiring. There were complaints about excessive light and noise in the environment, which go against the children's need for rest and protection, needs that are poorly respected by the staff. Furthermore, according to some of them, they felt inhibited in their spontaneity by the presence of other family members and staff in the room, limiting their ability to play with, talk to, and pray for their children, for example.

By encompassing all relational and emotional aspects and not restricting themselves to the physical dimension, the interviewees approach the Winnicottian concept of environment. According to the author, a human environment is constituted by emotional involvement and by people who are committed to caring for individuals effectively, affectively, and appropriately. Those who receive this kind of care can internalize it and begin to create and contribute to a personal environment, directing it toward caring for others (Serralha, 2016).

This is the personal environment that the interviewed family members reported missing, an environment that could contribute to less strain during hospitalization and help them discover a more spontaneous parenting style. In this way, the concept of holding can be recovered, which, beyond technical and care procedures, involves care at an emotional and personal level, sustained in space and time, allowing for measured, non-invasive contact with reality (Serralha, 2016). This is especially important for children with CCC and their parents, particularly those in a vulnerable emotional state.

The influence of time on the caregiving relationship

When discussing the provision of human environmental care in states of greater individual dependence, *reliability* is the central word associated with this personal environment, which is the result of continuous care, a process that takes place over time (Winnicott, 2021). Given that CCCs impose a persistent state of severe physical and emotional dependence, time was a preponderant factor in the results of this study. In the data analysis, the concept of time appeared with a double connotation: positive, from the relational perspective of family members with the child, and negative, when considering the strain of hospitalization and the relationship with the team, whose conflicts gain space over time.

Contextualizing the daily life described by family members, many of them established a counterpoint between the beginning and the course of hospitalization, regarding their emotional conditions and capacities for the exercise of care. It was noted that this care changed positively over time and with the clinical stability of the child.

> She was a child who always kept her eyes closed. She had little stimulation, and I didn't have much knowledge, so I thought there was nothing I could do; I couldn't talk to her or have any more contact, you know? As time went by, however, I realized that if I went there and talked to her now, she would open her eyes (F3).

According to Alves and Fleischer (2018), chronological and subjective time are threads that run through and guide relationships, considering that the temporal dimension is related to acquired experiences and knowledge, which allow for adapting and reconfiguring daily life. Safra (2005) highlights that the self is organized through different ways of occupying space, as well as through various senses of time. For the author, chronological time favors the spatial organization of lived experiences and the apprehension of shared reality, while, in subjective time, the existence and vivacity of the infant are discovered in the presence of another who is also part of the baby. “It is a time that, having arisen from the child's unique rhythm, is part of and is their self. It is the fruit of the individual's continuous being and removes them from the void of eternity and non-being” (SAFRA, 2005, p. 62).

Along these lines, Winnicott (2020, p. 80) points out that “[...] mothers and fathers, in general, grow together with each child in a very subtle way”. Such reflections are in line with the accounts of mothers, such as that of F3, who described the subtle details and ways in which her child was and communicated, which she recognized over time: as she discovered that her daughter could be stimulated to open her eyes, she also broadened her view of the whole and real child.

The data presents this discovery by parents about the care relationship with their child, but also about themselves and their abilities:

> So, at first it was kind of scary [...] having to change the fixation, which can't come off, because she stops breathing! But then, over time, I saw that it doesn't move. Then I started talking to her: “Mommy is going to change your fixation, because it's very wet. Will you stay still so Mommy can change it?” Then I went [...] alone! I held it, changed the gauze, changed the fixation, and removed it, wiped it with a dry cloth, put the other one on, and that was it! (F4, emphasis added).

Care is a dimension that encompasses a variety of meanings, interwoven with different times and experiences, so that there are many realities for the same subject at different moments in their life, especially when dealing with *long illnesses* (Fleischer & Franch, 2015). In association with Winnicottian theory, it can be thought that, more than discovering what to do and how to care for children with CCC, these family members are resuming their continuity of being, being a father or mother. A healthy process of being involves the possibility of discovering one's spontaneous gestures and personal ideas, allowing one to be creative and feel real, existing from a true *self* (Winnicott, 1983).

Through the theory of human maturation, there will only be a relationship if the parties involved can be themselves. In this sense, creativity is a human experience that involves a personal journey to find something or someone, which is inherent to being alive (Winnicott, 2021). Thus, considering the severe brain limitations of most children with CCC in this study, the importance of the family's role in care is evident, in the sense of offering their children something alive, human, and affectionate, even if the children cannot respond to them to the same extent. In the participants' accounts, it was noted that, over time, mothers and fathers discovered the life within their children, while simultaneously discovering and feeling their own vitality.

However, recognizing that the child is growing up in the hospital proved difficult for the parents because it exposed them to an ambiguous experience: following their child's development revealed the dimension of finitude and the possibility of losing their child. "Actually, I live with a lot of fear, you know? If I come here ten times to see her, I say goodbye to her ten times as if it were the last time" (F3).

> For me, she'll always be my little baby [...] I know she's growing up, but it's nice to take care of her when she's little [...] I look and I still see that little baby [...] So, I don't have to think too much about her growing up one day (F1).

Some interviewees expressed concern about their children growing up because they may go through age transitions. This would imply significant changes in hospital care, as they would no longer be under the responsibility of pediatrics, but rather, adolescents and/or adults. One mother expressed distress over her child's precocious puberty, a consequence of her diagnosis. This awakened taboos about menstruation in childhood experienced by the interviewee.

Considering the restricted growth of children with CCC in a hospital setting, it is understood that family members are constantly confronted with the reality of finitude. F1's speech may reflect an unconscious desire to stop time and avoid looking at a growing child who exposes the possibility of death. According to Novaes (2018), family members are caring for two children at once: one who can grow and develop within their limitations and exceed life expectations, and another who experiences gradual losses. Family members live in anticipatory grief with each passing day.

Final considerations

Based on the results presented, particularly those related to the last category, organized according to the elements of time and environment, it is possible to consider that caring for children with CCC involves something very specific to human uniqueness. According to Safra (2005), even if all babies were born with the same inherited potential, the dimensions of time and space would be essential for the constitution of a unique way of being, in which the presence and body of the mother and father in contact with the child, as well as their cultural background, play a significant role in this personal constitution. Thus, this study contributes to a broader perspective on the uniqueness and subjective dimension of these children and their families, rather than restricting them to the clinical dimension of illness.

From a Winnicottian perspective, the capacity to feel real is a gradual process, built up in relation to others, over time, and in a specific space. Therefore, the importance of the support from the hospital and professionals is highlighted, as it is the parents' experience of vitality that allows them to see their children as more than just sick bodies. This study observed that parental emotional involvement with their children was a significant factor because the motivation for care was fueled by the emotional experience of caregiving itself.

The autonomy of family members in providing care has gradually been established and is understood as a health factor because it strengthens and deepens the emotional bond with the child. The importance of these aspects in promoting the mental health of family members of children with CCC must be emphasized because when the team facilitates this caregiving relationship without interfering, family members report that their relationship with the child strengthens them. Thus, the team is simultaneously caring for these family members and strengthening them in the process of establishing parenthood within a complex scenario. Thus, the role of psychology in the hospital setting is emphasized, particularly in caring for family members of children with CCC and mediating their relationships with healthcare teams.

Studies on the hospital environment are necessary to understand how environmental factors influence the development of parenthood in the context of CCC. Beyond ensuring the organic survival of these patients through technical, pharmacological, and technological aspects, it is essential to expand healthcare actions and care by considering the histories and subjectivities of family members to guarantee a real and possible existence, at least. Understanding and considering the unique experiences of these family members will contribute to a humane and supportive environment adapted to the conditions necessary for emotional maturation and the different needs of children and their families in this context.

The involvement of family members with their children's extreme dependency states also led them to experience a type of dependency, particularly in emotional care and a human environment. Family members experience emotional vulnerability, leaving them exposed to potential suffering and illness. Therefore, a facilitating environment, a function that can be performed by the hospital staff, helps family members to get closer to their children, get to know them, and adapt to their rhythms, needs, and specific ways of being and communicating. For this reason, the importance of professionals assuming the psychosocial role of care is reaffirmed. In this study, this role was lacking due to the absence of psychologists and occupational therapists in the pediatric ward.

It is worth noting that the development of this study was affected by the pandemic, leading to changes in the initial objectives. The original goal was to collect diverse data through immersion in the hospital setting. Consequently, it was not possible to explore the hospital environment and its influences on children with CCC in greater depth. Nonetheless, the results and discussion with Winnicottian theory contributed to an in-depth analysis of family members' experiences and relational environment with children with CCC, as well as the constitution of parenthood in this scenario. Therefore, this research is expected to raise awareness of children with CCC and their families, who need support to continue providing care for their children.

References

Alves, R. L. C., & Fleischer, S. (2018). 'O que adianta conhecer muita gente e no fim das contas estar sempre só?' desafios da maternidade em tempos de Síndrome Congênita do Zika Vírus. *Revista Anthropológicas, 29*(2), 6-27.

Alves, S. P., & Bueno, D. (2018). O perfil dos cuidadores de pacientes pediátricos com fibrose cística. *Ciência & Saúde Coletiva, 23*(5), 1451-1457.

Braun V., Clarke, V., Hayfield, N., & Terry, G. (2019) Thematic analysis. In: P. Liamputtong (Ed.), *Handbook of research methods in health social sciences.* Springer.

Carvalho, M. S. N., Menezes, L. A., Cruz Filho, A. D., & Maciel, C. M. P. (2019). *Desospitalização de crianças com condições crônicas complexas: perspectivas e desafios*. Editora Valentina.

Castro, B. S. M., & Moreira, M. C. N. (2018). (Re)conhecendo suas casas: narrativas sobre a desospitalização de crianças com doenças de longa duração. *Physis: Revista de Saúde Coletiva, 28*(3), 1-19.

Fleischer, S., & Franch, M. (2015). Uma dor que não passa: aportes teórico-metodológicos de uma antropologia das doenças prolongadas. *Política & Trabalho: Revista de Ciências Sociais, 42*, 13-28.

Martins, P. L., Azevedo, C. S., & Afonso, S. B. C. (2018). O papel da família nos planos de tratamento e no cuidado pediátrico hospitalar em condições crônicas complexas de saúde. *Saúde e Sociedade, 27*(4), 1218-1229.

Moreira, M. C. N. (2019). Trajetórias e experiências morais de adoecimento raro e crônico em biografias: um ensaio teórico. *Ciência & Saúde Coletiva, 24*(10), 3561-3661.

Moreira, M. C. N., Albernaz, L. V., Calheiros de Sá, M. R., Correia, R. F., & Tanabe, R. F. (2017). Recomendações para uma linha de cuidados para crianças e adolescentes com condições crônicas complexas de saúde. *Cadernos de Saúde Pública 33*(11), 1-13.

Novaes, D. (2018). *Mães raras, essas mulheres fortes*. Pólen.

Paez, A. S., & Moreira, M. C. N. (2016). Construção de maternidade: experiência de mães de crianças com síndrome do intestino curto. *Physis: Revista de Saúde Coletiva, 26*(3), 1053-1072.

Paez, A. S., & Moreira, M. C. N. (2019). Sobre a performance de sofrimento na web: narrativas de mães de crianças com condições crônicas complexas de saúde em uma revista eletrônica. *Physis: Revista de Saúde Coletiva, 29*(1), 1-18.

Paez, A. S., & Moreira, M. C. N. (2021). Dádivas e testemunhos: o compartilhamento de experiências e memórias de mães de crianças com condições crônicas complexas de saúde. *Cadernos de Saúde Pública, 37*(1), e00046820.

Pinto, M., Gomes, R., Tanabe, R. F., Costa, A. C. C., & Moreira, M. C. N. (2019). Análise de custo da assistência de crianças e adolescentes com condições crônicas complexas. *Ciência & Saúde Coletiva, 24*(11), 4043-4052.

Ribeiro, S. E., & Calado, G. (2017). Necessidades em cuidados de enfermagem às famílias de crianças com doenças crônicas. *Revista Íbero-Americana de Saúde e Envelhecimento – RIASE, 3*(3), 1166-1179.

Safra, G. (2005). *A face estética do self: teoria e clínica.* Ideias & Letras.

Serralha, C. A. (2016). *O ambiente facilitador winnicottiano: teoria e prática clínica*. CRV.

Serralha, C. A. (2018). *"Não atendo criança": situações de risco para a não constituição do si mesmo individual*. CRV.

Silva, M. F., & Moreira, M. C. N. (2021). Dilemas na regulação do acesso à atenção especializada de crianças com condições crônicas complexas de saúde. *Ciência & Saúde Coletiva, 26*(6), 2215-2224.

Simonato, M. P., Mitre, R. M. A., & Galheigo, S. M. (2019). O cotidiano hospitalar de crianças com hospitalizações prolongadas: entre tramas dos cuidados com o corpo e as mediações possíveis. *Interface (Botucatu), 23*, e180383.

Smith, J., Swallow, V., & Coyne, I. (2015). Involving parents in managing their child's long-term condition: a concept synthesis of family-centered care and partnership-in-care. *Journal of Pediatric Nursing, 30*(1). 143-159.

Souza, L. K. (2019). Pesquisa com análise qualitativa de dados: conhecendo a Análise Temática. *Arquivos Brasileiros de Psicologia, Rio de Janeiro, 71*(2), 51-67.

Torquato, R. C., Rovere, G. P., Pitombeira, M. G. V., Pereira, A. S., & Santos, L. K. X. (2020). Preparação para o cuidar de crianças com doenças crônicas: a percepção dos cuidadores. *Revista Rene, 21*, 01-08.

Winnicott, D. W. (1983). *O ambiente e os processos de maturação: estudos sobre a teoria do desenvolvimento emocional*. Artes Médicas.

Winnicott, D. W. (2020). *Bebês e suas mães*. Ubu.

Winnicott, D. W. (2021). *Tudo começa em casa*. Ubu.

Woodgate, R. L., Edwards, M., Ripat, J. D., Borton, B., & Rempel, G. (2015). Intense parenting: a qualitative study detailing the experiences of parenting children with complex care needs. *BMC Pediatrics, 15*, 197.

Data Availability Statement: The dataset supporting the results of this study is available within the article.

Received: Sep. 12, 2020
Approved: Nov. 15, 2022