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RESEARCH ARTICLE (ORIGINAL)

Family Management Styles of Chronic Childhood Conditions: The caregivers' perspectives

Gestão familiar de crianças com condições crónicas: Perspetivas dos cuidadores
Gestión familiar de niños con enfermedades crónicas: Perspectivas de los cuidadores

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Abstract

Background: Different management styles can modify families' functioning, favoring or compromising the care delivered to chronic childhood conditions.
Objective: To analyze primary caregivers' perspectives on family management of chronic childhood conditions.
Methodology: This qualitative study is based on the Family Management Style Framework (FMSF). Thirty-eight (38) interviews were conducted with 38 caregivers of chronically ill children attending a health institution in southeastern Brazil. The data were submitted to deductive thematic analysis.
Results: Having a child with chronic illness was described as challenging and causing suffering, requiring families to reorganize their family routines to meet the chronically ill child's needs. The "perceived consequences" revealed families' perspectives and fears about the future and their recognition of the results of the "management behaviors" adopted. The family management styles identified were: "thriving," "accommodating," "struggling," "floundering," and "enduring."
Conclusion: The primary caregiver's ability to manage the chronically ill child's needs depends on their access to professional, care, and intra-family resources.

Keywords: nursing care; caregivers; chronic disease; child health; family health

Resumo

Enquadramento: Diferentes estilos de gestão podem modificar o funcionamento familiar, favorecendo ou comprometendo o cuidado das condições crónicas na infância.
Objetivo: Analisar, na perspetiva do cuidador principal, a gestão familiar em situações que envolvem condições crónicas na infância.
Metodologia: Estudo qualitativo, orientado pelo Family Management Style Framework, realizado a partir de entrevistas com 38 cuidadores de crianças com condições crónicas, atendidas numa instituição de saúde do sudeste brasileiro. Os dados foram submetidos a análise temática do tipo dedutiva.
Resultados: A situação da condição crónica é definida como difícil e causadora de sofrimento, exigindo uma reorganização da rotina familiar para atender às exigências da criança. As consequências percebidas expressam perspetivas e receios sobre o futuro e reconhecimento dos resultados dos comportamentos de gestão adotados. foram identificados estilos de gestão como a família ajustada, em adaptação, em luta, em conflito e em espera.
Conclusão: A capacidade do cuidador principal em gerenciar as necessidades da criança com condição crónica, de forma positiva, depende do acesso aos recursos profissionais, assistenciais e intrafamiliares.

Palavras-chave: cuidado de enfermagem; cuidadores; doença crónica; saúde da criança; saúde da família

Resumen

Marco contextual: Los diferentes estilos de gestión pueden modificar el funcionamiento familiar, lo que favorece o compromete el cuidado de las enfermedades crónicas en la infancia.
Objetivo: Analizar, desde la perspectiva del cuidador principal, la gestión familiar en situaciones de afecciones crónicas en la infancia.
Metodología: Estudio cualitativo, orientado por el Family Management Style Framework, realizado a partir de entrevistas a 38 cuidadores de niños con enfermedades crónicas, atendidos en una institución de salud del sudeste de Brasil. Los datos fueron sometidos a análisis temático de tipo deductivo.
Resultados: La situación de la enfermedad crónica se define como difícil y causante de sufrimiento, lo que exige una reorganización de la rutina familiar para atender a las demandas del niño. Las consecuencias percibidas expresan perspectivas y temores sobre el futuro y el reconocimiento de los resultados de los comportamientos de gestión adoptados. Se identificaron como estilos de gestión: la familia ajustada, en adaptación, en lucha, en conflicto y en espera.
Conclusión: La capacidad del cuidador principal para gestionar de forma positiva las necesidades del niño con una enfermedad crónica depende del acceso a recursos profesionales, asistenciales e intrafamiliares.

Palabras clave: atención de enfermería; cuidadores; enfermedad crónica; salud del niño; salud de la familia

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Introduction

Since 2003, the World Health Organization (WHO) has warned of the need for improving the care delivered to chronically ill children and adolescents, underscoring the significance of the matter. However, there is a lack of guidelines on chronic childhood conditions and associated health care and well-being promotion, which has hampered the planning of actions, the organization of healthcare services, and the qualification of health professionals for the comprehensive care of these children and their families (Ichikawa et al., 2018; Nóbrega et al., 2017).

The change in the epidemiological profile of child morbidity demonstrated by the increase in chronic conditions has become a global problem, as well as the need to redirect the care delivery models of healthcare services to serve chronically ill children and their families (Ichikawa et al., 2018; Nóbrega et al., 2017). Chronic conditions are not restricted to chronic illnesses, as they can be determined by multiple biological and non-biological causes, leading to the patient's loss of functionality and requiring continuous care and lifestyle changes (Nóbrega et al., 2017). In addition to the repercussions for the children themselves, evidence shows that chronic childhood conditions change family roles and functioning due to caregiver burden (experienced mainly by primary caregivers, a role performed mostly by mothers), mental suffering, and the increase in the need for care and support from health services. Furthermore, chronic childhood conditions lead to additional expenses with treatments and therapies, the reduction of leisure and self-care activities, and family and marital conflicts due to the experience of situations of constant tension (Mendes, 2022; Robinson, 2017). These factors contribute to a dysfunctional family experience, generating even more suffering and ruptures.

The nursing team plays a fundamental role in facing the challenges posed by chronic childhood conditions as it delivers care to children, their families, and primary caregivers, seeking to present a care plan that guides and supports the family in identifying resources and their potential as a family unit and recognizing and accepting the existing limitations (Vaz et al., 2018).

Thus, this study's premise is that the caregiver's decisions regarding their child's care and/ or how it is provided affect family functioning, favoring or compromising the child's care.

Moreover, this study believes that studying family management-related aspects in the context of chronic childhood conditions can promote the development of sound professional practices (particularly nursing practices) that consider families' needs and provide the most appropriate support for their adaptation. Identifying changes in family management styles during child care provides the support framework to implement practices that, in turn, will assist families' efforts to incorporate positive management strategies regarding their children's chronic conditions. This assumption justifies the present study.

Hence, this study uses the Family Management Style Framework to analyze the primary caregivers' perspectives on family management styles in situations involving chronic childhood conditions.

Background

Chronic childhood conditions can precipitate crises affecting the primary caregiver and the entire family, compromising its functioning (Ichikawa et al., 2018; Silva et al., 2020; Vaz et al., 2018). Also, families' lifestyle restructuring due to chronic childhood conditions has implications for the family members' physical and mental health (Vaz et al., 2018).

To study and intervene in family functioning, nurses need to understand how communication takes place, how family members' roles are played, how parenting, the management of adversities and needs, and decision-making are done, and how family members practice resilience, autonomy, and self-care (Herzer, 2010). Family functioning has proven to be a powerful determinant of chronically ill children's quality of life and well-being. In this sense, adaptive relationships and parental adjustment are identified as positive outcomes. On the other hand, disruptions in family life are associated with primary caregiver burden, emotional and behavioral problems, and difficulties in adhering to health care and therapies (Ichikawa et al., 2018; Mendes et al., 2022; Robinson, 2017).

Studies analyzing how primary caregivers manage adverse situations involving a family member's illness have contributed to highlighting care interventions that health professionals can implement as well as demonstrating how health professionals can make the illness process more manageable and less painful for caregivers (Ichikawa et al., 2018; Oliveira et al., 2018; Gesteira et al., 2020).

Research questions

What are the primary caregiver's perspectives on family management in situations of chronic childhood conditions?; What are the primary caregiver's perspectives on family management styles for chronic childhood conditions?

Methodology

This qualitative study was conducted based on the theoretical and methodological principles of the Family Management Style Framework (FMSF; Knafl & Deatrick, 2006).

The FMSF is a conceptual representation system that allows analyzing the family's response to a child's chronic illness by incorporating the individual family members' views, thus outlining the general patterns of response to situations of adversity (Knafl & Deatrick, 2006). North-american investigators Kathleen Knafl and Janet Deatrick (Knafl & Deatrick, 1990; Knalf & Deatrick, 2003; Knafl & Deatrick, 2006; Knalf et al., 2012; Knafl et al., 2021) developed this framework in the late 1980s. The FMSF has been adopted by research worldwide, as it allows the understanding of families' responses to the demands of chronic childhood conditions, showing the impact these have on families and revealing their adjustment strategies (Knafl & Deatrick, 1990; Knalf & Deatrick, 2003; Knafl & Deatrick, 2006; Knalf et al., 2012; Knafl et al., 2021).

This study adopted the FMSF's three major components: "Definition of the Situation" (how the family views the child's chronic illness, management mindset, and parental mutuality), "Management Behaviors" (parental goals, strategies, and behaviors associated with caring for a chronically ill child), and "Perceived Consequences" (the outcomes or expected outcomes of the family, child, and illness that shape management behaviors) (Knafl et al., 2012; Knafl et al., 2013).

This study was conducted in a healthcare philanthropic institution that provides care for patients with multiple physical and/ or intellectual disabilities in a municipality of the Brazilian state of Minas Gerais. The institution is a non-profit social organization founded in 1970 that currently provides health care and social support services to chronically ill children and their families. The outpatient care provided is classified as a specialty service with a multi-professional team. This study invited primary caregivers of chronically ill children up to 10 years who were diagnosed previously to data collection and used the services offered by the institution. Caregivers with cognitive impairment were not invited to participate in this study as they could have difficulty answering the questions.

Data were collected remotely between May and July 2021 due to the COVID-19 social distancing restrictions at the time. Despite the limitations that remote data collection can bring to qualitative research, this data collection method offered advantages to this study, such as the participants' privacy (participants were at home), the greater flexibility of schedules for conducting interviews, the reduction in travel expenses both for participants and investigators, and the opportunity for participants to present ideas freely, without inhibitions caused by recording devices (Lobe et al., 2020).

This study's investigators created a WhatsApp® account to establish contact with the participants and collect data remotely. The families' contacts were provided by the healthcare institution in which the study was conducted. Next, 279 invitations to participate in the study were sent to all families through the institution. After accepting participation, Informed Consent Form 1 was sent via WhatsApp®, and contact was maintained to clarify doubts and schedule the data collection. Participants could choose how they wanted their interviews to be conducted via WhatsApp® audio messages, text messages, or telephone calls. After receiving the invitation, 77 caregivers demonstrated interest in participating in the study. Nevertheless, only 38 family caregivers participated in the study by answering the research script.

The investigators designed a questionnaire to describe the families' sociodemographic characteristics with open and closed questions based on the CCEB - Brazilian Economic Classification Criteria of the ABEP - Brazilian Market Research Association. Subsequently, the caregivers answered the FMSF questions containing 25 open questions about the family's view of the child's chronic illness. Although the participation in this study focused on the primary caregiver, some questions reflected on dimensions that allowed including the family as a whole. Data were collected individually, at a time scheduled with the participants, bearing in mind the periods more convenient for them. The investigators were available throughout the interview to clarify any doubts participants could have about the questions or the study. Each interview lasted approximately 27 minutes on average.

No new semi-structured interviews were conducted when data theoretical saturation was reached. This occurred when the collected data answered the research questions and met the study's objectives (Nascimento et al., 2018). Data analysis coincided with data collection to identify saturation. Thus, during data coding, it was observed, in the 38th interview, that there were already enough data to meet the study's objectives, and no further interviews were conducted.

All data (text and audio messages) were fully transcribed using Microsoft Word software. Answers were organized, and the participants' identities were coded to guarantee anonymity – each participant was identified with the letter "F" followed by the sequential number of their interview, for example: "F1," "F2," and so on. The transcriptions were done after the interviews with each participant. Participants validated the content of the transcribed WhatsApp® messages, and subsequently, the messages were erased from the application.

The data collected were submitted to a deductive thematic analysis (Braun & Clarke, 2021) and coded according to the FMSF components and dimensions: "Definition of the Situation" ("Child's Identity," "Illness View," "Management Mindset," "Parental Mutuality"); "Management Behaviors" ("Parenting Philosophy," "Management Approach"); and "Perceived Consequences" ("Family Focus," "Future Expectations") (Knafl & Deatrick, 1990; Knafl et al., 2012). The family management styles "thriving," "accommodating," "struggling," "floundering," and "enduring" were applied (Knafl & Deatrick, 2003; Mendes-Castillo et al., 2012).

Two investigators initially coded the data independently, and a more experienced investigator reviewed their coding. After discrepancies were explained, a new round of coding was conducted with a new interview, which again signaled the need for explaining discrepancies. During the third coding round, the more experienced investigator considered the coding processes congruent, allowing each investigator to continue the process. The entire coding process was done using Microsoft Excel software to organize the data. During the analysis process, all doubts were resolved jointly by the investigators.

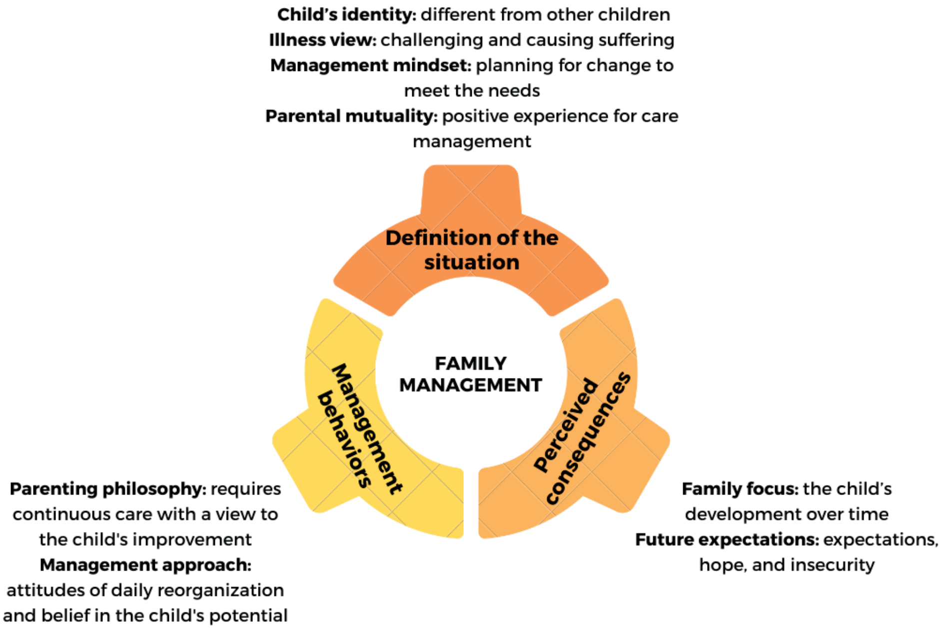
The research was approved by the Ethics Committee of the proposing institution according to Opinion 4.538.366. Before the interviews and the administration of the sociodemographic questionnaires, the participants signed informed consent forms granting authorization for data collection.

Results

This study allowed observing how the FMSF can contribute to structuring the primary caregivers' perspectives on family management in situations of chronic childhood conditions. Thus, bearing in mind the family management styles, this study identified families' response patterns to children's needs and their repercussions. Figure 1 represents these patterns schematically and synthetically according to the components and dimensions of the FMSF ("Definition of the Situation" – "Child's Identity," "Illness View," "Management Mindset," and "Parental Mutuality;" "Management Behaviors" – "Parenting Philosophy," and "Management Approach;" and "Perceived Consequences" – "Family Focus," and "Future Expectations").

Figure 1

Family patterns of response to children's needs and their repercussions



Among the 38 participants, 36 were mothers, one was a grandmother/legal guardian, and one was a sister/legal guardian. None of the participants chose the WhatsApp® telephone calls for their interviews. The study participants preferred to answer via typed messages, so the 38 interviews were conducted through WhatsApp® text messages. Four (4) participants also sent short audio recordings of approximately 58 seconds to further explain their answers or clarify doubts regarding the research script.

In terms of the chronically ill children's characterization, of the total of 38, 24 were male, and 14 were female. The children had the following chronic illnesses: autism spectrum disorder (n = 14; 36.8%), developmental delay (n = 7; 18.4%), brain injury (n = 3; 7.9%), Down syndrome (n = 3; 7.9%), epilepsy (n = 2; 5.7%), and other conditions (n = 9; 23.3%).

Considering the participants' age, 30 (78.9%) were between 20 and 40 years old, seven (18.4%) were between 40 and 50 years old, and one (2.6%) was over 50 years old. In terms of education, two (5.3%) were illiterate or had incomplete primary education; 15 (39.5%) had completed primary education; 15 (39.5%) had completed secondary education; and six (15.7%) had completed higher education.

Regarding their employment at the time of the interview, 63.1% of the primary caregivers were homemakers, 7.9% were teachers, 5.7% worked in sales, and 23.3% (nine) of the participants had other jobs, such as telemarketer, psychologist, manicurist, pedagogue, lawyer, civil servant, driving instructor, hairdresser, and nursing technician. Considering the participants' household income, 31 (81.6%) families earned up to two minimum wages/month, five (13.2%) from two to four minimum wages/month, and two (5.2%) received four to 10 minimum wages/month.

The results of the semi-structured interviews are presented in a table containing the FMSF components, a synthesis, and extracts from the participants' statements for each dimension.

Table 1 presents the results associated with the FMSF components "Definition of the Situation," "Management Behaviors," and "Perceived Consequences," and their respective dimensions "Child's Identity," "Illness View," "Management Mindset," "Parental Mutuality;" "Parenting Philosophy," "Management Approach;" "Family Focus," and "Future Expectations." The table demonstrates primary caregivers' perspectives on family management in situations of chronic childhood conditions in the investigated scenario.

Table 1

Definition of the Situation, Management Behaviors, and Perceived Consequences

Definition of the Situation	Statements
This component demonstrates how caregivers view their chronically ill children and their feelings of insecurity, fear, despair, anguish, and guilt. The child's illness is tiring and burdensome, but there is the recognition and expectation of the situation's improvement. In some cases, it was possible to observe parental mutuality.	Child's Identity: "I always saw she was different from other children of the same age. It was just the confirmation of something I already expected." (F11) Illness View: "It was despairing, distressing, I lost my ground and felt very insecure. Fear of losing him or not knowing how to deal with the disease." (F28) Management Mindset: "Well, at first the most substantial was the adaptation of the therapy schedules and the rush to consult different doctors. Besides this, feeding, daily hygiene, and closer monitoring, because as I am with her all day, I can understand better what she says." (F22) Parental Mutuality: "My husband is always with me, my sister who takes care of him so I can work, and my mother-in-law who also helps when we ask. The aunts and godmother also [help] when necessary." (F32)
Management Behaviors	**Statements**
These are demonstrated in the family's planning and daily (re)organizing to meet the child's needs and attitudes toward recognizing the child's potential. This component identifies the daily behaviors acquired by the caregiver to manage the child's illness.	Parenting Philosophy: "Care is permanent/continuous. It is tiring, with many ups and downs trying to control the seizures, many medication changes, and now the introduction of Cannabidiol. I do everything alone with him because it is just the two of us. But the result was and is fantastic, very positive. And one fact that helped a lot was early stimulation." (F16) "My life has changed a lot; I left my job and am dedicated to him. I go out from Monday to Thursday with him; I dedicate my life more to him now. On days when he does not have consultations, I stimulate him at home. I thank God very much." (F10) Management Approach: "We adapt, we prioritize. We try not to pamper him too much, not to sin by error or excess; we treat him as I treat my nephew. We always try to help without spoiling him. We show him how things are. I've already had my mother hen moments, overprotective, but we try to put him in the real world, talk, so he can always adapt." (F38)
Perceived Consequences	**Statements**
These express the repercussions of the children's chronic illness on families' daily lives, the primary caregiver's perspectives and fears regarding the future, and the positive outcomes for the children of the management behaviors adopted.	Family Focus: "Sometimes he surprises me; he is an extraordinary child, intelligent, who is already reading. He is now three years old; he has excellent feedback and sometimes impresses us because he is terrific at some things. In others, we need to understand better. Every day is a surprise, a novelty, a realization." (F27) Future Expectations: "The impact of having a special child is [felt on the need] to understand his syndrome more every day, how to deal with the situations that are presented daily, and how to do it. How it will be in the future, and how I will deal with it. We try to do everything so that he suffers less impact from society, at school, and everything so that he does not suffer prejudice. This chronic illness was frightening, overwhelming for the family. But today, we are dealing with it easily; we have been seeking knowledge to deal with this situation." (F18) "I had an active social life. Today we socialize more with my in-laws. This is due to my dedication to J. I miss being invited to other people's houses. Now and then, I try to promote something. But now, with the pandemic, it has become more difficult." (F17)

The data analysis allowed this study to identify five management styles associated with the FMSF components: "thriving," "accommodating," "struggling," "floundering," and "enduring." These family management styles and the statements that allowed their identification are presented in Table 2.

Table 2

Family management styles

Thriving	Statements
Caregivers with this style see their child as any other and understand the chronic illness as a fatality that happened; nevertheless, they also believe life must go on despite it.	"I don't know how to describe it, because for me he is like any other child, he does everything that the boys around here do, it doesn't even seem that he is chronically ill." (F04) "Thank God, we have been able to comply with the agenda; we receive a lot of support and help from our eldest son, parents, and siblings." (F35)
Accommodating	**Statements**
Caregivers integrated into this style category try to incorporate child care into family routines, meaning that the family also seeks normalization and adjustment as their significant themes; however, they still have a negative perception of their situation.	"For me, it is as if I had to be born and evolve again." (F01)
Struggling	**Statements**
Difficulties characterize this style. Caregivers and family members hold a pessimistic view of their situation.	"Uncomfortable. Emotionally very shaken. To this day." (F03) "I found out after the birth. It's a lot of responsibility, it's 24 hours a day, sometimes I don't even have time to go to the bathroom in peace." (F06) "The father. He still doesn't understand what it is. Scared." (F22)
Floundering	**Statements**
Caregivers with this style perceive their child as having a severe condition, which threatens the child's and family's life and quality of life. They often feel overwhelmed and overburdened with caring for their chronically ill children.	"Difficult, because I had several expectations, and I realized that she did not do what the other children did, I felt frustrated." (F05) "It is more difficult for my husband. I am still resistant in some aspects." (F02)
Enduring	**Statements**
In this family management style, families feel that life is paused. The caregiver and family members with this style category see the child as someone who needs special care and whose quality of life is compromised because of the chronic illness.	"The lack of professional support for him. But I don't dare to take the initiative." (F29) "The family does not accept it, and G. is without treatment because they do not accept it." (F29)

Discussion

Using the FMSF as a reference, this study observed that, regarding the sample analyzed, the "Situation" (Knafl & Deatrick, 1990; Knafl et al., 2012) was defined by the child's identity as different, with the initial focus on the child's illness and difference from other children. The comparison between the chronically ill child and other children was observed as part of the lived experience.

The "Illness" was viewed (Knafl & Deatrick, 1990; Knafl et al., 2012) as challenging and causing suffering. Nevertheless, there were also beliefs and expectations regarding the child's improvement and development. The "Management Mindset" identified (Knafl & Deatrick, 1990; Knafl et al., 2012) allowed realizing that the changes were planned to meet the chronically ill child's needs. Regarding "Parental Mutuality" (Knafl & Deatrick, 1990; Knafl et al., 2012), some parents in the sample revealed having a shared view of their child's situation, but others had different perspectives.

In situations involving the diagnosis of a child with a chronic illness, it is common for primary caregivers and family members to experience initial mental distress and have difficulties in dealing with unknown, unexpected, and different situations. When this study's caregivers received their child's chronic illness diagnosis, they experienced fear, denial, sacrifice, and guilt. These feelings describe how these caregivers perceived the moment they discovered their child's illness.

Research has demonstrated that when caregivers receive the diagnosis and the possible prognosis of their children's chronic illnesses, they experience sadness and despair. The discovery of their children's chronic illness has an strong emotional impact on caregivers and, consequently, constitutes a moment of anxiety and fear due to the lack of preparation to deal with the new situation and their fear of the unknown. Reactions of denial and loss of control over the situation are also frequent (Gesteira et al., 2020; Vaz et al., 2018).

Considering "Management Behaviors" (Knafl & Deatrick, 1990; Knafl et al., 2012), this study identified approaches based on (re)organizing daily routines and believing in the child's potential. The sample's "Parenting Philosophy" (Knafl & Deatrick, 1990; Knafl et al., 2012) showed that families recognized that the children required continuous care, and the priority, in most situations, was improving the child's health and development. Therefore, the caregivers and the children have developed routines and strategies to manage the chronic illness and integrate it into their daily lives, which aligns with the FMSF dimensions of "Parenting Philosophy" and "Management Approach."

This study observed that the primary caregivers, the majority of which are mothers, have assumed a large part of their chronically ill children's care, which has changed their lives. Also, it was perceived that father figures generally collaborated less with care and that there was a constant presence of other family members, usually friends and neighbors, that supported child care.

Recognizing women's overburden as mothers, caregivers, and professionals is crucial, as well as understanding the need to change family roles depending on the care needs of chronically ill children. Furthermore, it must be highlighted that most mothers must give up their work, adapt household chores, and adjust their schedules and the entire family environment due to their children's chronic illnesses (Braga et al., 2021; Lebert-Charron et al., 2018).

This study's results also show that the caregivers' strategies can contribute or not to family management and better quality of life, being directly related to the society/environment (Ichikawa et al., 2018). To achieve this goal, informal caregivers need to understand what their children's chronic illness means to them and expand their knowledge and behaviors related to the experience of living with a chronic childhood condition (Ichikawa et al., 2018).

Regarding caregivers' "Perceived Consequences" (Knafl & Deatrick, 1990; Knafl et al., 2012) of their children's chronic illnesses, this study identified expectations and hope regarding the future but also feelings of insecurity. The "Family Focus" is mainly turned to the child's development over time and the promotion of their independence. In this case, the caregivers were satisfied with how the chronic illness's management was incorporated into family life.

This study also noted that the families' dreams and expectations of having a healthy child were broken, and gradually, caregivers understood the chronic illness and learned to live with it, accepting the situation. Each family member's personal life and the family's life as a whole continued, with the emergence of feelings of joy, encouragement, and strength to live and provide care. For some, searching for information about their child's chronic illness became a necessary resource and an enabler of care (Ichikawa et al., 2018).

Family functionality is how caregivers articulate their essential functions in a way that is appropriate to the family members' identity and according to the reality that prevails in their social environment. Literature has pointed out that chronic childhood conditions affect social participation, education, sports practice, leisure, family members' relationships, group and interpersonal relationships, and financial status (Braga et al., 2021; Vaz et al., 2018). Chronically ill children and their families undergo an adaptation process, so each one experiences this process differently, which ultimately changes their lives, leading to the creation of new strategies to adapt to the new situation (Lebert-Charron et al., 2018; Vaz et al., 2018).

This study's results show that long-term care and the transition from childhood to adolescence and adulthood are significant concerns of caregivers and families regarding their chronically ill children's future. Therefore, it is vital to understand that to achieve comprehensive care, the children's needs must be considered and, bearing in mind their care network, think about short-, medium- and long-term improvement goals and define who will be responsible and for what actions over time (Vaz et al., 2018).

Also, the results demonstrate that the caregivers' management capacity is less favorable when chronically ill children do not have access to social or government benefits, qualified health services, and specific medication or in situations of low family income. Family arrangements undergo constant reorganizing in terms of expenses, income, work, and health care needs, thus requiring the readjustment of family income and work schedules, or even the resignation of caregivers' professional activity, and the need for public support and specialized health care. Therefore, chronic childhood conditions have a substantial financial impact on families and their management capacity (Vaz et al., 2018).

In this study's context, the FMSF allowed the understanding of informal caregivers' management experiences and families' management styles. Considering these styles, this study found characteristics and patterns of family responses to the needs of their chronically ill children consistent with the five proposed styles: a) "thriving," in which caregivers understand their children's chronic illness as something normal in their lives and are confident in their roles of managing it. Parents are mutually supportive, and care is directed towards normalizing family life; b) "accommodating," in which caregivers are still adjusting to their children's chronic illness, even perceiving the situation negatively. Parents support each other, but there are alternating periods of sadness when they imagine what their lives would be like if their children were not ill; c) "struggling," in which caregivers face difficulties and have a pessimistic view of their situation but join efforts to maintain the child's care. Parents tend to adopt an overprotective attitude, and there are often arguments about management; d) "floundering," in which caregivers' management behaviors regarding their children's chronic illness do not agree. Families feel overwhelmed, consider caregiving challenging, and believe that life can never be as expected; and e) "enduring," in which caregivers experience the feeling that life is on pause and believe that chronically ill children have their quality of life compromised. Parents may or may not be mutually supportive and tend to adopt an overprotective attitude, demonstrating reactive management behaviors (Mendes-Castillo et al., 2012).

It is worth noting that family management styles may change over time as primary caregivers acquire knowledge that challenges their previous beliefs about their children's chronic illness and gives way to new values and definitions. Furthermore, each family has its uniqueness, tending to manage chronic illness according to specific social, individual and/or cultural patterns and behaviors. Knowledge can be essential in understanding these children's and their families' needs.

This study was limited by the fact it was conducted remotely, which hindered the proximity with the participants. Also, interviewing other family members could have brought additional evidence and expanded the results achieved.

Conclusion

This study's participants demonstrated that family management capacity has different specificities and styles. Over time, health resources and the primary caregivers' and families' actions and behaviors are fundamental to overcoming daily adversities. Also, conditions of greater vulnerability can hinder the process of adaptation to the situations experienced. Families' ability to manage positively depends on professional, care, and family resources that are part of their daily organization.

This study's implications for clinical nursing practice indicate that nurses must identify family management styles to understand families' singularities and propose care interventions centered on chronically ill children rather than illness. This will favor the delivery of comprehensive and continuous care. It will also be crucial to identify the needs of the child, the caregiver, and their family, as well as the resources available for planning, implementing, and evaluating care. This process will strengthen families' adaptability, adjustment, and functionality and promote their well-being.

Further in-depth studies are recommended to identify new family management styles, primary caregivers' weaknesses and strengths in delivering care to their chronically ill children, and family management strategies.

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