

Family care pathway of children with Cystic Fibrosis

Trayectoria del cuidado familiar de niños con Fibrosis Quística

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What do we know about the subject matter of this study?

The experience of mothers caring for children with cystic fibrosis remains largely unexplored, especially in Medellín, despite the high physical and emotional burden they face in taking on this role on a constant and almost invisible basis.

What does this study contribute to what is already known?

This study provides a human understanding of family care for children with cystic fibrosis by highlighting the experiences of women caregivers from diagnosis to their resilient transformations. It reveals institutional gaps, gender role expectations, and the need for fairer and more empathetic public policies, enriching knowledge with intimate and structural perspectives that often remain invisible in the existing literature.

Abstract

Caring for children with cystic fibrosis within the family is a complex experience that involves moments of uncertainty and hopelessness that lead to a reinvention of the self through coping and adaptation. **Objective:** To explore the experience of family care in mothers of children with cystic fibrosis. **Subjects and Method:** Descriptive-exploratory qualitative study design. Semi-structured interviews were conducted between January and December 2024 with caregiving mothers, selected by convenience sampling and snowball techniques. The interviews were recorded and transcribed after signing the informed consent form. The information was analyzed using content analysis techniques, and the methodological rigor criteria of qualitative research were preserved. **Results:** Six women caregivers were interviewed. The analysis of the information yielded five key categories: the diagnostic trajectory, support networks, coping strategies, care dynamics, and systemic barriers. Each category intertwines emotions, thoughts, opinions, tasks, and responsibilities, ranging from uncertainty and learning to role burnout, as well as a constant struggle with institutionality. **Conclusion:** Family care in the context of cystic fibrosis is not only an institutional task, but also a practice deeply marked by structural and gender inequality. However, during adversity, mothers manage to redefine their role, defending their dignity and subjectivity through the radical act of caring.

Keywords:

Cystic Fibrosis;
Family Care;
Emotions;
Trajectory;
Social Support

Introduction

Cystic fibrosis (CF) is a chronic, multisystemic genetic disease that primarily affects the respiratory and digestive systems. Globally, the estimated incidence is 1 in every 2,500 to 3,500 live births, and in Colombia, socioeconomic and structural conditions limit access to comprehensive, continuous care¹. Managing this disease requires complex care that falls almost exclusively on the family environment, with mothers being the primary caregivers².

The care needs of children with cystic fibrosis include respiratory therapies, medication administration, strict nutritional monitoring, and constant symptom surveillance. These needs not only require technical skills but also a high level of emotional and physical availability on the part of the caregiver^{3,4}. Caring for these children at home is equivalent to an extended workday, causing physical and mental health problems for mothers who are caregivers⁵. The demands of caregiving, coupled with the uncertainty of the prognosis, cause high levels of anxiety, depression, and exhaustion⁶.

In this context, the challenges of family care are manifold and manifest in emotional overload, social isolation, loss of personal projects, and reorganization of the family structure. Mothers often take on the responsibility of care alone, neglecting their economic autonomy and individual well-being⁷.

Care trajectories, understood as the biographical paths that families follow from diagnosis to the establishment of care practices, are marked by moments of rupture and adaptation⁸. The initial impact of the diagnosis is an unexpected disruption of family and personal functioning that exceeds their capacity to respond; over time, families develop coping strategies, understood as actions or resources used to manage stressful or difficult situations. These trajectories range from exhaustion, hope, and emotional reactions of sadness and anxiety over the loss of health and family dynamics, to the emotional reconstruction of the maternal role, that is, the modification of the functions, activities, and responsibilities related to caring for the child in the context of motherhood¹⁰.

The caregiving relationships between the mother caregiver, the child, and the rest of the family are also transformed. Emotional tensions arise, but bonds are also strengthened by the shared experience of suffering, shaping a new relationship between mother and child based on trust and mutual understanding¹¹. When extended family networks exist, the emotional impact of caregiving tends to be mitigated, but in their absence, the burden increases exponentially¹².

The consequences of prolonged family care for a child with CF encompass economic, social, emotion-

al, and spiritual dimensions. In many cases, mothers abandon their studies or jobs, which limits their financial independence. Added to this is the fragmentation of health services, institutional bureaucracy, and the lack of gender-sensitive policies, which creates a sense of institutional abandonment¹³. The phenomenon of burnout or extreme exhaustion in mothers has also been identified, characterized by symptoms of insomnia, hopelessness, frustration, and crises of meaning in life^{14,15}. Considering this situation, evidence suggests that caregiver-centered care, with psychosocial support, psychological follow-up, and interdisciplinary networks, can improve the quality of life of both the child and their environment¹⁶. In this context, the objective of this study was to explore the experience of family care in mothers of children with CF.

Subjects and Method

This was a qualitative, descriptive, exploratory study conducted between January and December 2024. The study population consisted of mothers of children diagnosed with CF who were caregivers in Medellín. The inclusion criteria were mothers over 18 years of age, and their children aged under 14 years with a confirmed diagnosis; no exclusion criteria were considered. The study sample was achieved through theoretical saturation, that is, information was collected until there were no further contributions to the constructed categories of analysis. Participants were initially selected for convenience, meaning that two participants who met the inclusion criteria were selected, and then other potential participants were identified through them (snowball sampling).

To collect information, participants were contacted by telephone and WhatsApp. Initial contact with some participants was made through the health institution where these children were hospitalized. Caregiving mothers were approached and offered summary information about the study, and they gave their initial approval to participate. Subsequently, a semi-structured interview was conducted, with a pre-prepared script that included questions about the diagnosis, the care trajectory, and coping strategies, such as: What emotions and feelings did you experience when you received this diagnosis? How did your life change while caring for your child at home? How do you perceive the support provided by the health system in managing your child's condition? How do you manage to balance your daily life with caring for your child?

The interviews were conducted in settings chosen by the participants, including their homes, the hospital, and other open spaces; they lasted between 40 and 60 minutes. At the beginning of each interview, a

trusting relationship was established by asking general questions and creating a safe and comfortable environment. The interviews were recorded on a professional digital recorder for journalism and transcribed after the participants signed the informed consent form. Once transcribed, the interviews were returned to the participants to verify their content and determine whether they saw themselves reflected in the transcribed accounts.

The researchers are nurses with master's and doctoral degrees, with experience in qualitative research, and with caregivers who accompany the clinical care practices of undergraduate nursing students in maternal-child and chronic adult areas.

The data were analyzed using content analysis, one of the most widely used techniques in qualitative studies. It is an approach to the description and interpretation of textual data using a systematic coding process whose final product is the identification of categories, themes, and patterns. For this type of analysis, the steps proposed by Assarroudi et al.¹⁷ were considered.

Reflexivity was present throughout the study, especially in the design of the interview script, at the time of the interview, and at the time of data analysis, avoiding bias in the results based on prejudices, stereotypes, or preconceptions about what family care and the trajectories of mothers should be. The analysis began with the first interview, and from there, each interview was read in detail to gain a general understanding of the participants' stories. Coding and categorization were performed manually using a format designed in Microsoft Excel. The analysis process followed the steps described by Assarroudi et al.¹⁷ regarding the organization phase, which included the development of a coding and categorization matrix, the identification of units of meaning within the narratives, the assignment of codes, and the inductive abstraction of the main categories, which were initially preliminary. As the analysis of the interviews progressed, the preliminary categories became saturated until they were dense in a theoretical sense. The researchers constantly reviewed the information analysis exercise in order to validate and verify the results.

The interviews were identified with a code that included the letter E and the participant's number. Proper names were changed during transcription to fictitious names, and the same interview code was used in the Excel matrix. Sensitive data such as ID documents, names, or email addresses were not included.

The criteria of rigor, credibility, and reliability in the research findings were maintained by sharing the results with two of the study participants to identify whether they recognized them as real. The criterion of transferability, defined as the evaluation of the possibility of applying the findings of this study to other

contexts, was maintained through the demographic description of the participants, which can be viewed in the results section. The principle of confirmability, which involves ensuring that the findings come from the data and not from researcher bias, was maintained through reflexivity and veracity in the participants' accounts, as well as in the interview transcripts and the comparison of the results with the existing literature. This study was approved by the Ethics Committee of the Faculty of Nursing of the *Universidad de Antioquia* (CEI-FE 2020-12).

Results

Six caregiving mothers participated, although approximately 12 potential participants were approached. Six interviews were conducted. The participants were aged between 25 and 40 and lived in the city of Medellín, Colombia. They were engaged in household tasks, without constant support from other family members in caregiving, although some had occasional support from their partners or close relatives. Most had completed primary and secondary education.

Analysis of the interviews identified five categories: diagnostic trajectory, support and accompaniment networks, coping and adaptation, caregiving dynamics and transformations, and systemic barriers and inequalities. Table 1 shows the categories with their respective narratives.

Diagnostic trajectory

The journey usually begins with a suspicion, although there is still no diagnosis to confirm it. It is just a concern that grows over time. Faced with this uncertainty, all families embark on a journey full of questions, where the insistence on obtaining answers becomes part of the routine: consultations, opinions, tests, all in search of a little clarity. But that clarity often takes time. In the accounts, the diagnosis comes late and in a confusing way, which only increases the frustration and emotional distress of those who provide care.

When a clear diagnosis finally arrives from medical professionals through various tests and, above all, when it arrives with respect, time, and a humane attitude, it can feel like a relief. It gives a name to what was previously only a vague concern. This diagnosis explains the signs and gives meaning to the journey taken. From there, caregivers begin to search for information on the internet and through people who have had similar experiences. This is not only done to better understand, but also out of a need to find some light in tools, similar stories, and, above all, a sign that they are not alone in the world.

[...] At first, the doctors mentioned a genetic condition, but they didn't explain what that meant specifically. No one took the time to clarify it. I felt alone, with no tools to understand what was happening. Not knowing what to expect was, in itself, a form of suffering. The lack of clear and timely information not only caused distress but also fueled fears that could have been avoided. [...] (E5, P2).

Support networks and accompaniment

Genuine communication between caregivers and those who accompany them professionally opens a space where trust can grow, and suffering finds relief. Professional support is not only clinical but also involves listening and genuine presence. These expressions of support make the difference between feeling accompanied or abandoned. Of course, the system also comes into play. Institutional networks are perceived as structures that guarantee accessible and timely care. Additionally, it is possible to infer from the narratives that the family network also supports caregivers, becoming a framework that provides emotional support, practical assistance, and even financial support when needed.

[...] My mother-in-law, my sisters-in-law, even some neighbors... have been there. Not always with grand gestures, but with what was just right and needed: a timely word, a hot meal, the simple act of sitting beside us when we didn't know where to start. In the hardest moments, that sometimes silent but steadfast presence was a lifeline. Knowing that we were not alone, that there was an extended network that would not let us go, gave us the strength to carry on. [...] (E6, P4).

Coping and Adaptation Processes

Strategies for coping with what we are going through are not always obvious, but they are there. They are built up in everyday life, between the personal and the collective, as ways of sustaining ourselves in the face of uncertainty, fear, or feelings of loss. Emotional coping appears as the internal work that caregivers do to sort out what they are feeling, so as not to get caught up in distress. Sometimes, support comes from spirituality, not only as a belief, but as a space where meaning can be found. Over time, the way we talk about our experiences also changes. Different words appear, more closely linked to hope, to what we have been able to build, even amid difficulty. It is a silent, anticipated grief that transforms pain into another way of being.

[...] We stopped saying "illness" and started talking about "condition." It was no coincidence: it was a suggestion from the pulmonologist, who proposed that we look at the diagnosis from another perspective, without labels that weigh more than they should. At first, it was strange, but over time, this new way of naming also changed the way we looked at things. It helped us to see the treatment not as a burden, but as part of a life that can continue with hope and a certain normality. [...] (E1, P4).

Dynamics and transformations of care

Invisible care appears to be a central task in the daily lives of caregivers, although it is rarely recognized as such. This care is perceived as a combination of practical, emotional, and organizational actions that, because they are so present, are often taken for granted

Table 1. Categories and narratives

| Category | Narratives |
|---|--|
| Diagnostic Trajectory | <i>[...] When I received my daughter's diagnosis, the doctor recommended that I not come to the appointment alone. She insisted I bring someone I trusted. That gesture made me feel accompanied from the very first moment, as if I were not facing the news entirely on my own. [...]</i> (E4, P2). |
| Support Networks and Companionship | <i>[...] My husband has been a great source of support. Although the medical care falls mostly on me, he helps at home, allowing me to devote myself fully to xxx. He has also been emotionally present, accompanying the process and reminding me that I am not alone in this struggle. [...]</i> (E1, P3). |
| Coping and Adaptation | <i>[...] In the midst of the illness, I decided to hold on spiritually. I pray, I seek guidance in the word of God, and I trust that everything we experience has a purpose. That spiritual strength has sustained me and helps me make difficult decisions with greater calm and faith. [...]</i> (E6, P3). |
| Caregiving Dynamics and Transformations | <i>[...] Going to the hospital is exhausting. It is not only the stress of getting there, but also carrying medications, test results, and supplies. Nobody sees that part. As the primary caregiver, I often feel overwhelmed, without rest or support, having to manage everything on my own. [...]</i> (E5, P8). |
| Systemic Barriers and Inequalities | <i>[...] We had to change our EPS (health insurance provider) due to the many obstacles in accessing treatments and specialists. We went through a legal process to demand the change. It was draining, full of barriers, but necessary so that my daughter could receive proper and uninterrupted care. (E3, P5).</i> |

or underestimated in the social, family, and even institutional environment. Another type of care is intensive care, which could be understood as permanent care in which all activities are carried out for the well-being and quality of life of the child. This type of care shows the level of commitment of those who accompany the child daily, and caregivers say they do not find a family context prepared for the complex responsibilities that arise from this type of care. Added to these caregiving dynamics is a burden that is not always expressed but is felt: the feeling of having put one's own life on hold, of having postponed projects, relationships, and desires. The fatigue that caregivers inevitably express and experience is not only physical but also emotional and mental.

[...] Caring for my son has become the center of everything. Knowing that I am doing everything possible for his well-being gives me peace of mind. He maintains his energy and vitality, which motivates me to continue giving him love and attention every day. [...] (E2, P3).

Systemic barriers and inequalities

These barriers are not only evident in health services, but also in the educational and legal spheres. Economic limitations appear as a cross-cutting factor that conditions access to timely and quality services. Added to this is limited school support, which highlights the lack of adequate policies or resources for the educational inclusion of children with this health condition. Institutional activism emerges as a response of resistance to these barriers, with caregivers taking on active roles in defending their children's rights, while inequality in care and the crisis and struggle for care reflect the inequitable and exhausting nature of the health system, especially in the face of bureaucracy and lack of continuity of care.

[...] Barriers in the health system are always there. Sometimes it's missing paperwork, other times it's appointments that are postponed without explanation, or medications that never arrive. Every step becomes a struggle. And what should be a right ends up feeling like a constant battle. It's exhausting. Not only physically, but also mentally. Bureaucracy is not only slow: it is suffocating. [...] (E3, P12).

Discussion

This study sought to understand how mothers of children with CF experience caregiving. From their stories, five broad categories emerged that allow us to understand what it means to care for someone in a

context marked by uncertainty, but also by resilience and the ability to persevere.

One of the most difficult moments, which many remember in detail, was the diagnosis. In general, it was experienced as traumatic. There was shock, anxiety, and confusion. In some cases, because of the length and exhaustion of the process, in others, because of the abrupt or unempathetic way in which it was communicated. What was felt, beyond the nuances, was a shock. The emotions that arose—denial, guilt, sadness—are not unique; they are repeated in many families going through the same thing. And when the news is delivered in an inhumane manner, that wound can remain open for a long time. These experiences coincide with those reported by Rodríguez et al.¹³, who describe a common emotional pattern in families facing a recent diagnosis, including denial, guilt, and sadness. Pougheon et al.¹² emphasize that the way the diagnosis is communicated, if abrupt or lacking in empathy, can leave lasting emotional scars on caregivers.

Cordeiro, Silva, and Silva⁴ also point out that this moment abruptly redefines family life, forcing immediate restructuring.

This study identified a marked difference between the value of informal networks, such as family, and the weakness of institutional networks. The former offered emotional support and practical help; the latter were described as fragmented, bureaucratic, or absent. Fitzgerald et al.⁷ highlight this discrepancy, showing that community networks are better perceived by mothers than formal services. Enríquez et al.⁶ explain how this situation reflects structural gender inequalities. Nesser et al.¹¹ emphasize that, in rural areas, these shortcomings are exacerbated by geographical distance and lack of resources. Souza et al.¹⁵ propose comprehensive models with interdisciplinary teams to address these failures.

Coping showed an evolution from distress to active reconstruction of the caregiver role. Mothers gave up their personal projects and developed resilient mechanisms such as spirituality, empirical learning of caregiving, and daily resistance. Davies et al.⁵ describe similar trajectories, with spiritual, organizational, and affective coping strategies. In rural contexts, Coca et al.³ also report how cooperation among neighbors and mutual support take on essential value. Pougheon et al.¹², from a quantitative perspective, demonstrate that spirituality protects against emotional deterioration.

Mothers assumed almost exclusive responsibility for caregiving, causing tension within couples, loss of professional autonomy, and social isolation. Martínez and Casado¹⁰ document how these transformations profoundly impact women's life trajectories. Coca et al. and Enríquez et al.^{3,6} agree that this feminization of caregiving leads to high levels of stress, anxiety, and

emotional exhaustion. Girdwood et al.⁸ warn of symptoms of burnout, advocating for interventions that also focus on the well-being of caregivers.

Finally, systemic barriers to accessing medical and emotional resources were identified. These barriers are evident in both rural and urban settings, although they manifest themselves differently. Shadi et al.¹⁴ and Valencia, Iriarte, and Campos¹⁸ highlight the failures in the coordination of levels of care and the lack of differentiated programs for adolescents. Davies et al.⁵ show that even in developed countries, there are inequalities in access to advanced therapies.

Among the limitations of this study is the small number of participants, given the rare nature of the disease. In addition, the concentration of the study in a single city does not allow for the generalization of the findings, which does not allow for diversity in terms of education and access to resources.

Conclusion

It is concluded that the experiences of family care for women with children diagnosed with cystic fibrosis include a series of perceptions, emotions, feelings, practices, and opinions that range from the diagnosis of the disease to the identification of barriers to accessing treatments and support that favor and facilitate the responsibilities and tasks that come with assuming a caregiving role that is configured through intensive and, at the same time, invisible care; but which is in-

evitably physically, emotionally, and psychologically exhausting.

Ethical Responsibilities

Human Beings and animals protection: Disclosure the authors state that the procedures were followed according to the Declaration of Helsinki and the World Medical Association regarding human experimentation developed for the medical community.

Data confidentiality: The authors state that they have followed the protocols of their Center and Local regulations on the publication of patient data.

Rights to privacy and informed consent: The authors have obtained the informed consent of the patients and/or subjects referred to in the article. This document is in the possession of the correspondence author.

Conflicts of Interest

Authors declare no conflict of interest regarding the present study.

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