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RESEARCH ARTICLE (ORIGINAL)

Mothering Children with Special Health Care Needs in a Rural Context: A Phenomenological Study

Maternagem de Crianças com Necessidades Especiais de Saúde no Contexto Rural: Um Estudo Fenomenológico

Maternaje de niños con necesidades especiales de salud en el contexto rural: un estudio fenomenológico

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Abstract

Background: Mothering children with special health care needs (SHCNs) in rural areas entails multiple challenges associated with their clinical conditions and difficulties in accessing healthcare services.
Objective: To understand the experiences and meanings attributed to mothering in the daily lives of mothers of children with SHCNs living in rural settings.
Methodology: A phenomenological study was conducted through interviews with 26 mothers of children with SHCNs living in rural areas. The audio recordings were transcribed verbatim and analyzed in light of social phenomenology.
Results: The daily mothering focused on the child's survival and well-being and was characterized by personal sacrifices, physical and emotional overload, social exclusion, and a constant search for social inclusion.
Conclusion: The daily experience of mothering a child with SHCN highlights the need for emotional, affective, and social support for mothers, as well as for the reorganization of family and community dynamics. These responsibilities are largely assumed by mothers, intensifying the physical and emotional burden associated with caregiving.

Keywords: child health; mothers; rural health; persons with disabilities; rural areas

Resumo

Enquadramento: A maternagem de crianças com necessidades especiais de saúde (CRIANES) residentes em contexto rural é marcado por múltiplos desafios, associados às condições clínicas destas crianças e às dificuldades de acesso aos serviços de saúde.
Objetivo: Compreender as vivências e os significados atribuídos à maternagem no quotidiano de CRIANES residentes em contexto rural.
Metodologia: Estudo fenomenológico desenvolvido através de entrevistas a 26 mães de CRIANES residentes em contexto rural. Os áudios foram transcritos na íntegra e analisados à luz da fenomenologia social.
Resultados: O quotidiano da maternagem centra-se na sobrevivência e bem-estar da criança, sendo marcado por renúncias pessoais, sobrecarga física e emocional, exclusão social e a uma procura constante pela inserção social.
Conclusão: A maternagem no quotidiano de uma (CRIANES) evidencia a necessidade de suporte emocional, afetivo e social às mães, bem como à reorganização das dinâmicas familiares e comunitárias. Estes cuidados são assumidos, maioritariamente, pela figura materna, intensificando a carga física e emocional associada ao cuidar.

Palavras-chave: saúde da criança; mães; saúde da população rural; pessoas com deficiência; zona rural.

Resumen

Marco contextual: El maternaje de niños con necesidades especiales de salud (CRIANES) residentes en contextos rurales se caracteriza por múltiples desafíos, asociados a las condiciones clínicas de estos niños y a las dificultades de acceso a los servicios de salud.
Objetivo: Comprender las experiencias y los significados atribuidos al maternaje en la vida cotidiana de CRIANES residentes en contextos rurales.
Metodología: Estudio fenomenológico desarrollado a través de entrevistas a 26 madres de CRIANES residentes en un contexto rural. Las grabaciones de audio se transcribieron íntegramente y se analizaron según la fenomenología social.
Resultados: La vida cotidiana del maternaje se centra en la supervivencia y el bienestar del niño, y se caracteriza por renuncias personales, sobrecarga física y emocional, exclusión social y una búsqueda constante de la integración social.
Conclusión: El maternaje en la vida cotidiana de una (CRIANES) pone de manifiesto la necesidad de apoyo emocional, afectivo y social a las madres, así como la reorganización de las dinámicas familiares y comunitarias. Estos cuidados son asumidos, en su mayoría, por la figura materna, lo que intensifica la carga física y emocional asociada al cuidado.

Palabras clave: salud infantil; madres; salud de la población rural; personas con discapacidad; zona rural

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Introduction

The term *mothering* refers to the lived experiences of motherhood, as well as the responsibility of caring for and protecting children. Motherhood, in turn, is associated with the socially constructed role of being a mother, in which women are positioned at the center of care and commit to their children through this experience. However, women's desires must also be considered, as motherhood can become an oppressive experience for those who do not wish to assume this role (O'Reilly, 2019).

Mothering can be understood as a responsibility that extends beyond the biological dimensions of being a mother, encompassing emotional, social, and relational dimensions (Messias et al., 2025). In contrast, essentialist and romanticized views of motherhood assign women, either individually or collectively, the role of primary caregiver. Recognizing and valuing women's needs and expectations is therefore essential (Nunes & Veillette, 2022).

Caring goes far beyond conception and childbirth, involving responsibility, attention, respect, affection, and dedication. Many women, however, experience motherhood alone, balancing multiple daily activities without adequate support or support networks (Silva & Cavalcante, 2024).

Motherhood and mothering are complex processes, particularly when they involve caring for a child with special health care needs (SHCNs), a context in which mothers assume most care responsibilities (Santos et al., 2024).

The arrival of a child with SHCNs introduces a new dynamic into family relationships. Evidence indicates that caring for these children falls primarily on women, with mothers acting as the main providers of care and support (Seidel et al., 2022; Lins et al., 2024). Consequently, the solitary experience of mothering a child with SHCNs can lead to physical and mental illness.

In rural contexts, caregiving is even more challenging. In these realities, women accumulate domestic work, often withdraw from paid employment, and dedicate themselves entirely to caring for their children with SHCNs. Rural areas can also present specific challenges to accessing health services, including long distances and difficult travel, which frequently lead these mothers to abandon personal desires and life projects in favor of caregiving (Silveira et al., 2024).

Given this scenario, there is a need for studies that address the mothering of children with SHCNs, particularly among those living in rural areas, where social, emotional, and structural conditions render care even more complex and challenging. Therefore, this study aims to understand the experiences and meanings attributed to mothering in the daily lives of mothers of children with SHCNs living in rural areas.

Background

Children and youth with SHCNs are those aged 0 to 18 years who have a disability or chronic health condition requiring continuous and specialized care. The care demands of these children can be classified into six categories: 1) Developmental care demands, when the child requires monitoring by specialized professionals, such as physical therapists and psychologists; 2) Technological care demands, involving body-incorporated technologies, such as tracheostomy or colostomy; 3) Medication care demands, characterized by continuous dependence on medication; 4) Modified habits, involving adaptations to perform activities of daily living; 5) Mixed care demands, when more than one type of care is present; and 6) Clinically complex care, encompassing all of the above demands, including life support measures (Silveira et al., 2021).

Children with SHCNs may also present multiple and interdependent needs that directly influence their social participation. Early identification of these children is essential for health and education teams to plan integrated care strategies that promote health and social inclusion for this population (Pombal et al., 2024).

Having a child with a disability can be an experience marked by feelings of frustration and uncertainty, as the diagnosis often disrupts family expectations, plans, and dreams, generating a range of emotional responses (Ponte & Araújo (2022). These changes have a significant impact on everyday family life, particularly in rural areas where geographical distance and limited resources hinder access to services required for the care, development, and maintenance of these children's lives.

Research question

How is the everyday experience of mothering children with special health care needs who live in rural areas?

Methodology

This qualitative study was based on the theoretical and methodological framework of Alfred Schütz's Phenomenological Sociology (Schütz, 2012). This focuses on how individuals construct meaning through their actions, experiences, and social relationships within the life-world, allowing the interpretation of how they attribute meaning to their everyday experiences.

According to Schütz (2012), when individuals act based on past experiences, they reveal their "because motives," whereas when they act guided by future expectations and intentions, they express their "in-order-to motives." These concepts guided the phenomenological interpretation of the mothering experiences described by the participants.

This study was conducted with mothers of children with SHCNs registered in a Family Health Strategy service located in a rural area of a municipality in the northwestern region of Rio Grande do Sul, Brazil.

Women aged 18 years or older, who were directly responsible for the care of a child with SHCNs, registered with the rural Family Health Strategy, and members of a community mothers' group that met every two weeks were included in the study.

Participant recruitment and data collection occurred

between March and August 2024 and were carried out by the principal investigator and a research assistant, both women affiliated with undergraduate and graduate nursing programs at a federal public university. Recognizing that researchers' educational and professional background may influence the interpretation of attributed meanings, continuous reflective procedures were adopted throughout the study.

Initial contact occurred during the mothers' group meetings held every two weeks, when potential participants were invited to participate in the study and informed about the study objectives and procedures. This initial contact enabled the development of bonds of trust and empathy, which are essential conditions for conducting authentic phenomenological interviews.

Data were collected through phenomenological interviews using a semi-structured, open-ended format. The interviews were conducted by the principal investigator, who was trained by the faculty supervisor responsible for the study and who has extensive experience in phenomenological research.

The interview guide consisted of two sections: 1) Participants' sociodemographic characterization (age, marital status, education level, employment status, and household income); and 2) Phenomenological guiding questions developed based on the study objectives, such as: "How do you describe your everyday experience of caring for your child with special health care needs?"; "What changes have occurred in your life since your child's birth or diagnosis?"; and "What are the main challenges you face and what sources of support do you rely on when caring for your child?".

The interviews were scheduled in advance, following the mothers' group meetings, and were conducted in a private room adjacent to the health service to ensure privacy and confidentiality. Only the mother, the researcher, and the research assistant were present.

The interviews were audio-recorded, with an average duration of 37 minutes, and transcribed verbatim by the principal investigator. Data collection ended when data saturation was reached, that is, when the information began to repeat itself without emerging new meanings (Tisott et al., 2024).

To protect participants' anonymity, the interviews were identified using codes (I1, I2, I3...), in chronological order. Data analysis followed the assumptions of Schütz's Phenomenological Sociology (2012). The narratives were read and reread to identify the motives and expectations related to the mothering of children with SHCNs.

The units of meaning were identified, coded, and grouped by similarity, generating categories of lived experiences. Based on these categories, a typical lived experience of mothering was constructed, revealing the shared meaning structures across participants.

The interpretation of the results was grounded in the theoretical assumptions of Schütz's Phenomenological Sociology and relevant literature to support an intersubjective and contextualized understanding of the phenomenon. Purpose sampling was used to recruit mothers aligned with the phenomenon under study. The inclusion of 26 interviews was justified by data saturation, reached when new interviews no longer added relevant information about the lived experiences.

This study complied with the ethical principles for research involving human subjects under Brazilian National Health Council Resolutions No. 466/2012 and No. 510/2016. All participants signed the Informed Consent Form before the interviews. The project was approved by the Research Ethics Committee of the Federal University of Santa Maria (Opinion No. 6.116.638, issued on June 14, 2023).

Results

Twenty-six mothers aged 20 –41 years participated in the study. Thirteen reported being in a stable relationship, seven were married, four were single, and two were widowed. Regarding children's health conditions, 11 mothers cared for children with autism spectrum disorder, seven for children with intellectual disabilities, six for children with genetic syndromes, and two for children with cerebral palsy.

With regard to education, 18 women had completed ninth grade, four had completed ninth grade through Youth and Adult Education programs, and four had completed twelfth grade.

Regarding occupation, 19 women were exclusively dedicated to domestic work and childcare, while seven had formal employment. Concerning household income, 14 participants received government benefits, seven had an income of up to two minimum wages, and five reported living on up to one minimum wage.

The phenomenological analysis of the narratives resulted in the identification of three categories of lived experiences, which reflect the meaning of mothering children with SHCNs in rural contexts.

Category 1 – Intentionality of care for children with SHCNs

The daily routine of mothering was marked by intentional actions aimed at meeting each child's specific needs. Mothers oriented their caregiving toward ensuring their children's survival, well-being, and safety, providing continuous care related to feeding, hygiene, medication administration, and physical protection.

"I am the one who has to feed him. He still doesn't understand that he should bring the cutlery to his mouth like we do. He can't feed himself" (I1).

"He has no sense of danger, so I need to remove anything within his reach that could hurt him. I help with everything: hygiene, feeding, medication, social interactions, walking on the street... everything depends on me" (I12).

> I have to organize his entire routine. I start with hygiene, give him his medication, offer him food and liquids. I also brush his teeth, wash his face, bathe him, and wash his hair and body, because he can't do it himself. (I13)

"He cannot eat solid foods, only liquids. I have to be very careful when feeding him, because there is always a

risk of choking" (I14).
"He doesn't like taking medication, so I have to be constantly vigilant. As we live far from the city, if something happens, such as choking, help can take a long time to arrive" (I15).
"The health center staff taught me how to administer the medication. I monitor the schedules, dissolve the tablets in water, and make sure she swallows everything properly" (I22).
These narratives indicate that maternal actions are guided by both "in-order-to motives" (future intentions) and "because motives" (previous experiences), as proposed by Schütz (2012), revealing the total dedication and constant vigilance required to care for a child with SHCNs.

Category 2 – Impact of everyday mothering on mothers in rural contexts

Mothers described daily lives marked by sacrifice, physical and emotional overload, and constraints imposed by the rural context. Distance from urban centers, withdrawal from paid employment, and limited support networks contributed to loneliness and exhaustion.

> Since my son was born, everything in my life has changed. Living in the countryside, with so many limitations, means I can't have a job outside the home. He depends on me all the time. Besides caring for him, I'm responsible for the entire household routine: cooking, doing laundry, going to the market or the pharmacy, everything is far away and falls on me. I have no one around to help me; my family lives in the city and can't come because of the distance. Some days I'm so tired that I go to bed without dinner because I'm completely exhausted. It's not easy to deal with all of this alone! (I8)
>
> I take care of him all the time, take him to the Association of Parents and Friends of Exceptional Children, to medical appointments, to physical therapy sessions, and to everything else he needs. He is already big and heavy, and carrying him on my own for so long has caused me back problems. I also have to plan how I'm going to get to each appointment, because no one helps me. (I11)
>
> Before he was born, I worked. After his father passed away and the diagnosis came, I couldn't work anymore. I need to be present all the time. Living in the countryside wasn't the plan, but it was what we could afford. Getting a good night's sleep has become rare. I wake up several times during the night because his sleep is restless and he calls me all the time. We are also far from the city and our family. This emotional and physical distance weighs heavily on us! (I12)
>
> My social life ended after he was born. I used to go out with friends, go for walks, and enjoy moments, but I can't do that anymore. We also end up being excluded because when we visit someone, we can't adapt well. He finds new environments unfamiliar, gets agitated, and becomes uncomfortable. I had to give up everything to take care of him! (I19)

These accounts reflect the dual burden of domestic work and caregiving experienced by mothers, who must balance their household tasks with intensive childcare, often without institutional or family support. Rural living exacerbates geographical and emotional isolation, making caregiving a lonely and exhausting experience.

Category 3 – The search for social inclusion

Caregiving was also shaped by mothers' efforts to promote their children's social inclusion. Mothers tried to include their children in family and community settings, while encountering symbolic and behavioral barriers, such as prejudice, stigma, and limited understanding of SHCNs.

> I hardly ever go to family gatherings or dinners because the comments I hear, especially from the men, are very difficult to bear. My greatest wish is that he would be truly accepted, truly loved, at least within his own family. (I13)
>
> At first, they said I was crazy. They questioned why I let a five-year-old autistic boy ride the bus alone. But we live in a rural area, in the countryside, and he needs to learn to be more independent. The hardest part is dealing with prejudice, especially from people close to us. Friends or acquaintances often lack knowledge. When they see a child with a disability, they feel uncomfortable and don't know how to react or welcome them! (I18)
>
> He was bullied at school. Over time, he became aggressive. He realized that the activities given to his classmates were different from those he received, and that frustrated him. He tore up the sheets, he wanted to do the same as the others, he didn't accept being treated differently . . . (I15)
>
> Her classmates often made fun of her. I ended up taking my daughter out of school. They kept calling her stupid. She endured it until fifth grade because it was mandatory, but after that she didn't go anymore. It makes no sense to continue suffering if no one does anything, if everyone pretends it's not happening. (I24)

In addition to social challenges, mothers also described functional and communication barriers that restricted children's interaction with the environment and reinforced the need for multidisciplinary support.
"He speaks in a way that is difficult to understand. So much so that he needs to see a speech therapist. This makes it difficult because people can't interact with him as well" (I7).
She has a visual impairment that was detected right away during an eye exam, which yielded unexpected results. That's why I'm always close by to prevent her from hurting herself and to help her with everything. This means that she hardly interacts with other children. Children want to run, move around, but she stays still, sitting, waiting for someone to come to her. It breaks my heart to see that! (I9)
She doesn't communicate with words, she has developed her own way of expressing herself. But I'm the only one who understands what she means, because I'm with her all the time. Even so, I have faith that one day she will be able to speak... (I14)

"He has become very sensitive to sounds again, noises bother him a lot. So I have to think ahead about whether the place we're going to will be quiet or whether it will affect him. This requires constant planning!" (I15)

These narratives suggest that social inclusion remains limited and constrained by structural prejudice. Mothers assume a central role as mediators of communication, safety, and social participation for their children, while experiencing emotional overload and limited public support. These accounts reveal the typical lived experience of mothering in rural contexts: an everyday life marked by loneliness, unconditional love, and resilience, in which mothers build new meanings for caregiving in the face of adversity through lived experiences.

Discussion

From a Schutzian perspective, everyday mothering can be understood through intersubjective relationships within the life-world, where individuals interact directly through face-to-face relationships and coexist in the same time and space (Schütz, 2012). Within this context, mothers establish bonds of affection, care, and mutual recognition with their children, which form the foundations of everyday maternal experience.

The intersubjective relationship between mothers and children with SHCNs is characterized by bonds of familiarity and continuity, marked by daily coexistence and sustained involvement in activities such as feeding, hygiene, medication administration, and protection. This face-to-face relationship is expressed through mothers' efforts to cultivate closeness, empathy, and emotional harmony with their children with SHCNs, as they share the same space and time (Schütz, 2012).

Care intentionality if evident in actions oriented toward sustaining life and promoting the well-being of children with SHCNs. Mothers assume a central role in their children's care, development, and upbringing. However, it is important to acknowledge the distinction between the roles of mother and woman, as these perspectives challenge the notion that being a woman is synonymous with being a mother. Such social constructions impose on women a presumed obligation of maternal instinct (Souza & Calzavara, 2023).

Participants' narratives reveal everyday lives marked by physical and emotional overload, social isolation, and psychological vulnerability associated with complex caregiving demands. This intense routine restricts time for self-care, leisure, paid employment, and social interaction, thus compromising women's mental health and autonomy. Previous studies reveal that mothers are commonly perceived as primary caregivers and assume most caregiving responsibilities, which causes physical and emotional exhaustion (Chaves et al., 2022).

From Schütz's perspective, each individual has a unique biographical situation, composed of memories and lived experiences (Schütz, 2012). Mothers recall their daily lives before the birth of children with SHCNs, and these memories evoke feelings of loss, longing, and disruption. Withdrawal from social and professional life generates emotional distress and intensifies the burden of full-time caregiving. Thus, mothers of children with SHCNs experience stress and loneliness, immersed in routines of continuous treatment and vigilance (Silva et al., 2024). In this context, nursing professionals and other healthcare providers must connect mothers/caregivers with community resources, offering psychological and social support. Promoting the provision of respite care and the strengthening of collaborative support networks can reduce the stress and stigma associated with long-term caregiving (Lam et al., 2025).

Mothers living in rural areas also reported sacrificing paid employment and accumulating domestic responsibilities. The absence of fathers and other family members reinforced the solitary nature of maternal care. Insufficient parental support and unequal division of responsibilities suggest that, in many cases, fathers remain limited to the role of financial providers, while mothers concentrate caregiving functions (Baldini et al., 2021).

Among mothers living in rural areas, the difficulties are even greater. Geographical isolation restricts access to specialized and rehabilitation services, requiring long journeys to urban centers (Medeiros et al., 2022). In addition, many families experience socioeconomic vulnerability, including food insecurity, inadequate housing, and financial instability. Most families of children with SHCNs have unmet social needs, which intensifies inequalities (Yeoh et al., 2025).

According to Schütz (2012), the life-world is the setting in which individuals construct meanings through social interaction and shared experiences. Mothers described fragile support networks and an ongoing search for social inclusion that was not always achieved. For many, expectations regarding shared caregiving and family acceptance were unmet, revealing fragile social relationships that are further strained by rural living.

The life-world is intersubjective and cultural, as individuals live together, interpret, and project future experiences based on past experiences. However, these expectations do not always materialize. This contradiction becomes evident when mothers strive for the social inclusion of children with SHCNs but encounter prejudice and school bullying, which disrupt their expectations of acceptance and recognition. These findings underscore the importance of welcoming, safe, and empathetic school environments that foster children's holistic development despite health-related limitations (Andreato et al., 2024).

The mothering of children with SHCNs living in rural areas is driven by the intention to ensure their children's life, development, and well-being, sustained by emotional bonds and intersubjective caregiving relationships.

The everyday lives of these women are marked by sacrifice, physical and emotional overload, social exclusion, and the struggle for inclusion. Their expectations of acceptance and belonging for children with SHCNs were not always met within family and social relationships.

Therefore, intersectoral care systems should be strengthened to provide continuous and coordinated clinical, psychological, and community support to both children with SHCNs and their mothers (Nonoyama et al., 2025).

Conclusion

Everyday mothering in the care of children with SHCNs highlights the need for emotional, affective, and social support for mothers, as well as the reorganization of family and community dynamics. Because mothers assume most caregiving responsibilities, the physical and emotional burden associated with care is substantial.

Children with SHCNs require multiple forms of daily care, ranging from basic activities such as feeding and hygiene to complex and specialized actions related to life maintenance and the management of chronic health conditions.

In rural areas, everyday mothering is shaped by unique confrontations and challenges related both to children's health conditions, including physical and intellectual disabilities, genetic syndromes, and chronic diseases, and to barriers to access services and social inclusion faced by these families. Participants also identified divergent experiences and tensions, including differences in family acceptance, coping strategies, and perceptions of institutional support.

Further research focused on the experiences of mothers and family members of children with SHCNs living in rural areas is needed to increase the visibility and voice of this population, which is often invisible in public policies and health practices.

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