








Care of children and youth with special healthcare needs: repercussions on rural mothers' mental health

Cuidado de crianças com necessidades de saúde especial: repercussões na saúde mental de mães rurais

Cuidado de niños y adolescentes con necesidades especiales de salud: repercusiones en la salud mental de las madres rurales

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ABSTRACT

Objective: to understand the repercussions of caring for children and youth with special healthcare needs on rural mothers' mental health. **Method:** a qualitative, descriptive, and exploratory study was conducted through semi-structured interviews with 28 mothers linked to two *Associação de Pais e Amigos dos Excepcionais* in rural municipalities in the northwest of Rio Grande do Sul. Data were collected between August and September 2024 and subsequently subjected to Inductive Thematic Analysis. **Results:** challenges were identified from the moment of diagnosis disclosure, including experienced feelings, an exhausting routine, solo caregiving, and restricted access to support networks, as well as the physical and mental overload of these mothers. **Final considerations:** caring for children and youth with special healthcare needs leads to maternal psychological distress, marked by social isolation, fragility of support networks, and the near-exclusive responsibility placed on women. These findings highlight the need for intersectoral policies aimed at maternal mental health in rural contexts.

Descriptors: Nursing; Health Services Needs and Demand; Hospitals, Maternity; Mental Health; Rural Areas.

RESUMO

Objetivo: compreender as repercussões do cuidado de crianças com necessidades de saúde especial na saúde mental de mães rurais. **Método:** estudo qualitativo, descritivo e exploratório realizado por meio de entrevistas semiestruturadas com 28 mães vinculadas a duas Associação de Pais e Amigos dos Excepcionais de municípios rurais do noroeste do Rio Grande do Sul. Os dados foram coletados entre agosto e setembro de 2024 e, após, o material foi submetido à Análise Temática Indutiva. **Resultados:** evidenciaram-se desafios desde a descoberta do diagnóstico, sentimentos vivenciados, rotina exaustiva, cuidado solo e acesso restrito a redes de apoio, assim como a sobrecarga física e mental dessas mães. **Considerações finais:** o cuidado de crianças com necessidades de saúde especial repercute em sofrimento psíquico materno, marcado pelo isolamento social, fragilidade das redes de apoio e responsabilização quase exclusiva das mulheres. Esses achados evidenciam a necessidade de políticas intersetoriais voltadas à saúde mental materna no contexto rural.

Descritores: Enfermagem; Necessidades e Demandas de Serviços de Saúde; Maternidades; Saúde Mental; Zona Rural.

RESUMEN

Objetivo: comprender las repercusiones del cuidado de niños y adolescentes con necesidades especiales de salud en la salud mental de madres rurales. **Método:** estudio cualitativo, descriptivo y exploratorio realizado mediante entrevistas semiestructuradas con 28 madres vinculadas a dos *Associação de Pais e Amigos dos Excepcionais* de municipios rurales del noroeste de Rio Grande do Sul. Los datos fueron recolectados entre agosto y septiembre de 2024 y posteriormente sometidos a Análisis Temático Inductivo. **Resultados:** se evidenciaron desafíos desde el momento del diagnóstico, incluyendo los sentimientos experimentados, una rutina agotadora, el cuidado en solitario y el acceso restringido a redes de apoyo, así como la sobrecarga física y mental de estas madres. **Consideraciones finales:** el cuidado de niños y adolescentes con necesidades especiales de salud genera angustia psicológica materna, caracterizada por el aislamiento social, redes de apoyo frágiles y una responsabilidad casi exclusiva sobre las mujeres. Estos hallazgos resaltan la necesidad de políticas intersectoriales centradas en la salud mental materna en contextos rurales.

Descritores: Enfermería; Necesidades y Demandas de Servicios de Salud; Maternidades; Salud Mental; Medio Rural.

INTRODUCTION

In recent decades, technological advances and public policies aimed at maternal and child health have contributed to the survival of children with chronic and complex health conditions, especially those assisted in Intensive Care Units^{1,2}. This group, known as children and youth with special healthcare needs (CYSHCN), includes individuals aged between zero and 18 years who require continuous, temporary, or permanent care due to conditions that demand support beyond the general population's usual needs³⁻⁵.

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Advances in science and public policies directed at CYSHCN have enabled their care to take place within home environments, as well as their inclusion in school and social settings, extending beyond the boundaries of health institutions¹. CYSHCN have or are at greater risk of developing health conditions—whether physical, developmental, behavioral, emotional, or chronic—that require increased healthcare².

According to the World Health Organization, approximately 240 million children and adolescents worldwide live with some type of disability⁵. In Brazil, the 2022 Continuous National Household Sample Survey identified 18.6 million people with disabilities, of whom approximately 20% live in rural areas, facing greater difficulties in accessing essential services⁴.

CYSHCN may require different types of care: developmental, technological, pharmacological, modified usual care, mixed care, or clinically complex care⁵. These demands include, in addition to healthcare, educational, social, and family support. For this, articulation among different services is necessary in order to better assist this population. The importance of the family in this context is emphasized, as it requires support and assistance to enable the care of CYSHCN⁶.

The rural context imposes additional challenges on the population with disabilities, such as barriers to accessing health, education, and social assistance⁷. Within the scope of the Brazilian Unified Health System, care for this group should occur through Healthcare Networks, respecting territorial realities and promoting comprehensive and equitable care, with access to these services, as well as continuity of care, being a responsibility of the State⁸.

The Brazilian National Care Policy recognizes care as essential work for human life, involving both domestic activities and direct support for individuals with functional limitations⁹. In the case of CYSHCN, care is often taken over by mothers, who play the role of primary caregivers. This role implies intense dedication, frequently at the expense of professional and personal life, generating physical, emotional, and social overload^{10,11}.

Maternal care involves actions such as feeding, hygiene, therapeutic and emotional support, and is shaped by issues of gender, morality, and social structure¹². The burden may be objective, related to tasks and physical demands, or subjective, related to the personal perception of strain. In this context, implications for mental health emerge, such as anxiety, depression, social isolation, and feelings of guilt, affecting quality of life and the mother-child relationship¹³.

Despite the relevance of the topic, studies exploring the mental health of mothers who are caregivers of CYSHCN living in rural areas remain scarce. A survey conducted in the *Coordenação de Aperfeiçoamento de Pessoal de Nível Superior* Theses and Dissertations Database, in 2023, revealed the absence of research with this focus in southern Brazil, highlighting gaps in scientific knowledge. The present investigation seeks to contribute to advancing the understanding of this reality, considering the social and territorial determinants that influence maternal experiences.

Given the above, this study focuses on the repercussions of caring for CYSHCN on rural mothers' mental health. Thus, the following research question was established: "What are the repercussions of caring for CYSHCN on rural mothers' mental health?"

This study aimed to understand the repercussions of caring for CYSHCN on rural mothers' mental health.

METHOD

This is a field study with a qualitative, descriptive, and exploratory design, aimed at uncovering little-known social processes related to specific groups, thus supporting the development of new analytical categories¹⁴. Descriptive studies seek to define characteristics of a population or phenomenon, while exploratory studies aim to provide greater familiarity with the problem, allowing refinement of ideas and hypotheses¹⁵.

Data collection was carried out between August and September 2024 in two *Associações de Pais e Amigos dos Excepcionais* (APAEs) located in rural municipalities in northwestern Rio Grande do Sul. The first setting has its own facilities, with a structure divided between school and clinic, and serves approximately 68 students with the support of 27 staff members. The second setting, provided by the local government, was adapted to offer educational and clinical services, serving 22 students in the afternoon shift and supported by a multidisciplinary team.

Participants were rural mothers aged over 18 years who were responsible for the care of CYSHCN linked to one of the APAEs. Those who did not identify themselves as the primary caregivers of their children were excluded. A group meeting was held with the mothers to provide initial engagement and present the study proposal, with the participation of 32 women. Subsequently, those who met the inclusion criteria were contacted via the WhatsApp® application and invited to participate voluntarily.

Interviews were conducted at the APAE facilities, by prior appointment, in private rooms to ensure confidentiality and appropriate conditions for data collection. Initially, a structured instrument was used to collect sociodemographic data, followed by a semi-structured interview consisting of open-ended questions. The interview guide addressed subjective aspects of motherhood, daily care routines at home, the experience of motherhood in rural contexts, as well as emotional aspects and health-related issues among mothers living in rural areas, totaling 26 questions, including sociodemographic data and open-ended questions. The interviews allowed for flexible dialogue, enabling the construction of meanings based on participants' narratives¹⁶.

The interviews were audio-recorded, with an average duration of 40 minutes, and later fully transcribed with the assistance of a research assistant. Data collection was concluded after the 28th interview, when theoretical saturation was reached, as evidenced by the recurrence of topics and the absence of new relevant information to expand and deepen understanding of the investigated phenomenon¹⁷.

Data were subjected to Inductive Thematic Analysis proposed by Braun and Clarke¹⁸, which allows the identification, analysis, and interpretation of topics based on textual data. The analysis followed six phases: (1) familiarization with the data; (2) generation of initial codes; (3) search for topics; (4) review of topics; (5) definition and naming of topics; and (6) production of a final report. These stages involved in-depth data reading, coding, and categorization, enabling a rich and meaningful interpretation.

To ensure transparency and methodological rigor, the study was conducted and reported in accordance with CONSolidated criteria for REporting Qualitative research recommendations, which guide the rigorous description of procedures and findings in qualitative studies¹⁹.

The research protocol was approved by the Institutional Review Board of the proposing institution in June 2023. To ensure anonymity and preserve participants' identities, statements were identified using the letter "M" (referring to mother), followed by a number corresponding to the order of the interviews.

RESULTS

A total of 28 mothers of CYSHCN participated in the study, all residing in rural areas and linked to the APAEs that constituted the study setting. Participants were aged between 27 and 50 years, and most of them combined daily caregiving with paid work (n=18), highlighting the coexistence of work-related and caregiving responsibilities in the rural context.

Regarding family composition, 14 participants were married or in a stable union. In terms of socioeconomic conditions, most reported a monthly income of up to one minimum wage, indicating a context of economic constraint among 12 of the interviewed mothers.

The findings of this study emerged from the analysis of participants' narratives, allowing an understanding of the experiences of rural mothers caring for CYSHCN. From the empirical material, three thematic categories were constructed, which synthesize the main meaning units present in these women's reports: Impact of the diagnosis on maternal mental health; Feelings experienced by mothers caring for children and youth with special healthcare needs in rural areas; and Sources of support in the daily lives of mothers caring for children and youth with special healthcare needs in rural areas.

Impact of the diagnosis on maternal mental health

Participants revealed the plurality of these experiences and converged in showing how facing the diagnosis represents a turning point in the maternal trajectory. The way these women were informed, supported, and the resources available to deal with the new family condition influenced their emotional adaptation.

At first, it was scary, especially since he was my second child. I thought it would be much worse, but, over time, things fell into place. (M1)

At first, I was in denial, grieving, for about three months. It was hard to accept that my son was completely dependent on me. (M2)

It was a shock when the doctor told me that my baby had been born with Down Syndrome. The worst part was when the doctor explained all the problems that could arise over time. (M6)

I was also very scared and lost. (M7)

It was a huge shock, I freaked out. I couldn't accept it because I didn't see her as a child with a disability. So, I rebelled, I started blaming myself, I couldn't accept it. (M8)

It was a shock, because until then we thought he was normal. (M9)

It was a very difficult change for the whole family. (M10)

At first, I couldn't accept it, but not in the sense of rejection, I just didn't understand why this happened to her, since she had all the support. It's not easy, but you get used to the routine. (M16)

It was a very big shock, after seven months, our lives turned upside down with so many doctors and exams. (M20)

Rural mothers of CYSHCN also highlighted the scarcity of inclusive spaces and the presence of social stigma. The lack of social support guarantees and the unpreparedness of institutions to embrace diversity contribute to emotional and psychological burden.

My biggest anxiety is about what his future will be like. If he will be able to be independent, if he will learn to read and write. This affects me a lot. (M1)

I feel discouraged when I think about her future, you know? [...] I keep thinking that there is a very high possibility that she won't succeed, and that terrifies me. (M10)

What worries me most is what he will face in the future. We live in a society that is not prepared to accept these children. (M11)

These statements show that mothers are concerned not only with the children's clinical development, but also with their social inclusion, life opportunities, and survival in a world that often excludes those who are different.

Feelings experienced by mothers caring for children and youth with special healthcare needs in rural areas

Some mothers reported feelings of guilt related to attitudes adopted before the diagnosis, such as reprimands or misinterpretations of a child's behavior. This feeling is intensified by the lack of adequate emotional support and by maternal overload, which makes self-care more difficult.

I blamed myself a lot. I did all the prenatal care perfectly, I followed all the doctor's instructions, so I didn't understand why this was happening to me. [...] why me, if I did everything right? (M8)

I blamed myself deeply because I thought he wasn't understanding things out of spite. When I found out the problem, I felt enormous pain for having been so harsh with him. (M14)

I felt very guilty, I thought it was something of mine. That's why I went for a genetic test and it came back negative. I took care of myself throughout the pregnancy; I didn't do anything wrong. (M25)

The maternal role, especially in the context of caring for CYSHCN, is marked by challenging experiences that deeply affect these women's mental health, as they tend to prioritize their children's care over their own needs.

There came a point where I didn't know where to find the strength anymore. I attempted suicide because I saw no way out. His father doesn't help, and I had to take care of everything alone. (M3)

It's a constant worry about her, especially when she's sleeping. (M4)

I feel like a lioness, fighting for him every day. I have to fight for everything: for therapies, for medical care, for simply ensuring he has a dignified life. (M6)

Taking care of her is a full-time job. I need to help with everything, [...] it's not easy. (M8)

It's tiring to live, tiring to do everything. It's very exhausting... They drain our energy. (M9)

I do almost everything for her, which overwhelms me a lot and leaves her limited. (M10)

Mothers described caregiving as a daily struggle, oscillating between strength and exhaustion. Some see themselves as fighters advocating for their children's rights, while others reported having reached extreme emotional distress due to lack of support and prospects.

Sources of support in the daily lives of mothers caring for children and youth with special healthcare needs in rural areas

Participants reported that, although there are family members nearby, their involvement in caregiving is limited. These women's daily lives are shaped by an exhausting routine, often combined with domestic responsibilities and, when possible, paid work.

I can only work in the afternoon because in the morning I have to take care of him. He has therapy from Monday to Friday mornings, every day. (M2)

If it were up to me, I would have already abandoned my husband and his family. They don't understand my daughter's problem. I feel tied down and very frustrated. (M8)

Many times, the people around us don't understand his behavior, and this isolates us. I've heard comments like "give this child an education", and that hurts. (M9)

We only go to places where he already knows the people because that makes things easier. Going to new environments is very complicated; he doesn't adapt well. (M11)

I don't have time for myself. I live their lives, my children's lives. I'm with them all the time. (M14)

Mothers in this study reported that, as they became intensely dedicated to their children's demands, they distanced themselves from their own identities, preferences, and personal desires. This reality highlights how maternal care, although essential, can lead to emotional exhaustion and a sense of self-negation.

These last two years have been very difficult. I cry every day and I'm constantly exhausted, but I know I can't let things fall apart because he depends on me. (M2)

I don't take care of myself, you know? I got to a point where I didn't recognize myself anymore. (M11)

Sometimes we put self-care aside because of our children. You dedicate more time to them and end up neglecting yourself. [...] we have to take care of everything, and it's not easy. (M12)

Sometimes I want to do something for myself, but there's no way I can leave him alone. (M13)

Thus, daily activities revolve around CYSHCN's needs, affecting these women's rest, autonomy, and social life. Although most caregiving responsibilities fall on mothers, some receive occasional support from family members, which helps reduce the burden.

My dedication is 24 hours a day. I have to take him to appointments, and the entire household routine revolves around him. (M1)

She doesn't speak, doesn't walk, and doesn't tell me when she needs to go to the bathroom, so she wears diapers. She needs full-time care all the time. (M4)

I had to create a fixed and organized routine to be able to cope with everything. It changed my life a lot. It was like living a completely different life after that moment. (M10)

I always need to be attentive to the medication and care schedules. The routine is very rigid; I can't let my guard down. (M17)

My mother and I take care of him, and when my husband is home, he also helps. The care routine is continuous. (M26)

In the beginning, our routine with her was difficult, but over time we got used to it. She became the family's darling. (M28)

The reports highlight the emotional and subjective impact of caregiving. In this context, APAE is mentioned as an important source of technical and emotional support, functioning as a space for care, learning, and exchange.

He attends APAE, where he does hydrotherapy, equine therapy, as well as sessions with a psychologist and speech therapist. (M6)

She taught me how to live in this world, which I didn't even know before, like APAE, which was viewed in the wrong way. She teaches me something new every day, because she needs continuous care. (M8)

Caring for CYSHCN directly affects mothers' personal and professional lives. Many are forced to reduce or give up work to meet their children's needs, leading to financial difficulties and a sense of sacrifice.

I work 20 hours, I would need to work 40 hours, but I can't. (M4)

I gave up a job. I had two jobs; I couldn't handle it anymore. (M10)

Today I realize I made the right choice in leaving my job to dedicate myself more to him. (M21)

I had to quit my job to take care of her. (M28)

These statements reveal that motherhood and the care of CYSHCN are marked by silent sacrifices made by these women.

DISCUSSION

The analysis of participants' reports made it possible to understand the care of CYSHCN and its repercussions on rural mothers' mental health. The findings show that, from the initial impact of the diagnosis, mothers face the need to reorganize personal and family dynamics, experiencing significant effects on their mental health. Receiving a diagnosis of CYSHCN is often experienced as a process of symbolic mourning, resulting from the deconstruction of the idealized child²⁰. This moment is marked by feelings of pain, insecurity, and helplessness, highlighting the immediate emotional impact of the diagnosis, especially among mothers, who are usually primarily responsible for caregiving^{21,22}.

Motherhood in rural settings is shaped by structural and subjective challenges, requiring continuous adaptation in the face of fragile support networks and overlapping social and emotional roles. From this point on, a profound reorganization of maternal routines begins, involving personal, social, and professional changes²³. In rural areas, this reality becomes even more intense due to the scarcity of specialized services, geographic isolation, and the accumulation of roles attributed to women. Furthermore, the way mothers cope with the diagnosis directly affects their mental health, potentially increasing vulnerability to psychological distress²⁴.

Mental health disorders experienced by mothers caring for CYSHCN go beyond individual burden and reflect structural inequalities related to gender, territory, and access to services, particularly intensified in rural contexts²⁵. From the perspective of Freirean pedagogy, these experiences can be understood as expressions of historical oppression that naturalizes caregiving as a female responsibility, rendering women invisible as subjects of rights²⁶.

Overcoming oppression requires critical awareness of lived reality. In this sense, understanding motherhood under conditions of overload as a form of structured oppression allows questioning of the myth of the “devoted mother”, which demands total self-sacrifice and silencing of one’s own needs²⁷. The transition from “oppressed motherhood” to “conscious motherhood” requires spaces for listening, knowledge exchange, and public policies that recognize and value caregiving as a shared family responsibility, rather than solely a maternal duty.

The literature shows that maternal caregiving, when performed alone and continuously, poses serious risks to women’s physical and emotional health²⁸. In this study, the absence of support networks was recurrent, combined with insufficient preparedness among family members to deal with the specific demands of care. The exclusive responsibility placed on mothers intensifies feelings of helplessness and frustration²⁹.

Motherhood as a historical and social construct, and not as a biological essence, is a central theme of Badinter’s work, denouncing the effects of the normative ideal of the fulfilled and selfless mother²⁹. This model reinforces maternal guilt in the face of the impossibility of meeting social expectations, especially in contexts of vulnerability and isolation, such as in rural areas. However, this internalized guilt is marked by self-criticism and a constant feeling of inadequacy³⁰.

Uncertainty regarding children’s future and the absence of structured intersectoral policies further intensify mothers’ emotional distress. Reports of loneliness, overload, and personal sacrifice demonstrate the magnitude of the responsibility placed on women, especially when fathers are absent or socially exempt from caregiving roles^{31,32}. The sexual division of labor, still strongly rooted in rural contexts, reinforces the idea that men should provide while women should care, a reality that requires significant transformation³³.

The repercussions of this overload on self-care are evident: abandonment of professional life, reduced social interaction, and loss of personal fulfillment, as already documented in the literature³⁴. Self-neglect is a recurrent practice among participants and constitutes a risk factor for mental health, especially in contexts of social vulnerability^{24,35}. In rural areas, many mothers continue to perform domestic, agricultural, and productive activities even in the face of intense caregiving demands. Although they demonstrate resilience and strength, the lack of recognition and institutional support compromises their health and well-being³⁶. These women must be recognized as full subjects who deserve care, visibility, and opportunities to pursue their life projects.

Institutional neglect is also expressed in the scarcity of specialized services. In this context, APAE is highlighted as a space for support, emotional care, and knowledge exchange. Although limited, its role demonstrates the potential of dialogical and collective practices in building bonds, strengthening autonomy, and valuing lived experiences^{24,37}.

The findings reinforce the need for integrated public policies that recognize the social role of mothers caring for CYSHCN. Caring for caregivers is not only an ethical demand but also a social necessity. Care should not continue to be a naturalized and invisible function, but rather a shared responsibility, valued and supported by institutional and community networks.

Study limitations

The research was conducted with mothers of CYSHCN residing in rural areas, which may limit the generalizability of the findings to other populations, especially in urban contexts or different sociocultural realities. Data production through interviews may be subject to social desirability bias, as participants may have modulated their reports according to perceived expectations, particularly when addressing sensitive aspects related to care and motherhood.

The findings derive from narratives constructed from participants' disposition, which may have limited the expression of experiences marked by greater suffering, isolation, or vulnerability. These limitations reinforce the need for future research that considers other approaches to deepen the understanding of the multiple dimensions of maternal care for CYSHCN in rural areas and maternal mental health.

FINAL CONSIDERATIONS

Mothers of CYSHCN living in rural areas experience intense physical and emotional overload, aggravated by social isolation, fragile support networks, and the near-exclusive responsibility placed on women for caregiving, resulting in mental distress.

Under these conditions, maternal care for CYSHCN ceases to be a choice and becomes an imposed responsibility, often marked by the absence of institutional and family support. This reinforces the need for intersectoral policies that are sensitive to the specificities of maternal care in rural contexts, with particular attention to the mental health of these mothers.

By giving visibility to the voices of a historically marginalized social group, this study contributes to the development of care strategies that are more sensitive to issues of gender, territory, and social vulnerability, as well as to the training of professionals capable of acting in an ethical, committed, and emancipatory manner.

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Use of artificial intelligence tools

Authors declare that no artificial intelligence tools were used in the composition of the manuscript “Care of children and youth with special healthcare needs: repercussions on rural mothers’ mental health”.