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RESEARCH ARTICLE (ORIGINAL)

Adoptive Parenting and Making Care Possible in Contexts of Disability

Parentalidade por Adoção e a Possibilidade de Cuidado em Contextos de Deficiência

Parentalidad Adoptiva y la Posibilidad del Cuidado en Contextos de Discapacidad

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Abstract

Background: Adopting children with disabilities challenges norms of care and belonging. **Objective:** To understand how care is expressed and sustained every day by families with adopted children with disabilities.
Methodology: A qualitative phenomenological-hermeneutic study based on interviews with primary caregivers *n* = 11), conducted between November 2023 and June 2024 in southern Brazil, using iterative part–whole analysis.
Results: Five dimensions emerged — (1) Addressing incomplete information and institutional barriers; (2) Organizing flexible routines in the face of the unpredictable; (3) Activating support networks and advocating for rights; (4) Building connections and a sense of belonging in everyday life; (5) Recognizing what makes care possible. Participants portray care as translation, clinical co-authorship, and *an architecture of the ordinary* across homes, services, and cities.
Conclusion: Over time**,** caring builds worlds: families create conditions for care by translating opacity, weaving responsive networks, and introducing plans that *breathe*. The PPCC model is recommended for communicating care and guiding flexible daily plans.

Keywords: adoption; persons with disabilities; adoptive parents; continuity of patient care; patient advocacy; phenomenology

Resumo

Enquadramento: A adoção de crianças com deficiência desafia as normas de cuidado e de pertencimento. **Objetivo:** Compreender como o cuidado se manifesta e sustenta no quotidiano de famílias que adotaram crianças com deficiência.
Metodologia: Estudo qualitativo fenomenológico-hermenêutico, com entrevistas a cuidadores principais (*n* = 11), entre novembro de 2023 e junho de 2024, num município do sul do Brasil; análise iterativa (parte–todo).
Resultados: Emergiram cinco dimensões — (1) Enfrentamento de informações incompletas e barreiras institucionais; (2) Organização de rotinas flexíveis diante do imprevisível; (3) Ativação de redes de apoio e defesa de direitos; (4) Construção de vínculo e pertencimento no quotidiano; (5) Reconhecimento do que torna o cuidado possível. As falas evidenciam o cuidado como tradução, coautoria clínica e arquitetura do ordinário entre a casa, os serviços e a cidade.
Conclusão: Cuidar é trabalho temporal que produz mundo: famílias fabricam condições ao traduzir opacidades, tecer redes responsivas e instituir planos que respiram. Propõem-se os quatro critérios — Participação, Previsibilidade, Conforto e Continuidade — para comunicar o cuidado e orientar planos flexíveis no quotidiano.

Palavras-chave: adoção; pessoas com deficiência; pais adotivos; continuidade da assistência ao paciente; defesa do paciente; fenomenologia

Resumen

Marco contextual: La adopción de niños con discapacidad desafía las normas de cuidado y pertinência. **Objetivo:** Comprender cómo se manifiesta y sostiene el cuidado en la vida cotidiana de familias com niños con discapacidad.
Metodología: Estudio cualitativo fenomenológico-hermenéutico, con entrevistas a cuidadores principales (*n* = 11), entre noviembre de 2023 y junio de 2024 en un municipio de Brasil; análisis iterativo (partes/todo).
Resultados: Emergieron cinco dimensiones — (1) Afrontar la información incompleta y las barreras institucionales; (2) Organizar rutinas flexibles ante lo imprevisible; (3) Activar redes de apoyo y defensa de los derechos; (4) Fomentar los vínculos y el sentido de pertenencia en el día a día; (5) Reconocer qué es lo que hace posible el cuidado. Los relatos muestran el cuidado como traducción, coautoría clínica y *arquitectura de lo cotidiano* entre el hogar, los servicios y la ciudad.
Conclusión: Las familias construyen condiciones de cuidado al traducir opacidades, tejer redes responsivas y establecer planes que *respiran*. Se propone el modelo PPCC para transmitir la atención y orientar planes flexibles en la vida cotidiana.

Palabras clave: adopción; personas con discapacidad; padres adoptivos; continuidad de la atención al paciente; defensa del paciente; fenomenología

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Introduction

Adoptive parenting of children with disabilities entails complex demands related to organizing daily care, ensuring continuity of care, and coordinating with health, education, and social assistance services (Gréaux et al., 2023; Mitra et al., 2022). Beyond the challenges inherent in the adoption process itself, these families often face additional needs stemming from the children's specific clinical, functional, and social conditions, requiring primary caregivers to make ongoing adaptations, provide intensive therapeutic management, and maintain continuous coordination across multiple institutional systems (Santos et al., 2022).

Although public policies, specialized services, and social protection programs are essential to this trajectory, significant gaps remain in care coordination, access to services, and institutional equity. These shortcomings often place greater responsibility on families to maintain continuity of care and to advocate for their children's rights in everyday life (Mitra et al., 2022; Santos et al., 2022). In this context, care extends beyond technical interventions, taking on a relational, organizational, and ethical dimension, particularly when formal protocols are insufficient to address the complexity of families' lived needs.

From a nursing perspective, understanding these experiences broadens the analysis of care in contexts of vulnerability, inclusion, and family diversity, contributing to a deeper understanding of comprehensive, continuous, and responsive care across health and social care networks (Djukanovic et al., 2024). However, despite advances in describing barriers, care trajectories, and the challenges faced by adoptive families, there remains limited research that explores in depth how care is experienced, organized, and sustained in the everyday lives of families who have adopted children with disabilities, particularly in the context of institutional inadequacies and fragmented support systems (Gréaux et al., 2023; Norlyk et al., 2023).

Against this background, the aim of this study was to understand how care is experienced and sustained in the everyday lives of families who have adopted children with disabilities.

Background

Care, a central concept in nursing and the health sciences, extends beyond technical and procedural interventions to include relational, ethical, and organizational practices that sustain life within specific contexts (Collière, 1999; Waldow, 2012). Historically, care has been understood as a process that integrates protection, responsiveness, and continuity to meet individuals' unique needs. It requires not only clinical interventions but also presence, interpretation, and mediation among individuals, families, and institutions. In the context of disability, this understanding is particularly relevant, as caregiving often entails reorganizing daily routines, negotiating access to services, fostering predictability, and sustaining relationships in environments marked by complex care demands and variable institutional support.

Disability, in turn, is a multidimensional phenomenon shaped by bodily, functional, social, and political factors, and its effects profoundly influence family organization, particularly the lives of primary caregivers (Gréaux et al., 2023; Mitra et al., 2022). Studies have shown that families of children with disabilities frequently experience physical, emotional, financial, and organizational burdens associated with the need for ongoing care, coordination of multiple services, advocacy for rights, and navigating persistent institutional barriers (Mitra et al., 2022; Taylor et al., 2023). For primary caregivers, these demands may entail adjustments to employment, restrictions on social participation, increased psychological burden, and ongoing adaptation, particularly when coordination among health, education, and social care services is fragmented or insufficient.

In the context of adoption, these challenges may be even more complex, as the development of parenthood occurs alongside the formation of emotional bonds, the understanding of the child's unique needs, and the navigation of systems that are often bureaucratic or insufficiently prepared to address the intersection of adoption and disability (Gréaux et al., 2023). Although previous research has advanced understanding of barriers, care trajectories, and structural inequalities, important gaps remain regarding how care becomes feasible and sustainable in the everyday lives of these families, particularly from an experiential and relational perspective (Norlyk et al., 2023).

Accordingly, it is essential to understand not only the structural challenges but also the concrete mechanisms that enable care in everyday life, including family agreements, relationships with healthcare professionals, environmental adaptations, advocacy strategies, and daily practices that promote continuity of care and participation (Taylor et al., 2023). There is also a need to further explore the temporal dimensions of care, understood as the ways participation, predictability, comfort, and continuity shape everyday life and influence families' lived experiences (van Pijkeren et al., 2023; Santos et al., 2022).

A phenomenological-hermeneutic approach offers an important contribution to this understanding by enabling analysis of how care is expressed, meaning is constructed, and care is sustained within lived experience through the interplay between individual narratives and broader institutional contexts (Rentmeester & Liebzeit, 2023; Hurley, 2022). This perspective makes it possible to understand care in adoptive families of children with disabilities as a situated, relational, and interpretive practice that emerges from the interaction of vulnerabilities, support networks, temporality, and concrete strategies for sustaining everyday life.

From this perspective, investigating how care is expressed and sustained in these experiences contributes to advancing nursing knowledge of family caregiving practices, continuity of care, and the everyday production of care in contexts of considerable complexity.

Research question

How do families with adopted children with disabilities experience and sustain daily care?

Methodology

Study design

This qualitative study employed a phenomenological-hermeneutic approach (Rentmeester & Liebzeit, 2023). This interpretive framework allows for exploring how care is experienced and expressed by adoptive parents of children with disabilities. It aims to understand how care is lived and maintained in everyday life, using rich descriptions and reflective interpretation to highlight its meanings.

Study scenario and participants

The study was conducted in a municipality in southern Brazil and involved families who provided care for children and adolescents with disabilities across the health, education, and social care sectors.

Purposive sampling was used, guided by participants' experiential relevance to the phenomenon under investigation. Eligible participants were primary caregivers in adoptive families of children or adolescents with disabilities who were responsible for day-to-day care and had established experience interacting with public services and institutional support networks.

A total of 11 primary caregivers participated in the study. The sample size was determined by interpretive sufficiency and was considered adequate when the interviews showed thematic recurrence and sufficient depth to support analytic stability, with no substantially new dimensions of meaning emerging. The diversity of family configurations and disability conditions contributed to the interpretive richness and robustness of the dataset.

Data collection technique and instruments

Data were collected between November 2023 and June 2024 through face-to-face semi-structured interviews conducted by the principal investigator. Each interview lasted 60 to 120 minutes.

The interview script included open-ended questions about participants' adoption trajectories, the organization of everyday care, relationships with health and social care services, support networks, challenges encountered, and family strategies for managing care.

All interviews were audio-recorded and transcribed verbatim. They were also supplemented by field notes written by the principal investigator immediately after each interview. These notes captured contextual, expressive, and situational aspects of the interviews.

Reflective notes were also kept throughout the study to document analytic impressions, emerging insights, and interpretive developments, thereby enhancing reflexivity and supporting the hermeneutic rigor of the analysis.

Ethical considerations

The study was conducted in accordance with the ethical principles set forth in the Brazilian National Health Council Resolution No. 510/2016, which governs research involving human participants in the social and human sciences. Participants received detailed information about the study's objectives and procedures and provided written informed consent before participating (Resolução nº 510/2016 do Conselho Nacional de Saúde, 2016).

Participants were assured of anonymity, confidentiality, and the right to withdraw from the study at any time without penalty (Resolução nº 510/2016 do Conselho Nacional de Saúde, 2016). To protect participants' identities, all names were replaced with pseudonyms inspired by Greek mythology, including those of spouses and children whenever they were mentioned in the interviews.

The study protocol was approved by the Research Ethics Committee of the Faculty of Nursing at Pelotas Federal University - Approval No. 6,532,379; CAAE No. 75718623.8.0000.5316 (Resolução nº 510/2016 do Conselho Nacional de Saúde, 2016).

Data analysis and treatment

Data analysis was conducted iteratively and concurrently with data collection, guided by a phenomenological-hermeneutic approach and three core principles: understanding care as a lived and narrated experience; engaging in a hermeneutic movement between the parts and the whole of the dataset; and maintaining researcher reflexivity regarding the meanings generated through participants' narratives. After transcription, anonymization, and review of the dataset, the interviews were read repeatedly to identify units of meaning, which were then grouped into interpretive themes and broader dimensions of meaning through a continuous movement between individual accounts and the dataset as a whole. Analytic memos were maintained throughout the process to ensure transparency, interpretive coherence, and ongoing reflexive engagement.

Each narrative was initially analyzed as a distinct account, with attention to participants' language, contextual circumstances, and lived experiences. Emerging meanings were then compared across interviews to identify recurring patterns, tensions, and variations. The researcher adopted an active interpretive stance, integrating participants' narratives with field notes, reflexive memos, and the theoretical framework while avoiding the imposition of predetermined analytical categories.

Methodological rigor was ensured through: comprehensive description of the study context and participants; experiential diversity within the sample; inclusion of verbatim quotations; a documented audit trail; reflexive memoing; continuous engagement with the dataset throughout the analytic process; and adherence to the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Braun & Clarke, 2024). Collectively, these strategies strengthened the study's credibility, dependability, confirmability, and transferability.

Results

The analysis identified five key dimensions that explain how care is structured and sustained in families with adopted children with disabilities. These dimensions of meaning highlight institutional hurdles, family strategies, support systems, the development of relational bonds, and the practical criteria caregivers use to assess what enables care in everyday life.

Dimension 1 – Navigating incomplete information and institutional barriers

Within this dimension of meaning, care emerged as a process shaped by fragmented information, insufficient institutional responses, barriers to accessing services, and bureaucratic demands. Families described the need to reconstruct care trajectories, actively seek referrals, maintain relationships with healthcare professionals, and ensure continuity of care. When consistent professional support and stable relationships with services were available, caregiving became more secure, coordinated, and predictable.

> So, to sum it up, our relationship with the healthcare system is one of love and frustration. Gratitude and exhaustion. We struggle. But we also recognize that without SUS [Brazil's Unified Health System], Hesperus [the participant's adopted son] would never have a chance. Neither would we. (Atlas)
>
> In addition, she has neurological follow-up every three months with the same pediatric neurologist who has cared for her since the beginning in Porto Alegre, [and] with whom we have developed a strong relationship, built on complete trust in her clinical expertise. We had the autonomy to choose the healthcare professionals based on technical criteria and [their] rapport with the family. We never had to go through public screening procedures, waiting lists, or the SUS referral bureaucracy. (Athena)

Dimension 2 – Organizing flexible routines in the face of unpredictability

Families described everyday care as requiring continuous planning, adaptation, and flexibility. Daily routines had to be organized to reduce caregiving demands, anticipate challenging situations, and promote the child's or adolescent's participation in family, school, and social activities. At the same time, caregivers recognized that not every situation could be anticipated, so plans had to be adjusted in response to the child's reactions, the surrounding environment, and the circumstances of each day.

> Our family's social life was not put on hold because of the disability. On the contrary, it was transformed. That transformation requires planning, sensitivity, and a certain degree of improvisation every time we go out. But it isn't easy. There are two main factors we always need to consider. He is a level 3 autistic child, which means he faces significant challenges with sensory regulation, communication, and independence . . . and there is an almost complete lack of preparedness in both public and private spaces to accommodate people with invisible disabilities. (Rhea)
>
> He always takes care of his responsibilities before he is allowed to watch television. Every evening, our boy studies for two hours. He chooses which subject to study. That's from Monday to Friday. Even though our son is almost in high school, he still faces many difficulties. My husband has often said that he knows our son will not be a brilliant student who will go to college and win a Nobel Prize. But he still needs to master the basics so he can at least manage independently. (Prometheus)

Dimension 3 – Mobilizing support networks and advocating for rights

Within this dimension of meaning, care was sustained through family, professional, and institutional support networks. Participants emphasized that these networks were not always extensive or readily accessible; however, when they were responsive, they became essential to sustaining everyday care. Conversations between spouses, support from extended family members, trusted healthcare professionals, and coordination with services helped distribute caregiving responsibilities, support decision-making, and advocate for the child's rights.

> Whenever a more difficult situation arises, a dilemma or a question—whether related to health, education, or even family life—our first response is almost always to talk to each other. Before anything else, before seeking outside or professional support, we try to listen to one another. We have this habit... I think this openness in our conversations is one of the most valuable things in our lives. Of course, not every conversation is easy. (Orpheus)
>
> We do have a support network, but it is quite limited: family support, professional support, and, to some extent, institutional support. Even so, although this network exists, it is neither extensive nor readily available. We have had to learn through experience how to organize our everyday lives using the resources available to us. (Artemis)

Dimension 4 – Building bonds and a sense of belonging in everyday life

Within this dimension of meaning, adoptive parenthood was described as a relationship that develops over time, especially when children face difficulties with communication, emotional expression, or immediate reciprocity. Participants emphasized that attachment does not emerge automatically but is gradually cultivated through consistent presence, repeated acts of care, attentive listening, and recognition of each child's unique ways of communicating. In this sense, care also fosters security, attachment, and belonging.

> Attachment does not come ready-made . . . One of the greatest challenges to developing a bond with our daughter at the beginning was, without question, her difficulty communicating. She does not speak and has very particular ways of expressing what she feels, what she wants, and what makes her uncomfortable. At first, this left us with a profound sense of helplessness. (Hestia)
>
> Our bond was built not through grand gestures

> but through everyday life: preparing meals the way they like them, carefully putting away their toys, honoring the agreements we made, and the quiet moments of listening in the hallway... Today, Mnemosyne already calls me Dad. Iapetus hugs me when I come home from work. Thetis . . . waits for me at the door whenever she knows I'm particularly tired. (Cronus)

Dimension 5 – Recognizing what makes care possible

Within this dimension of meaning, participants indicated that care is not evaluated solely by the provision of clinical procedures or formal services. Rather, care is recognized by its ability to promote participation, predictability, comfort, and continuity (PPCC) in everyday life. These four criteria form the PPCC model, developed through phenomenological interpretation of participants' lived experiences. Rather than proposing a scale or prescriptive protocol, the model synthesizes the practical criteria families use to recognize when care supports a more organized, secure, and sustainable everyday life.

> Calliope [the participant's adopted daughter] takes dance classes. So, we make sure they have plenty of physical activity to promote their health. They love music, so whenever there's a concert, we go. I've also taken Calliope and Orion [the participant's adopted son with a disability] to the theater to see performances too. He loves it. He sits in the front row and dances... He keeps to himself, but he really enjoys the performance and the music. No, he has no problem with loud noises. (Hermes)
>
> It's a daily ritual that helps Uranus [the participant's adopted son] regulate his emotions—and, honestly, mine as well. Sometimes it's the most playful moment of our day. He loves filling and emptying containers, letting water run through his hands, and slowly dipping his face into the water as if he were listening to it speak. (Gaia)
>
> Today, he attends weekly sessions there, including speech-language therapy, physical therapy, and occupational therapy. He also has opportunities to socialize with other children, play, listen to music, and [participate in] adapted activities. Everything is carried out with great care and attention. (Demeter)

Thus, the PPCC model emerged as an interpretive synthesis of the meanings participants attributed to everyday care. It makes visible dimensions that, although not always reflected in formal service records, are central to families' lived experiences: enabling the child's participation, reducing uncertainty, respecting bodily and sensory boundaries, and maintaining continuity across the contexts of everyday life.

Discussion

The findings demonstrate that care in adoptive parenting of children with disabilities is organized as a relational and coordinating practice in response to institutional gaps, requiring families to continuously mediate between the child's needs and the functioning of health, education, and social care services. Rather than serving as passive recipients of formal interventions, caregivers assume an active role in translating information, organizing daily routines, advocating for their children's rights, and maintaining continuity of care. These findings align with previous research highlighting family care coordination and advocacy as essential components of caregiving for children with complex care needs (Khatri et al., 2023; Taylor et al., 2023).

The challenges of fragmented services, bureaucratic processes, and insufficient communication reinforce existing evidence that structural barriers often intensify the burden on primary caregivers, particularly in the context of disability (Gréaux et al., 2023; Mitra et al., 2022). In this context, continuity of care depends not only on the availability of services but also on families' capacity to coordinate resources, build collaborative relationships with healthcare professionals, and maintain relatively stable care trajectories over time (Santos et al., 2022).

The organization of everyday care was also strongly shaped by the need for flexible planning, with structured routines designed to reduce uncertainty while remaining adaptable to changing circumstances. This finding aligns with studies identifying predictability, environmental adaptations, and flexibility as key components that promote participation and well-being among children with disabilities, particularly those with neurodevelopmental conditions (Antosh et al., 2024; Walløe et al., 2024).

Another central finding concerns the role of support networks. The results suggest that the effectiveness of these networks depends not only on their size but also on their capacity to provide responsive support, share caregiving responsibilities, and facilitate timely decision-making. Strong spousal relationships, family support, and trusted healthcare professionals emerged as essential resources for reducing caregiver burden and promoting stability, corroborating prior evidence on relational care coordination and continuity of care (Kerrissey et al., 2024; Khatri et al., 2023).

The development of adoptive parenthood emerged as a gradual process, particularly in situations marked by communication difficulties or complex care needs. Consistent presence, everyday caregiving practices, and relational stability fostered attachment and a sense of belonging, indicating that care also serves as a source of emotional security and family integration. This finding extends current understandings of adoptive parenthood beyond its legal dimensions and aligns with perspectives that conceptualize care and attachment as processes constructed over time (Coupé & Ollagnier-Beldame, 2022).

Finally, the PPCC model synthesizes the practical criteria identified in families' lived experiences as essential to sustaining care in everyday life. Although grounded in phenomenological interpretation, the model offers a conceptual resource for nursing practice by supporting a broader understanding of family needs beyond isolated clinical procedures. Its value lies in its potential to inform more context-sensitive assessments and care plans and to strengthen family-centered care, intersectoral coordination, and continuity of care.

Taken together, these findings reinforce that caring in this context requires integrating clinical practice, family organization, support networks, and institutional strategies. They also underscore the expanded role of nursing in care coordination, communication, and the provision of longitudinal support for families raising adopted children with disabilities.

Conclusion

This study demonstrated that, in the context of adoptive parenting of children with disabilities, care is a continuous process of organizing, adapting, and sustaining everyday life. Families play a central role in translating institutional demands, coordinating daily routines, mobilizing support networks, and fostering relationships that promote attachment, a sense of belonging, emotional security, and continuity of care.

The analysis identified four fundamental principles of sustainable everyday care, namely participation, predictability, comfort, and continuity (PPCC), which serve as practical criteria for guiding family decision-making and organizing everyday life beyond strictly technical interventions. Together, these principles provide a useful interpretive model for understanding families' concrete needs and for fostering greater sensitivity when developing individualized care plans.

For nursing, these findings reinforce the importance of extending practice beyond the delivery of clinical procedures by embracing a broader role in care coordination, relationship-building, mediation between families and services, and the development of flexible strategies that respond to each family's unique circumstances.

From an organizational perspective, the PPCC model may serve as a conceptual resource for strengthening family-centered practice, supporting intersectoral collaboration, and enhancing continuity of care across services.

In summary, caring in this context involves fostering conditions that enable children and their families to maintain manageable routines, stable relationships, and meaningful engagement despite ongoing institutional and social obstacles. Recognizing these areas enhances the nursing discipline's view of care and promotes practices that are more responsive, inclusive, and sustained over time.

Author contributions

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Thesis/Dissertation

This study is based on the doctoral dissertation titled "Produzindo cuidado inclusivo na adoção de crianças com deficiência: participação, previsibilidade, conforto e continuidade em contextos de desigualdade", submitted to the Pelotas Federal University (UFPel), Brazil, in March 2026.

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