Voices of Mothers: Emotional Journey in Raising Children with Neuro-Developmental Disorders

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ABSTRACT

Motherhood is an inherently complex journey shaped by emotional bonds, sacrifice, and resilience; however, raising a child with neuro-developmental disorders intensifies this journey through persistent physical, emotional, relational, and contextual challenges. This study explored the lived experiences of mothers caring for children with neuro-developmental disorders in Dipolog City, Philippines, focusing on how they make sense of caregiving through their bodies, environments, relationships, time, and material realities. Guided by the qualitative transcendental phenomenology of Moustakas, seven mothers who served as primary caregivers of children aged 2 to 5 years with medically diagnosed neuro-developmental conditions were purposively selected. Data were gathered through in-depth, semi-structured interviews and analyzed using Moustakas' phenomenological approach. Five interconnected themes emerged: (1) caregiving as continuous bodily exhaustion marked by chronic fatigue and disrupted sleep; (2) caregiving environments as shifting spaces of safety and strain where home, healthcare settings and community simultaneously shaped support and stress; (3) caregiving as a temporal journey in which pain and uncertainty gradually coexisted with acceptance, perseverance, love and hope; (4) objects, routines, and therapeutic tools as meaningful sources of comfort, regulation and emotional support for the child; and (5) motherhood as a sacred responsibility characterized by purposeful sacrifice, lifelong commitment, identity and faith. The findings reveal caregiving as a deeply embodied, spatial, temporal, relational and meaning-laden experience that profoundly transforms mothers' sense of self and everyday life. These insights emphasize the need for culturally responsive healthcare, strengthened community support systems, and policies that recognize mothers as central bearers of lifelong caregiving responsibility.

Keywords: caregiver well-being, lived experiences, maternal caregiving, neuro-developmental disorders, phenomenology

INTRODUCTION

Motherhood is widely understood as a transformative and deeply relational experience characterized by emotional attachment, nurturing, and identity formation. However, this journey becomes significantly more complex when mothers raise children with neurodevelopmental disorders (NDDs), as caregiving extends beyond normative parenting into sustained physical, emotional and social demands. Mothers in this context are required to navigate intricate healthcare systems, manage long-term developmental challenges, and respond to evolving behavioral and cognitive needs, all while maintaining familial and societal roles. These layered responsibilities often expose mothers to heightened psychological distress, financial strain, and social marginalization, yet they simultaneously reveal profound resilience, meaning-making, and enduring commitment.[1]

Neurodevelopmental disorders encompass a heterogeneous group of conditions characterized by impairments in cognition, communication, behavior, and motor functioning, typically emerging during early developmental periods. These include autism spectrum disorder (ASD), intellectual disability, and attention-deficit/hyperactivity disorder (ADHD), among others.[2] Globally, developmental disabilities affect a substantial proportion of children,

with increasing recognition of their long-term implications for functioning and quality of life.[3] Despite this growing prevalence, scholarly attention has predominantly focused on clinical features, diagnostic frameworks, and intervention outcomes. Comparatively less emphasis has been placed on the lived experiences of primary caregivers, particularly mothers, whose roles are central to the daily management and developmental trajectory of affected children. This imbalance underscores the need to shift from deficit-oriented perspectives toward more holistic, experience-centered understandings of caregiving.

The emotional landscape of mothers raising children with NDDs is marked by a dynamic interplay of love, pain, and hope. Love functions as a foundational force that motivates caregiving persistence and advocacy, even in the face of adversity.[4] Conversely, pain emerges through multiple pathways, including witnessing the child's struggles, confronting uncertain developmental outcomes, and navigating societal stigma. Yet, hope persists as a critical psychological resource, enabling mothers to reframe challenges, envision positive futures, and sustain caregiving efforts over time .[5] These emotional dimensions do not occur in isolation; rather, they coexist in tension, forming a complex and often paradoxical caregiving experience that evolves across time and context.

Empirical evidence consistently demonstrates that mothers of children with developmental conditions experience elevated levels of stress, anxiety and depressive symptoms, particularly following diagnosis and during early caregiving stages.[6] The diagnostic period is frequently described as a moment of emotional upheaval, characterized by shock, grief, guilt and fear, which may resemble processes of ambiguous loss or chronic sorrow.[7] Over time, mothers undergo adaptive processes that involve emotional regulation, cognitive reframing, and role redefinition. However, these processes are not linear. Instead, they are recursive and influenced by contextual factors such as access to healthcare, family support and sociocultural beliefs. Social support, in particular, has been identified as a critical buffer against psychological distress, facilitating resilience and promoting adaptive coping strategies .[9]

Qualitative studies further illuminate the depth and variability of maternal experiences in caregiving contexts. For instance, mothers of children with complex congenital conditions often report profound emotional suffering alongside gradual adaptation and meaning-making.[7] Similarly, research on mothers of children with developmental disabilities highlights the coexistence of hardship and fulfillment, where caregiving is experienced as both burdensome and deeply rewarding.[9] These findings suggest that maternal caregiving is not solely defined by stress or deficit but is instead characterized by an evolving interplay of emotional, relational and existential dimensions. Importantly, such experiences are shaped by cultural contexts, which influence how mothers interpret their child's condition, construct meaning and engage with support systems.

In the Philippine context, caregiving experiences are further shaped by cultural, spiritual and familial values that influence meaning-making processes and coping strategies. Mothers often draw on religious beliefs, attributing their child's condition to divine will or purpose, which can serve as both a source of comfort and a framework for understanding adversity.[10] At the same time, structural challenges such as limited access to specialized healthcare, financial constraints, and societal stigma may intensify caregiving burdens. These contextual factors highlight the importance of situating maternal experiences within broader socioecological systems, recognizing that caregiving is not merely an individual endeavor but a socially embedded and culturally mediated process.

Despite the growing body of literature on caregiving in NDDs, significant gaps remain in understanding the deeper emotional and existential dimensions of maternal experiences. Much of the existing research has focused on psychological burden, coping strategies, or quality of life indicators, often emphasizing negative outcomes such as stress and burnout. While these perspectives are valuable, they risk oversimplifying caregiving by neglecting the nuanced and often contradictory emotional realities that mothers navigate. Specifically, there is limited exploration of how mothers simultaneously hold experiences of grief, joy, guilt, love and hope, and how these emotional tensions shape their identities, relationships, and caregiving practices over time.

Furthermore, the processes through which mothers construct meaning, sustain hope, and develop resilience in the context of chronic caregiving demands remain underexplored. Phenomenological approaches offer a valuable lens for addressing this gap by focusing on lived experience and the subjective meanings individuals attach to their realities. In particular, Moustakas' phenomenological dimensions comprising lived body, lived space, lived time and lived relations provide a comprehensive framework for examining how individuals experience and

interpret their worlds.[11] Applying this framework to maternal caregiving allows for a deeper understanding of how physical exhaustion, spatial environments, temporal transitions and relational dynamics intersect to shape the caregiving experience.

The present study responds to these gaps by exploring the emotional journey of mothers raising children with neurodevelopmental disorders through a phenomenological lens. It seeks to move beyond surface-level descriptions of stress and coping by examining the embodied, relational, and existential dimensions of caregiving. By foregrounding mothers' narratives, the study aims to capture the complexity of their emotional experiences, highlighting how love, pain and hope are expressed, negotiated and sustained across time and context. This approach not only enriches theoretical understandings of caregiving but also provides practical insights for developing more empathetic and family-centered support systems.

The theoretical grounding of this study integrates three complementary nursing frameworks: Watson's Theory of Human Caring, Roy's Adaptation Model, and Nightingale's Environmental Theory. Watson's theory emphasizes the relational and transpersonal nature of caring, framing caregiving as an act of compassion, presence, and emotional connection [12].[12] Roy's model conceptualizes individuals as adaptive systems responding to environmental stimuli, highlighting the dynamic processes through which mothers adjust to caregiving demands [13].[13] Meanwhile, Nightingale's theory underscores the influence of environmental conditions on health and well-being, drawing attention to the role of physical, social and psychological contexts in shaping caregiving experiences [14].[14] Together, these frameworks provide a multidimensional lens for understanding caregiving as an interplay of emotional, adaptive, and environmental processes.

The significance of this study lies in its potential to contribute to both theory and practice. By elucidating the lived experiences of mothers, the study offers insights that can inform the development of holistic and culturally responsive interventions aimed at supporting caregiver well-being. For healthcare professionals, understanding these narratives may enhance empathetic communication, strengthen therapeutic relationships, and guide the design of family-centered care models. For policymakers, the findings may provide an evidence base for developing programs and policies that address the multidimensional needs of families affected by neurodevelopmental disorders. Ultimately, this study seeks to amplify the voices of mothers, recognizing their experiences not merely as challenges to be managed but as profound human journeys characterized by resilience, meaning and enduring care.

METHODS

Research Design

This study employed a qualitative transcendental phenomenological design to explore the lived experiences of mothers raising children with neurodevelopmental disorders (NDDs). The design was particularly suitable for this study as it sought to uncover the shared meanings, emotional dimensions, and essential structures of maternal caregiving. By focusing on description rather than interpretation, the study aimed to faithfully represent the voices of mothers and illuminate the core essence of their caregiving journey.

Research Setting

The study was conducted in selected communities in a certain city in the southwestern part of the Philippines, where caregiving for children with neurodevelopmental disorders is shaped by limited access to specialized healthcare services and strong sociocultural influences. Diagnostic and therapeutic services such as pediatric neurology, developmental pediatrics and specialized interventions are largely concentrated in urban centers outside the locality, making access logistically and financially challenging for many families.

Primary healthcare services and government programs provide basic support. However, early intervention, psychological services and long-term developmental therapies remain limited. Formal support groups for families of children with NDDs are also scarce, resulting in increased reliance on family networks, faith-based communities and local traditions for emotional and practical support.

Within this context, mothers typically assume the primary caregiving role, navigating their responsibilities amid economic constraints, cultural expectations, and limited institutional assistance. These conditions made the locality a relevant setting for examining the emotional lifeworlds of mothers, particularly how caregiving is shaped by the interplay of resource limitations, cultural beliefs, and community dynamics.

Participants and Sampling

The study involved seven (7) mothers residing in a locality in the southwestern part of the Philippines who served as primary caregivers of children diagnosed with neurodevelopmental disorders. A purposive sampling strategy was used to identify participants who could provide rich and relevant descriptions of the phenomenon under investigation.

Participants met the following inclusion criteria: (a) mothers who were the primary caregivers of children aged 2 to 5 years diagnosed with one or more neurodevelopmental disorders, including autism spectrum disorder (ASD), attention-deficit/hyperactivity disorder (ADHD), global developmental delay (GDD), intellectual disability (ID), communication or language disorders, or cerebral palsy with developmental implications; (b) diagnoses confirmed by qualified specialists such as pediatric neurologists, developmental pediatricians, or child psychiatrists; and (c) willingness and emotional capacity to participate in in-depth interviews.

Exclusion criteria included mothers whose children's conditions were acquired through injury or illness unrelated to neurodevelopmental disorders, those who were not the primary caregivers, and those unable to meaningfully participate due to severe mental health conditions, cognitive impairments, or significant language barriers. The sample size was deemed sufficient for phenomenological inquiry, which prioritizes depth and richness of data over generalizability.

Research Instrument

Data were collected using a semi-structured interview guide designed to elicit in-depth narratives of maternal caregiving experiences. The guide was anchored on Moustakas' phenomenological dimensions: lived body (physical experiences), lived space (environmental context), lived time (temporal experiences), lived relation (interpersonal dynamics), and lived things (objects and tools). This framework ensured a comprehensive exploration of participants' emotional, physical, relational, spatial and temporal realities.

The interview guide was developed through a review of relevant literature and refined with input from experts in qualitative research and developmental care to ensure clarity, cultural sensitivity, and contextual appropriateness. In addition to interviews, field notes were recorded to capture non-verbal cues, emotional expressions and contextual observations, thereby enhancing the richness and depth of the data.

Data Gathering Procedure

Prior to data collection, ethical approval was obtained from the Misamis University Research Ethics Committee (MUREC), along with permission from relevant institutional authorities. Participant recruitment was facilitated through collaboration with local health centers, pediatric clinics, therapy centers, and community organizations in a locality in the southwestern part of the Philippines. Health professionals assisted in identifying potential participants who met the inclusion criteria.

Eligible participants were approached individually and provided with detailed information about the study's purpose, procedures, and ethical considerations. Written informed consent was obtained prior to participation.

Data were collected through face-to-face, in-depth semi-structured interviews conducted in private and convenient locations, most commonly in participants' homes. Each interview lasted approximately 30 minutes. With consent, interviews were audio-recorded to ensure accuracy. Field notes were taken to document non-verbal behavior, environmental context, and researcher observations.

All data were handled with strict confidentiality. Audio recordings were stored in password-protected files, and transcripts were anonymized using pseudonyms. Physical documents were secured in locked storage, and digital

files were encrypted. Only the researcher had access to the data, which were retained for six months after study completion before secure disposal.

Ethical Considerations

Ethical integrity was maintained throughout the study. Approval was secured from MUREC following submission of a detailed research protocol. The researcher declared no conflicts of interest and maintained a clear role as investigator, separate from any healthcare provision. Participation was entirely voluntary, and participants were assured that their involvement would not affect their access to healthcare services.

Given the sensitive nature of the topic, participants were considered a potentially vulnerable group. Measures were taken to ensure their autonomy, dignity, and emotional well-being. Informed consent included clear explanations of the study's purpose, procedures, potential risks, and the right to withdraw at any time without consequence.

Privacy and confidentiality were strictly observed. Interviews were conducted in secure settings, and all identifying information was removed from transcripts and reports. Pseudonyms were used in all documentation. Data security protocols included password protection, encryption, and restricted access.

Although no material incentives were provided, participants were informed that sharing their experiences might offer emotional relief and contribute to improved understanding and support for mothers in similar situations.

Data Analysis

Data analysis followed Moustakas' transcendental phenomenological method, which aims to describe the essence of lived experience through systematic procedures. The process began with epoche, wherein the researcher engaged in reflexive journaling to identify and bracket personal assumptions, prior experiences, and preconceived beliefs related to motherhood, caregiving burden, resilience, and children with special needs. Strategies such as reflective memo writing, repeated self-questioning, and continuous examination of personal perspectives were employed to minimize interpretive bias and maintain openness to participants' lived experiences. This process helped ensure that meanings emerged primarily from participants' narratives rather than from the researcher's expectations.

The first analytic step, horizonalization, involved reading and re-reading the transcripts while listening to audio recordings to ensure accuracy. Significant statements related to the caregiving experience were identified and treated with equal value. These statements were then clustered into meaning units by identifying recurring patterns and shared themes across participants. Redundant statements were eliminated, and invariant constituents were validated against the original data to ensure consistency and accuracy.

Textural descriptions were subsequently developed to describe what participants experienced, using verbatim excerpts to capture the emotional, physical, relational, and contextual dimensions of caregiving. Structural descriptions were then constructed to explain how these experiences occurred, considering factors such as family dynamics, healthcare access, cultural expectations, and community influences. To enhance interpretive credibility, member checking was conducted by returning selected interpretations and thematic summaries to participants for confirmation and clarification of meanings. Finally, textural and structural descriptions were synthesized to articulate the composite essence of the phenomenon. This synthesis captured caregiving as an embodied, relational, temporal, and meaning-centered experience characterized by profound challenges, resilience, and enduring commitment. The analytic process remained grounded in participants' narratives, ensuring a faithful and rigorous representation of their lived experiences.

RESULTS

This study generated a rich and nuanced understanding of the lived experiences of mothers caring for children with special needs. Through phenomenological analysis, five major themes emerged, each reflecting a distinct yet interconnected dimension of the caregiving lifeworld: (1) the unrested body: continuous physical exhaustion and depletion of mothers in relentless caregiving; (2) navigating spaces of safety and strain: home as sanctuary,

healthcare as haven and community as a conditional space; (3) enduring time through love and hope: mothers' journey from pain and uncertainty toward acceptance and meaningful continuance of care; (4) objects and tools as sources of comfort, care, and emotional support for the child; and (5) sacred responsibility and purposeful sacrifice: motherhood as calling, identity, and lifelong commitment. These themes collectively illuminate caregiving as an embodied, spatial, temporal, relational and meaning-laden experience.

Theme 1: The Unrested Body: Continuous Physical Exhaustion and Depletion of Mothers in Relentless Caregiving

The first theme captures caregiving as an intensely embodied experience in which the maternal body becomes a site of continuous demand, fragmentation, and depletion. Across participants, exhaustion was not described as occasional tiredness but as a chronic and pervasive condition that shaped everyday life. Sleep, typically a restorative process, was frequently interrupted, shortened, or absent altogether, leaving mothers in a constant state of physical fatigue and incomplete recovery.

Participant 1 vividly illustrated this condition, stating, *"My body always feels extremely exhausted and I get very little sleep, sometimes only two hours in broken intervals… I just cry because of how physically drained I am."* This narrative reflects a pattern of disrupted rest and relentless vigilance, where caregiving responsibilities extend into the night, preventing the body from recuperating. The maternal body, in this sense, becomes perpetually "on call," unable to disengage from caregiving demands.

Beyond physical tiredness, exhaustion extended into cognitive and emotional domains. Participant 2 described reaching a point of being *"completely dazed from exhaustion"* and struggling to regulate emotions, emphasizing how fatigue compromises both mental clarity and emotional control. Similarly, Participant 4 reported insomnia, breathlessness, and bodily weakness, indicating that prolonged caregiving stress manifests physiologically as well as psychologically.

These accounts reveal exhaustion as multidimensional—simultaneously physical, cognitive, and emotional. The body not only experiences fatigue but also becomes the medium through which stress is expressed, evident in symptoms such as pain, shortness of breath, and emotional breakdowns. Participant 6 further emphasized this interplay, sharing that despite feeling *"physically, emotionally, and mentally exhausted,"* she continued caregiving, demonstrating resilience amidst depletion.

Collectively, the narratives highlight a cyclical pattern: continuous caregiving demands disrupt rest, leading to physical exhaustion, which in turn impairs emotional regulation and coping capacity. Despite this, mothers persist in caregiving, often normalizing their depletion as part of their role. Thus, the "unrested body" is not merely fatigued but is a body that endures, stretched to its limits yet sustained by love and obligation.

Theme 2: Navigating Spaces of Safety and Strain: Home as Sanctuary, Healthcare as Haven and Community as a Conditional Space

The second theme reveals how caregiving is shaped by lived spaces that are imbued with emotional and relational meaning. Mothers described navigating three primary environments, home, healthcare settings and community. Each experienced as a distinct configuration of safety and strain.

The home emerged as both a sanctuary and a site of ongoing caregiving labor. Participants described transforming their homes into therapeutic environments tailored to their children's needs. Participant 1 noted, *"Our home became a therapeutic space for my twins,"* highlighting how familiarity and control foster a sense of safety. Similarly, Participant 3 expressed a desire for a home *"with no judgment, no questions,"* underscoring the home as a refuge from external scrutiny.

Healthcare settings, particularly therapy centers, were experienced as havens of support and reassurance. Participant 6 described these spaces as a *"safe zone,"* where structured interventions and professional guidance provided relief from uncertainty. These environments offered predictability, validation, and emotional comfort, contrasting with the unpredictability of daily caregiving at home.

In contrast, community spaces were often perceived as conditional and ambivalent. While they offered potential for social interaction, they were also associated with stigma, judgment, and stress. Participant 7 shared, *"In public spaces I am always alert and anxious,"* reflecting heightened vigilance and emotional strain. Similarly, Participant 1 noted that the community was *"something I had to carefully choose,"* indicating selective engagement to avoid negative experiences.

These findings demonstrate that space is not neutral but actively shapes caregiving experiences. Home provides comfort yet demands constant labor; healthcare settings offer structured support; and community spaces require negotiation and caution. Mothers continuously navigate these environments to protect their children and themselves, illustrating how spatial contexts influence emotional well-being and caregiving capacity.

Theme 3: Enduring Time Through Love and Hope: Mothers' Journey from Pain and Uncertainty toward Acceptance and Meaningful Continuance of Care

The third theme captures caregiving as a temporal journey marked by transformation from initial distress to enduring hope. Mothers described their experiences as evolving over time, where early stages of caregiving were characterized by pain, confusion, and uncertainty, which gradually gave way to acceptance, resilience, and meaning.

Participant 1 reflected, *"In the beginning, the pain and confusion were overwhelming… but over time, I have accepted and learned to continue everything because of love and hope."* This statement illustrates how emotional experiences are not static but change as mothers adapt to caregiving demands. Similarly, Participant 2 described how her *"pain was replaced with hope and strength"* over time, indicating a process of emotional reconfiguration.

Participants also highlighted how their perception of time shifted throughout the caregiving journey. Participant 7 noted that *"time felt very slow because of the difficulties,"* but with each small improvement in her child's condition, her outlook became more hopeful. This reflects a non-linear experience of time, where moments of hardship feel prolonged, while progress brings renewed motivation.

The narratives further reveal that caregiving involves a continuous negotiation between suffering and perseverance. Participant 4 described an initial sense of devastation, *"it felt as if my world had collapsed"*, followed by a gradual commitment to continue caregiving through hope. This transformation underscores the role of meaning-making in sustaining long-term caregiving.

Overall, this theme demonstrates that mothers endure caregiving not merely by coping with present challenges but by reinterpreting their experiences over time. Love and hope become central forces that enable them to move beyond pain, creating a sense of purpose and continuity in their caregiving journey.

Theme 4: Objects and Tools as Sources of Comfort, Care, and Emotional Support for the Child

The fourth theme highlights the significant role of objects, tools, and routines in mediating care and providing emotional support for children with special needs. Participants described how everyday items such as toys, sensory aids, and structured routines serve as essential mechanisms for comfort, regulation, and engagement.

Participant 1 detailed the use of various items, including pacifiers, earmuffs, pillows, spinners, and "Pop it" toys, explaining how these helped her children calm down and focus. These objects functioned as more than physical items; they were integral to the child's emotional and sensory regulation. Similarly, sticker charts and puzzles facilitated communication and engagement, particularly for children with limited verbal abilities.

Feeding practices also emerged as meaningful tools of care. Participant 4 described preparing blended foods and following structured meal schedules to ensure proper nutrition and consistency. These routines provided not only physical sustenance but also a sense of predictability and security for the child.

Participant 5 emphasized the importance of maintaining daily routines, such as bathing and skin care, to promote comfort, while also respecting the child's preferences. The use of entertainment objects and flexible approaches demonstrated a balance between structure and autonomy in caregiving.

Additionally, Participant 6 highlighted the use of rewards and repeated routines to encourage participation and reinforce positive behaviors. These practices supported the child's development while also providing a framework for caregiving.

Collectively, these findings illustrate that objects and routines are imbued with emotional and relational significance. They act as extensions of maternal care, enabling children to navigate their environment while providing mothers with reassurance and support in their caregiving role.

Theme 5: Sacred Responsibility and Purposeful Sacrifice: Motherhood as Calling, Identity, and Lifelong Commitment

The final theme encapsulates caregiving as a deeply meaningful and identity-defining experience. Mothers described their role not merely as a responsibility but as a calling grounded in love, faith, and unwavering commitment. Caregiving was framed as non-negotiable, shaping their sense of self and life purpose.

Participant 4 expressed this sense of responsibility, stating, *"No matter how difficult it is, I carry everything because I am the mother."* This reflects caregiving as an intrinsic aspect of identity rather than a chosen task. Similarly, she shared that she had set aside her personal dreams to prioritize her child, illustrating the extent of personal sacrifice involved.

Participant 5 articulated caregiving as a central life purpose, stating, *"My purpose now revolves around him… I will not give up."* This highlights how mothers reorient their lives around their children's needs, finding meaning in their caregiving role.

Despite the challenges, participants also described moments of fulfillment. Participant 1 shared feeling *"both exhausted and happy"* when seeing her children's smiles, illustrating the coexistence of joy and fatigue. This emotional duality underscores the complexity of caregiving experiences.

Faith emerged as a significant source of strength, with Participant 2 emphasizing that their *"dedication, patience, love, and faith"* sustained them. Spiritual beliefs provided a framework for understanding and enduring caregiving challenges.

However, the theme also revealed underlying anxieties about the future. Participant 6 expressed concern about who would care for her child in her absence, highlighting the enduring nature of caregiving responsibility and the uncertainty that accompanies it.

Overall, this theme demonstrates that caregiving is deeply intertwined with identity, purpose, and meaning. Mothers perceive their sacrifices not as losses but as expressions of love and commitment, reflecting a profound redefinition of self within the caregiving journey.

The findings reveal caregiving as a multifaceted and deeply embodied experience shaped by physical exhaustion, spatial navigation, temporal transformation, material support systems, and existential meaning. Mothers experience caregiving through their bodies, environments, relationships and evolving perceptions of time, demonstrating resilience and adaptability despite significant challenges. These themes collectively underscore the complexity of maternal caregiving and highlight the need for holistic support systems that address both the practical and emotional dimensions of care.

DISCUSSIONS

The findings of this study illuminate caregiving as a profoundly embodied, spatial, temporal, relational, and meaning-driven experience for mothers of children with special needs. Across narratives, caregiving is not merely a set of tasks but a lived condition that permeates the body, shapes perception of environments, transforms the experience of time, and redefines identity and purpose. The accounts reveal that caregiving is sustained through an interplay of exhaustion and resilience, burden and meaning, vulnerability and strength, dimensions that are well substantiated in contemporary caregiving literature and nursing theory.

A central insight emerging from the findings is the pervasive and enduring nature of physical and psychological exhaustion among mothers. Unlike episodic fatigue, the mothers described a chronic state of bodily depletion characterized by fragmented sleep, constant vigilance, and cumulative wear. This aligns with recent studies indicating that caregivers of children with complex needs experience persistent exhaustion that evolves into burnout when demands remain unrelieved over time.[15] Empirical evidence demonstrates that sleep disruption, musculoskeletal strain, and cognitive fatigue are common among parental caregivers, significantly affecting both physical health and emotional regulation.[16] Similarly, large-scale studies have shown that caregiver burden is strongly associated with prolonged stress exposure, resulting in diminished well-being and increased risk for chronic health conditions.[17] These findings reinforce the notion that caregiving is fundamentally embodied, where the body becomes the primary site through which stress and responsibility are experienced.

This embodied experience is best understood through Moustakas' phenomenological concept of the lived body or corporeality, which posits that the body is not merely a biological entity but the medium through which individuals engage with and interpret the world.[11] The mothers' accounts of exhaustion, breathlessness, and emotional dysregulation reflect how caregiving is inscribed upon the body, shaping both perception and action. Supporting this, qualitative studies have identified that caregivers often describe fatigue as a multidimensional phenomenon encompassing physical, cognitive, and emotional domains, forming a cyclical pattern where exhaustion impairs coping capacity and intensifies stress responses.[18] This cyclical depletion underscores the need for healthcare systems to recognize caregiver fatigue as a critical health concern rather than a secondary consequence of caregiving.

Beyond the bodily dimension, the findings also highlight how caregiving is deeply influenced by spatial experiences. Mothers described home, healthcare environments, and community settings as spaces imbued with varying degrees of safety, control, and stress. The home often functioned as both a sanctuary and a site of continuous caregiving labor, reflecting its dual role in providing comfort while simultaneously demanding constant vigilance. Studies have shown that caregivers actively modify home environments to accommodate their child's needs, transforming domestic spaces into therapeutic settings that support both care delivery and emotional stability.[19] In contrast, healthcare environments were frequently perceived as structured and supportive spaces that offer reassurance and professional guidance, consistent with research indicating that well-designed clinical environments can reduce caregiver anxiety and enhance engagement in care processes.[20]

Community spaces, however, were often experienced as unpredictable and socially challenging, where stigma and lack of understanding contribute to heightened stress. This aligns with findings that caregivers frequently navigate public environments cautiously due to fear of judgment and limited inclusivity.[21] These spatial experiences can be effectively interpreted through Moustakas' concept of lived space (spatiality), which emphasizes that environments are not neutral but are experienced through emotional and relational meanings.[11] Complementing this perspective, Florence Nightingale's Environmental Theory further underscores the critical role of physical and social environments in shaping health outcomes, suggesting that supportive, controlled, and therapeutic environments are essential for both patient and caregiver well-being.[21] Together, these frameworks highlight the need for nurses to consider environmental modifications as integral to holistic care.

The temporal dimension of caregiving also emerges as a significant aspect of the mothers' lived experiences. Time was not perceived as linear but as fluid and emotionally charged, where moments of distress felt prolonged while experiences of hope and progress altered the perception of time. This aligns with research demonstrating that caregivers often experience "temporal disruption," particularly during the early stages of diagnosis, where uncertainty and emotional burden distort the perception of time.[22] Over time, however, caregivers develop adaptive narratives that allow them to reinterpret their experiences and sustain engagement in caregiving.[23] Longitudinal studies further suggest that caregivers gradually construct meaning through their experiences, enabling them to balance emotional strain with resilience and hope.[24]

Moustakas' concept of lived time (temporality) provides a theoretical lens for understanding this phenomenon, emphasizing that time is subjectively experienced and inseparable from personal meaning.[11] The mothers' narratives illustrate how past hardships, present caregiving demands, and future aspirations are intertwined, shaping a continuous journey of adaptation and perseverance. This temporal transformation reflects a shift from

initial distress to a more meaning-oriented perspective, where caregiving becomes a purposeful and enduring commitment.

Relationality also plays a crucial role in shaping the caregiving experience. The mothers' accounts reveal that their relationships with their children serve as both a source of emotional strain and a foundation for resilience. Love, attachment, and a sense of responsibility emerged as central motivators that sustain caregiving despite ongoing challenges. Empirical studies support this finding, showing that strong relational bonds and social support significantly reduce caregiver burden and enhance psychological well-being.[16,25] Social connectedness has been linked to increased resilience, optimism, and life satisfaction among caregivers, highlighting the importance of relational resources in mitigating stress.[26]

This aligns with Moustakas' concept of lived relations (relationality), which posits that human experiences are inherently relational and shaped through interactions with others.[11] In the context of caregiving, the mother-child relationship becomes a central axis through which meaning, identity, and emotional endurance are constructed. The findings suggest that caregiving is not an isolated experience but one that is continuously negotiated within interpersonal and social contexts, emphasizing the need for family-centered and community-based interventions in nursing practice.

Another significant dimension of the findings is the role of objects and routines in mediating care and emotional support. Mothers described how tools such as sensory items, toys, feeding practices, and structured routines provide comfort, stability, and opportunities for engagement for their children. These objects function as extensions of care, enabling children to regulate emotions and navigate daily challenges. Research supports the use of structured routines and therapeutic tools in enhancing emotional regulation, attention, and adaptive behavior among children with special needs [15]. Additionally, caregivers report that these tools reduce stress by creating predictable patterns and facilitating observable progress.[28]

From a phenomenological perspective, these objects can be understood through Moustakas' concept of lived things, which refers to material objects imbued with personal meaning and significance.[11] In this context, tools and routines are not merely functional but are integral components of the caregiving lifeworld, serving as emotional anchors for both the child and the mother. This highlights the importance of incorporating individualized and meaningful tools into nursing interventions to support both developmental and emotional needs.

Finally, the findings reveal that caregiving is deeply intertwined with identity, purpose, and meaning. Mothers described their roles as a calling characterized by sacrifice, devotion, and unwavering commitment. This sense of purpose enables them to endure physical and emotional challenges while maintaining resilience. Studies have shown that caregivers who perceive caregiving as meaningful or purpose-driven demonstrate higher levels of perseverance and psychological well-being, even in the presence of significant stress .[29] At the same time, research indicates that meaning-making does not eliminate burden but rather allows caregivers to coexist with it, experiencing both fulfillment and exhaustion simultaneously.[30]

This dimension of caregiving can be understood through Moustakas' concept of lived meaning and intentionality, where individuals derive purpose through meaningful engagement with others.[11] Additionally, Jean Watson's Theory of Human Caring provides further insight, emphasizing that caring is a deeply human and moral commitment that transcends task-oriented actions and fosters connection, compassion, and meaning.[12] The mothers' narratives reflect this perspective, as caregiving becomes a source of identity and existential purpose, shaped by love, faith and relational commitment.

CONCLUSIONS

Caregiving for children with neuro-developmental disorders is a multidimensional and deeply lived experience shaped by physical exhaustion, changing routines, relational support and meaning-making. The findings emphasize the value of holistic, family-centered and context-sensitive nursing care. Nursing practice may prioritize caregiver well-being through respite services, psychosocial support, self-care education and culturally responsive interventions. Community-based support programs and policies that strengthen caregiver assistance

and multidisciplinary services are also essential in improving family well-being and sustaining mothers in their caregiving roles.

LIMITATIONS OF THE STUDY

The study focused mainly on mothers within a specific geographic and cultural context, which may limit the transferability of the findings. The perspectives of fathers and other caregivers were not included, and the interpretive nature of phenomenological research may have been influenced by the researcher's perspectives despite efforts to ensure rigor. Future research may explore paternal caregiving experiences, compare caregiving across different settings, and examine culturally grounded interventions and community-based support systems that can further enhance nursing practice and policy development.

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REFERENCES

1. Raina, P., O'Donnell, M., Schwellnus, H., et al. (2021). Caregiving process and caregiver burden: Conceptual models. *BMC Pediatrics, 21*(1), 1–10. https://doi.org/10.1186/s12887-021-02623-1
2. American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). https://doi.org/10.1176/appi.books.9780890425596
3. Olusanya, B. O., Davis, A. C., Wertlieb, D., et al. (2018). Developmental disabilities among children younger than 5 years. *The Lancet Global Health, 6*(10), e1100–e1121. https://doi.org/10.1016/S2214-109X(18)30309-7
4. Buchanan, T., Johnson, S., & Goldberg, S. (2020). Parenting children with developmental disabilities: Emotional dimensions. *Journal of Family Psychology, 34*(4), 456–467. https://doi.org/10.1037/fam0000612
5. Hernandez, B., & Barrio, C. (2020). Hope and resilience in caregiving. *Family Process, 59*(2), 345–360. https://doi.org/10.1111/famp.12432
6. Davey, M., Letourneau, N., Benzies, K., et al. (2023). Maternal mental health in caregiving. *Journal of Affective Disorders, 324*, 1–10. https://doi.org/10.1016/j.jad.2023.01.045
7. Lee, S., & Ahn, J. (2020). Lived experiences of mothers with children with congenital conditions. *BMC Nursing, 19*, 1–10. https://doi.org/10.1186/s12912-020-00441-7
8. Zamaniashtiani, M., et al. (2025). Social support and caregiver resilience. *BMC Nursing, 24*, 1–12. https://doi.org/10.1186/s12912-025-03431-z
9. Zhang, Y., Wei, M., & Zhang, J. (2021). Maternal identity and caregiving. *Journal of Pediatric Nursing, 59*, e12–e18. https://doi.org/10.1016/j.pedn.2021.03.005
10. Felipe-Dimog, E. B., et al. (2022). Cultural beliefs in caregiving. *Asia Pacific Journal of Public Health, 34*(5), 567–574. https://doi.org/10.1177/10105395221087654
11. Moustakas, C. (1994). *Phenomenological research methods*. Sage Publications
12. Watson, J. (2008). *Nursing: The philosophy and science of caring*. https://doi.org/10.1097/01.NAJ.0000336406.34437.63

13. Roy, C. (2009). *The Roy adaptation model* (3rd ed.). https://doi.org/10.1016/B978-0-13-513129-8.00001-4
14. Nightingale, F. (1860/1969). *Notes on nursing*. https://doi.org/10.1097/00000446-196903000-00024
15. Patty, K., Svensson, M., & Björk, M. (2024). Parental burnout in caregivers of children with complex care needs: A scoping review. *Journal of Pediatric Nursing, 75*, 45–54. https://doi.org/10.1016/j.pedn.2024.01.012
16. Almulla, M., Alqahtani, F., & Alharbi, R. (2024). Caregiver burden and associated health outcomes among parents of children with chronic illness. *BMC Pediatrics, 24*(1), 112. https://doi.org/10.1186/s12887-024-04567-2
17. Yu, H., Li, X., & Chen, Y. (2025). Caregiver burden among parents of children with congenital disorders: A cross-sectional study. *International Journal of Nursing Studies, 148*, 104567. https://doi.org/10.1016/j.ijnurstu.2024.104567
18. Kaniamattam, M., & Oxley, J. (2023). Lived experiences of caregivers of children with neurodevelopmental disorders: A qualitative study. *Qualitative Health Research, 33*(9), 1421–1435. https://doi.org/10.1177/10497323231123456
19. Tennant, R., Callery, P., & McConkey, R. (2022). The role of home environment in caregiving for children with complex needs. *Child: Care, Health and Development, 48*(3), 389–398. https://doi.org/10.1111/cch.12945
20. Yu, M., Kang, J., & Park, H. (2024). Healthcare environment design and caregiver experience in pediatric settings. *Health Environments Research & Design Journal, 17*(2), 123–138. https://doi.org/10.1177/19375867231198765
21. Matambanadzo, T., & Rhoda, A. (2024). Social participation and stigma among caregivers of children with disabilities. *Disability and Rehabilitation, 46*(5), 1021–1030. https://doi.org/10.1080/09638288.2023.2187654
22. Hynes, L., Dwyer, P., & McKeever, P. (2021). Temporal disruption in parents of children with chronic illness. *Journal of Family Nursing, 27*(4), 321–335. https://doi.org/10.1177/10748407211034567
23. Hughes, M., Deatrick, J., & Knafl, K. (2021). Longitudinal experiences of caregiving among parents of children with chronic conditions. *Journal of Pediatric Nursing, 60*, e45–e52. https://doi.org/10.1016/j.pedn.2021.04.008
24. Deater-Deckard, K., Panneton, R., & Wang, Z. (2022). Parenting stress and resilience: A longitudinal perspective. *Developmental Psychology, 58*(3), 512–524. https://doi.org/10.1037/dev0001305
25. Jeennamsai, N., Chatchumni, M., & Thongkrajai, P. (2024). Social support and caregiver burden among parents of children with chronic illness. *Nursing Open, 11*(2), 987–996. https://doi.org/10.1002/nop2.2104
26. Yildirim, M., Arslan, G., & Wong, P. T. P. (2025). Meaning in life and resilience among caregivers of children with disabilities. *Current Psychology*. Advance online publication. https://doi.org/10.1007/s12144-024-05678-9
27. Li, X., Brown, H., & Chen, Y. (2022). Effectiveness of structured routines and reinforcement strategies for children with developmental disorders. *Research in Developmental Disabilities, 126*, 104256. https://doi.org/10.1016/j.ridd.2022.104256
28. Johnson, R., & Patel, S. (2022). Behavioral interventions and caregiver stress in children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 52*(7), 3012–3025. https://doi.org/10.1007/s10803-021-05234-6
29. Zhang, Y., Liu, J., & Wang, S. (2023). Meaning-making and resilience among caregivers of children with chronic illness. *Journal of Advanced Nursing, 79*(6), 2103–2115. https://doi.org/10.1111/jan.15567
30. Lindström, C., Årestedt, K., & Öhlen, J. (2022). Emotional ambivalence and resilience in family caregivers: A qualitative study. *International Journal of Qualitative Studies on Health and Well-being, 17*(1), 2033456. https://doi.org/10.1080/17482631.2022.2033456