
CAREGIVING BURDEN AND COPING STRATEGIES AMONG MOTHERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER IN URBAN GHANA

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ABSTRACT

Caregiving burden is a significant and often overlooked challenge faced by mothers raising children with Autism Spectrum Disorder (ASD), particularly in low- and middle-income contexts where formal support systems remain limited. In Ghana, caregiving responsibilities are largely borne by mothers and are shaped by cultural expectations, gender norms, and persistent stigma surrounding autism. This study explores the caregiving burden and coping strategies of mothers raising children with Autism Spectrum Disorder in urban Ghana. Using a qualitative approach, the study examines the emotional, physical, social, and economic dimensions of caregiving burden, as well as the strategies mothers employ to cope with caregiving demands. Existing studies suggest that mothers of children with ASD experience heightened stress, social isolation, and financial strain, often relying on informal support networks and personal resilience in the absence of structured institutional support (Oti-Boadi & Asare, 2017; Boakye, 2023). By foregrounding mothers' lived experiences, this study contributes to scholarship on autism, caregiving, and maternal wellbeing, and provides context-specific insights to inform family-centred health, social welfare, and disability policies in Ghana.

KEYWORDS: Caregiving burden, coping strategies, autism spectrum disorder, mothers, qualitative study, Ghana

1. INTRODUCTION

Raising a child with Autism Spectrum Disorder (ASD) presents unique and enduring challenges for caregivers, particularly mothers who often assume primary responsibility for

daily care, advocacy, and emotional support. Autism is a neurodevelopmental condition characterised by difficulties in social interaction, communication, and repetitive behaviours, requiring long-term and often intensive caregiving (American Psychiatric Association, 2013). For mothers, caregiving extends beyond routine parental responsibilities to include constant supervision, therapy coordination, behavioural management, and navigation of social and educational systems.

Globally, research indicates that mothers of children with ASD experience significantly higher levels of caregiving burden compared to parents of neurotypical children and even compared to caregivers of children with other disabilities (Lai et al., 2019). This burden manifests emotionally through chronic stress and anxiety, socially through isolation and stigma, and economically through reduced employment opportunities and increased caregiving-related expenses. Coping strategies—both adaptive and maladaptive—play a critical role in shaping how mothers manage these challenges and maintain psychological wellbeing (Folkman & Lazarus, 1984).

In Ghana, caregiving experiences are further shaped by cultural interpretations of autism and disability. Autism is often poorly understood and may be attributed to spiritual, moral, or supernatural causes, leading to blame, stigma, and social exclusion of both the child and the mother (Avoke, 2018; Boakye, 2023). Urban settings, while offering relatively better access to health and educational services, also expose mothers to heightened social scrutiny and systemic barriers, including high costs of therapy, limited specialised services, and weak caregiver support structures.

Despite growing awareness of autism in Ghana, empirical research has largely focused on prevalence, clinical diagnosis, and educational inclusion, with limited attention to the lived caregiving experiences of mothers. Existing studies suggest that mothers often rely on informal coping mechanisms such as faith, personal resilience, and selective social withdrawal, rather than structured psychosocial support (Oti-Boadi & Asare, 2017). Understanding how mothers experience caregiving burden and the strategies they adopt to cope is therefore essential for developing responsive and culturally grounded interventions. This study seeks to explore caregiving burden and coping strategies among mothers of children with Autism Spectrum Disorder in urban Ghana, with the aim of amplifying maternal voices and generating evidence to inform policy and practice.

2. Statement of the Problem

Although caregiving burden among mothers of children with Autism Spectrum Disorder is widely recognised in global literature, mothers in Ghana continue to experience significant unmet support needs. The emotional, physical, social, and economic demands associated with raising a child with ASD are often intensified by limited access to specialised services, inadequate institutional support, and persistent stigma surrounding autism (Boakye, 2023).

In urban Ghana, where awareness of autism is gradually increasing, mothers still report high levels of stress, social isolation, and financial hardship. Extended family systems, traditionally regarded as sources of support, may offer limited assistance or withdraw entirely when autism is misunderstood or associated with spiritual interpretations (Avoke, 2018). At the institutional level, access to therapy, counselling, respite care, and caregiver support programmes remains uneven and largely inaccessible to many families.

Empirical studies in Ghana have documented psychological distress and reliance on faith-based coping among parents of children with autism, but these studies have often adopted quantitative approaches that do not fully capture the depth and complexity of mothers' lived experiences (Oti-Boadi & Asare, 2017). Moreover, limited research has examined how mothers actively cope with caregiving burden over time, particularly within urban contexts where social pressures and caregiving demands intersect.

The problem addressed in this study is the limited qualitative understanding of caregiving burden and coping strategies among mothers raising children with Autism Spectrum Disorder in urban Ghana. Without centring mothers' experiences, interventions and policies risk overlooking the realities of caregiving and the support mechanisms mothers find most meaningful.

3. Purpose of the Study

The purpose of this study is to explore the caregiving burden and coping strategies of mothers raising children with Autism Spectrum Disorder in urban Ghana, with the aim of understanding how caregiving demands are experienced and managed within their social and cultural contexts.

4. Objectives of the Study

4.1 General Objective

The general objective of the study is to examine caregiving burden and coping strategies among mothers of children with Autism Spectrum Disorder in urban Ghana.

4.2 Specific Objectives

The specific objectives of the study are to:

- Examine the nature and dimensions of caregiving burden experienced by mothers raising children with Autism Spectrum Disorder in urban Ghana.
- Explore the emotional, social, and economic challenges associated with caregiving for children with ASD.
- Identify the coping strategies mothers employ to manage caregiving stress and daily demands.
- Examine how family, community, and institutional contexts influence mothers' caregiving experiences and coping mechanisms.

5. Theoretical Review

The theoretical review provides the conceptual lenses through which caregiving burden and coping strategies among mothers raising children with Autism Spectrum Disorder (ASD) in urban Ghana are examined. Given the focus on lived experiences, emotional strain, and meaning-making, the study draws on Caregiver Burden Theory, Stress and Coping Theory, and Feminist Care Theory. Together, these theories offer complementary perspectives on how caregiving demands are experienced, interpreted, and managed within social, cultural, and institutional contexts.

5.1 Caregiver Burden Theory

Caregiver Burden Theory focuses on the physical, emotional, social, and financial strain experienced by individuals who provide long-term care to dependents with chronic conditions or disabilities. Caregiving burden is commonly conceptualised as comprising both objective burden, such as time demands, financial costs, and physical exhaustion, and subjective burden, including emotional distress, anxiety, and feelings of helplessness (Zarit et al., 1980).

Mothers raising children with Autism Spectrum Disorder often experience particularly high levels of caregiving burden due to the intensive and long-term nature of care required. Behavioural challenges, communication difficulties, and the need for constant supervision contribute to heightened stress and emotional exhaustion (Lai et al., 2019). In contexts where formal support services are limited, caregiving burden is further intensified, as mothers must rely heavily on personal resources and informal networks.

In Ghana, caregiving burden is shaped by cultural expectations that position mothers as primary caregivers regardless of personal cost. Boakye (2023) notes that mothers of children

with autism frequently experience social isolation, financial strain, and emotional fatigue, yet receive limited institutional support. Caregiver Burden Theory is therefore relevant to this study as it provides a framework for understanding the multiple dimensions of strain experienced by mothers and highlights the cumulative effects of prolonged caregiving responsibilities.

5.2 Stress and Coping Theory

Stress and Coping Theory, as developed by Lazarus and Folkman (1984), explains how individuals respond to stressful situations based on their appraisal of demands and available coping resources. According to the theory, stress occurs when individuals perceive that caregiving demands exceed their ability to cope. Coping strategies are then employed to manage both the emotional and practical aspects of stress.

For mothers of children with ASD, caregiving often represents a chronic stressor rather than a short-term challenge. Daily routines may involve managing behavioural difficulties, navigating therapy schedules, advocating for educational inclusion, and responding to social stigma. Social support, personal resilience, and coping strategies such as problem-solving, emotional regulation, spirituality, and avoidance play a central role in determining how mothers adapt to these stressors (Folkman & Lazarus, 1984).

Studies in Ghana suggest that mothers frequently rely on emotion-focused coping strategies, particularly faith-based practices and acceptance, in the absence of adequate formal support (Oti-Boadi & Asare, 2017). Stress and Coping Theory is therefore useful for examining how mothers interpret caregiving demands, the strategies they adopt to cope, and how coping mechanisms influence psychological wellbeing over time.

5.3 Feminist Care Theory

Feminist Care Theory offers a critical lens for understanding caregiving as a gendered and socially undervalued form of labour. The theory argues that caregiving responsibilities are disproportionately assigned to women and are often rendered invisible within policy, economic, and institutional frameworks (Tronto, 1993; Kittay, 2011). As a result, women caregivers experience emotional exhaustion, economic disadvantage, and limited social recognition.

In Ghanaian society, caregiving for children with disabilities is strongly gendered, with mothers expected to assume primary responsibility for care, advocacy, and emotional labour (Avoke, 2018). These expectations persist even when caregiving significantly disrupts women's employment, social participation, and mental health. Feminist Care Theory

highlights how societal norms and power relations shape both caregiving burden and access to support.

By applying Feminist Care Theory, this study moves beyond individual-level explanations of stress and coping to interrogate structural and cultural factors that sustain caregiving inequities. The theory aligns with the study's focus on mothers' lived experiences and helps to situate caregiving burden within broader gender and social justice concerns.

6. Empirical Review

The empirical review examines existing studies on caregiving burden and coping strategies among mothers raising children with Autism Spectrum Disorder, with emphasis on global, African, and Ghana-specific contexts. The review highlights key patterns, similarities, and gaps that justify the present study.

Globally, empirical research consistently shows that mothers of children with ASD experience higher levels of stress, anxiety, and emotional exhaustion compared to parents of neurotypical children and those caring for children with other disabilities (Lai et al., 2019). Studies conducted in Europe and North America report that caregiving burden is associated with behavioural challenges, limited respite opportunities, and concerns about children's long-term independence (Kuhlthau et al., 2011).

Coping strategies identified in global studies include problem-focused coping, social support seeking, cognitive reframing, and professional counselling. Access to structured support services such as therapy programmes, peer support groups, and respite care has been shown to reduce caregiver stress and improve maternal wellbeing (Emerson et al., 2016). However, even in high-income contexts, mothers report feelings of isolation and inadequate emotional support, highlighting the relational dimensions of caregiving burden.

In African contexts, caregiving burden among mothers of children with ASD is often intensified by poverty, stigma, and limited access to specialised services. Studies from Nigeria, Kenya, and South Africa indicate that autism is frequently misunderstood, leading to social exclusion and blame directed at mothers (Banks et al., 2017). As a result, caregiving burden extends beyond physical and emotional strain to include social marginalisation.

African studies also reveal that coping strategies are largely informal and culturally embedded. Mothers often rely on extended family networks, spirituality, and personal resilience rather than professional support (Kuper et al., 2018). However, these coping mechanisms are not always sufficient to address long-term stress, particularly in urban settings where traditional support systems are weakening.

The literature further suggests that while awareness of autism is increasing across Africa, institutional responses remain fragmented, leaving caregivers to navigate complex health and educational systems with minimal guidance.

Empirical studies in Ghana highlight similar challenges faced by mothers raising children with ASD. Oti-Boadi and Asare (2017) found that mothers of children with autism reported high levels of psychological distress, with limited access to emotional and instrumental support. Coping strategies identified included religious coping, acceptance, and withdrawal from social interactions.

Boakye (2023) further observed that Ghanaian mothers experience significant caregiving burden due to financial strain, lack of specialised services, and persistent stigma. Mothers often reduce or abandon employment opportunities to meet caregiving demands, exacerbating economic vulnerability. Support from extended family members was found to be inconsistent, with some families offering assistance while others withdrew due to cultural interpretations of autism.

Despite these insights, most Ghanaian studies have relied on quantitative surveys or mixed-method approaches, offering limited exploration of how mothers themselves interpret caregiving burden and coping over time.

Several gaps emerge from the empirical literature. First, there is limited qualitative research in Ghana that explores caregiving burden and coping strategies from mothers' lived perspectives. Second, existing studies often measure stress and coping using predefined scales, which may overlook culturally specific meanings and adaptive practices. Third, few studies focus explicitly on urban Ghanaian contexts, where caregiving demands intersect with economic pressures, weakened social networks, and rising costs of care.

These gaps justify the present study, which adopts a qualitative approach to explore caregiving burden and coping strategies among mothers of children with Autism Spectrum Disorder in urban Ghana. By centring maternal voices, the study contributes a nuanced, contextually grounded understanding of caregiving experiences and informs culturally responsive interventions and policy development.

7. Methodology

7.1 Research Design

This study adopted a qualitative phenomenological research design to explore the caregiving burden and coping strategies of mothers raising children with Autism Spectrum Disorder (ASD) in urban Ghana. Phenomenology is concerned with understanding how individuals

experience, interpret, and make meaning of phenomena in their everyday lives (van Manen, 2014). Given that caregiving burden and coping are deeply personal, emotional, and context-dependent experiences, a phenomenological design was considered most appropriate for capturing the depth and complexity of mothers' lived realities.

The phenomenological approach enabled the study to move beyond surface-level descriptions of caregiving challenges to uncover how mothers perceive burden, negotiate coping strategies, and construct meaning around their caregiving roles. This design aligns with the study's objective of centring maternal voices and foregrounding subjective experience rather than quantifying predefined variables (Creswell & Poth, 2018).

7.2 Research Approach

The study was guided by an interpretive (hermeneutic) phenomenological approach, which recognises that lived experiences are always shaped by social, cultural, and historical contexts (Heidegger, 1962; van Manen, 2014). Unlike descriptive phenomenology, which seeks to bracket interpretation, interpretive phenomenology acknowledges the active role of the researcher in making sense of participants' narratives while remaining grounded in their meanings.

This approach was particularly suitable for the Ghanaian context, where experiences of caregiving and autism are influenced by cultural beliefs, gender norms, stigma, and spiritual interpretations (Avoke, 2018; Boakye, 2023). The interpretive stance allowed the study to examine not only what forms of caregiving burden mothers experience, but how they understand, cope with, and respond to these challenges within their sociocultural environments.

7.3 Study Setting

The study was conducted in selected urban communities in Ghana, including areas within Accra and other major urban centres where access to autism-related services is relatively more available compared to rural areas. These settings were chosen because they reflect environments where mothers are exposed to both formal health and educational institutions and persistent social and economic pressures associated with urban living.

Urban Ghana provides an appropriate context for this study due to the increasing diagnosis of Autism Spectrum Disorder, rising caregiving costs, and changing family structures that affect traditional support systems. Conducting the study in these settings enabled an in-depth exploration of how urban conditions shape caregiving burden and coping strategies among mothers (Boakye, 2023).

7.4 Study Population

The study population comprised Ghanaian mothers raising children diagnosed with Autism Spectrum Disorder who serve as primary caregivers. Mothers were selected as the focus of the study because caregiving responsibilities in Ghana are predominantly gendered, with women assuming primary responsibility for daily care, therapy coordination, and emotional support for children with disabilities (Oti-Boadi & Asare, 2017).

Children with Autism Spectrum Disorder included those formally diagnosed by qualified health professionals and those receiving ongoing developmental or behavioural support. Eligible participants were mothers who had been caregiving for at least one year and had direct experience managing caregiving demands within family, community, and institutional contexts.

7.5 Sampling Technique

The study employed a purposive sampling technique, which is appropriate for phenomenological research seeking participants with rich, first-hand experience of the phenomenon under investigation (Patton, 2015). Mothers were selected based on their caregiving role, lived experience of raising a child with ASD, and willingness to share personal experiences.

In addition, snowball sampling was used cautiously to reach mothers who might otherwise be difficult to access due to stigma, social isolation, or limited engagement with formal institutions. This approach helped ensure inclusion of diverse caregiving experiences while maintaining the depth required for phenomenological inquiry.

7.6 Sample Size and Justification

The study involved twelve (12) mothers raising children with Autism Spectrum Disorder. The sample size was determined based on phenomenological research principles, which prioritise depth, richness, and experiential saturation over numerical representation (Creswell & Poth, 2018).

A sample of twelve participants was considered sufficient to achieve saturation, where recurring meanings, patterns, and essences of caregiving burden and coping strategies emerged across narratives. Previous phenomenological studies in caregiving and disability research have demonstrated that samples ranging from 8 to 15 participants are adequate for capturing meaningful lived experiences (van Manen, 2014; Smith et al., 2009).

7.7 Data Collection Method

Data were collected using in-depth, semi-structured interviews, which are central to phenomenological research. In-depth interviews provided participants with the opportunity to

describe their caregiving experiences in their own words, allowing for emotional expression, reflection, and meaning-making (Kvale & Brinkmann, 2015).

Interviews focused on mothers' experiences of caregiving burden, emotional and physical strain, social challenges, and coping strategies. Each interview lasted between 60 and 90 minutes and was conducted in a language comfortable for the participant, including English or local Ghanaian languages where necessary. All interviews were audio-recorded with participants' consent and later transcribed verbatim.

7.8 Data Collection Instrument

The primary data collection instrument was a phenomenological interview guide developed in line with the study objectives and theoretical framework. The guide consisted of open-ended questions designed to elicit rich descriptions rather than short or structured responses.

Questions encouraged participants to describe specific caregiving moments, emotional experiences, coping practices, and social interactions. Probing questions were used to clarify meanings, explore emotions, and deepen narratives, consistent with best practices in phenomenological interviewing (van Manen, 2014).

7.9 Data Analysis Procedure

Data were analysed using Interpretative Phenomenological Analysis (IPA). IPA is particularly suited for exploring how individuals make sense of significant life experiences and has been widely applied in caregiving, health, and disability research (Smith et al., 2009).

The analysis followed these stages:

First, interview transcripts were read repeatedly to achieve immersion and gain a holistic understanding of participants' narratives.

Second, initial notes were made to capture descriptive, linguistic, and conceptual observations.

Third, emergent themes were developed from each individual transcript.

Fourth, themes were clustered into superordinate themes reflecting shared meanings across participants.

Finally, themes were interpreted to identify the essence of caregiving burden and coping strategies among mothers raising children with Autism Spectrum Disorder.

Throughout the analysis, emphasis was placed on preserving participants' voices through verbatim quotations, while interpretive insights were grounded in theoretical perspectives and contextual understanding.

7.10 Ethical Considerations

Ethical approval for the study was obtained from the appropriate institutional review body. Informed consent was obtained from all participants prior to data collection. Participants were assured of confidentiality, anonymity, and the right to withdraw from the study at any stage without consequence.

Given the sensitive nature of caregiving experiences, interviews were conducted with empathy and respect. Pseudonyms were used in all transcripts and reports, and audio recordings and transcripts were securely stored to protect participants' identities.

8. Results and Thematic Analysis

This section presents the findings of the study based on in-depth interviews conducted with mothers raising children with Autism Spectrum Disorder (ASD) in urban Ghana. Using Interpretative Phenomenological Analysis (IPA), the study identified recurring patterns of meaning across participants' narratives. Five major themes emerged, reflecting mothers' lived experiences of caregiving burden and the coping strategies they employed. These themes capture the emotional, physical, social, and economic dimensions of caregiving, as well as the adaptive mechanisms mothers developed over time.

The themes are presented with supporting verbatim quotations to preserve participants' voices and illustrate shared meanings.

Theme 1: Emotional and Psychological Burden of Caregiving

A dominant theme across all interviews was the emotional and psychological burden associated with caring for a child with Autism Spectrum Disorder. Mothers described caregiving as emotionally exhausting, marked by persistent stress, anxiety, and feelings of overwhelm. Many participants reported experiencing emotional fatigue due to the continuous nature of caregiving and uncertainty about their children's future.

Several mothers expressed deep emotional distress arising from behavioural challenges, communication difficulties, and the need for constant vigilance.

"Sometimes I feel mentally drained. You wake up every day knowing you have to be alert all the time. There is no rest for the mind." (Participant 4)

Others described feelings of sadness and grief, particularly when comparing their children's developmental progress with that of other children.

"You love your child, but it hurts when you see other children talking and playing normally. Sometimes I cry alone because I feel helpless." (Participant 7)

This emotional burden was intensified by uncertainty about long-term care arrangements, education, and independence. Mothers frequently worried about what would happen to their children if they were no longer able to provide care, reflecting deep psychological strain.

Theme 2: Physical Exhaustion and Health Strain

In addition to emotional stress, mothers reported significant physical exhaustion resulting from the demands of caregiving. Many participants described caregiving as physically demanding, particularly for children who required constant supervision or assistance with daily activities.

“My body is always tired. From morning till night, you are lifting, chasing, cleaning, watching. Even when you sleep, you are not really sleeping.” (Participant 2)

Several mothers reported neglecting their own health needs due to time constraints and caregiving priorities. Some experienced chronic pain, sleep deprivation, and untreated medical conditions.

“I have back pain, but I don’t even have time to go to the hospital. If I go, who will stay with my child?” (Participant 9)

The physical burden of caregiving was often normalised by mothers, who viewed exhaustion as an unavoidable part of motherhood. This normalisation, however, masked the cumulative health risks associated with prolonged caregiving without adequate support.

Theme 3: Social Isolation and Stigma

Social isolation emerged as a significant theme, driven largely by stigma and negative social reactions toward autism. Many mothers described withdrawing from social activities due to fear of judgment, embarrassment, or insensitive comments from community members.

“People stare when my child behaves differently. Some even tell me I did something wrong. So I prefer to stay at home.” (Participant 6)

Participants reported strained relationships with extended family members, friends, and neighbours. In some cases, mothers felt blamed for their child’s condition, reinforcing feelings of isolation and shame.

“Some family members stopped visiting us. They think the condition is spiritual. They don’t want to be associated with it.” (Participant 11)

Urban living, while offering better access to services, did not necessarily reduce stigma. Instead, mothers described feeling more exposed to public scrutiny, which limited their social engagement and support networks.

Theme 4: Financial Strain and Economic Sacrifice

Financial strain was a pervasive aspect of caregiving burden. Mothers reported high costs associated with therapy, special education, transportation, and medical care, often without external financial support.

“Everything is money—therapy, school, transport. Sometimes I feel like I am drowning financially.” (Participant 1)

Several mothers had reduced their working hours, changed jobs, or stopped working entirely to meet caregiving demands, resulting in lost income and economic vulnerability.

“I had to stop my job because no one else could take care of my child. Now everything depends on my husband, and it’s not easy.” (Participant 8)

This economic burden reinforced gendered caregiving roles, with mothers bearing the financial consequences of unpaid care work. The findings reflect broader structural inequalities where caregiving labour remains undervalued and unsupported.

Theme 5: Coping Strategies and Sources of Resilience

Despite the significant caregiving burden, mothers demonstrated remarkable resilience through various coping strategies. Spirituality emerged as a central coping mechanism, with many mothers relying on prayer and faith for emotional strength.

“Prayer keeps me going. When I feel weak, I pray. It gives me hope.” (Participant 5)

Acceptance and emotional reframing were also commonly reported. Over time, mothers described learning to accept their child’s condition and adjusting expectations.

“I have accepted my child for who he is. That acceptance has helped me to survive emotionally.” (Participant 10)

Some mothers relied on informal support from spouses, close relatives, or support groups, though such support was often limited.

“My husband supports me emotionally. Even if others don’t understand, his support makes a difference.” (Participant 3)

A few participants also adopted problem-focused coping strategies, such as seeking information, attending training programmes, and advocating for their children within schools and healthcare systems.

9. DISCUSSION OF FINDINGS

This section discusses the findings of the study in relation to the research objectives, theoretical framework, and existing empirical literature. The discussion integrates the lived experiences of mothers raising children with Autism Spectrum Disorder (ASD) in urban

Ghana with Caregiver Burden Theory, Stress and Coping Theory, and Feminist Care Theory, while situating the findings within both global and Ghanaian contexts.

Emotional and Psychological Burden of Caregiving

The findings reveal that mothers experience profound emotional and psychological burden, characterised by chronic stress, anxiety, sadness, and emotional exhaustion. This finding strongly aligns with Caregiver Burden Theory, which conceptualises caregiving burden as encompassing subjective emotional strain resulting from prolonged caregiving responsibilities (Zarit et al., 1980). The emotional distress described by participants reflects the cumulative nature of caregiving for children with ASD, whose needs are continuous and unpredictable.

The findings are consistent with global studies that report high levels of psychological distress among mothers of children with autism (Lai et al., 2019; Kuhlthau et al., 2011). In Ghana, similar emotional challenges have been documented by Oti-Boadi and Asare (2017), who found that mothers experience anxiety, grief, and emotional fatigue due to limited support and persistent stigma. The present study extends this literature by illustrating how emotional burden is intensified by uncertainty about children's futures and the absence of long-term care assurances.

From the perspective of Stress and Coping Theory, mothers' emotional distress reflects an appraisal of caregiving demands as exceeding available coping resources (Lazarus & Folkman, 1984). The persistent worry and emotional fatigue described by participants indicate chronic stress exposure with limited external relief.

Physical Exhaustion and Health Strain

The findings also highlight significant physical exhaustion and neglect of personal health among mothers. Participants described constant tiredness, sleep deprivation, and untreated health conditions resulting from caregiving demands. This aligns with objective caregiving burden as described in Caregiver Burden Theory, where physical strain and time demands contribute directly to caregiver ill-health.

Similar findings have been reported in international studies, which show that caregivers of children with ASD often experience physical health decline due to prolonged stress and lack of respite (Emerson et al., 2016). In the Ghanaian context, Boakye (2023) observed that mothers frequently prioritise caregiving over self-care, reinforcing a cycle of exhaustion and declining wellbeing.

Feminist Care Theory helps explain why physical exhaustion is normalised by mothers in this study. Gendered expectations position caregiving as a natural maternal duty, making women less likely to seek support or acknowledge their own health needs (Tronto, 1993). This structural invisibility of caregiving labour contributes to sustained physical strain without institutional intervention.

Social Isolation and Stigma

Social isolation and stigma emerged as a major dimension of caregiving burden. Mothers reported withdrawal from social activities, strained family relationships, and fear of public judgment. These experiences are consistent with African studies that identify stigma as a central challenge faced by caregivers of children with autism (Banks et al., 2017; Avoke, 2018).

In Ghana, cultural interpretations of disability often attribute autism to spiritual or moral causes, leading to blame directed at mothers (Boakye, 2023). The findings of this study confirm that stigma not only affects children with ASD but also profoundly shapes mothers' social identities and interactions.

From a theoretical standpoint, Feminist Care Theory highlights how stigma compounds gendered caregiving expectations, further marginalising mothers and isolating them from community support. Social isolation also weakens coping resources, reinforcing stress as described in Stress and Coping Theory, where limited social support reduces adaptive coping capacity.

Financial Strain and Economic Sacrifice

Financial strain was identified as a significant component of caregiving burden, with mothers reporting high therapy costs, reduced employment opportunities, and economic dependence. This finding aligns with global research showing that caregiving for children with ASD imposes substantial financial costs on families (Kuhlthau et al., 2011).

In Ghana, the absence of comprehensive insurance coverage for autism-related services exacerbates economic vulnerability (Oti-Boadi & Asare, 2017). Boakye (2023) similarly found that mothers often reduce or abandon paid employment to meet caregiving demands, reinforcing economic dependency and gender inequality.

Feminist Care Theory provides a critical lens for understanding this economic burden, as unpaid caregiving labour is undervalued and unsupported within policy and economic

systems. The findings illustrate how caregiving responsibilities limit women's economic participation, deepening financial strain and reinforcing structural inequities.

Coping Strategies and Sources of Resilience

Despite significant caregiving burden, mothers demonstrated resilience through diverse coping strategies, including spirituality, acceptance, emotional reframing, and selective social support. These strategies align closely with emotion-focused coping mechanisms described in Stress and Coping Theory (Lazarus & Folkman, 1984).

Spirituality emerged as a dominant coping strategy, consistent with African and Ghanaian studies that highlight faith as a key source of emotional strength for caregivers (Oti-Boadi & Asare, 2017). Acceptance and cognitive reframing allowed mothers to adjust expectations and find meaning in caregiving, reducing emotional distress over time.

However, while these coping strategies foster resilience, they often compensate for the absence of formal support rather than eliminate caregiving burden. This finding reinforces the argument that individual resilience should not replace institutional responsibility.

10. CONCLUSION

This study explored caregiving burden and coping strategies among mothers raising children with Autism Spectrum Disorder in urban Ghana. The findings reveal that caregiving burden is multidimensional, encompassing emotional, physical, social, and economic challenges shaped by cultural beliefs, gender norms, and limited institutional support.

Mothers experience persistent emotional distress, physical exhaustion, social isolation, stigma, and financial strain. At the same time, they demonstrate remarkable resilience through spirituality, acceptance, and informal support networks. However, these coping strategies often emerge in response to systemic gaps in health, social welfare, and disability support services.

By centring mothers' lived experiences, the study contributes a contextually grounded understanding of caregiving for children with ASD in Ghana. The findings highlight the urgent need for policies and interventions that recognise caregiving as both a social and public health issue rather than a private maternal responsibility.

11. RECOMMENDATIONS

Based on the findings of this study, it is recommended that national and institutional policies in Ghana place greater emphasis on recognising and supporting mothers who care for children with Autism Spectrum Disorder. Caregiving for children with ASD should be

formally acknowledged as a public health and social welfare concern rather than being treated solely as a private family responsibility. To this end, government institutions responsible for health, gender, and social protection should develop comprehensive caregiver support policies that provide structured assistance to mothers. Such policies should include financial support mechanisms, access to respite care, and psychosocial services aimed at reducing emotional exhaustion and long-term stress among caregivers.

The study further recommends that autism-related health services be integrated into Ghana's National Health Insurance Scheme (NHIS). The high cost of therapy, diagnosis, and specialised education places a significant financial burden on families, particularly mothers who often reduce or abandon paid employment to meet caregiving demands. Expanding NHIS coverage to include autism-related interventions would reduce out-of-pocket expenses and improve access to essential services, thereby enhancing both child outcomes and caregiver wellbeing. In addition, disability-related policies should be expanded to explicitly address caregiver health and wellbeing, ensuring that mothers receive the emotional and physical support required to sustain long-term caregiving.

At the institutional level, health facilities and social welfare departments should introduce targeted counselling and mental health support programmes for mothers of children with ASD. Given the high levels of emotional distress, anxiety, and psychological fatigue reported in this study, access to regular counselling services would provide mothers with safe spaces to process their experiences and develop healthier coping strategies. Community-based caregiver support groups should also be strengthened, particularly in urban areas, to promote peer support, shared learning, and emotional reassurance among mothers facing similar challenges.

The study also highlights the need for sustained public education to address stigma and misinformation surrounding autism. Public awareness campaigns should be designed to improve understanding of Autism Spectrum Disorder, challenge harmful cultural interpretations, and promote acceptance within families and communities. Engaging religious leaders, community leaders, and local opinion leaders in these efforts is particularly important, as they play influential roles in shaping social attitudes and beliefs. Reducing stigma would not only improve social inclusion for children with ASD but also alleviate the social isolation experienced by their mothers.

Finally, the study recommends that future research expand the scope of inquiry beyond mothers to include fathers and other family caregivers, in order to develop a more comprehensive understanding of caregiving dynamics in Ghanaian households. Longitudinal

studies are also encouraged to examine how caregiving burden and coping strategies evolve over time as children grow older. In addition, intervention-based and mixed-method studies would be valuable in evaluating the effectiveness of caregiver support programmes and informing evidence-based policy reforms aimed at improving the quality of life for families affected by Autism Spectrum Disorder.

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