

Psychological Distress among Informal Caregivers of Children with Autism: A Thematic Analysis

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ABSTRACT

This study examined the psychological distress experienced by informal caregivers of children with autism spectrum disorder (ASD). The study was conducted in two phases: Phase One focused on developing the interview guide, which included defining research questions and creating open-ended questions to explore the caregivers' experiences. The guide was piloted, refined, and finalized for clarity and relevance. Phase Two involved conducting semi-structured interviews with 30 caregivers using the finalized guide. Data were analyzed using thematic analysis, which involved coding and categorizing recurring themes and patterns in caregivers' responses to identify key challenges and coping strategies. The study identified five key themes: emotional impact, stigmatization and social isolation, financial strain, physical exhaustion, and uncertainty about the future. Caregivers reported high levels of stress, anxiety, and depression, often feeling helpless and emotionally exhausted. The lack of adequate support services and social understanding exacerbated their distress, with many feeling isolated. Financial strain and the physical demands of caregiving further contributed to psychological distress, while concerns about their children's long-term well-being intensified anxiety. The findings highlighted the multidimensional challenges faced by caregivers, underscoring the need for comprehensive support systems. It was concluded that addressing these challenges requires a multifaceted approach, including improved public awareness, policy interventions, and tailored support for caregivers.

Keywords: Psychological Distress, Informal Caregivers, Autism Spectrum Disorder, Anxiety.

INTRODUCTION

The demands of caregiving for children with autism spectrum disorder (ASD) pose unique challenges that extend beyond basic support. ASD affects millions of families globally, requiring caregivers, often parents and relatives, to provide not only practical assistance but also consistent emotional and tailored care to meet the specific needs of these children. Such caregiving responsibilities are both physically and emotionally taxing, with informal caregivers frequently facing obstacles that impact their mental health and overall quality of life.

ASD has emerged as a significant global health issue, affecting approximately 1 in 160 children worldwide, according to recent World Health Organization (WHO, 2022) estimates. This rising prevalence, now reaching around 52 million affected individuals globally since 2010 (Elsabbagh et al., 2012; Baxter et al., 2015), highlights the expanding scope of caregiving needs and the pressures placed on caregivers worldwide. In the United States, the prevalence is estimated at 1 in 68 children (Baxter et al., 2015), while in the sub-Saharan African region, prevalence rates among children with intellectual disabilities are reported to be around 0.8% (Hayes & Watson, 2018). Local epidemiological data underscore varying rates: for instance, approximately 1 in 190 children in Nigeria is diagnosed with ASD (Okorie, 2018). Cross-national studies reveal even higher ASD rates among children with developmental disorders—11.4% among Nigerian children with intellectual disabilities (Bakare et al., 2012), 33.6% in Egypt, and 11.5% in Tunisia (Seif Eldin et al., 2008). These statistics illustrate the pervasive nature of ASD and underscore the burden on caregivers, whose own well-being is often jeopardized by the intensity of their caregiving roles.

The disease represents a wide continuum of associated cognitive and neuro-behavioural disorders,

characterized by three core defining symptoms (American Psychiatric Association [APA], 2013). These symptoms include deficits in socialization, deficits in verbal and nonverbal communication, and restricted and repetitive patterns of behaviour (APA, 2013). Autism Spectrum Disorder is a neurodevelopmental condition characterized by challenges in social interaction, communication difficulties, and repetitive behaviours. The term "spectrum" underscores the vast variation in the manifestation of symptoms, ranging from mild to severe (APA, 2013). The prevalence of ASD has been on the rise, with global estimates indicating its widespread impact on individuals and their families (Centre for Disease Control, 2021). Children with ASD often encounter difficulties in establishing and maintaining social relationships. The complex nature of their communication challenges can manifest in delayed language development or atypical use of gestures and expressions. Additionally, the presence of repetitive behaviours or intense focus on specific interests contributes to the unique profile of individuals with ASD. The impact of autism extends beyond the affected child, shaping the dynamics of the entire family unit (Lord and Bishop, 2010). Furthermore, the daily routines of families with a child with ASD are often marked by a need for structure and predictability. Any deviation from established routines can be distressing for the child, amplifying the stress experienced by caregivers. The challenges in maintaining a balance between the needs of the child with ASD and those of other family members add layer of complexity (Karst and Van Hecke, 2012).

Children with ASD may require tailored interventions to address their unique needs, including speech therapy, occupational therapy, and behavioural interventions. However, accessing these services can be a formidable task, particularly in regions with limited resources or during situations such as the COVID-19 pandemic, where disruptions have become the norm (Matson *et al.*, 2012).

Autism Spectrum Disorder is diagnosed based on specific criteria outlined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). These criteria include persistent deficits in social communication and interaction, as well as restricted, repetitive patterns of behaviour, interests, or activities (APA, 2013). The onset of symptoms typically occurs in early childhood, and the severity of ASD can vary widely. Children with ASD may exhibit challenges in reciprocal social interactions, including difficulties in understanding and responding to social cues. Impaired nonverbal communication, such as limited eye contact and gestures, is often observed. Additionally, repetitive movements, insistence on sameness, and intense fixations on specific interests contribute to the diagnostic profile (Lord and Bishop, 2010).

The caregiving responsibilities associated with raising a child with ASD have profound implications for the psychological well-being of informal caregivers. A multitude of factors contribute to the heightened levels of psychological distress experienced by these caregivers. Challenges in accessing essential services, including educational and therapeutic interventions, can be a source of frustration and helplessness (Matson *et al.*, 2012). The unique needs of children with ASD often translate into an increased demand for time and energy from caregivers. The daily routines of families may revolve around the specific requirements of the child, leaving caregivers with limited opportunities for respite or self-care. This continuous and often overwhelming caregiving responsibility can lead to a sense of emotional exhaustion and burnout (Karst and Van Hecke, 2012).

Moreover, the societal stigmatisation associated with autism adds layer of stress for caregivers. Misunderstandings and misconceptions about the condition may lead to social isolation, further compounding the psychological distress experienced by caregivers. The financial burden associated with procuring specialized healthcare and interventions for the child with ASD can contribute to economic strain, exacerbating overall stress levels (Falk *et al.*, 2014). The ongoing challenges associated with raising a child with autism, coupled with the lack of societal understanding and support, create a perfect storm for heightened psychological distress among informal caregivers. The intricate relationship of factors underscores the urgency of examining the help-seeking behaviour of these caregivers, as understanding their willingness or reluctance to seek support can offer valuable insights into developing targeted interventions to alleviate psychological distress in this vulnerable population.

Psychological distress is a complex and multifaceted concept that encompasses a range of emotional, cognitive, and behavioural symptoms indicating mental suffering or discomfort. Various definitions and

perspectives exist within the literature, reflecting the diverse nature of this phenomenon. One definition, proposed by Kessler *et al.* (2010), characterises psychological distress as a state of emotional suffering that involves symptoms such as depression and anxiety. According to this perspective, distress is viewed as a continuum, ranging from mild symptoms to severe psychiatric disorders. This conceptualisation highlights the interconnectedness of various mental health issues and emphasizes the importance of understanding distress within a broader spectrum. Another perspective on psychological distress is offered by Lazarus and Folkman (1984), who define it as the emotional response to a perceived imbalance between the demands placed on an individual and the resources available to cope with those demands. This stress-based view suggests that distress arises when individuals perceive their environmental stressors as exceeding their ability to effectively cope.

Moreover, Pearlin and Schooler (1978) propose a sociological perspective, defining psychological distress as the psychological consequence of chronic strains resulting from social roles and life events. From this viewpoint, distress is not solely an individual experience but is influenced by external factors, such as caregiving responsibilities, societal expectations, and life circumstances. The impact of psychological distress on family caregivers of children with autism spectrum disorder (ASD) is profound. Caregivers often experience elevated levels of stress, anxiety, and depression (Smith *et al.*, 2010). The chronic nature of caregiving responsibilities, coupled with the unique challenges associated with raising a child with ASD, contributes to ongoing psychological distress. Psychological distress can manifest in various ways, affecting different aspects of the caregiver's life. For example, the emotional well-being of caregivers is significantly impacted, with heightened levels of stress and anxiety (Davis and Carter, 2008). The constant need for vigilance, the unpredictability of the child's behaviour, and the challenges in communication can contribute to emotional exhaustion and burnout.

The cognitive aspects of psychological distress are evident in the form of intrusive thoughts, worry, and rumination about the child's future and well-being (Hayes and Watson, 2018). The ongoing demands of caregiving may lead to cognitive overload, affecting the caregiver's ability to concentrate, make decisions, and solve problems effectively. Behaviourally, psychological distress may result in changes in the caregiver's coping strategies, potentially leading to maladaptive behaviours such as avoidance or social withdrawal (Smith *et al.*, 2010). The strain on social relationships, including marital and familial bonds, is a common consequence, further exacerbating the caregiver's distress (Gray, 2006). The quality of care provided by family caregivers is intricately linked to their psychological well-being. Research indicates that caregivers experiencing higher levels of psychological distress may struggle to engage effectively with their child, implement therapeutic interventions, and maintain consistency in caregiving practices (Benson, 2014). This, in turn, can impact the child's development and well-being.

While considerable research has been done on the psychological distress experienced by parents of children with autism spectrum disorder (ASD), most of it is quantitative and focused on the disorder's prevalence, symptoms, and contributing causes. The lived experiences, individual narratives, and complex emotional and social difficulties that informal caregivers face daily are not adequately captured. There is insufficient knowledge of how caregiving affects these caregivers' mental health since their viewpoints—their individual opinions, coping strategies, and the socio-cultural factors influencing their distress—are frequently disregarded. The current study used a qualitative methodology to fill this gap, specifically using discourse analysis to investigate psychological distress in informal caregivers of children with ASD.

METHODS

The study was done in two phases. Phase One focused on the development of the interview guide, which included defining research questions, identifying key themes, and crafting open-ended questions to explore the experiences of informal caregivers of children with autism spectrum disorder (ASD). The guide was piloted with a small sample, refined, and finalized for clarity and relevance. Phase Two involved conducting semi-structured interviews with informal caregivers using the finalized guide. These interviews aimed to gain insights into their challenges, coping strategies, and emotional well-being, providing rich qualitative data to address the research objectives.

Phase One: Development of the Interview Guide

Phase One of the study was dedicated to the development of the interview guide aimed at exploring the psychological distress experienced by informal caregivers of children with autism spectrum disorder (ASD). This process began with the identification of the key research questions to ensure the guide covered the emotional, social, and psychological challenges caregivers face, as well as their coping mechanisms and perceptions of available support. The interview guide was designed to include open-ended questions, which would allow caregivers to provide detailed responses about their experiences. The questions covered various areas, including the emotional toll of caregiving, the impact of ASD on family dynamics, the caregivers' coping strategies, and their perceptions of support systems. To ensure the validity and cultural relevance of the guide, it underwent a rigorous vetting process. A panel consisting of two clinical psychologists, one social psychologist, and one child and family psychologist reviewed the guide. Their feedback helped refine the language, structure, and content to ensure clarity, appropriateness, and comprehensiveness.

Additionally, the guide was piloted with five informal caregivers, drawn from a population of caregivers who receive support from the Women and Community Livelihood Foundation (WOCLIF) in Uyo Local Government Area, Akwa Ibom State. WOCLIF specializes in providing care and support services for children with special needs, including those with autism. The foundation offers comprehensive services such as diagnosis, therapy, and intervention, and provides training and guidance for parents and caregivers on optimizing care for children with disabilities. These caregivers provided valuable feedback on the interview guide's ability to generate meaningful data, leading to further revisions for clarity and flow. Once the pilot study was completed and the necessary adjustments were made, the interview guide was finalised and prepared for Phase Two of the study, which involved conducting the actual research interviews.

Phase Two: Main Study

Research Design

A qualitative research design was employed for this phase of the study. This approach was appropriate for exploring the lived experiences and psychological distress of informal caregivers of children with autism spectrum disorder (ASD). Qualitative research allows for an in-depth understanding of complex issues such as stigmatisation, help-seeking behaviour, and coping mechanisms, which are subjective and difficult to quantify.

Research Area

The study was conducted in Akwa Ibom State, Nigeria, specifically across six care facilities that provide comprehensive support for children with autism spectrum disorder. The facilities selected were: Women and Community Livelihood Foundation (WOCLIF) and Brainy Hives Special School in Uyo Senatorial District; African Children Centre and Shalom Children Care Centre in Eket Senatorial District; and First Love Foundation (FLF) and St Joseph Rehabilitation Centre in Ikot Ekpene Senatorial District. These facilities were recommended by the Ministry of Women and Social Welfare and are known for their expertise in offering diagnosis, therapy, intervention, and caregiver training for children with autism.

Population of Study

The study focused on informal caregivers of children diagnosed with autism spectrum disorder (ASD) who were receiving care from the selected facilities in Akwa Ibom State, Nigeria. Approximately 700 caregivers were identified in the six facilities.

Sample and Sampling Techniques

Given the qualitative design of the study, a purposive sampling technique was used to select 30 caregivers. The sample size was chosen to ensure rich, detailed, and diverse insights into the caregiving experiences. The criteria for inclusion were:

1. Caregivers who were primary caregivers of children clinically diagnosed with ASD by a qualified healthcare professional.
2. Caregivers with at least one year of experience in caregiving for children with ASD to ensure sufficient knowledge of caregiving experiences.
3. Caregivers willing to participate in an in-depth interview and provide informed consent.

Exclusion criteria included:

1. Caregivers not directly involved in the daily care of children with ASD.
2. Caregivers whose children were not clinically diagnosed with ASD.
3. Caregivers with less than one year of caregiving experience.

Data Collection Procedure

The interviews were conducted in person at the six selected care facilities, during regular caregiver visits. Each caregiver was informed about the study's purpose, and informed consent was obtained before the interview. The researchers administered the interview guide, ensuring that participants were comfortable and free to share their experiences. No identifying information was collected to ensure confidentiality. A total of 30 caregivers participated in the interviews.

Research Instrument

The primary tool for data collection was an interview guide, which included 12 open-ended questions. These questions were developed to explore various aspects of caregiving, including the psychological distress faced by caregivers, coping mechanisms, and the role of social support. The guide was reviewed by clinical psychologists, social psychologists, and caregivers in a pilot study to ensure clarity and relevance. The final version of the guide was used for the data collection.

Method of Data Analysis

Thematic analysis was employed to analyse the qualitative data collected through the interviews. This approach allowed for the identification of recurring themes and patterns across caregivers' responses. Data were coded and grouped into key themes such as psychological distress, social support, coping strategies, and the impact of stigma. The findings were then used to generate an understanding of the caregivers' experiences and inform recommendations for interventions and support services.

Ethical Considerations

Ethical approval was obtained from the Akwa Ibom State Health Research Committee. Participants were required to sign an informed consent form before taking part in the study. They were fully informed about the nature of the study, their right to withdraw at any time, and the confidentiality of their responses. Caregivers were assured that no identifying information would be collected and that their participation would not affect their relationship with the care facilities. Confidentiality was maintained throughout the study by using coded identifiers and securing the data.

Findings

The findings of this study revealed the multifaceted challenges faced by informal caregivers of children with autism. Through in-depth interviews with caregivers, several key themes emerged, highlighting the significant emotional, physical, and financial toll of caregiving, and uncertainty about the future. These themes reflect the complex nature of caregiving and provide insight into the psychological distress and the overall burden carried by caregivers. Below, each of these themes is discussed in detail.

Theme 1: Emotional Impact of Caregiving

The emotional impact of caregiving emerged as a predominant theme in the experiences of informal caregivers of children with autism. Caregivers reported that the ongoing responsibilities and challenges of caregiving took a profound toll on their mental well-being, with feelings of stress, anxiety, and depression being prevalent. Many caregivers spoke about how their emotional struggles were compounded by the lack of sufficient support, both from family and the broader community.

M. L. E, a 45-year-old mother of a 10-year-old child with autism, described her emotional state as one of constant worry. She expressed, *“There is never a day I don’t feel overwhelmed. I wake up anxious, wondering if today will be better or worse for my child. Sometimes, I feel like I am losing myself in the process of caring for him.”* This sentiment was echoed by several other caregivers, who described feelings of helplessness, particularly when their child’s behaviour became difficult to manage or when their caregiving duties felt beyond their capacity due to a lack of resources and support services. M. L. E further shared, *“It is emotionally draining to watch your child struggle and not be able to do much to help. You feel guilty, even when it’s not your fault.”* This sense of guilt, paired with a feeling of helplessness, was a recurring theme in the interviews, as caregivers wrestled with the day-to-day challenges of managing their child’s behavioural difficulties, communication struggles, and sensory sensitivities.

Similarly, R. N. (39 years old) reflected on the emotional burden of caregiving, stating, *“The stress is constant. Some days I just cry in the bathroom, but I have to get up and keep going. The pressure to keep up with everything—school, therapies, household responsibilities—it’s all too much sometimes.”* This feeling of being stretched too thin resonated strongly with the caregivers, as they navigated the emotional toll of balancing multiple roles, including those of a parent, counsellor, teacher, and homemaker, all while maintaining a semblance of normalcy in their family life. The emotional exhaustion described by R. N. is consistent with the experience of caregivers feeling overwhelmed by the weight of their responsibilities.

The emotional burden of caregiving was also accompanied by a profound sense of anxiety about the future. Many caregivers raised concerns about what would happen to their children as they grew older, especially if they were no longer able to provide care. M. L. E voiced a common fear, saying, *“I worry about what will happen to my son when I’m no longer able to care for him. He will always need help, and I fear there won’t be enough services to support him as an adult.”* This anxiety about the future of their children was coupled with uncertainty about the adequacy of support services, particularly when it came to long-term care and future independence.

Another emotional consequence highlighted by the caregivers was a pervasive sense of isolation. Many reported feelings disconnected from others who did not understand their experiences. Caregivers often mentioned the stigma surrounding autism and how it isolated them both socially and emotionally. The lack of understanding from others, as well as the absence of a strong support system, exacerbated feelings of loneliness and alienation. One caregiver said, *“People don’t understand what we go through. They think it’s just about the child’s behaviour, but it’s so much more than that. It’s draining on every level.”*

Theme 2: Stigmatization and Social Isolation

The second theme that emerged from the analysis was the experience of stigmatisation and social isolation faced by informal caregivers of children with autism. Many caregivers reported feeling judged and misunderstood by their communities, which intensified their sense of isolation and compounded the emotional challenges of caregiving. Stigmatisation often stems from a lack of awareness and acceptance of autism within their communities, leading caregivers to feel alienated and unsupported.

J. B (41 years), shared how social stigma affected her family’s social interactions: *“People look at my son differently. When he has an outburst in public, I feel the stares. They think he’s just a badly behaved child, and that it’s my fault as a mother.”* For J.B., this recurring judgement had led her to avoid public places where her child’s behaviour might attract negative attention, limiting her social activities and contributing to feelings of isolation.

Another caregiver, S. J. (34 years old), described her struggles with the stigma associated with autism in her community: *“Some people think autism is a curse or a punishment. They say things that hurt, like, ‘Maybe you did something wrong to deserve this.’ It’s painful, and sometimes I feel I have to hide my child to avoid the shame.”* This stigma discouraged S. J. from reaching out for help and reduced her opportunities to build a support network among friends, neighbours, and family members.

Additionally, caregivers reported a lack of understanding and empathy from extended family members. R. N., a 39-year-old caregiver, expressed disappointment in the absence of family support: *“My family doesn’t understand. They say things like, ‘Just be strict with him,’ as if it’s that simple. It hurts, so I stopped talking to them about my struggles.”* This lack of family understanding made caregivers feel isolated even within their own families, further compounding the sense of social isolation.

Theme 3: Financial Strain and Psychological Distress

The financial strain and resource constraints faced by informal caregivers of children with autism emerged as a significant theme, deeply influencing both their financial well-being and psychological health. Many caregivers reported the overwhelming burden of autism-related care expenses, which created significant stress and emotional distress, as they struggled to balance these costs with the demands of daily life. The financial strain, in turn, exacerbated feelings of anxiety, frustration, and helplessness.

I.U., a 33-year-old caregiver, shared how the financial demands of caregiving affected her family: *“It’s draining. There are days when I wonder if we can keep up with all the expenses—therapy, doctors, schooling. It feels like we’re always choosing between essentials and my child’s needs.”* The constant worry about financial stability contributed to psychological distress, as caregivers faced the emotional toll of making difficult choices between their financial security and the care their child needed. The uncertainty about whether they could continue to provide essential services for their child heightened caregivers’ anxiety and stress, contributing to overall emotional exhaustion.

E.A., a 29-year-old caregiver, expressed frustration with the lack of affordable services and resources: *“Everything costs so much. Public support is nearly non-existent, and private services are just beyond reach. If you can’t afford it, you’re left with nothing for your child.”* The lack of accessible, affordable support services left caregivers feeling trapped and isolated. This scarcity of resources contributed to a sense of helplessness and hopelessness, intensifying the emotional burden. The inability to provide the best care for their children despite their best efforts added to feelings of guilt, inadequacy, and distress, which are common psychological responses to resource limitations.

Moreover, the financial strain affected caregivers’ employment, with many adjusting their work situations to accommodate caregiving responsibilities. I.U. reflected on how this impacted her work-life balance: *“I had to take a job with low time demands, but that also meant less income. Balancing work and caregiving is difficult; every decision feels like a compromise.”* The need to reduce working hours or accept lower-paying roles created additional stress, as caregivers faced the challenge of maintaining their financial stability while fulfilling their caregiving responsibilities. This financial compromise often led to feelings of frustration and resentment, further heightening emotional distress and creating a sense of loss of control over their lives.

The absence of government assistance or financial aid only intensified these challenges. E.A. noted the lack of support: *“It feels like we’re completely on our own. If there was even a little financial aid or more affordable options for therapy, it would make a world of difference.”* The absence of external support left caregivers feeling abandoned and overwhelmed. This lack of assistance, combined with the financial pressures they faced, led to emotional exhaustion, increased anxiety, and a diminished sense of hope. The persistent stress from financial strain not only undermined caregivers’ ability to meet their own needs but also exacerbated the psychological burden of caregiving, contributing to burnout, depression, and anxiety.

Theme 4: Physical Exhaustion and Psychological Distress

Physical exhaustion emerged as a significant theme in the caregiving experiences of parents of children with

autism. Many caregivers reported the continuous and demanding nature of their roles, which had profound implications for their physical health and psychological well-being. The relentless physical activity required to meet their children's needs—such as constant supervision, managing challenging behaviours, and attending to basic care tasks—often led to persistent fatigue. This physical toll, coupled with the lack of adequate respite, contributed significantly to psychological distress.

For instance, N.C., a 27-year-old caregiver, expressed the constant strain of caregiving, highlighting the physical exhaustion that became a defining feature of her life: *"It's physically exhausting. I'm up early, constantly on the move, making sure my child is safe, fed, bathed, and entertained. By the end of the day, my body is completely drained."* The exhaustion described by N.C. reflects the emotional and psychological burden of caregiving, as fatigue limits caregivers' ability to engage in self-care and leisure activities, leading to feelings of frustration and emotional depletion. The constant physical demand not only affects caregivers' stamina but also contributes to their psychological distress, as the ongoing fatigue increases anxiety, stress, and depression.

D.B., a 31-year-old caregiver, further illustrated the physical toll of managing meltdowns and sensory-related behaviours. *"Sometimes my child needs constant guidance to avoid harm. I have to watch him every second, and there are days when I'm lifting or holding him down to calm him, which takes a huge toll on me physically."* This experience highlights how the constant need for vigilance and the unpredictability of a child's behaviour contribute to emotional exhaustion and burnout among caregivers. The physical exertion required to manage these challenges not only leads to bodily strain but also increases the emotional and psychological burden, creating a cycle of stress and anxiety.

The long-term effects of caregiving on caregivers' physical health were also evident. I.U. remarked, *"It's not just a day or two—this is every day. My back aches, my feet hurt, and I don't have time to rest or recover. It's wearing me down."* The accumulation of physical strain over time has profound psychological effects, as caregivers' bodies suffer from neglect while they prioritize their children's needs. This neglect of self-care, as described by I.U., often leads to feelings of helplessness and emotional exhaustion. These physical manifestations of stress are linked to deeper psychological distress, as fatigue reduces caregivers' resilience and coping abilities, making them more vulnerable to anxiety and depression.

Furthermore, the absence of respite services left caregivers without any opportunity to recover, both physically and psychologically. E.A. reflected on the absence of support: *"There's no one else to step in. I'm the one who has to do it all, day after day. It's exhausting, but there's no alternative."* This lack of relief from the constant physical demands of caregiving exacerbated caregivers' feelings of isolation and distress. The unrelenting nature of caregiving, without respite, not only contributes to physical fatigue but also amplifies psychological strain, as caregivers feel trapped in a cycle of stress and exhaustion.

Theme 5: Uncertainty and Fear About the Future

The emotional burden of uncertainty and fear about the future emerged as another significant theme for caregivers, deeply linked to the psychological distress they experienced. Caregivers often expressed profound anxiety and worry regarding their children's long-term well-being, especially concerning their ability to live independently as they grow older. This fear for the future added a layer of emotional strain, compounding the already overwhelming demands of caregiving.

A. E., a 52-year-old caregiver, shared the extent of her concern for her child's future: *"I wake up every day with a heavy heart, wondering who will take care of my daughter when I am no longer able to. I fear that no one will understand her needs the way I do. The thought of her growing up and being neglected scares me."* For A. E., this fear of abandonment and lack of support systems created a constant source of anxiety, significantly affecting her psychological well-being.

B. E., a 40-year-old mother, also described how the uncertainty of her child's future contributed to her emotional distress: *"It's hard to imagine a time when I won't be around to help him. I worry that society won't be kind to him as he gets older, that he'll be left out or mistreated. The thought of him being alone in the world"*

without support is terrifying.” This deep concern for her child’s future led to chronic stress, as B. E. felt burdened by the overwhelming responsibility of ensuring her child would have a secure and supportive future.

E. E., a 31-year-old caregiver, reflected on the fear of societal neglect and isolation for her child: *“I constantly fear that when my son grows older, there won’t be enough services for him. He’s already struggling to fit in, and the idea of him being left behind because the world isn’t ready for him is a constant worry in my mind.”* The uncertainty surrounding the availability of resources and understanding in society made E. E. feel helpless and anxious, affecting her emotional state as she tried to navigate her caregiving responsibilities.

DISCUSSION OF FINDINGS

The findings from this study underscore the significant emotional, psychological, and physical toll of caregiving for children with autism spectrum disorder (ASD). The results highlight several key themes, including emotional and psychological impact, stigmatization and social isolation, financial strain, physical exhaustion, and uncertainty about the future. These themes intersect to provide an understanding of the multidimensional distress that caregivers experience.

Emotional and Psychological Impact of Caregiving: The emotional burden of caregiving was a central theme, with caregivers reporting high levels of stress, anxiety, and depression. These findings align with Smith et al. (2010), who discussed the elevated levels of psychological distress, including anxiety and depression, experienced by caregivers of children with ASD. The caregivers in this study frequently expressed feelings of helplessness and emotional exhaustion, resonating with the findings of Davis and Carter (2008), who highlighted how the constant need for vigilance and the unpredictability of a child's behaviour contributes to emotional burnout. The emotional toll of caregiving was further amplified by the lack of sufficient support, both from family and community, intensifying caregivers’ emotional burden.

Stigmatization and Social Isolation: Stigmatization emerged as a major source of emotional and psychological distress. The negative societal perceptions of autism often led to social exclusion, as experienced by caregivers like J.B. and S.J., whose personal accounts reflect the isolation brought about by societal ignorance and judgment. These experiences resonate with the findings of Gray (2006), who noted that caregiving strain negatively impacts social relationships, including marital and familial bonds, which were often strained in this study. Caregivers faced social exclusion and a deepened sense of alienation due to the misunderstanding and stigma surrounding autism. The societal pressure and judgment exacerbated their psychological distress, highlighting the importance of greater public awareness of autism.

Financial Strain and Resource Constraints: Financial strain was another significant theme, as many caregivers expressed the overwhelming cost of therapies, medical treatments, and special education services and its impact on their psychological wellbeing. These findings have a draining effect on the mental wellbeing of caregivers. Caregivers such as I.U. and E.A. discussed the challenge of balancing the financial costs of essential needs and specialized care. This financial strain was compounded by the caregivers' limited access to affordable resources and government support. Moreover, caregivers often had to adjust their employment to meet caregiving demands, which resulted in reduced income and heightened financial stress. .

Physical Exhaustion in Caregiving: The physical toll of caregiving was another significant theme. Caregivers reported feeling physically drained due to the constant supervision and management of their children’s behaviours. This finding echoes the work of Smith et al. (2010), who documented the long-term health issues caregivers experience, such as sleep deprivation and musculoskeletal problems, as a result of the physical demands of caregiving. The caregivers in this study, including N.C. and D.B., described chronic fatigue resulting from their caregiving responsibilities, exacerbated by the lack of respite services. Without adequate rest, caregivers struggled to manage the physical demands of their roles.

Uncertainty and Fear About the Future: Uncertainty and fear about the future were recurring concerns among caregivers, with many expressing anxiety about their children’s long-term well-being. This fear, particularly about their child’s ability to live independently as they grow older, aligns with the findings of Hayes and Watson (2018), who described the cognitive distress caused by intrusive thoughts and worries about the future.

Caregivers such as A. E., B. E., and E. E. voiced concerns about the lack of sufficient services or societal acceptance to support their children as they transitioned into adulthood. These fears were compounded by the lack of long-term planning and inadequate social or government support, which further elevated caregivers' anxiety and psychological distress.

CONCLUSION

This study offers significant insights into the emotional and psychological discomfort encountered by informal caregivers of children with autism spectrum disorder (ASD). The findings highlight the considerable emotional burden of caregiving, as caregivers experience elevated levels of stress, anxiety, despair, and loneliness. The five principal themes identified—emotional effect, stigmatization and social isolation, financial hardship, physical tiredness, and anxiety over the future—underscore the intricate, varied nature of caregiving for children with ASD. Caregivers frequently traverse a challenging emotional terrain, exacerbated by insufficient support systems, financial difficulties, and the physical strains of caregiving.

The study's findings highlight the pressing necessity for comprehensive support systems that cater to the psychological, emotional, and practical requirements of these caregivers. Interventions must prioritize enhancing public understanding of ASD, addressing stigma, and offering accessible resources to mitigate the financial and physical challenges of caregiving. Moreover, legislative modifications are essential to guarantee that caregivers can access vital services, including training, counselling, and respite care. Policymakers, healthcare professionals, and communities must unite to foster a more supportive environment for caregivers of children with ASD, thereby enhancing their well-being and the quality of care they deliver.

RECOMMENDATIONS

It is recommended that community-based support groups and mental health services should be established to help caregivers manage stress, anxiety, and depression. These services will provide a safe space for caregivers to share experiences and access psychological support. It is also recommended that accessible and affordable respite care programs should be expanded to allow caregivers time for rest and recovery. This will help reduce caregiver burnout and promote mental well-being by providing a break from the continuous caregiving demands.

It is further recommended that financial aid or subsidies should be provided for autism-related therapies and services to alleviate the financial strain on caregivers. This will ensure that families can access the necessary resources to support their child's development without facing financial hardship. It is also recommended that public awareness campaigns should be launched to promote autism awareness and the importance of caregiver support. Such campaigns will help reduce stigma, increase understanding, and foster a more inclusive and supportive community for caregivers and individuals with autism.

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