International Journal for Multidisciplinary Research (IJFMR)
E-ISSN: 2582-2160 ● Website: www.ijfmr.com ● Email: editor@ijfmr.com

Between Uncertainty and Adaptation: Experiences of Parents Rearing Children with Autism in Zambia

Authors A. Kambole Salimu[1], Daniel Ndhlovu[2]

[1,2]School of Education University of Zambia; Lusaka, Zambia

ABSTRACT

This study explored the experiences of parents raising children with autism in Zambia with particular attention to the relationship between parental uncertainty and adaptation. The study was guided by the recognition that raising a child with autism may involve challenges related to limited knowledge, inadequate support, financial demands and uncertainty about the child's development and needs. A qualitative research approach was employed to gain an in-depth understanding of parents' lived experiences. Six parents of children with autism participated in the study and were selected using qualitative sampling techniques. Data were collected through in-depth interviews and analysed thematically. The findings revealed that parents experienced considerable uncertainty arising from limited knowledge about autism, difficulties understanding their children's behaviours and developmental needs and limited access to appropriate professional and social support. Parents also experienced emotional strain, feelings of inadequacy and financial challenges associated with meeting their children's needs. Despite these challenges, parents demonstrated adaptation through learning from experience, developing strategies to support their children and seeking information and support from available sources. The findings suggest that parental experiences were shaped not only by the demands of raising a child with autism but also by the limited support systems available to assist parents in understanding and responding to their children's needs. The study highlights the need for accessible parent education, coordinated support services and psychosocial interventions that can reduce uncertainty and strengthen parents' capacity to adapt.

Keywords: Autism, Parental Uncertainty, Parental Adaptation, Lived experiences, Parenting, Zambia

1. INTRODUCTION

The arrival of an autism diagnosis can alter the way parents understand their child, their parenting role, and the future they had anticipated for their family. Rather than representing a single event that parents simply learn to accept, it can mark the beginning of an ongoing process of uncertainty, meaning making and adaptation. Parents may find themselves questioning their understanding of their child's development, searching for explanations, and attempting to determine how best to respond to behaviours and developmental differences. This period can be particularly challenging when parents have limited information or guidance about autism, as uncertainty may be accompanied by disbelief, anxiety, and concerns about the child's future (Naicker et al., 2023; Qin et al., 2021). In contexts where autism is poorly understood, cultural beliefs, stigma and misconceptions may further influence how parents interpret the

diagnosis and their role in supporting their child (Oduyemi et al., 2021; Daley et al., 2021). Consequently, the parental journey may involve not only emotional adjustment but also changes in everyday routines, social relationships and decisions about education and intervention.

Over time, however, parents may develop ways of adapting to the changing demands of raising a child with autism. Adaptation may involve learning to interpret the child's behaviour, modifying communication approaches, establishing predictable routines and reorganising family life around the child's needs (Gentles et al., 2020; Jacobs et al., 2020; Yi et al., 2020). Yet, adaptation does not necessarily mean that uncertainty or difficulty disappears. Parents may continue to encounter stigma, social isolation, inadequate support, financial pressures and difficulties accessing appropriate educational and therapeutic services (Yaacob et al., 2021; Chirwa et al., 2024; Azubuike et al., 2024). These realities suggest that parental experiences are better understood as an evolving journey in which uncertainty and adaptation may coexist. Despite growing international evidence, there remains limited understanding of how parents in Zambia experience this journey within their own social, cultural and service context. This article therefore explored the experiences of parents raising children with autism in Zambia, with particular attention to how they navigated uncertainty and adapted to the demands of caregiving.

2. LITERATURE REVIEW

Raising a child with autism is a complex experience that involves continuous adjustment to developmental, emotional, social and practical demands. Across different contexts, parents have described a journey that often begins with uncertainty and difficulty understanding their child's development and gradually develops into adaptation as parents learn to respond to their child's needs. The experience is therefore not necessarily linear; rather, parents may move between uncertainty, distress, acceptance, adjustment and renewed concern as their children develop and their circumstances change. Although international literature has documented these experiences extensively, there remains a need to understand how parents in Zambia experience and make meaning of raising children with autism within their own social, cultural and economic context.

One of the earliest experiences reported by parents is uncertainty about their child's development. Parents may initially notice differences in communication, behaviour or developmental milestones without immediately understanding their significance. Gentles et al. (2020) found that Canadian parents of young children with autism gradually developed an understanding of their children's development as they observed developmental differences and sought information. Similarly, Jacobs et al. (2020) reported that parents in the United Kingdom experienced confusion, hope and concern as they monitored their children's development and attempted to interpret unusual behaviours. In Belgium, parents similarly moved from trying to explain early behaviours to developing more structured approaches after diagnosis, including modifying communication, creating predictable environments and adjusting expectations (Jacobs et al., 2020).

This uncertainty may be intensified by limited knowledge and inadequate guidance. Papoudi et al. (2021), in the United Kingdom, found that parents experienced difficulties understanding autism, particularly their children's communication, behaviour and developmental needs. Many parents consequently had to search independently for information because professional guidance was perceived as insufficient. Similar findings were reported by Cortese et al. (2023) in Italy and Guillon et al. (2022) in Spain, where parents experienced uncertainty during the period between noticing developmental concerns and obtaining a diagnosis. Limited information about autism, diagnosis and available services left some parents confused

and helpless. Simlesa et al. (2021) similarly found that inadequate professional knowledge and weak support structures increased parents' difficulties in understanding and managing their children's needs.

The period surrounding diagnosis may therefore be characterised by disbelief and denial. Acharya and Sharma (2021) found that parents experienced emotional challenges, including denial, after learning that their children had autism. Naicker et al. (2023) similarly described denial as a frequently observed initial reaction to an autism diagnosis. Parents may question the diagnosis, minimise behaviours, search for alternative explanations or delay engaging with services. Qin et al. (2021) found comparable experiences among Chinese parents, where disbelief and avoidance sometimes delayed acknowledgement of developmental differences. In Nigeria, Oduyemi et al. (2021) reported that parents sometimes attributed children's behaviours to temperament, spiritual influences or poor behaviour rather than autism. Similar cultural interpretations were identified in South Africa, where Marais (2020) found that myths about autism, parental wrongdoing and supernatural explanations could reinforce disbelief.

These findings suggest that uncertainty is influenced not only by the diagnosis itself but also by how autism is understood within families and communities. Raft et al. (2023) found in Istanbul that some parents initially questioned the accuracy of the diagnosis or believed that their children were experiencing temporary developmental delays. Cultural attitudes towards disability, expectations of children and social perceptions of autism influenced the duration of this uncertainty. Thus, parents' responses to autism cannot be separated from the social and cultural environments in which they raise their children. However, the way parents in Zambia experience this period of uncertainty and transition remains insufficiently understood.

As parents gradually develop an understanding of autism, uncertainty may coexist with significant emotional strain. Papanikolaou et al. (2021) found that mothers in Greece described persistent distress, sadness and vulnerability, particularly because of concerns about their children's future, developmental progress and social stigma. Caputi et al. (2020) similarly reported higher emotional distress among parents of children with autism, linking this to the demands of caregiving, challenging behaviours, communication difficulties and the need for constant vigilance. A review by Samodurova et al. (2021) found similar patterns of stress, exhaustion and isolation across Eastern European contexts, particularly where families experienced limited access to services.

Bujnowska et al. (2023) further demonstrated that parents' quality of life was influenced by the social and cultural environment in which they raised their children. Although anxiety, sadness and emotional distress were common across contexts, their intensity differed according to social attitudes towards disability, availability of support and cultural expectations surrounding parenting. Yaacob et al. (2021) similarly found that parents in Malaysia experienced persistent anxiety, sleep disturbances and emotional fatigue, particularly where caregiving demands were accompanied by inadequate knowledge and limited resources. Psychological distress was closely connected to social isolation, demonstrating that parents' experiences are interconnected rather than occurring as separate challenges.

The emotional experience may also be intensified when parents lack reliable support. Samsell et al. (2022) reported that parents in the United States experienced psychological distress partly because they had difficulty obtaining clear, trustworthy and accessible information from schools, healthcare providers and community networks. Kalb et al. (2021) similarly found elevated psychological distress among parents of children with autism, including anxiety, loneliness and heightened emotional needs. Wang et al. (2022) reported higher anxiety and depression and lower resilience among Chinese parents, while Liu et al. (2024) linked child behaviour challenges to increased parental psychological distress. These findings indicate that

parents' emotional experiences are shaped by the interaction between their children's needs and the availability of resources that enable parents to respond to those needs.

As parents become more familiar with their children's needs, adaptation becomes an important feature of their experience. Adaptation may involve changing routines, modifying communication, increasing supervision and learning how to anticipate behaviours. Yi et al. (2020) found that parents in Hong Kong often had to manage developmental needs at home while simultaneously navigating medical and educational systems. In India, Daley et al. (2021) found that parents relied on informal advice while developing ways of managing behaviour and communication. In Japan, Inada et al. (2022) reported that parents initially attempted to manage concerns within the home and gradually became more willing to access formal services as they recognised persistent developmental differences. Paula et al. (2023) similarly found that parents in Brazil and wider Latin American contexts adapted daily routines, communication strategies and caregiving responsibilities, often drawing on extended family support.

Adaptation, however, may require substantial changes to parents' social lives. Yaacob et al. (2021) found that parents sometimes withdrew from social activities because they anticipated misunderstanding or negative judgement of their children's behaviour. Routine activities such as shopping, attending community events or visiting schools could require extensive preparation because parents feared anxiety, meltdowns or public misunderstanding. Goh et al. (2021) similarly found that parents in Singapore reduced social gatherings, reorganised daily schedules and learned to anticipate and manage overstimulation. Kalb et al. (2021) also reported that parents modified home environments, developed strict routines and adjusted schedules around their children's needs.

Social withdrawal is particularly evident where parents encounter stigma. O'Sullivan et al. (2020) found that parents in the United Kingdom sometimes avoided shops, infant groups and social events because they felt watched, judged or misunderstood. Vigouroux et al. (2022) similarly reported shame, embarrassment and fear of negative judgement among parents in Greece, leading some to reduce their movements and social participation. Pyszkowska et al. (2021) found that perceived public stigma could become internalised, resulting in self-blame, shame and reduced self-worth. Zaplatar and Garrote (2022) also showed that even parents who had a strong understanding of inclusion could encounter people who questioned their parenting practices or interpreted their children's behaviour as the result of being spoiled.

Stigma may therefore influence how parents adapt to public life. Whelan et al. (2025) found that parents in Ireland described public outings as particularly difficult when children experienced meltdowns, as parents felt that these incidents attracted accusatory or negative attention. Some parents consequently reduced outings or relied on others to accompany their children. Re et al. (2024) similarly found that Italian parents received comments questioning their parenting approaches. These experiences demonstrate that adaptation is sometimes protective: parents modify where they go, when they go and whom they interact with to minimise negative experiences.

Evidence from African contexts reveals similar patterns but also highlights the influence of cultural interpretations of autism. In Nigeria, Nwosu et al. (2021) found that parents avoided public gatherings because of fears of judgement and misunderstanding. Makhubele et al. (2022) reported withdrawal from church events, neighbourhood meetings and family celebrations among South African caregivers following experiences of criticism, pity and unsolicited advice. In Kenya, Odhiambo et al. (2023) found that parents, particularly those in rural areas, had limited opportunities to interact with people who understood autism. Gender roles further contributed to isolation because mothers often carried greater caregiving responsibilities.

Research in Zambia provides an important indication of the local context. Chirwa et al. (2024) found that parents in peri-urban and rural communities experienced difficulties accessing autism-related services and support groups, which were largely concentrated in urban areas. This geographical separation contributed to parents feeling disconnected from others who could provide understanding or practical advice. The finding is important because it suggests that parents' experiences in Zambia may be shaped not only by individual or family circumstances but also by where they live and the availability of services around them.

Cultural beliefs and stigma may further influence how parents understand and respond to their children's behaviour. In Nigeria, Oduyemi et al. (2021) reported that parents experienced blame from extended family and the wider community. Akinreni et al. (2024) and Abuo et al. (2024) similarly found that repeated public blame led some parents to withdraw from church activities, markets and festivities. In South Africa, Manono and Clasquin-Johnson (2023) found that parents were sometimes told that their children's behaviours resulted from poor parenting, spiritual causes or parental wrongdoing. Sefotho and Letsoalo (2023) similarly reported experiences of public judgement and pressure to hide children from visitors or avoid social gatherings. Mogamisi et al. (2024) showed that cultural narratives could result in blame from relatives, while Simelane and Dlamini (2024) found that repeated encounters with disapproval encouraged parents in Eswatini to avoid crowded places and social gatherings. Tekola et al. (2022) and Benzarti et al. (2023) also documented how community misunderstanding, discrimination and institutional experiences contributed to parental withdrawal.

These experiences illustrate that adaptation does not necessarily mean that uncertainty or distress disappears. Rather, parents may learn to negotiate their circumstances by changing routines, managing public encounters, educating others or limiting exposure to situations perceived as threatening. Asare and Azu (2024) found that some Ghanaian families rotated attendance at social events or limited public outings to protect themselves and their children from negative encounters. Oduyemi et al. (2021) and Manono and Clasquin-Johnson (2023) further suggest that where reliable information about autism is limited, parents may themselves become responsible for explaining autism to others, adding another layer to their caregiving role.

The demands of adaptation may also influence family relationships. Baena et al. (2025) found that parents reorganised homes and routines around children's needs, but these changes could reduce the time and emotional energy available to partners, siblings and extended family. Whelan et al. (2025) similarly found that couple time could become occupied by managing routines, bedtime difficulties and recovery from challenging public experiences. Dijkstra-de Neijs et al. (2024) reported that parents of young children with autism experienced stress associated with school, therapy appointments and everyday management, which affected couple leisure, friendships and overall quality of life.

The impact of caregiving can extend to siblings. Pavlopoulou et al. (2022) found that siblings sometimes became more independent or protective of their siblings with autism, while others felt emotionally distant from parents because greater attention was directed towards the child with higher needs. Baena et al. (2025) similarly found that family leisure activities, outings and opportunities for connection could decrease when parents were emotionally and physically exhausted. Parents consequently experienced guilt about not being able to give equal attention to all their children.

Extended family relationships may provide support but may also become sources of tension. Whelan et al. (2025) found that grandparents and relatives sometimes wanted to help but did not understand the child's needs, while Frigerio et al. (2024) found that parents could feel responsible for teaching relatives

how to accommodate sensory and behavioural needs. Dijkstra-de Neijs et al. (2024) described the accumulation of everyday negotiations, including who would attend appointments, communicate with schools or change plans, as a source of relational strain. African studies similarly demonstrate that relatives' spiritual explanations and conflicting advice can increase tension within families (Lentoor et al., 2023; Tekola et al., 2022; Dlamini & Nxumalo, 2024; Appah et al., 2024).

The experience of adaptation is also closely connected to financial realities. Raising a child with autism may require expenditure on assessment, therapy, education, transportation and specialised care while simultaneously reducing parents' opportunities for employment. Zhao et al. (2023) found substantial direct and indirect costs among Chinese families, including expenditure on rehabilitation, private schooling, transportation and specialised caregiving, alongside productivity losses when parents reduced employment. Kamaralzaman et al. (2023) similarly found considerable annual care costs in Malaysia, with some families borrowing money or reducing essential household expenditure to maintain therapy.

Comparable financial pressures have been documented in other contexts. Bhatta et al. (2021) found that Nepalese families frequently paid for therapy themselves because insurance and state support were limited. Hassan et al. (2022) reported that Pakistani families experienced additional transport and accommodation costs when services were concentrated in cities. Azubuike et al. (2024) found that Nigerian parents often paid for speech and occupational therapies themselves, while Pillay et al. (2024) reported that South African families sometimes had to choose between private interventions and essential household expenses. Acheampong (2024) similarly found that Ghanaian families experienced costs associated with school fees, transportation and learning materials, with rural families experiencing additional expenses because of long distances to services.

Financial adaptation may therefore involve difficult choices about work and family priorities. Kiambati et al. (2025) found that Kenyan mothers experienced lost employment and educational opportunities because of caregiving responsibilities. Höfer et al. (2022) found that greater service use among children with autism was associated with increased healthcare expenditure, while parents also experienced indirect costs through work absences and care coordination. Micai et al. (2024) reported that Italian families often relied on private assessments and therapies because of gaps in public provision. Ten Hoopen et al. (2025) similarly found that accessing services could increase the time parents spent coordinating care and advocating for their children, consequently reducing paid working hours.

Employment therefore becomes another area in which parents may have to adapt. Blackwell (2024) found that parents in the United Kingdom reduced working hours or left employment because of school difficulties, appointments and behavioural crises. Huang et al. (2023) reported that Chinese mothers sometimes abandoned employment to become full-time caregivers. Papadopoulos (2021) similarly identified the effects of caregiving responsibilities on employment among South African parents. Lynch et al. (2023) found that parents in the United States changed jobs, reduced working hours or withdrew from employment because of caregiving demands. These findings suggest that adaptation may come at the cost of career development and household economic stability.

Access to education and services represents another important part of parents' experiences. Genovesi et al. (2022) highlighted significant gaps in specialist and inclusive educational provision across sub-Saharan Africa, including Zambia. Parents may therefore depend on distant urban schools or under-resourced mainstream settings. Kiambati et al. (2024) found that Kenyan parents experienced uneven access to autism support, while Nthibeli et al. (2022) reported that South African parents faced shortages of specialised schools, inadequate teacher competence and transport difficulties. Nalugya et al. (2022) found

that Ugandan parents often relied on informal networks to identify suitable schools because specialised services were scarce. Tekola et al. (2022) similarly found that Ethiopian families outside major urban areas experienced severe limitations in accessing appropriate education.

These educational barriers can increase the responsibilities placed on parents. Yi et al. (2020) showed that parents may simultaneously act as caregivers and navigators of health and educational systems. Blackwell (2024) found that when schools failed to provide adequate support, parents experienced repeated disruptions to employment and family routines. Boukhriss (2024) similarly demonstrated how school-related challenges could result in early dismissals, changes in family arrangements and disagreements regarding caregiving responsibilities.

Overall, the literature suggests that parents' experiences of raising children with autism are better understood as an evolving process rather than as a collection of isolated challenges. Parents may begin with uncertainty as they attempt to understand developmental differences, experience disbelief or distress following diagnosis, and gradually adapt their caregiving practices as they learn more about their children. However, adaptation occurs within social, cultural, institutional and economic environments that can either support or constrain parents. Limited knowledge, stigma, inadequate services, financial demands, educational barriers and employment disruptions may repeatedly recreate feelings of uncertainty even after parents have developed greater understanding of autism.

The literature also demonstrates that parents are not passive recipients of these challenges. They actively reorganise routines, seek information, negotiate relationships, modify social participation, advocate for their children and make difficult financial and employment decisions. Adaptation may therefore be understood as an ongoing process through which parents attempt to create workable lives around their children's needs. At the same time, these adaptations may carry consequences for parents' emotional well-being, relationships, social participation and economic security.

Despite the growing international and African evidence, there remains limited understanding of how parents in Zambia personally experience this movement between uncertainty and adaptation. Existing Zambian evidence has identified geographical and service-related barriers (Chirwa et al., 2024), while broader African literature has documented stigma, social isolation, financial pressures and limited educational provision. However, there is insufficient qualitative evidence showing how these experiences intersect within the everyday lives of Zambian parents and how parents themselves make meaning of the changes required of them. The present study therefore contributes to the literature by exploring the lived experiences of parents raising children with autism in Zambia, with particular attention to the movement between uncertainty, emotional adjustment and adaptation.

3. METHODOLOGY

The study was situated within the constructivist research paradigm, which recognises reality as being socially constructed through individuals' experiences, interpretations and interactions with their social contexts. According to Creswell and Poth (2018), constructivism provides a qualitative worldview that seeks to understand the meanings individuals or groups attribute to their experiences. It acknowledges that reality is subjective and multifaceted, with multiple interpretations emerging from individuals' lived experiences rather than from a single objective reality. A hermeneutic phenomenological research design was employed to gain an in-depth understanding of parents' lived experiences of raising children with autism during the preoperational stage of development. The design was appropriate for exploring how parents experienced, interpreted and made meaning of their children's development between the ages of

two and seven years. The study was conducted at Bauleni Special School in Lusaka Province, Zambia. Parents of children who had received a formal diagnosis of autism and were attending the school were purposively identified as participants. They were engaged in interviews to obtain first-hand accounts of their experiences of raising and supporting their children during the preoperational stage of development.

3.1 Research design

The study employed a hermeneutic phenomenological design to explore and interpret the lived experiences of parents raising children with autism. Phenomenology, introduced by Husserl (1970), focuses on understanding lived experience and exploring how phenomena are experienced and become meaningful within an individual's consciousness. Within the constructivist paradigm, this approach is consistent with the view that reality is subjective, multiple and shaped through interactions between individuals and their contexts (Guba & Lincoln, 1994). The hermeneutic phenomenological approach was therefore considered appropriate for interpreting parents' experiences and the meanings they attributed to their children's developmental differences.

The study further drew on van Manen's (1990) four existential lifeworlds: lived body, lived space, lived time and lived human relations. These dimensions provide a framework for attending to the different ways individuals experience and make sense of their everyday worlds. Rather than treating experience as a single, isolated phenomenon, the four lifeworlds facilitate an exploration of how experiences are embodied, situated within particular spaces and contexts, experienced over time, and shaped through relationships with others. This perspective was particularly relevant to the study as it enabled an in-depth exploration of how parents experienced, interpreted and responded to their children's developmental differences and the realities of raising a child with autism.

3.2 Study Population

The population of this study were parents who have experience in rearing children at the preoperational developmental stage with autism in Lusaka. These parents were selected because they have experience of rearing children with autism at the preoperational developmental stage which was central to the study objectives.

3.3 Sample Size

In qualitative research, sample size is not necessarily determined in advance but is guided by the point at which data saturation is achieved. For this study, an estimated sample of six (6) participants was targeted, with data collection continuing until saturation was reached, indicated by the point at which no new information, meanings or themes were emerging from the data. Morse (1994) and Guest et al. (2020) suggested that saturation may be achieved with as few as six participants in qualitative research, depending on the nature and depth of the inquiry. The final sample comprised six parents, with three residing in urban areas of Lusaka and three from peri-urban areas. The inclusion of participants from both settings provided an opportunity to capture potentially diverse experiences of raising children with autism across different contexts within Lusaka.

3.4 Participants

Six parents of children with autism were purposively selected to participate in the study. Eligibility was limited to parents who were directly involved in raising their children and were currently living with them. Additionally, participants were required to have children who had received a formal diagnosis of autism.

3.5 Sampling Procedure

Data were collected at Bauleni Special School, which provides educational services to children, including those with autism. The school register was used to identify parents whose children had received a formal

diagnosis of autism and were either within or had progressed beyond the preoperational developmental stage. Participants were subsequently selected based on their eligibility and willingness to share their lived experiences.

3.6 Data collection

Data were collected using a semi-structured interview guide and a non-participant observation checklist. The instruments focused on parents' lived experiences of raising children with autism during the preoperational developmental stage. Their use was consistent with the phenomenological and constructivist orientation of the study, which sought to understand how participants interpreted and made meaning of their experiences. The interviews enabled parents to describe their experiences in their own words, while the observations provided contextual insight into the environments in which these experiences occurred.

3.7 Data Analysis

Data were analysed using thematic analysis following the six stages proposed by Braun and Clarke (2006): familiarisation with the data, generation of initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report. Thematic analysis was selected because it provided a systematic yet flexible approach to identifying, analysing and reporting patterns within the collected data.

3.8 Ethical Considerations and Trustworthiness

Ethical approval was obtained from the Humanities and Social Science Ethics Committee of the University of Zambia. Ethical principles were observed throughout the research process, and participation was voluntary. Interviews were conducted only after participants had provided their informed consent.

Trustworthiness was established using the four criteria of credibility, transferability, dependability and confirmability (Guba, 1985; Shenton, 2004). Credibility was enhanced through the use of multiple data collection instruments and detailed accounts of participants' experiences. Transferability was supported by providing contextual descriptions of participants' family structures and socio-economic backgrounds. Dependability was addressed through systematic scrutiny of the research processes, including data collection and analysis. Confirmability was strengthened through maintaining clear records of the data and interpretations to ensure that the findings remained grounded in participants' perspectives.

4. RESULTS AND DISCUSSIONS

For this study, the researcher conducted interviews with six parents who had lived experiences of raising children with autism. Their accounts provided insight into the uncertainty, challenges and adjustments associated with raising a child with autism. The participants described how they navigated emotional, social, financial and caregiving demands while gradually adapting their parenting approaches to respond to their children's needs. Their experiences highlighted the complex journey between uncertainty and adaptation as parents sought to understand autism, support their children and manage the realities of everyday family life.

Table 1. Development of emergent themes

Main Theme	Sub-Themes	Code/indicators (Participants Expressions)	Verbatim Extracts "Participants"	Key findings

Emotional stress	Emotional distress; denial; feelings of helplessness; feeling overwhelmed	Shock; denial of diagnosis; sadness; worry about the child's future; helplessness; emotional exhaustion; difficulty accepting the diagnosis	"I remember feeling deeply hurt and constantly comparing her with other children who were progressing normally." "Even when I could clearly see the delays, I did not want to accept it."	Parents experienced considerable emotional stress while raising their children with autism. The demands associated with the child's developmental needs contributed to feelings of being overwhelmed, helplessness, sadness and, in some cases, denial.
Limited knowledge on autism	Lack of understanding of autism; inadequate information; uncertainty about developmental needs	Limited prior knowledge; difficulty understanding behaviours; uncertainty about the diagnosis; inadequate information from communities and professionals; feeling unprepared	"I had no idea what was happening to my child." "I had never come across such a condition before, so everything felt confusing ."	Parents reported limited knowledge about autism, particularly at the time of diagnosis. This lack of understanding left some parents feeling unprepared to interpret their children's behaviours and respond appropriately to their developmental needs.
Financial challenges	Cost of food and daily care; therapy costs; educational expenses; transportation	Cost of specialised foods increased food requirements, therapy expenses, school fees transportation costs; learning materials;	"Due to limited income, it becomes difficult to maintain a proper diet for her as I would want." "The school he attends is very far from where we live and I have to spend	Financial constraints affected parents' ability to meet the diverse needs of their children. Expenses associated with food, therapy, education, transportation and supplementary learning resources

		dependence on personal income	money on transport almost every day."	placed additional pressure on household finances.
Social challenges	Stigma and discrimination; restricted social participation; fear of public judgement	negative community perceptions; public staring; labelling of children as badly behaved; fear of meltdowns; avoidance of social events; reduced interaction with others	"when I go shopping with her and she starts crying, people stare at me as if I am not in control." "there was a time at a restaurant when my son touched something and the waiter shouted at him. It hurt me because I knew he would not understand, but people still reacted harshly."	Parents experienced social challenges arising from limited community understanding of autism. Fear of judgement, stigma and children's behaviours in public settings contributed to reduced social participation and, in some cases, withdrawal from social activities.
Insufficient support	Limited family support; community misunderstanding; inappropriate advice	Advice without practical assistance; misconceptions about autism; spiritual explanations; disciplinary explanations; limited assistance with caregiving; lack of understanding from relatives	"but from her father's side, they do not really know how to handle her, which makes it difficult to leave her with them." "I have reached a point where I just move with him everywhere because I have realised that people do not understand him and I cannot force anyone to take responsibility."	Parents perceived the support available from relatives and the wider community as inadequate. Although advice was sometimes offered, parents reported limited practical assistance and encountered misconceptions about the causes and management of autism.

Caregiving a full-time responsibility	Constant supervision; impact on employment; caregiving demands; reduced personal time	Continuous childcare; supervision; inability to work consistently; difficulty running businesses; reduced personal freedom; changes in family roles.	"because of her condition, I have not been able to focus on my own work or business." "I have to stay with her most of the time or be available for her needs, which limits my opportunities."	Raising a child with autism was experienced as a demanding, full-time responsibility. The need for continuous supervision and support affected parents' employment, business activities, personal time and everyday family routines.

4.1 DISCUSSION OF FINDINGS

4.1.1 Navigating Emotional Uncertainty

The findings revealed that parents' experiences of raising children with autism were characterised by considerable emotional uncertainty. Rather than viewing emotional stress as an isolated response to the diagnosis, the findings suggest that parents moved through an ongoing process of trying to understand what autism meant for their child, themselves and their family. Feelings of being overwhelmed, helplessness and denial emerged as parents confronted developmental differences that they did not always understand or anticipate. This finding is consistent with Acharya and Sharma (2021), who reported that parents experienced emotional challenges, including denial, when confronted with the responsibility of raising a child with autism. Qin et al. (2021) similarly identified denial as a common experience following an autism diagnosis, while Raft et al. (2023) reported that parents often initially questioned or rejected the diagnosis. Oduyemi et al. (2021) further found that shock and disbelief were common initial parental responses.

The findings also resonate with Papanikolaou et al. (2021), who found that mothers described their lives as emotionally overwhelming, characterised by persistent distress, sadness and vulnerability. However, the present findings extend this understanding by suggesting that emotional uncertainty may not be confined to the period immediately following diagnosis. For parents, uncertainty appeared to be sustained by the continuing demands of caregiving, changing developmental needs and concerns about the future. Thus, the emotional experience can be understood as part of an ongoing process of adjustment rather than a single stage that parents simply pass through. Parents were not only responding to the diagnosis; they were continually trying to make sense of what raising a child with autism would mean in their everyday lives. This provides an important dimension to understanding the movement between uncertainty and adaptation.

4.1.2 Learning to Understand Autism

A second important finding was parents' perceived lack of knowledge about autism. Parents indicated that they often began learning about autism only after their child had been identified or diagnosed, leaving them feeling inadequately prepared to understand and respond to their children's needs. This lack of

knowledge contributed to uncertainty regarding communication, behaviour, development and appropriate caregiving strategies. Jacobs et al. (2020) similarly found that parents initially spent considerable time trying to explain and make sense of developmental differences in their children. Simlesa et al. (2021) identified limited autism knowledge as a significant challenge for parents, while Guillon et al. (2022) found that parents experienced difficulties because of inadequate information about autism, diagnosis and available support.

The present findings suggest that knowledge acquisition was therefore an important part of parental adaptation. Parents were not passive recipients of information; rather, they were required to learn about autism while simultaneously responding to their children's everyday needs. This creates a situation in which parents are expected to become knowledgeable caregivers while still experiencing uncertainty themselves. The findings therefore indicate that adaptation may begin through a process of learning and developing an understanding of the child. The challenge is that when reliable information is limited, parents may be required to navigate this process largely on their own. This suggests that access to understandable and contextually relevant information may be important in supporting parents to move from uncertainty towards greater confidence in their caregiving role.

4.1.3 Adapting Under Financial challenges

Financial challenges emerged as another significant aspect of parents' experiences. Participants described the financial demands associated with meeting their children's every day and specialised needs. Food requirements were identified as one area of expenditure, particularly where children had selective eating patterns or required particular foods. Although food was not the primary focus of the studies reviewed, its emergence in the present findings is significant because it demonstrates how financial pressure may extend beyond formal autism interventions into ordinary household expenditure. Pillay et al. (2024) similarly reported that parents sometimes had to choose between continuing interventions and meeting essential household needs such as food, rent and school fees for other children.

The financial demands became more pronounced where children required specialised services such as speech and occupational therapy. Azubuike et al. (2024) found that parents frequently paid for such therapies from their own resources, with the costs consuming a substantial proportion of household income. Pillay et al. (2024) similarly described private interventions and specialist consultations as overwhelming and unaffordable for many families, while Bhatta et al. (2021) found that families often carried therapy costs themselves because insurance and state support were limited. These findings indicate that financial adaptation involves more than simply finding money for therapy; parents may have to continually prioritise competing household needs.

Educational provision added another dimension to the financial challenges. Acheampong (2024) reported that parents experienced financial insecurity associated with school fees, transportation and learning materials, particularly where services were concentrated in urban areas. Nthibeli et al. (2022) similarly found that specialised schools were scarce and unevenly distributed, with many learners placed in mainstream classrooms without adequate support. The present findings therefore suggest that parents' financial experiences are closely connected to the availability and accessibility of services. In this sense, adaptation may involve making difficult decisions about which needs can be prioritised when available resources are insufficient. Financial strain consequently becomes part of the broader process through which parents negotiate how best to support their children within the resources available to them.

4.1.4 Negotiating Social Participation

The findings demonstrated that raising a child with autism also required parents to reconsider their partici-

pation in social life. Parents described experiences of stigma, misunderstanding and judgement, particularly when their children displayed behaviours that others interpreted as poor discipline or inappropriate behaviour. Consequently, some parents became reluctant to attend social events or take their children into public spaces because of concerns about meltdowns, negative attention or misunderstanding. Benzarti et al. (2023) similarly reported experiences of social discrimination, strained friendships and feelings of being talked about following children's public episodes. Simelane and Dlamini (2024) found that parents experienced stares and disapproval when their children vocalised loudly or experienced difficulties in public spaces.

These findings are also consistent with Goh et al. (2021), who found that parents reduced social gatherings and reorganised their daily schedules in response to the demands of raising a child with autism. Konowalek et al. (2025) further demonstrated that parents experienced reduced quality of life within their social and relational circles, while Dijkstra-de Neijs et al. (2024) found that parents' social quality of life declined as stress increased. The present findings suggest, however, that social withdrawal may be understood as an adaptive response to an environment perceived as unsupportive. Parents may limit social participation not because they do not value relationships, but because withdrawal can protect them and their children from judgement, embarrassment and emotional exhaustion. This presents an important tension within parental adaptation. The strategies parents use to protect themselves and their children may simultaneously reduce opportunities for social connection and support. Thus, adaptation does not necessarily result in improved well-being. Parents may become increasingly skilled at anticipating difficult situations, selecting less crowded places or limiting social activities, yet these adaptations can also narrow their social worlds. The findings therefore position social withdrawal as both a coping response and a potential source of further isolation.

4.1.5 Inadequate Support

The findings further revealed a gap between the support parents needed and the support they actually received. Participants described receiving considerable advice from relatives and members of the community, but less practical assistance in the day to day care of their children. Whelan et al. (2025) similarly found that grandparents and relatives sometimes wanted to assist but were uncertain about how to do so or minimised the child's needs through comments suggesting that the child would eventually "grow out of it." Appah et al. (2024) also reported that parents negotiated with relatives who offered explanations and advice based on spiritual or disciplinary assumptions. An important interpretation emerging from the present findings is therefore the distinction between being advised and being supported. Advice may communicate concern, but it does not necessarily reduce the practical demands placed on parents. Where advice is based on misunderstanding or assumptions about autism, it may instead increase parents' uncertainty and emotional burden. Parents may consequently find themselves having to educate others about autism while simultaneously caring for their children. This can place parents in the difficult position of being both caregivers and advocates within their own families and communities. The findings suggest that meaningful support should therefore extend beyond verbal encouragement or advice. Parents may require practical assistance, understanding and reliable networks that enable them to share caregiving responsibilities. Without such support, adaptation remains largely an individual responsibility, leaving parents to develop coping strategies while continuing to carry the majority of the caregiving demands.

4.1.6 Caregiving and the Reorganisation of Life

The findings indicated that caregiving was experienced as a full-time responsibility, with significant implications for parents' ability to maintain employment or operate businesses. Parents described the

demands of continuously caring for their children as making it difficult to pursue work-related responsibilities with the same flexibility as before. Dijkstra-de Neijs et al. (2024) similarly found that mothers often felt confined by caregiving responsibilities, while fathers associated their stress with changes to their social lives. Blackmore (2024) reported that extensive caregiving demands disrupted parents' working lives, particularly during the early years when children required substantial supervision and support. Papadopoulos (2021) similarly identified significant caregiving burdens among parents, particularly mothers, while Lynch et al. (2023) found that parents frequently reduced working hours, changed jobs or withdrew from employment because of caregiving demands.

Rather than interpreting this finding only as an employment challenge, the present study suggests that full-time caregiving represents a broader reorganisation of parents' lives. Work, social activities, family routines and personal time may all become structured around the needs of the child. Adaptation therefore requires parents to continually negotiate how available time, energy and financial resources are distributed. In some cases, this may involve reducing employment or changing the nature of work in order to remain available to the child.

5. CONCLUSION

Taken together, the findings demonstrate that parents' experiences were not characterised simply by a collection of difficulties. Instead, they reflected an ongoing movement between uncertainty and adaptation. Emotional distress and lack of knowledge created uncertainty, while learning about autism, modifying routines, adjusting social participation and reorganising work represented ways through which parents attempted to adapt. However, adaptation occurred within broader constraints, including financial pressure, stigma and insufficient support. The findings therefore suggest that parents' adaptation should not be interpreted as complete adjustment to autism, but as a continuous process of negotiating changing needs and circumstances. This perspective provides a more nuanced understanding of parental experiences in Zambia by showing that parents are not merely recipients of the challenges associated with autism, instead they actively develop strategies to make everyday life possible, even when the social, financial and support environments within which they adapt remain challenging.

RECOMMENDATIONS

Strengthen parent education and psychosocial support: Schools and health facilities should provide regular parent education on autism, child development and practical caregiving strategies, alongside counselling and parent support groups to address emotional stress and isolation.

Improve access to affordable services: Government and relevant service providers should strengthen access to affordable speech therapy, occupational therapy, educational support and other essential services for children with autism, particularly for families with limited financial resources.

Increase community awareness and reduce stigma: Community-based autism awareness programmes should be implemented to improve understanding of autism, address misconceptions and reduce stigma and negative perceptions towards children and their families.

Provide practical support for caregivers: Schools, community organisations and employers should develop practical support mechanisms, including respite opportunities, flexible working arrangements and stronger school–parent collaboration, to help parents manage the demands of full-time caregiving.

STUDY IMPLICATIONS

Implications for Policy: The findings highlight the need for policies that strengthen access to affordable autism-related services, parent support and inclusive educational opportunities for families.

Implications for Practice: Professionals working with children with autism should adopt family-centred approaches that provide parents with practical guidance, psychosocial support and strategies for managing developmental and caregiving needs.

Implications for Schools: Schools should strengthen collaboration with parents by providing regular feedback, practical home-based strategies and coordinated support to address children's developmental needs and reduce the burden on families.

Implications for Research: The findings provide a basis for further research on parents' lived experiences of raising children with autism, particularly regarding access to support services, financial pressures, social participation and the long-term impact of caregiving responsibilities.

REFERENCES

1. Acharya, S., & Sharma, K. (2021). Lived Experiences of Mothers Raising Children with Autism in Chitwan District, Nepal. *Autism research and treatment, 2021*, 6614490. https://doi.org/10.1155/2021/6614490
2. Acheampong, J. O. (2024). Caring for autism in Ghana: Exploring the psychological impact and coping strategies of caregivers. *Cogent Education, 11*(1), 2374686. https://doi.org/10.1080/2331186X.2024.2374686
3. Appah, J., Senoo-Dogbey, V. E., Armah, D., Wuaku, D. A., & Ohene, L. A. (2024). A qualitative enquiry into the challenging roles of caregivers caring for children with autism spectrum disorders in Ghana. *Journal of Pediatric Nursing, 76*, 23–29. https://doi.org/10.1016/j.pedn.2024.01.029
4. Azubuike, Albright & Azubuike, Precious & Onyekachi, Ebuka & Enyam, Michael & Akinreni, Temidayo & Abuo, James & Ogbonna, Chimankpam & Uchegbu, Eberechukwu & Adai, George. (2024). Experiences and unmet needs among caregivers of children living with autism spectrum disorder in Nigeria: a qualitative study using the socio-ecological model. Discover Social Science and Health. 4. 10.1007/s44155-024-0014-w
5. Benzarti, I., Ben Lamine, S., Chouikha, A., & Siala, H. (2023). Psychosocial difficulties of Tunisian parents and siblings of children with autism spectrum disorder: A descriptive cross-sectional study. *Heliyon, 9*(10), e20379. https://doi.org/10.1016/j.heliyon.2023.e20379
6. Bhatta, B., Shrestha, R., & Sapkota, K. (2021). Experiences of parents of children with autism spectrum disorder in Nepal: Financial and social challenges. *Journal of Autism and Developmental Disorders*, 51(12), 4482–4494. https://doi.org/10.1007/s10803-021-04912-7
7. Blackwell, C. (2024). The impact of school challenges on parental employment among families with children on the autism spectrum. *Disability & Society*. Advance online publication https://doi.org/10.1080/09687599.2024.2313096
8. Dijkstra-de Neijs, L., Boeke, D.B., van Berckelaer-Onnes, I.A. (2024). Parental Stress and Quality of Life in Parents of Young Children with Autism. *Child Psychiatry Hum Dev* (2024). https://doi.org/10.1007/s10578-024-01693-3
9. Goh, J. X., Aishworiya, R., Ho, R. C. M., Wang, W., & He, H.-G. (2021). A qualitative study exploring experiences and support needs of parents of children with autism spectrum disorder in Singapore. *Journal of Clinical Nursing, 30*(21–22), 3268–3280. https://doi.org/10.1111/jocn.15836

10. Guillon, Q., Baduel, S., Bejarano, A., & Canal, R. (2022). Determinants of satisfaction with the detection process of autism in Europe: Results from the ASDEU study. *Autism, 26*(8), 2136–2150. https://doi.org/10.1177/13623613221080318
11. Jacob, N., McKenzie, J., Ahali, M., Taylor, C., De Barros, M., & Ekerete, C. (2022). Parenting style and child expressive language among children with autism spectrum disorders in Nigeria and South Africa. *Journal on Disability & Developmental Therapy, 10*(2), 1–16. https://doi.org/10.29121/joddt.v10.i2.2022.327
12. Konowałek. L, Kotowska-Bąbol., M, Łukasik., J, Remiszewski, P & Wolańczyk, T. (2025). Quality of life among parents of autistic children: questionnaire validation study and multivariate analysis of associated factors. Frontiers in Psychiatry. 16. 10.3389/fpsyt.2025.1554368.
13. Lynch, F. L., Bulkley, J. E., Varga, A., Crawford, P., Croen, L. A., Daida, Y. G., Fombonne, E., Hatch, B., Massolo, M., & Dickerson, J. F. (2023). The impact of autism spectrum disorder on parent employment: Results from the r-Kids study. *Autism Research, 16*(3), 642–652. https://doi.org/10.1002/aur.2882
14. Nthibeli, M. et al. (2022). Teaching learners with autism in South African inclusive classrooms. *African Journal of Disability*. https://doi.org/10.4102/ajod.v11i0.979
15. Oduyemi, A. Y., Okafor, I. P., Eze, U. T., Akodu, B. A., & Roberts, A. A. (2021). Internalization of stigma among parents of children with autism spectrum disorder in Nigeria: A mixed-method study. *BMC Psychology, 9,* 182. https://doi.org/10.1186/s40359-021-00687-3
16. Papanikolaou, K., Zygouris, N. C., Karkanias, A., & Sofologi, M. (2021). Mothers' experiences and challenges raising a child with autism spectrum disorder: A qualitative study. *Maternal and Child Health Journal, 25*(5), 787–794. https://doi.org/10.1007/s10995-020-03096-4
17. Pillay, S., Duncan, M., & de Vries, P. J. (2024). 'We wait and we wait'-caregiver perspectives on autism spectrum disorder services in the Western Cape Province of South Africa. *Child and adolescent mental health, 29*(2), 145–153. https://doi.org/10.1111/camh.12704
18. Qin, X., Feng, Y., Qu, F., Luo, Y., Chen, B., Chen, M., … Zhang, L. (2021). Posttraumatic growth among parents of children with autism spectrum disorder in China and its relationship to family function and mental resilience: A cross-sectional study. *Journal of Pediatric Nursing,* 57, e59–e67. https://doi.org/10.1016/j.pedn.2020.10.026
19. Rfat, M., Koçak, O., & Uzun, B. (2023). Parenting Challenges in Families of Children with a Diagnosis of Autism Spectrum Disorder: A Qualitative Research Study in Istanbul. *Global social welfare: research, policy & practice,* 1–10. Advance online publication. https://doi.org/10.1007/s40609-023-00270-1
20. Simelane, N., & Dlamini, T. (2024). Lived experiences of parents caring for children and adolescents with autism spectrum disorder in Eswatini. *Nursing and Health Sciences Journal, 4*(2), 45–56. https://doi.org/10.56557/nhs.v4i2.399.
21. Simlesa, S., & Cepanec, M. (2021). Parental perspectives on support needs and availability of autism services in South and South-Eastern Europe. *Advances in Autism, 8*(2), 132–146.
22. Whelan, S., Caulfield, N., O'Doherty, S., Mannion, A., & Leader, G. (2025). Parental experiences of raising an autistic child in Ireland: A qualitative thematic analysis. *Autism, 29*(2), 395–407. Advance online publication 2024. https://doi.org/10.1177/13623613241277040.