Experiences of Caregivers of Autistic Children in Urban South India: Navigating Diagnosis, Daily Life, and Coping

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Abstract

Caregivers of autistic children in resource-limited countries such as India face multifaceted challenges. Research on culturally specific experiences of caregivers navigating their child's autism diagnosis is limited and hinders effective adaptation of evidence-based interventions. This study explored the experiences of caregivers of autistic children in Bengaluru, South India. In-depth, semi-structured interviews were conducted with twenty caregivers of autistic children and eight providers, including educators and early-intervention providers. Transcripts were analyzed using inductive thematic analysis. Five themes describe caregivers' complex journeys of receiving, navigating, and coping with their child's autism diagnosis. Parental and healthcare provider awareness regarding autism is limited, leading to widespread normalization of developmental delays. Second, caregivers experience a high burden of care and prominent stigma regarding autism, which affect their interpersonal, psychological, and financial well-being. Third, beliefs on the etiology of autism vary and inform how caregivers approach solutions and therapies. Finally, caregivers use various coping strategies to navigate stigma and accept their child's diagnosis, which influences caregiver views on spirituality and advocacy. These findings highlight the need for culturally adapted interventions that support caregiver well-being and coping and empower caregivers as pivotal stakeholders in their child's development.

1. Introduction

Research in high-income countries has reported that caregivers of autistic children experience heightened stress and depression (Altiere & von Kluge, 2009), burden of care (Safe et al., 2012), interpersonal relationship strain, and financial challenges (Nealy et al., 2012). However, cultural values, caregiving structures, and explanatory models of disability, prognosis, and course of care in India differ significantly from Western contexts (Daley, 2004; de Leeuw et al., 2020; Mak & Cheung, 2008). Future research should prioritize understanding the perspectives of Indian caregivers within their cultural context.

India accounts for roughly a quarter of global autism cases, with an estimated 1.7 to 2 million autistic children (Arora et al., 2018; Olusanya et al., 2018). Families raising autistic children in India encounter multifaceted challenges shaped by sociocultural, structural, and informational barriers. In East and South Asian cultures, including India, individuals with disabilities often experience higher levels of social stigma compared to other cultures due to pressures of social conformity (Daley & Sigman, 2002; Shorey et al., 2020). Within India, disability is frequently interpreted as "bad karma," or a reflection of past misdeeds (Ghai, 2019), leading to the marginalization of families and labeling of children as *pagal* (mad) (Lockwood Estrin et al., 2023; Minhas et al., 2015).

Compounding stigma, public awareness and professional understanding of autism in India remain lower compared to high-income countries which hinders timely diagnosis and help-seeking (Bhavnani et al., 2022; Daley, 2004; Desai et al., 2012; Divan et al., 2012; Vaidya, 2016). After diagnosis, many caregivers struggle to receive adequate information and counselling regarding autism (Balachandran & Bhuvaneswari, 2024). These cumulative challenges, including stigma, lack of awareness, and insufficient systemic infrastructure, contribute to caregiver depression, stress, social isolation, and a high burden of care (Das et al., 2017; Lockwood Estrin et al., 2023). Particularly, women in India traditionally bear caregiving responsibilities for disabled individuals which impact her career, mental health, and social network (Daley, 2004; Divan et al., 2012; Vaidya, 2016).

In response to their child's diagnosis, caregivers conceptualize their child's autism diagnosis by adapting culturally mediated perspectives of autism that span biomedical, religious, and environmental explanations (de Leeuw et al., 2020; Desai et al., 2012; Singh, 2016). For example, while some parents may interpret autism as a neurodevelopmental disorder requiring medical treatment, others may view it as a result of divine will, spiritual imbalance, or environmental factors during pregnancy (Chadda, 2014; Gupta & Singhal, 2005; John, 2012). Further investigation of caregiver perspectives on the causes of disability, pathways to acceptance, and coping strategies will inform the development of culturally responsive support systems for caregivers of autistic children (Daley, 2004; Divan et al., 2012; Durkin et al., 2015).

Understanding caregivers' complex journeys in recognizing, receiving, and navigating their child's autism diagnosis within family and societal ecosystems is crucial for effective partnership with caregivers to adapt and deliver resources (Wainer et al., 2017). To further center the perspectives of caregivers of autistic children, we describe caregivers' experiences in seeking, receiving, and navigating an autism diagnosis within an urban population in Bengaluru, South India.

2. Methodology

2.1 Setting

Karnataka, India's sixth largest state, has a population of 61,130,704 (*Census India*, 2011a) and a literacy rate of 75.60%. Bengaluru, the capital of Karnataka, has a population of 12,352,000 people *(Census India,* 2011b). Bengaluru is also one of the world's fastest growing cities, in part due to the large IT industry and transient migrant populations. As a cosmopolitan city with a concentration of public and private hospitals, diagnostic services, and therapy centers, Bengaluru has service options, yet access in urban areas remains stratified along socioeconomic and demographic lines (Das et al., 2017; Divan et al., 2012).

2.2 Participants

Caregivers and child development providers of autistic children were included. Participants were recruited by consecutive and snowball sampling at early-intervention centers, special and inclusive schools, and parent support groups in Bengaluru. All participants lived or worked in Bengaluru and were approached in-person or via telephone.

Caregiver eligibility criteria were: (1) caregiver of a child diagnosed or provisionally diagnosed with autism previously and was ages 3-8 years at the time of interview, and (2) the caregiver had enrolled or was seeking to enroll their child in early education. Thirty-four caregivers were contacted for participation and twenty completed the study. Eleven caregivers expressed initial interest in participating but did not complete interviews. One caregiver was ineligible due to a non-autism diagnosis, and two prospective participants withdrew due to competing time commitments. Eighteen caregivers self-reported their child's autism diagnosis, and two stated that their children were "high-risk" for autism but not yet diagnosed. Three fathers and 13 mothers were interviewed individually. Two pairs of mothers and fathers completed joint interviews. The majority of caregiver participants were female, Hindu, and upper-class (median income=109,580 - 146,103 rupees/month). 83.3% of children were male and were a mean age of 5.4 years (SD=1.6). See Table 1 for child and caregiver demographic information.

Providers were eligible if they (1) worked in early-intervention (psychologist, speech language pathologist, occupational therapist) or early education (special educators, inclusive educators, and primary school teachers), and (2) were currently working with autistic children and their families. All provider participants who expressed interest were interviewed. All providers (n=8) identified as female and reported M=9.3 years experience in the workforce (SD=8.2). See Table 2 for provider demographic information.

2.3 Interview Design

In-depth, semi-structured interview guides were developed for caregivers and providers of autistic children. These were piloted with four early-intervention center directors and five caregivers and edited based on feedback. The interviews explored experiences in seeking and receiving a diagnosis, social stigma, and coping processes. Providers were also asked about counseling and supporting parents. The interviewer was open to topics introduced by participants and asked follow-up questions. The caregiver and provider interview guides used are available as supplementary materials.

2.4 Data Collection

Interviews were conducted by the first author and occurred in early-intervention centers, participants' homes, or online. The interviewer accommodated participants' interview location preferences. Interviews ranged from 1-3.5 hours and were completed in one or two sittings, as some caregivers conducted interviews over multiple sessions while their child was in therapy. Interviews were audio-recorded. Before starting the interview, participants were informed that (1) they could take breaks at any time, (2) they did not have to discuss anything they did not want to talk about, and (3) they could elaborate upon any topic in more detail if desired.

Interviews were conducted in participants' preferred language and included 27 English interviews and one Kannada interview. The interview guide, consent form, and recruitment flyer were translated to Kannada by a bilingual native Kannada-speaker. The same Kannada-speaker assisted in the consent discussion and was a translator during the interview.

2.5 Analysis

Recordings were transcribed verbatim by an Indian transcription service. Audiotapes and transcripts were compared for accuracy by the first author. The Kannada interview was translated into English by another bilingual, native Kannada-speaker. Redundancy offering no additional meaning (e.g., "you know," "um,") was removed to aid in readability, and identifying details were redacted. Added language intended to clarify meaning was placed in brackets. Each transcript was assigned a letter code (C for caregiver or P for provider) and a unique number.

We conducted an inductive thematic analysis using Braun & Clarke's (2006) six-phase framework to identify prominent patterns in the data. To further conceptualize the data, we drew from de Leeuw et al.'s (2020) framework on global cultural and contextual factors in the identification and diagnosis of autism. We employed three levels of their described factors: recognition, interpretation, and reporting. Because caregivers sought medical attention (Reporting) before conceptualizing autism (Interpretation), we present Reporting prior to Interpretation. The first author and a practicing speech-language pathologist independently familiarized themselves with the data by reviewing the transcriptions. NVivo 14 was used for coding and organization of data. The first author coded the three interviews to generate a preliminary coding system, which was evaluated and refined collaboratively through double-coding two additional transcripts. The remaining transcripts were consensus coded with the revised framework, and iterative refinements were made in a second round of coding. Throughout the coding process, the group met multiple times to discuss initial codes, refine codes, generate themes, and clarify and define themes (Figure 1).

2.6 Ethics

Ethical approval was obtained by the XXX and the XXX. Early intervention centers that agreed to participate as recruitment sites provided written informed consent. All study participants provided informed consent for interviews and audio recording.

3. Results

This study describes caregiver journeys in suspecting and seeking their child's diagnosis, the social, psychological, and financial impacts of autism, and their coping processes. We recruited 20 caregivers and 8 providers.

Audio transcripts were systematically coded and analyzed (Figure 1). Drawing from the framework for understanding global cultural and contextual factors on autism developed by de Leeuw et al., (2020), we found three themes highly relevant to our data: Recognition, Reporting, and Interpretation (Figure 2). Additionally, we explored two additional themes: Reaction and Coping and growth.

3.1 Recognition

Recognition of differences in their child's behaviors was impacted by both caregivers' awareness of their child's development and cultural norms of typical behavior.

3.1.1 Caregivers' awareness of developmental status of the child

All parents expressed no or limited prior knowledge of autism before their child was diagnosed.

> *"I was not aware of this kind of thing. Also never heard from, never seen my family, not in my neighbors, not in my society." - C105"*

Despite a lack of knowledge regarding autism, caregivers recalled suspicions in their child's behaviors in comparison to known developmental milestones, including lack of speech, limited eye-contact, sensory needs, or regression in behavior.

3.1.2 Cultural norms of typical behavior

Caregiver knowledge of normative developmental milestones came from elders. However, caregiver concerns were often normalized by family. These justifications were rooted in cultural norms such as "boys speak late" or a family history of speech delay.

> *"We thought it was OK because we heard that boys will speak late...His father started talking a little late, even my brother." -C113*

Others felt labelled as overly concerned, anxious, or attention-seeking by family. The widespread normalization of their child's behavior resulted in delays in seeking medical attention or a lack of concern when delays were mentioned by medical providers.

> *"The doctor had told us to take him to the psychiatrist. But we thought, 'he is such a small baby, why should we take him to a psychiatrist?' We were a little careless this way… we waited until he was 3 years old." -C123*

3.2 Reporting

When caregiver concerns exceeded a threshold that was no longer justified by age and behavior, caregivers sought medical attention. However, the availability and acceptability of information from clinicians varied widely.

3.2.1 Availability: quality of the medical provider and diagnosis

Availability was characterized by the accessibility to services, trained personnel, and diagnostic materials. While major government tertiary care centers provided reliable and credible diagnoses, they had long waitlists and required multiple days of assessments. In other medical

settings, parents received inconsistent information on the appropriate age of diagnosis, the diagnostic process, or next steps. Diagnostic inefficiency was also exacerbated by the COVID-19 pandemic, as clinics and hospitals were unable to operate in person.

> *"They said you have to wait till three years or five years [to receive a diagnosis]…[in] the diagnosis process, there were very kind of generic questions which he asked how he was behaving and all… it took around 30 minutes." -C123*

3.2.2 Acceptability: satisfaction with medical provider

Acceptability was defined by the perceived satisfaction of care delivered by the medical provider. Caregivers first consulted a general pediatrician with concerns, yet doctors were generally unaware of autism and further emphasized that "boys speak late" or adopted a "wait and see" approach. Participant C118 recalled consulting six general pediatricians before being referred to a developmental pediatrician.

> *"This third doctor, he's supposed to be the senior…would just reinforce "he's a boy, he'll talk later." Inside I was screaming, 'nobody's taking me seriously.' My husband was reinforcing what the doctors were saying. I was very alone in this quest that I felt like something was off." -C118*

When receiving the diagnosis, a lack of doctor counselling and explanation contributed to caregiver confusion and anxiety. Caregivers felt blamed for their child's diagnosis, as doctors stated that parents caused their child's autism due to a lack of attention.

> *"'Because of you, because of all this situation, your child has become like this…for the next two years, you have to give full 100% attention to your child. Otherwise, your child will not be [okay].' So actually those words made me depressed" -C112*

3.2.3 Acceptability of therapy providers in therapy settings

Even after enrolling in therapies, caregivers struggled to access counselling, information, and resources from therapy providers.

> *"We go to occupational therapy and nobody really tells me what exactly they're doing or why they're doing something…I realized there was no one around to actually sit and teach me about autism. There were no proper courses as such, and the therapist didn't really listen to you or try to explain to you." -C107*

To fill this gap, multiple caregivers enrolled in classes directed at professionals and read scholarly literature regarding autism.

3.3 Reaction

This theme describes how caregivers responded to their child's diagnosis, including its impact on caregiver mental health, social life, financial well-being, and interpersonal relationships.

3.3.1 Impact on mental health

Upon receiving their child's autism diagnosis, parents reported a variety of emotions such as shock, fear, anger, anxiety, denial, depression, and self-blame. Parents held deep-rooted anxiety about the future, particularly the child's fate after the parents' passing. Parents also noted physical health consequences as a result of their stress.

> *"I went into depression because I did a lot of research… I found that it is a lifelong condition. It will not be treated…I was on antidepressants. You can figure out how traumatic it was for me." -C112*

3.3.2 Withdrawal from society

Caregivers withdrew socially due to an increased burden of care and avoidance of stigma. Parents began intensive therapy for their children immediately after the autism diagnosis. Burden of care manifested differently by gender. To coordinate care, mothers frequently quit their jobs or worked from home. Mothers also left work due to stigma in which her child's autism was ascribed to her career and a subsequent lack of attention for the child.

> *"Most of the things I hear is 'because you're working, you're not able to give more time to your kid.' We don't want to hear such things." -C113*

Fathers generally shouldered financial responsibilities. Caregivers reported their earnings were largely directed towards their child's out-of-pocket therapy sessions. While they carried financial responsibilities, they retained social connectivity through their careers.

> *"Therapies… [were] half of our salaries…it was crossing 65-70 thousand [rupees] per month" -C129*

Parents made their personal lives, including where they lived and their jobs, revolve around their child's therapy and needs. They reduced leisure activities and vacations because of their child's therapy, fear of regression, and care coordination challenges.

> *"Once I took a holiday break in November 2023... there was a huge regression...Since then I got scared, and I don't take breaks." -C119*

Caregivers experienced significant public stigma regarding their child's diagnosis and behaviors. Autistic children were viewed as *pagal* (mad), intellectually disabled, violent, dangerous, or disruptive.

> *"In Hindi, we call it 'pagal ek hai.' Is he mad? Or is he brain dead?" -C120*

Parents, particularly mothers, felt perceived as incompetent parents in public. They experienced shame and embarrassment, prompting them to subdue their child's stimming behaviors. Parents also reported facing culturally attributed and religious stigmas for their child's autism, such as "bad karma." In response, caregivers withdrew by decreasing public appearances, limiting travel to hometowns, and avoiding disclosure to family, friends, and strangers.

> *"Whenever we go for functions, they look at us in a very different light. No one includes him in anything. I only dislike going to such functions. When other people question his behavior, they say that he is 'mental.' Listening to such things makes me not want to attend the functions." -C121*

3.3.3 Impact on interpersonal relationships

While some caregivers avoided disclosure of the autism diagnosis due to fear of stigmatization or shame, others described family tensions due to disclosure. Notably, the father's side was less supportive of the family, while the mother's side contributed to caregiving responsibilities.

> *"It's a very weird thing in Indian households that usually it's the girl side of the family who are more open and accepting and kind. And I see that in my real life as well…his parents were adamant that we don't consider you family anymore." -C119*

Marital strain due to disagreements regarding autism or practices of care was common. Three mothers described the immense burden of care in single parenting an autistic child, including housing insecurity and stigma regarding single motherhood.

> *"He locked the door and left. I [had] taken my son to therapy center…when we came back home the door was locked…He said, 'I'll stop paying the EMIs (loan payments) and I will push you out.'… Just saying that I'm a single mother would not get me houses… autism is something I can manage, but the judgment [about separation] that I face is getting an extra load on top of me, which is affecting my mental health." -C119"*

Parents stated that their other neurotypical children felt neglected.

> *"We spend a lot more time with him than my daughter…Now that she has grown up, she says, 'you take care of him so much and you neglect me.'" -C121*

3.4 Interpretation and action

This theme describes caregivers' explanatory models of autism, including both biological and social causes.

3.4.1 Biological Explanations

Caregivers cited the biological and neurological etiologies of their child's behaviors and sought further medical evaluations to identify the genetic cause for their child's symptoms. These models of explanation accompanied the "blame-game" seen in marital strain.

> *"I'm have not said so to my husband yet, but for the longest time I feel it is because his family carries neurodiversity in the family. So that's where it comes in from genes, because I don't have it from my family side." -C120*

Many parents described therapies and interventions as a way to help the child "come out of autism" or return to "normal." Often, caregivers attempted to quantify normalcy.

"If at least 70-80% [improved], he will become normal." -C103

Caregivers also expressed their dislike of the diagnostic label because they believed it would inherently limit their child's ability to eventually become "normal."

"Don't tag him as autistic or neurodivergent…it's very difficult to pull the child out of that tag…with all this support system of therapy and extra care…he will be back to normal. If as a society and parents start tagging our kids now, then our kids will never be in the mainstream." -C112

3.4.2 Social Explanations

Caregivers also ascribed their child's autism to environmental or socially induced factors. Multiple caregivers stated that their child was autistic due to a lack of socialization caused by media exposure, the COVID pandemic, or a lack of attention toward the child during early childhood. These sentiments were often expressed with self-blame and regret.

"We left him for the screen. Outside, the kids were not playing with the kids [due to COVID]. So because of this, the problem that our child is facing is not natural, it's environmentally induced." -C112

3.5 Coping and growth

Caregivers expressed two main approaches to accepting their child's autism: an assumption of responsibility and reframing expectations.

3.5.1 Assumption of responsibility

Prevailing duties and a role from God were fatalistic motives for continuing care.

"We have to learn to live with this…Who else will do it if we will not do it?…We are just players on this chess board, and we are here doing a job, a responsibility, a role we have been granted." -C120

3.5.2 Reframing expectations

Caregivers reoriented their expectations of their child towards independence and communication. They focused on meeting small, manageable goals and living in the moment with their child.

"He has been the North Star to us. With his small achievements, whenever she takes him to any therapy, every day I ask her how has it been. That particular small, five-minute feedback gives a mental calmness to me…We are on the right track." -C115

Acknowledging their child's differences, they adapted their environments, parenting practices, or expectations to accommodate their child's needs and abilities. Multiple caregivers endorsed the neurodiversity movement and stated their children were "normal" children who deserved equal access to educational and social opportunities. Therapy goals shifted to focus on independence and communication.

> *"This is who you are, this is your innate character. I'll respect that. As long as you are able to keep yourself calm and happy and sustain yourself in an environment outside of your home, then it's good for us...he finally feels understood and heard."-C107*

3.5.3 Navigating stigma

Caregivers navigated internal perceptions of autism and external public stigmas. For example, reorienting to the child's needs and happiness was described alongside a disregard for public opinions and hurtful assumptions. Participants frequently recounted "fighting" against stigma or passively accepted others' words.

> *"I became a warrior. Because opposing others' words and standing up for my child was very difficult for me. Taking her out in crowds, people staring at us, people making faces at us, all that was there. But I did not care for anything. I was like 'OK, fine, my child is happy. It's more than enough for me.'" -C104*

3.5.4 Re-integration into social life

Neurodiversity parent support groups were essential sources of support for caregivers, as parents could ask questions, get recommendations, and find solidarity in shared experiences.

Caregivers disclosed their child's diagnosis to family and friends, and maternal relatives particularly offered both caregiving and emotional support.

> *"My mother used to say, 'he's your child and he's like a blessing. You should not feel ashamed because of him...Why are you restricting you and your child because of that?'...she never feels ashamed in sharing with anyone... with this I gained confidence." -C128*

3.5.5 Caregiving and spirituality

Reflecting upon the profound impact of autism on their lives, caregivers described that their perspectives on caregiving, parenting, and spirituality metamorphosed. Many stressed the importance of self-care.

> *"I really feel I was meant to go through it because I was expected to be transformed as a person to be really helpful for our kids…I was more into sacrificing. [I thought] that is what life is about, that's what parenting is about. No, it is not." -C120*

3.5.6 Advocacy

Participants stated the need for broader societal awareness and acceptance of autism. Caregivers and providers emphasized that therapy centers or hospitals should provide caregiver education or training programs following diagnosis. They also advocated for increased accessibility to government schemes such as benefits offered through UDID (disability) cards.

> *"For every counsellor, there are almost 25 to 50 children that they have to work with… there is a gap that we have to bridge. I think the [solution to the]*

gap would be to have more trained professionals but also have parents themselves come into the training seat." -P108

4. Discussion

This study elucidates the challenges and coping experiences of caregivers of autistic children in urban South India. Four prominent findings emerged. First, caregiver and healthcare provider awareness regarding autism continues to be limited even amongst a highly educated, middle-upper class, urban population and leads to widespread normalization of developmental delay. Second, caregivers must re-negotiate their careers, social well-being, interpersonal relationships, and psychological health because of stigma and a high burden of care. Third, caregiver conceptualization regarding autism influences the approaches caregivers take in their child's care. Finally, caregivers use various coping strategies to navigate stigma and accept their child's diagnosis. Overall, these results highlight the critical need for increased caregiver support and improved caregiver and provider knowledge to facilitate positive caregiver coping and trajectories for care.

4.1 Limited caregiver and healthcare provider awareness of autism

Previous Indian studies have documented that caregivers lack knowledge and awareness about autism which hinders the process of diagnosing autism or learning about the condition (Bhavnani et al., 2022; Daley, 2004; Desai et al., 2012; Divan et al., 2012; Lockwood Estrin et al., 2023; Minhas et al., 2015). Caregivers in our study corroborated previous evidence that a child's delays are often justified by both doctors and family members (Divan et al., 2012) using culturally-attributed myths that "boys speak late" or that speech delays are hereditary from the father (Bhavnani et al., 2022). Our findings indicate that knowledge gaps persist even among highly educated, urban caregivers with access to resources and suggest a broad societal lack of awareness.

While more recent studies of physicians in India have suggested an improved awareness of autism than before (Daley & Barua, 2010), many caregivers in our study reported negative experiences with healthcare providers in terms of acceptability and availability. The widespread lack of medical provider knowledge (Bhavnani et al., 2022; Daley, 2004; Vaidya, 2016) also likely contributes to caregivers receiving inconsistent information from physicians, such as the suitable age for a reliable autism diagnosis. Given that many doctors continue to lack the knowledge or psychoeducation skills to direct caregivers toward appropriate pathways of care, future research may seek to evaluate the impact of training on physicians' understanding of autism and their comfortability providing evidence-based recommendations.

4.2 Caregiver renegotiation of their lives following diagnosis

Having an autistic child has a gendered impact on caregivers' lives, as mothers experience disruptions to their careers and needed to return to the home (Daley, 2004; Divan et al., 2012; Vaidya, 2016) while fathers navigate financial burdens to afford out-of-pocket therapies. The magnification of caregiving burden—mentally, physically, and financially—contributed to depressive symptoms and a deep anxiety about the future in both mothers and fathers. Gendered patterns in receipt of social support may also reflect patriarchal norms of caregiving. Vaidya (2016) describes the "blame game" that mothers' in-laws use to accuse women of causing the child's diagnosis through her parenting practices or "bad genes," while fathers' involvement may

translate to wider family support (Navalkar, 2010). Our findings extend the prior research by demonstrating how blame may stigmatize mothers and restructure caregiving networks by impacting intergenerational caregiving responsibilities. Results underscore the need for supports that alleviate emotional and financial strain, are adapted to existing caregiving structures, and consider the distribution of responsibilities among parents and other primary caregivers.

These gendered dynamics are further compounded by autism stigma, which characterizes the child as *pagal* or mad (Minhas et al., 2015) or the child, mother, or family as having bad karma or genes (Ghai, 2019). While with prior studies have linked autism signs to parenting incompetence and a lack of behavioral discipline (Broady et al., 2017; Gray, 2002), our findings also demonstrate how stigma directly reshapes caregivers' everyday lives and limits their ability to participate in public, familial, and community spaces. As Indian society is characterized by collectivism which emphasizes social cohesion and interdependence (Shorey et al., 2020), the avoidance of stigma due to anticipated judgment negatively impacts caregiver wellbeing.

4.3 Understanding of the cause of autism informs perspectives on treatment

Caregivers' emphasis on biological explanations for autism further demonstrates how cultural attributions shape understandings of disability and its causes (de Leeuw et al., 2020; Mak & Cheung, 2008). In our study, biological explanations of autism were accompanied by hopes that therapies could help their children achieve greater "normalcy." Similar medical models of autism have been reported in India (Desai et al., 2012) alongside maternal guilt and blame (Lockwood Estrin et al., 2023). These medicalized frameworks may serve a pragmatic yet mentally taxing way for caregivers to understand their child in contexts of stigma, limited awareness, scarce resources, and an uncertain future (de Leeuw et al., 2020; Singh, 2016). References to children's progress relative to "normal" peers may highlight caregivers' desire to love and accept their child while simultaneously desiring an easier life for themselves and their children (Brezis et al., 2015; Safe et al., 2012). Acknowledging the complexity of caregiver perspectives and emotions underscores the importance of empowering caregivers as advocates and shifting the narrative from deficit-based understandings toward opportunities meaningful participation in communities.

4.4 Caregivers employ diverse coping strategies

Facing a paucity of knowledge and a discouraging perspective of their child's future, parents employ a variety of coping strategies. Some caregivers resisted diagnostic labels in the hope of aligning their child with 'normative' developmental pathways, while others embraced the diagnosis and shifted goals toward independence and communication. Caregivers' perspectives could reflect not just a simple acceptance or rejection of labels but rather a negotiation between the local cultural norms for normalcy and the neurodiversity movement advocating for strength-based perspectives. Singh describes a similar negotiation of disability models where parents initially ascribe to a medical model of disability when seeking a diagnosis and pursuing treatments but begin to challenge limits placed on their children by providing them with opportunities, possible futures, and a sense of individuality (Singh, 2016). A caregiver's ability to adopt a positive perception of their child's diagnosis may reflect a constructive coping strategy which affirms their child's personhood (Ilias et al., 2018; Vaidya, 2016). Interventions may benefit from gently incorporating strength-based perspectives and encouraging caregivers to reframe therapies as tools for promoting independence and inclusion.

Caregivers exhibited a positive reappraisal coping strategy where they turned reflection inward on their own growth and spirituality. Some caregivers assumed parenting responsibilities as their duty from God as previously documented (Chadda, 2014; Gupta & Singhal, 2005; John, 2012), yet they also rejected negative fatalistic beliefs such as karma. Within a highly educated and wealthy population, caregivers may be shifting from cultural beliefs of parental sins, karma, or curses as explanation for their child's autism diagnosis (Ilias et al., 2018) and use their spirituality as a source of strength. Further work on psychoeducation could validate religion and spirituality as tools for resilience and coping. Future research should also examine how socioeconomic status influences coping, as wealthier families may have greater access to interventions and alternative explanatory models, while lower-income caregivers may face more persistent stigma and fewer opportunities for adaptive coping.

4.5 Limitations

Despite its strengths providing culturally grounded, in-depth insights from caregivers of young autistic children, this study has limitations. Its small, largely homogenous sample size comprising of mostly female participants with high socioeconomic statuses is not representative of Bengaluru's urban population and could introduce a gender bias. While autism does not discriminate along class, caste, or other sociodemographic determinants, knowledge about autism in India trickles down along sociodemographic disparities (Daley, 2004; Durkin et al., 2015). Future research of caregiver experiences in India must investigate the experiences of less privileged families and communities to understand how they conceptualize autism and cope with their child's diagnosis. Similarly, the results from this research cannot extend to India's rural population who face additional barriers in access to services and awareness (Das et al., 2017; Minhas et al., 2015).

5. Conclusions

Our study provides detailed descriptions of the experiences of caregivers of young autistic children in urban South India. Overall, our study underscores the critical need for culturally responsive training and psychoeducation for caregivers to improve caregiver mental health, awareness, and knowledge (Balachandran & Bhuvaneswari, 2024; Lockwood Estrin et al., 2023). While community- and parent-delivered interventions have shown promise in India (Brian et al., 2024; Divan et al., 2015, 2019; Manohar et al., 2019; Sengupta et al., 2020, 2023), high caregiver stress can undermine intervention effectiveness (Stadnick et al., 2015). Caregiver psychoeducation programs may be an important precursor or complement to intervention delivery (Weitlauf et al., 2020). Programs could include autism education, stress management, and acknowledgement of stigma, and these programs should respect diverse explanatory models of autism and religious coping. Designing these programs with caregivers and embedding them within existing family and therapeutic structures is key for effective delivery, relevance, and sustainability.

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Table 1
Child and Caregiver Demographics

	N	Percent (%)	Mean and SD
Child Characteristics			
Age (years)	18		5.6 ± 1.4
Gender			
Male	15	83.3	
Female	3	16.7	
Years in therapy			
0-1	1	5.6	
1-2	6	33.3	
2-3	5	27.8	
3+	7	38.9	
School			
Private	16	88.9	
Government	1	5.6	
Other	1	5.6	
Sibling			
No siblings	9	50	
One sibling	9	50	
Sibling age (years)			7.6 ± 4.3
Sibling autism	0	0.0	
Caregiver and Household Characteristics			
Age (years)	20		35.5 ± 4.2
Gender			
Male	5	25.0	
Female	15	75.0	
Marital Status			
Married	14	70.0	
Separated	1	5.0	
Religion			
Christian	3	15.0	
Hindu	14	70.0	
Not specified	3	15.0	
In labor force			
No	7	35.0	
Yes	13	65.0	
Monthly household income (rupees)			
7,316 - 21,913	1	5.0	

36,527 - 45,588	4	20.0
45,589 - 54,650	2	10.0
68,455 - 73,053	1	5.0
73,054 - 109,579	1	5.0
109,580 - 146,103	3	15.0
> 146,104	6	30.0
Not specified	2	10.0

Table 2

Provider participant demographics

	N	Percent (%)	Mean and SD
Age (years)	8		38.5 ± 14.7
Gender			
Male	0	0.0	
Female	8	100.0	
Years in labor force			9.3 ± 8.2
Profession			
Speech language pathologist	1	12.5	
Psychologist	1	12.5	
Occupational therapist	1	12.5	
Special educator	3	37.5	
Educator	2	25.0	

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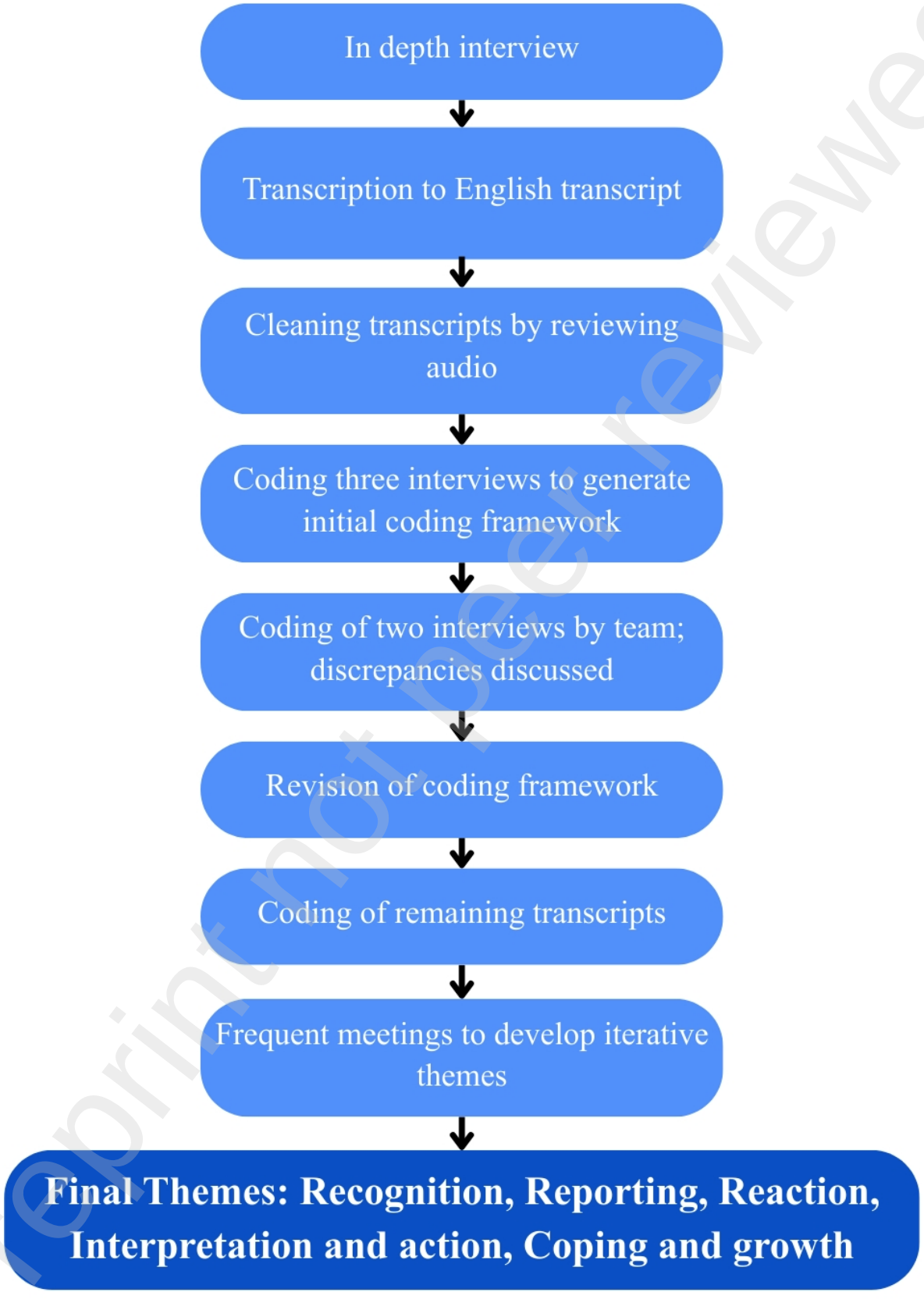

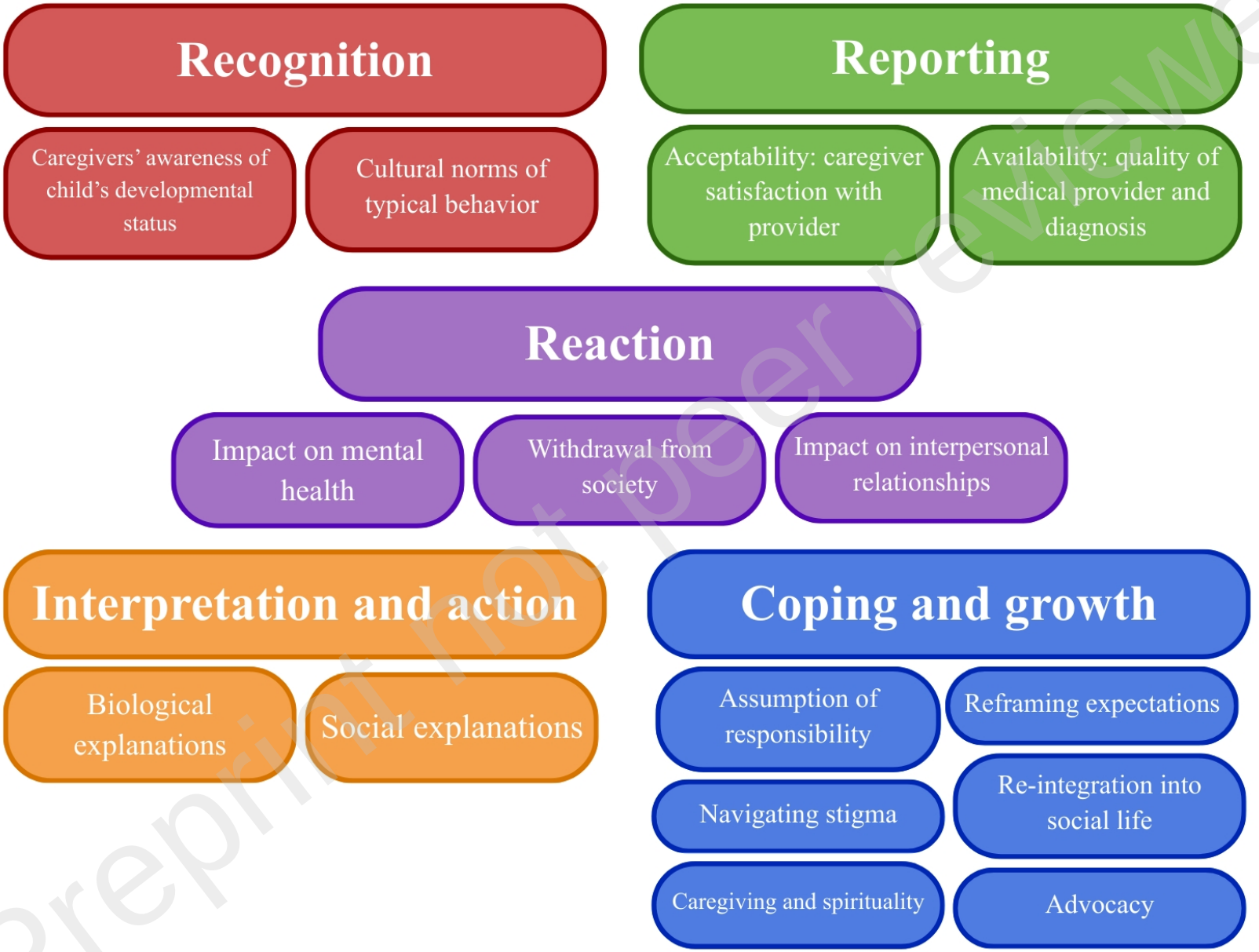

Figure 1
Coding and Analytic Process.

Figure 2
Thematic Analysis Results.