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NAVIGATING STIGMA AND SOCIAL EXCLUSION: EXPERIENCES OF FAMILIES LIVING WITH CHILDREN WITH NEURODEVELOPMENTAL DISORDERS: A QUALITATIVE RESEARCH

Original Article

Shaista Irshad[1]*, Saba Syed[2], Sarah Mahmood[3], Laiba Shahzad[4], Tehreem Talat[5], Sabeen Sabir[6]
[1]PhD Scholar, Department of Applied Psychology, Government College University Faisalabad, Pakistan.
[2]Clinical Psychologist, Health Department, Project Management and Implementation Unit (PMIU), Saidu Group of Teaching Hospital, Swat, Pakistan.
[3]Assistant Professor, Department of Applied Psychology, Bahauddin Zakariya University, Multan, Pakistan.
[4]BS Applied Psychology Graduate, Institute of Applied Psychology, University of the Punjab, Lahore Campus, Pakistan.
[5]Principal Psychologist, Rahman institute of special education (RISE), Lahore, Pakistan.
[6]Former Visiting Faculty, Department of Psychology, Bahria University Islamabad, Pakistan.

Corresponding Author: Shaista Irshad, PhD Scholar, Department of Applied Psychology, Government College University Faisalabad, Pakistan., psycho_alliance@yahoo.com

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ABSTRACT

Background: Families of children with neurodevelopmental disorders frequently encounter stigma and social exclusion that extend beyond the diagnosed child and influence parental identity, emotional health, and social participation. Although quantitative research has documented caregiver burden and affiliate stigma, less is understood about how parents interpret and negotiate these experiences within their sociocultural contexts. A deeper exploration of lived experience is essential to inform culturally responsive, family-centered support strategies.

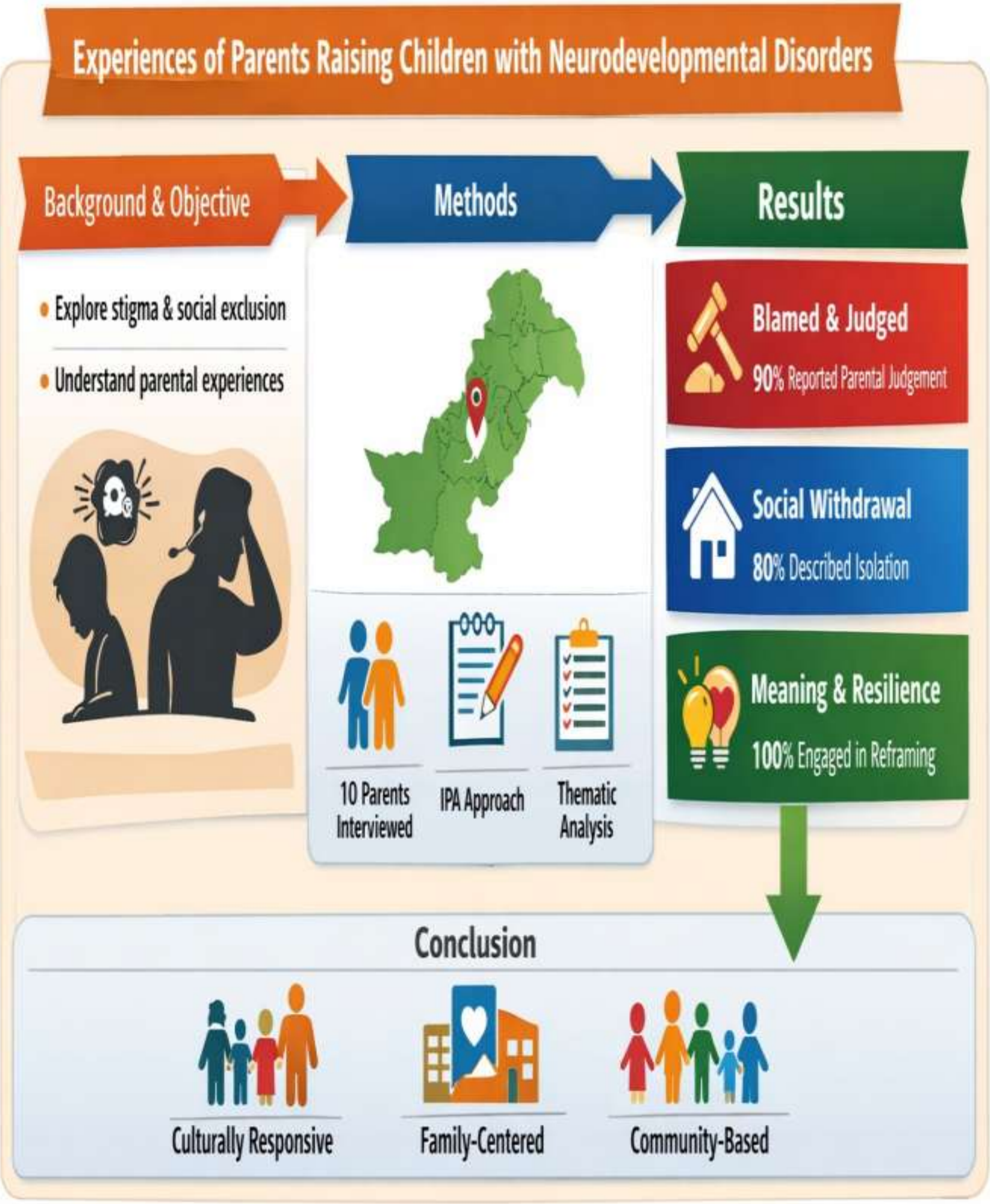
Objective: To explore how parents of children with neurodevelopmental disorders experienced, interpreted, and made meaning of stigma and social exclusion within their everyday sociocultural environments.

Methods: A qualitative design grounded in Interpretative Phenomenological Analysis was employed. Purposive sampling was used to recruit 10 primary caregivers of children formally diagnosed with autism spectrum disorder, attention-deficit/hyperactivity disorder, or intellectual disability from special education institutions in three major urban centers of Pakistan. In-depth semi-structured interviews lasting 60–90 minutes were conducted in participants' preferred language. Interviews were audio-recorded, transcribed verbatim, translated where necessary, and analyzed through iterative idiographic and cross-case thematic procedures consistent with established IPA guidelines.

Results: The sample comprised 10 parents, each representing one child with a diagnosed neurodevelopmental disorder. Three interrelated themes were identified. Perceived parental blame and moral judgment were reported by 9 of 10 participants, with 8 describing recurrent public scrutiny and 7 reporting unsolicited parenting advice. Social withdrawal as a protective strategy was described by 8 participants, of whom 6 simultaneously reported feelings of isolation and loss of belonging. All 10 participants described processes of meaning reconstruction over time, with 8 explicitly reframing stigma as societal misunderstanding rather than personal failure. Advocacy or selective engagement with supportive networks was reported by 6 participants. Findings indicated that stigma operated through both overt and subtle social mechanisms, contributing to self-doubt, emotional fatigue, and anticipatory stress, while also prompting adaptive coping and identity renegotiation.

Conclusion: Stigma and social exclusion were experienced as cumulative and relational processes that shaped parental identity and social participation. Parents actively interpreted and negotiated these experiences, demonstrating resilience through meaning reconstruction and selective engagement. The findings underscore the importance of culturally responsive, family-centered, and community-level interventions that address both structural stigma and parental psychological adaptation.

Keywords: Adaptation, Psychological; Autism Spectrum Disorder; Caregivers; Neurodevelopmental Disorders; Qualitative Research; Social Stigma; Social Isolation.



Experiences of Parents Raising Children with Neurodevelopmental Disorders

Background & Objective

- Explore stigma & social exclusion
- Understand parental experiences

Methods

10 Parents Interviewed

IPA Approach

Thematic Analysis

Results

Blamed & Judged
90% Reported Parental Judgement

Social Withdrawal
80% Described Isolation

Meaning & Resilience
100% Engaged in Reframing

Conclusion

Culturally Responsive

Family-Centered

Community-Based

INTRODUCTION

Neurodevelopmental disorders (NDDs), including autism spectrum disorder and attention-deficit/hyperactivity disorder, are characterized by early-onset differences in cognition, behavior, and social communication that persist across the lifespan and shape multiple domains of functioning (1). Contemporary diagnostic frameworks emphasize neurobiological underpinnings and heterogeneity of presentation, yet the lived reality of NDDs extends well beyond clinical symptom clusters. While a substantial body of research has focused on etiology, comorbidity, and therapeutic interventions, comparatively less attention has been directed toward the social ecologies in which affected children and their families are embedded. Parenting a child with an NDD is not solely a matter of navigating appointments, educational plans, or behavioral management strategies; it involves sustained engagement with societal attitudes, institutional structures, and culturally informed expectations about development and family roles. These contextual influences can shape parental identity, family cohesion, and long-term psychological well-being. Increasingly, scholars recognize that health outcomes are co-constructed within social environments, making it essential to situate neurodevelopmental conditions within broader relational and cultural frameworks rather than viewing them exclusively through a biomedical lens (1).

Among the most pervasive social forces shaping family experience is stigma. Conceptually defined as a process involving labeling, stereotyping, separation, and status loss within contexts of unequal power, stigma functions as a mechanism of social regulation that marks difference as deviance (2,3). In the case of NDDs, atypical behaviors—such as sensory sensitivities, communication differences, or impulsivity—may elicit public scrutiny and misinterpretation, frequently resulting in social distancing and moral judgment (4). Importantly, stigma often extends beyond the diagnosed child to encompass parents and caregivers, a phenomenon described as courtesy stigma and, when internalized, affiliate stigma (5,6). Parents may be implicitly or explicitly blamed for their child's condition, criticized for perceived disciplinary failures, or subjected to intrusive questioning in public and institutional settings. Empirical investigations have linked affiliate stigma with elevated psychological distress, diminished parental self-efficacy, and compromised family functioning (7,8). These findings underscore that stigma operates not merely as a social perception but as a chronic psychosocial stressor with measurable mental health consequences, reinforcing the need to examine its experiential dimensions within family life.

Closely intertwined with stigma is social exclusion, defined as restricted participation in social, educational, and community spheres through both overt discrimination and subtle processes of marginalization. Families raising children with NDDs frequently report reduced invitations to social gatherings, strained extended-family relationships, and limited access to inclusive recreational environments. Within formal systems, barriers may manifest as inadequate educational accommodations, dismissive professional attitudes, or constrained involvement in decision-making processes (9). Although policy frameworks increasingly endorse inclusion, implementation gaps persist, often leaving families to negotiate fragmented support structures. Over time, repeated experiences of exclusion may foster anticipatory anxiety and voluntary withdrawal from social spaces as a protective strategy. While such withdrawal may reduce immediate exposure to stigmatizing encounters, it can inadvertently intensify isolation and diminish access to buffering social resources. Cultural context further shapes these processes; beliefs regarding disability, parenting responsibility, and family reputation influence how NDDs are interpreted and managed across societies (10). In collectivist settings, stigma may reverberate across extended kinship networks, amplifying concerns about social standing and future opportunities. Despite these complexities, much of the extant literature remains rooted in Western populations and quantitative paradigms, often conceptualizing stigma and exclusion as static variables rather than dynamic, relational experiences embedded in everyday life.

Methodologically, prevailing research has prioritized measurement of caregiver burden, stress indices, and attitudinal scales, generating valuable epidemiological insight yet offering limited exploration of how parents interpret and negotiate stigmatizing encounters. Quantitative metrics, while indispensable for establishing prevalence and correlational patterns, may inadvertently obscure the nuanced processes through which stigma is internalized, resisted, or reframed over time. Qualitative approaches, particularly Interpretative Phenomenological Analysis (IPA), provide a rigorous framework for examining lived experience and meaning-making within specific sociocultural contexts (11). By engaging deeply with parents' narratives, IPA facilitates understanding of how social exclusion is perceived, how identity is reconstructed in the aftermath of diagnosis, and how coping strategies evolve across developmental stages. Such insight is critical for informing culturally responsive, family-centered interventions that move beyond symptom management to address relational well-being and social inclusion. Therefore, the objective of the present study is to explore, through an IPA framework, how parents of children with neurodevelopmental disorders experience and interpret stigma and social exclusion within their sociocultural contexts, and to elucidate the implications of these experiences for psychological well-being and family functioning.

METHODS

This study employed a qualitative research design grounded in Interpretative Phenomenological Analysis (IPA) to examine how parents made sense of stigma and social exclusion while raising children with neurodevelopmental disorders. IPA is theoretically rooted in phenomenology, hermeneutics, and idiography, and is particularly suited to exploring experiences that are emotionally nuanced and socially situated (1). The approach prioritizes depth of understanding over statistical generalizability and seeks to illuminate how individuals interpret and attribute meaning to significant life events within their sociocultural contexts. The study was conducted in major urban centers of Pakistan, including Lahore, Multan, and Islamabad, between [insert study period if applicable], following approval from an institutional ethics review committee. A purposive sampling strategy was used to recruit participants through special education institutions after obtaining formal administrative permission. Inclusion criteria comprised parents who were primary caregivers of a child formally diagnosed by a qualified clinician with Autism Spectrum Disorder, Attention-Deficit/Hyperactivity Disorder, or Intellectual Disability, and who had at least one year of caregiving experience following diagnosis to ensure sufficient exposure to social contexts relevant to stigma. Parents with severe psychiatric illness or those unable to participate in an in-depth interview were excluded to safeguard participant well-being and data quality.

The final sample consisted of ten parents (mothers or fathers) of ten children with diagnosed neurodevelopmental disorders. Consistent with IPA methodology, the sample size was intentionally small to allow for detailed idiographic examination of each case before identifying patterns across participants (1). Efforts were made to ensure variation in parental gender and child diagnosis; however, recruitment was contingent upon institutional access and voluntary participation. Data were collected through in-depth, semi-structured interviews lasting approximately 60 to 90 minutes. An interview guide was developed based on existing literature and expert consultation, covering domains such as perceptions of public attitudes, experiences within educational and healthcare settings, family responses, coping strategies, and perceived psychological impact. Interviews were conducted in a private and quiet setting within institutional premises or another mutually agreed location to maintain confidentiality. Participants selected their preferred language (Urdu, English, or a bilingual format) to facilitate expressive comfort. All interviews were audio-recorded with written informed consent and transcribed verbatim. Where interviews were conducted in Urdu, transcripts were translated into English using a forward-translation process, with bilingual review to preserve semantic and contextual fidelity.

Data analysis followed the systematic stages of IPA as described by Smith and colleagues (1). Each transcript was analyzed individually through repeated readings to ensure immersion in the data. Initial noting involved descriptive, linguistic, and conceptual comments, which were subsequently developed into emergent themes reflecting participants' meaning-making processes. Themes were then clustered to generate superordinate themes within each case before examining patterns of convergence and divergence across cases. Reflexive journaling was maintained throughout analysis to enhance transparency regarding the researcher's interpretative role and to support analytic rigor. Credibility was strengthened through peer debriefing and independent review of selected transcripts to ensure that thematic interpretations remained grounded in participants' accounts. An audit trail documenting analytic decisions was maintained to enhance dependability.

Ethical safeguards were rigorously upheld. Participants were informed of the study's purpose, voluntary nature, confidentiality measures, and their right to withdraw at any point without consequence. Given the sensitive nature of discussing stigma and exclusion, interviews were conducted with attentiveness to emotional cues, and participants were provided with information about available psychological support services if needed. All identifying information was removed from transcripts, and data were securely stored in password-protected files accessible only to the research team.

RESULTS

A total of 10 parents participated in the study, each representing one child formally diagnosed with a neurodevelopmental disorder. All participants were primary caregivers and had direct and sustained involvement in the child's educational, social, and healthcare-related interactions. Interviews ranged from 60 to 90 minutes in duration, allowing for in-depth exploration of lived experiences. The analytic process yielded three interrelated superordinate themes reflecting shared experiential patterns across cases while preserving idiographic nuance. These themes captured the psychosocial processes through which parents interpreted stigma and negotiated social exclusion.

The first superordinate theme, perceived parental blame and moral judgment, was evident in 9 out of 10 participants. Parents consistently described experiences of implicit or explicit blame directed toward them rather than toward the child's diagnosis. Judgments were conveyed through direct remarks (reported by 6 participants), unsolicited parenting advice (7 participants), and non-verbal cues such as prolonged staring or visible disapproval in public settings (8 participants). These encounters were most frequently reported in public environments, including markets, family gatherings, and educational settings. Participants interpreted such reactions as challenges to their competence and identity as caregivers. Emotional consequences included persistent self-doubt (reported by 6 participants), guilt (5 participants), and psychological fatigue (7 participants). Several participants described internal conflict between clinical understanding of the diagnosis and residual self-questioning, particularly during periods of behavioral dysregulation in public spaces.

The second theme, social withdrawal as both protection and loss, was identified in 8 participants. Subtle forms of exclusion, including reduced invitations to family or social events, were reported by 7 participants, while 6 described perceived distancing within extended family networks. Although overt discrimination was less commonly reported (3 participants), cumulative micro-level interactions contributed to anticipatory stress in social contexts. In response, 8 participants described deliberate reduction of social engagement to avoid repeated judgment. While withdrawal functioned as a protective coping mechanism, 6 participants simultaneously described feelings of isolation and diminished belonging. The dual nature of withdrawal—shielding from stigma while intensifying social loss—reflected a complex psychological negotiation. Notably, participants who reported higher frequencies of public scrutiny also described greater tendencies toward avoidance behaviors, suggesting an experiential link between stigma exposure and adaptive retreat.

The third theme, meaning reconstruction and emergent resilience, was present across all 10 participants, although its expression varied in depth and intensity. Seven participants described an early phase characterized by self-blame or internalized stigma, followed by gradual cognitive reframing. Over time, 8 participants reported attributing negative reactions to societal misunderstanding rather than personal failure. Advocacy behaviors, including educating others or selectively engaging supportive networks, were described by 6 participants as empowering strategies. Identity transformation was particularly evident among parents who articulated a shift from defensive positioning to assertive acceptance. Rather than denying stigma, participants described altering its psychological impact through reinterpretation and boundary-setting. Although stigma persisted across social contexts, its internalization appeared to decrease as parents reconstructed meaning and redefined parental competence on their own terms.

Collectively, the findings demonstrated that stigma operated not only as an external social process but also as an internal psychological negotiation shaped by repeated interactions. Social exclusion was experienced as both imposed and strategically enacted, with emotional consequences extending to identity, belongingness, and perceived parental efficacy. Importantly, resilience did not eliminate stigma; rather, it modified its interpretative and emotional impa

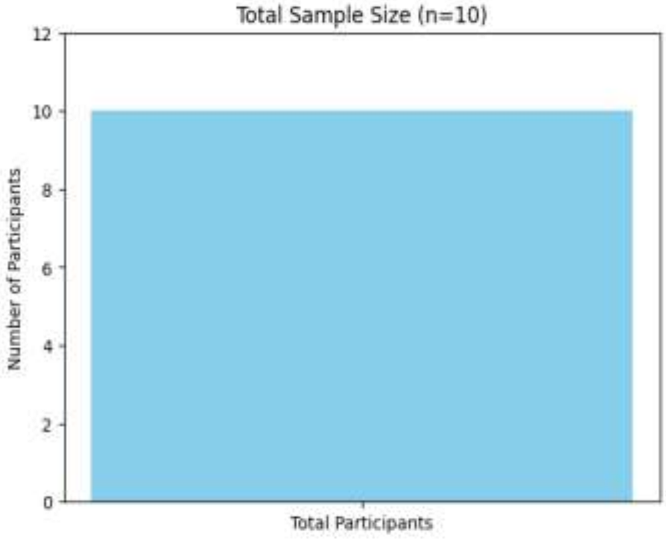


Figure 2 Total Sample Size Distribution

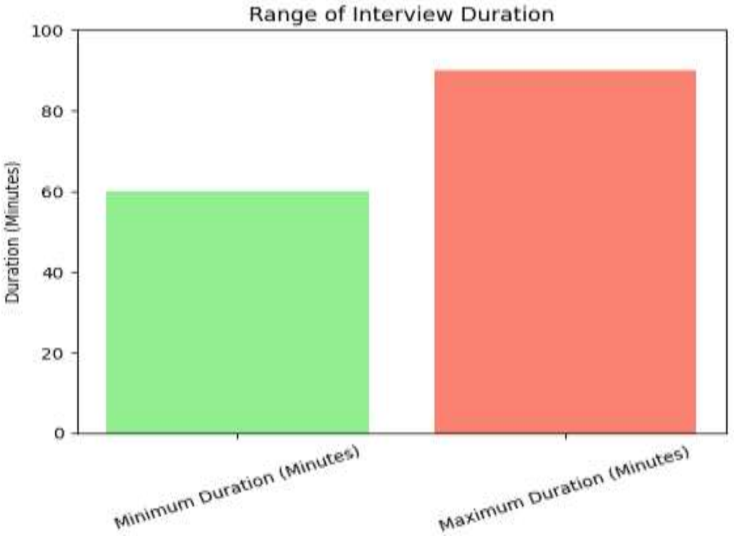


Figure 2 Range of Interview Duration

DISCUSSION

The present study examined how parents of children with neurodevelopmental disorders experienced and interpreted stigma and social exclusion within their sociocultural environments, and the findings offered a nuanced understanding of stigma as both a social and psychological process. Rather than operating solely as an external label imposed upon families, stigma was experienced as an evolving relational phenomenon that shaped parental identity, emotional regulation, and everyday decision-making. The results demonstrated that parents did not encounter blame and judgment as isolated events; instead, these experiences accumulated across public, familial, and institutional contexts, gradually influencing self-perception and caregiving confidence. This interpretation aligned with established conceptualizations of stigma as a process involving labeling, stereotyping, and status loss enacted through power-laden social interactions (12,13). Consistent with prior research on courtesy and affiliate stigma, parents described being implicitly held responsible for their child's diagnosis and behavior (14,15). However, the present findings extended this literature by illustrating how such judgments were actively interpreted, negotiated, and, in some cases, resisted. The threat to parental identity emerged as a central mechanism through which stigma exerted psychological impact, contributing to self-doubt and emotional fatigue while simultaneously prompting processes of reflection and reinterpretation. In this respect, the study underscored the dynamic interplay between social evaluation and internal meaning-making.

Social exclusion emerged as both an externally imposed condition and an internally enacted coping strategy, reflecting a complex relational adaptation to repeated stigmatizing encounters. In line with earlier scholarship documenting marginalization within educational and community settings (16,17), participants described subtle distancing behaviors, reduced invitations, and limited institutional inclusion. However, the findings also demonstrated that parents exercised agency by withdrawing from social spaces as a protective mechanism. This pattern echoed previous evidence linking stigma exposure to anticipatory avoidance and social retreat (18). The dual character of withdrawal—simultaneously protective and isolating—highlighted the emotional ambivalence embedded in coping strategies. While withdrawal reduced immediate exposure to scrutiny, it also diminished opportunities for social support, potentially reinforcing isolation over time. Importantly, the study situated these experiences within culturally embedded norms concerning parenting responsibility, family reputation, and public conduct. In collectivist and reputation-sensitive contexts, stigma appeared to reverberate beyond the parent–child dyad, influencing broader family identity and perceived social standing. By foregrounding these sociocultural dimensions, the study contributed to ongoing debates that caution against universalizing Western individualistic models of stigma and emphasize the need for culturally contextualized interpretations (19).

A notable contribution of this research was the identification of meaning reconstruction and emergent resilience as integral components of parental adaptation. Although stigma was consistently present, its psychological impact evolved over time as parents reframed external judgments as reflections of societal misunderstanding rather than personal inadequacy. This shift from internalized blame to critical reinterpretation reflected processes of cognitive and identity restructuring. Prior qualitative investigations have similarly suggested that families actively negotiate and resist stigmatizing narratives rather than passively absorbing them (20). The use of Interpretative Phenomenological Analysis facilitated detailed examination of these interpretative shifts, capturing subtle transitions in language, self-description, and perceived agency that might remain obscured within quantitative paradigms. The findings suggested that resilience did not signify the absence of stigma; rather, it involved recalibrating its meaning and limiting its intrusion into core parental identity. Advocacy, selective social engagement, and alignment with supportive networks functioned as mechanisms through which parents reclaimed agency. These insights underscored the importance of psychosocial interventions that address identity reconstruction and meaning-making alongside practical caregiving support (20).

From a clinical and public health perspective, the findings reinforced the necessity of family-centered and culturally responsive frameworks. Interventions aimed solely at increasing public awareness may be insufficient if institutional practices and professional attitudes continue to perpetuate subtle exclusion. Training for educators and healthcare professionals that emphasizes empathetic engagement, collaborative decision-making, and culturally informed communication may mitigate secondary stigma experienced by parents. Furthermore, structured peer-support platforms could provide safe environments for shared meaning-making and normalization of experiences. The study possessed several strengths, including methodological coherence with IPA principles, in-depth engagement with participants' narratives, and reflexive analytic procedures that enhanced credibility and transparency. The idiographic focus enabled rich contextual interpretation and preserved experiential complexity. Nevertheless, certain limitations warranted consideration. The small, urban-based sample constrained transferability to rural or socioeconomically diverse populations. Reliance on self-reported narratives introduced the possibility of recall bias and social desirability influences, although such subjectivity was intrinsic to phenomenological inquiry. The cross-sectional design precluded examination of longitudinal changes in stigma interpretation across developmental stages. Additionally, perspectives of children, siblings, and extended family members were not directly incorporated, limiting systemic analysis. Future research would benefit from longitudinal qualitative designs, multi-informant approaches, and integration of complementary quantitative measures to explore trajectories of stigma negotiation across time and contexts (21, 22).

CONCLUSION

This study sought to explore how parents of children with neurodevelopmental disorders experienced and made sense of stigma and social exclusion within their sociocultural environments, and the findings affirmed that these experiences were neither isolated nor superficial. Stigma emerged as a deeply relational and evolving process that extended beyond the child's diagnosis, gradually influencing parental identity, social engagement, and emotional well-being. Rather than depicting parents as passive recipients of negative societal attitudes, the analysis illuminated their ongoing efforts to interpret, negotiate, and at times resist stigmatizing narratives embedded in everyday interactions. Social withdrawal, identity reconstruction, and selective advocacy reflected adaptive responses shaped by context, culture, and lived experience. By situating these processes within broader social and institutional structures, the study reinforced the understanding of stigma as a family-level phenomenon requiring responses that move beyond awareness alone. Meaningful support must integrate culturally responsive, family-centered strategies while addressing systemic practices that perpetuate subtle exclusion. In doing so, the study fulfilled its objective by providing a nuanced account of how stigma and social exclusion were experienced, interpreted, and transformed within the realities of family life affected by neurodevelopmental disorders.

AUTHOR CONTRIBUTIONS

Author	**Contribution**
Shaista Irshad*	Substantial Contribution to study design, analysis, acquisition of Data Manuscript Writing Has given Final Approval of the version to be published
Saba Syed	Substantial Contribution to study design, acquisition and interpretation of Data Critical Review and Manuscript Writing Has given Final Approval of the version to be published
Sarah Mahmood	Substantial Contribution to acquisition and interpretation of Data Has given Final Approval of the version to be published
Laiba Shahzad	Contributed to Data Collection and Analysis Has given Final Approval of the version to be published
Tehreem Talat	Contributed to Data Collection and Analysis Has given Final Approval of the version to be published
Sabeen Sabir	Substantial Contribution to study design and Data Analysis Has given Final Approval of the version to be published

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