

Symbolic and Socioeconomic Responses of Families to Early Neonatal Indicators of Autism Spectrum Disorder: A Qualitative Study

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Cite this paper as: Putu Melaya, Juraid, M. Sabir, Nuraisyah, (2025). Symbolic and Socioeconomic Responses of Families to Early Neonatal Indicators of Autism Spectrum Disorder: A Qualitative Study. *Journal of Neonatal Surgery*, 14 (21s), 720-729.

ABSTRACT

The early identification of Autism Spectrum Disorder (ASD) remains a significant challenge, particularly in resource-limited settings where diagnostic infrastructure is lacking. This study explores how families interpret and respond to early signs of ASD observed during the neonatal period, explicitly focusing on symbolic interactions and socioeconomic factors. Using a qualitative approach grounded in symbolic interactionism, data were gathered through in-depth interviews with parents of children later diagnosed with ASD. Though subtle, the findings reveal that early behavioural cues often evoke emotional confusion, cultural interpretations, and varying parental denial or acceptance. Cultural norms, prior knowledge, and access to healthcare strongly influenced the symbolic meanings attributed to neonatal behaviours. Simultaneously, the financial strain from seeking consultations, therapies, and specialised care often heightened psychological stress within the household. The study highlights a crucial gap in early awareness and intervention pathways for ASD, especially in low- and middle-income countries. It calls for improved neonatal screening methods, culturally sensitive counselling, and socioeconomically inclusive support systems. Understanding how families symbolically construct and economically navigate their experiences with early ASD indicators can inform more holistic and empathetic neonatal care models.

Keyword: Autism Spectrum Disorder, Symbolic Interaction, Neonatal Signs, Socioeconomic Impact, Family Response, Qualitative Study

1. INTRODUCTION

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental condition marked by persistent challenges in social communication, coupled with the presence of restricted and repetitive behaviours (Hughes et al., 2023; Matta et al., 2019; Nilsson Jobs et al., 2019; Thom et al., 2021). Although a conclusive diagnosis typically occurs post the first year of life, emerging research suggests preliminary signs of ASD may be detectable during the neonatal phase (Q. Wei et al., 2024; Zhou et al., 2025). These initial indicators, such as diminished eye contact, atypical muscle tone, or irregular responsiveness, are nuanced and frequently disregarded, especially in settings with insufficient diagnostic awareness or resources (Colombi et al., 2023; Fish et al., 2021; Rudling et al., 2024).

In resource-constrained countries, early identification and intervention for ASD are hindered by a variety of systemic and socio-cultural factors. The absence of standardised neonatal screening tools, inadequate training among healthcare professionals, and prevailing social stigmas contribute to delays in diagnosis (Duggal et al., 2020; Roman-Urrestarazu et al., 2021). Consequently, families often find themselves navigating the ambiguous behavioural cues of their newborns without clear guidance, resulting in missed opportunities for early support and intervention (Divan et al., 2021; Hoekstra, 2022; Naithani et al., 2022).

Beyond the clinical perspective, families play a crucial role in interpreting and responding to early behavioural deviations in their children. Their responses are not merely reactive but are influenced by underlying symbolic frameworks, including cultural beliefs, religious interpretations, and family dynamics (Hughes et al., 2023; Nilsson Jobs et al., 2019). In many instances, unusual neonatal behaviour is viewed not as a medical issue but as a spiritual or behavioural anomaly, affecting subsequent health-seeking decisions.

Symbolic interactionism offers a valuable theoretical framework for examining these familial interpretations. According to

meaning around early signs and how these meanings mould their emotional and behavioural responses (Herrero et al., 2024; Marsack-Topolewski & Wang, 2022; Zhao et al., 2024).

Equally important are the socioeconomic challenges faced by families dealing with suspected ASD in neonates. The economic burden begins with the costs of diagnosis and therapy and indirect expenses such as parental work absences, social isolation, and long-term caregiving demands (Bozkurt et al., 2019; Rizzo et al., 2024). For families with limited financial resources, these burdens may significantly restrict access to care and heighten emotional stress.

Research indicates that families in low- and middle-income countries encounter compounded difficulties in recognising and responding to ASD. These challenges arise from both material limitations and the symbolic meanings associated with the disorder. Despite increasing global awareness of ASD, localised research that integrates both symbolic and socioeconomic perspectives in neonatal contexts remains scarce, particularly in the Global South.

This study addresses a critical research gap by exploring how families construct symbolic meaning and respond socioeconomically to early signs of ASD during the neonatal period. By centring the voices of parents and caregivers, this research aims to enhance understanding of the lived experiences that influence early decision-making processes and health-seeking behaviours (Dückert et al., 2023; Marsack-Topolewski & Church, 2019; Patel et al., 2022).

A qualitative approach rooted in symbolic interactionism is particularly adept at capturing the nuances of familial experiences. Through in-depth interviews and narrative analysis, this study investigates how cultural scripts, economic pressures, and personal beliefs intersect in shaping responses to early ASD indicators.

Ultimately, understanding these symbolic and socioeconomic dimensions can inform more culturally sensitive and economically accessible models of early ASD care. The findings have implications for health policy, clinical practice, and family counselling, especially in developing countries where formal support systems are still evolving

2. RESEARCH METHODS

This study employed a qualitative research design grounded in symbolic interactionism to explore how families interpret and respond to early neonatal signs of Autism Spectrum Disorder (ASD). A qualitative approach was deemed appropriate for capturing the depth of subjective experiences, symbolic constructions, and socio-cultural nuances associated with early behavioural cues in neonates. The interpretive framework was particularly suited to understanding how meaning is socially constructed and negotiated within the familial context (Jenabi et al., 2020; Mordaunt et al., 2020).

Data were collected through in-depth, semi-structured interviews with twelve families whose children had received a clinical diagnosis of ASD between the ages of 2 and 5. These families were purposively selected from three pediatric clinics and two community health centres in urban and semi-urban regions of Indonesia. Participants were chosen to reflect diverse socioeconomic backgrounds, educational levels, and access to healthcare services. Interviews lasted between 45 and 90 minutes and were conducted in the participants' native language, then transcribed and translated into English for analysis (Thiemann-Bourque et al., 2019; Wainwright et al., 2020).

The interview guide was designed to elicit detailed narratives regarding the first observations of atypical neonatal behaviours, symbolic meanings, and emotional and financial responses. Questions were open-ended and flexible, allowing participants to elaborate on their experiences and perceptions. Field notes were taken to capture non-verbal cues and contextual details, enriching the data and ensuring a holistic interpretation of the narratives (Cordero et al., 2020; Gardner et al., 2021).

Data analysis followed a thematic approach using Braun and Clarke's six-phase framework. Transcripts were coded manually, and themes were developed inductively to remain grounded in the participants' experiences. Special attention was paid to the interplay between symbolic interpretations and socioeconomic realities, allowing for the emergence of patterns across cultural and class-based dimensions (Bahasoan et al., 2019; Golson et al., 2022). Member checking was conducted with selected participants to enhance trustworthiness, and peer debriefing was conducted among the research team.

The institutional ethics committee approved the study. All participants provided informed consent and maintained confidentiality throughout the research. To protect participant identity, pseudonyms were used in all transcripts and reports. The study adhered to the ethical principles of respect, beneficence, and justice outlined in the Declaration of Helsinki (Appiah, 2021; Modi, 2021; Øye et al., 2019).

3. RESULTS AND DISCUSSION

Constructing Meaning: How Families Interpret Neonatal Atypicalities

Parents' initial observations of atypical behaviours in neonates often fall into a complex terrain of meaning-making, where medical neutrality is replaced by culturally and emotionally charged interpretations (Crespi et al., 2019; Kikuchi et al., 2022). In this study, parents identified early signs such as reduced eye contact, abnormal muscle tone, prolonged sleepiness, or an

unusual lack of social responsiveness. However, these signs were rarely recognised as indicators of a neurodevelopmental condition. Rather than prompting clinical concern, such behaviours were often interpreted within a symbolic framework emphasising individuality, spiritual uniqueness, or temperamental differences.

This finding resonates with the core proposition of symbolic interactionism: individuals act not based on objective realities, but based on the meanings they ascribe to their experiences. In the context of neonatal care, parents do not simply observe behaviours; they interpret them through filters of prior knowledge, cultural norms, religious teachings, and intergenerational wisdom. For instance, a baby who rarely cries might be perceived as "an easy child" or "a peaceful soul," rather than a child showing early symptoms of under-responsiveness. Once socially validated within the family or community, these meanings become internalised truths that shape health-seeking behaviour (Silva & Fiske, 2021; Thorsson et al., 2024).

The complexity intensifies in households where extended family members play a dominant role. In such environments, the symbolic meanings attached to behaviour are not individually constructed, but co-created and negotiated across generations. A grandmother may interpret the child's behaviour through the lens of past experiences, religious narratives, or local folklore. Her interpretation may sway more than a young mother's intuition, especially in patriarchal or collectivist settings. This intergenerational negotiation of meaning further delays clinical recognition of ASD.

Furthermore, societal scripts about normal child development heavily influence what is noticed and what is dismissed. Many participants in this study viewed early signs not as warning signals but as transient behaviours. This interpretive inertia, fueled by the absence of clear, culturally embedded education on ASD, creates a gap between symptom onset and diagnostic pursuit. Even when parents begin to doubt, the lack of medical vocabulary or behavioural benchmarks for neonates often prevents them from articulating their concerns during clinical encounters.

The consequence is a delay in diagnosis that begins not in the clinic, but in the living room—in the daily conversations, comparisons, and collective understandings that frame infant behaviour. These symbolic interpretations are not merely benign misunderstandings but decisive forces in the family's interaction with healthcare systems. As such, any attempt to improve early ASD detection must go beyond training pediatricians; it must engage with the symbolic world where behaviours are interpreted and decisions are made (Garvey et al., 2024; Hills et al., 2019; Hirsch et al., 2022).

This study adds depth to existing understandings of delayed diagnosis in autism by illuminating how meanings are constructed and maintained. It also challenges the universality of developmental milestones, highlighting the need for culturally contextualised health messaging. In a world where knowledge does not circulate equally, the meanings people construct are often more potent than the symptoms they see.

Navigating Emotion: The Psychological Landscape of Parental Response

Beneath the surface of symbolic interpretation lies an emotional terrain shaped by uncertainty, fear, denial, and, eventually, adaptation. Parents in this study described a layered emotional experience that began with confusion and evolved into self-doubt, distress, and profound psychological exhaustion (Marshall et al., 2024; Szőcs et al., 2022). What begins as a slight worry in the first month of life can metastasise into enduring anxiety by the time developmental gaps become more obvious.

A conflict between intuition and validation is at the heart of this emotional response. Several mothers described a "gut feeling" that something was not typical. Still, when this intuition was countered by dismissive comments from relatives or even healthcare workers, they began to doubt themselves. This emotional dissonance, trusting one's instincts but lacking social affirmation, created internalised guilt and emotional isolation. For fathers, societal expectations of emotional stoicism further silenced their anxieties, leading to a division of labour where mothers largely carried the emotional burden.

The symbolic lens through which neonatal behaviour is viewed also extends to emotional management. In many cultural contexts, emotional restraint is valorised, and showing distress over an infant's behaviour may be seen as overreacting or even attracting bad luck. This social expectation forces parents, especially mothers, to suppress legitimate concerns, often until they become overwhelming. As a result, early stress is not externalised through help-seeking but internalised as self-blame or helplessness (Dijkstra-de Neijs et al., 2024; Kwok & Kwok, 2020).

The emotional toll is compounded by anticipatory grief, the mourning of the "ideal child" parents had envisioned. Even before a formal diagnosis, parents begin a silent process of letting go of expectations, milestones, and dreams. This ambiguous loss, unrecognised and unsupported by many systems, is psychologically devastating. Parents in this study frequently used metaphors such as "walking in fog" or "carrying a silent burden" to describe their emotional state during this phase (Alostaz et al., 2022; Fernández-Ávalos et al., 2021).

Moreover, the emotional response is socially patterned. The absence of peer support groups or culturally safe spaces to share experiences means that emotional suffering remains private and, therefore, medically invisible. This invisibility reinforces a feedback loop, because emotional distress is not seen, it is not addressed, and because it is not addressed, it intensifies (Alimohamadi et al., 2024; Rasmussen et al., 2020; Wang et al., 2024).

In this regard, the emotional journey is not merely personal; it is a consequence of social silence, symbolic denial, and

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institutional neglect. Any early intervention model that fails to acknowledge families' emotional and symbolic lives risks being ineffective, no matter how clinically sound.

The study urges the integration of psychological first aid and culturally attuned counselling in neonatal care for families at risk of or exposed to early signs of ASD. Emotional guidance should not be a post-diagnostic privilege but a parallel support process that begins with the first hint of parental concern.

In essence, the psychological journey of parents is a hidden narrative of early ASD, a narrative filled with invisible wounds, unheard fears, and unmet emotional needs.

Economic Disruption and Household Trade-offs in the Shadow of Uncertainty

The emergence of atypical behaviours in a neonate does not merely evoke emotional reactions; it activates an economic recalibration within the household, often before a formal diagnosis is even pursued. Financial resources are not simply stretched for families in low- and middle-income contexts; they are re-prioritised in ways that have long-term implications for the household economy. In this study, parents described a range of economic disruptions that began with the first medical consultations and expanded with each uncertainty about their child's development (Liu et al., 2022; Marsack-Topolewski & Wang, 2022).

Several families reported that early concerns prompted multiple, and often redundant, visits to general practitioners or pediatricians, each incurring consultation fees, transport costs, and time away from work. The uncertainty of the symptoms lacking a clear diagnostic endpoint meant that financial expenditures were spread across various health avenues without yielding definitive answers. This fragmented healthcare-seeking behaviour produced economic fatigue, wherein families eventually chose to wait for "clearer signs," not for lack of concern, but due to resource exhaustion.

The economic burden was not confined to direct medical costs. Lost income due to caregiving responsibilities, particularly affecting mothers who had to reduce or quit employment, was a consistent theme. Reduced household income created tension within families, particularly when the symptoms were still considered "uncertain." In these cases, financial trade-offs were weighed against ambiguous benefits, often delaying further action (Marsack-Topolewski et al., 2025; Zhao et al., 2023).

Symbolically, economic investment in health is guided by perceived value. Spending money on a child who is visibly ill or injured aligns with cultural logic; investing in behavioural differences that are neither visible nor universally acknowledged often lacks symbolic legitimacy. Thus, families questioned the rationality of investing in interventions when symptoms did not match their internalised notions of medical urgency.

The informal economy also came into play. Some participants described borrowing from relatives, selling personal assets, or relying on community-based lending groups to fund their healthcare journeys. While demonstrating resilience, these actions also reveal the extent to which families bore the burden of systemic gaps in early childhood health support. These informal strategies were often unsustainable and led to longer-term financial vulnerability.

This financial stress, in turn, influenced emotional and social dynamics. Marital conflicts, intergenerational tensions, and internalised guilt emerged as secondary consequences of economic strain. The inability to afford follow-up consultations or specialised services bred feelings of inadequacy among parents, particularly fathers who are culturally expected to be financial providers.

Moreover, socioeconomic status affected access not only to services but also to information. Higher-income families reported faster access to developmental pediatricians and early therapy services, while lower-income families described being stuck in cycles of uncertainty and informal advice-seeking. This disparity underscores how economic capital translates into knowledge and care quality (Schofield et al., 2019; Zhao et al., 2024).

The findings signal a pressing need for state-sponsored early intervention subsidies, targeted financial support for at-risk families, and the integration of ASD screening into universal neonatal health services. Early diagnosis remains a privilege rather than a standard without economic scaffolding, and the neonatal window of opportunity is lost to financial gatekeeping.

Culture, Community, and the Duality of Symbolic Support and Stigma

Community structures, often celebrated as sources of resilience, emerged in this study as both enablers and inhibitors of early ASD response. Parents repeatedly emphasised the ambivalence of social reactions, while some community members provided emotional support, others reinforced stigma, silencing, or misinformation (Botha et al., 2022; Fisher et al., 2023). This duality reveals how community environments act as symbolic arenas where the meaning of early behaviour is contested and solidified.

In many cases, cultural scripts emphasised patience and silence. Phrases such as "he's just slow" or "some children take longer" were repeated by neighbours and elders, reflecting a shared social framework that normalises developmental variability (Clarke et al., 2024; Salleh et al., 2020). While comforting on the surface, such messages often invalidated maternal concerns and contributed to diagnostic delay.

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Symbolic interpretations rooted in spirituality also emerged prominently. A quiet baby was sometimes viewed as "a child of special blessings," while atypical movements were explained as "manifestations of inherited wisdom" or "divine markers." These interpretations, though well-intentioned, acted as buffers against medical reasoning and created a layer of sacredness that seemed to intervene irreverently (Ashrafun et al., 2024; Y. Wei et al., 2025).

Religious institutions played varied roles. Some faith leaders encouraged acceptance and provided counselling, reinforcing parental strength. Others attributed behavioural deviations to spiritual transgressions or ancestral debts, prompting parents to seek ritual solutions rather than clinical ones. The result was a misalignment between community-driven responses and medically advised pathways (Chu et al., 2020; Liao et al., 2019).

This symbolic divergence became more pronounced when parents attempted to speak publicly about their concerns. Mothers who voiced distress were sometimes accused of being ungrateful or paranoid. In patriarchal communities, their authority in interpreting neonatal behaviour was undermined by male relatives or elders, reinforcing a gendered dimension of symbolic power.

However, not all community engagement was negative. Some parents described finding solidarity in informal parenting groups or among others with similar experiences. These "micro-communities of empathy" became safe spaces for information sharing, emotional validation, and eventual mobilisation toward seeking professional help.

The coexistence of stigma and support underscores the complexity of community-based symbolic systems. Culture does not merely determine meaning; it distributes symbolic legitimacy, decides who may speak, and defines which behaviours warrant action. For parents navigating these systems, the path to early ASD care is not linear; it is negotiated, relational, and often fraught with contradiction (Gulsrud et al., 2019; van 't Hof et al., 2020).

Public health strategies must therefore move beyond biomedical messaging and invest in community-based symbolic reform. Engaging local leaders, faith institutions, and traditional healers in ASD awareness initiatives can help align symbolic meanings with developmental science, creating a foundation for timely and culturally accepted care.

Toward an Inclusive Policy Framework: Rethinking Neonatal ASD Pathways

The findings of this study have far-reaching policy implications, particularly in early childhood development, public health communication, and social welfare. The absence of clear pathways for early ASD screening during the neonatal period reflects a critical oversight in pediatric health infrastructure, especially in developing contexts (Pierce et al., 2021; Roberts et al., 2020; Williams et al., 2021).

First, neonatal care policies must acknowledge that early signs of ASD, though subtle and not yet diagnosable, are symbolically and emotionally potent for families. Integrating observational developmental checklists into routine neonatal assessments allows healthcare systems to prompt earlier reflection and conversation between parents and clinicians, even without definitive criteria (Khozaei et al., 2020; Zhang et al., 2022).

Second, health communication must be redesigned to accommodate linguistic clarity and symbolic resonance. Messages about early ASD must not only inform but also reframe prevailing beliefs about child development, spirituality, and caregiving. Public awareness campaigns should be multilingual, culturally contextualised, and grounded in narratives that local communities can identify with and trust (Layden et al., 2024; Murray & Barton, 2021; Siller et al., 2021).

Third, screening programs must address economic and logistical access barriers. Even free programs can be inaccessible for families already stretched thin if travel, time, and social stigma are not mitigated. Mobile screening units, teleconsultations, and integration of developmental checks into vaccination schedules can increase reach and uptake (Chiri et al., 2022; D'Agostino & Douglas, 2021).

Fourth, training programs for healthcare professionals must move beyond diagnostic expertise and include cultural competency. Physicians, nurses, and midwives should be equipped to recognise symptoms and the symbolic and emotional worlds that parents inhabit. Counselling skills, empathic listening, and respectful meaning negotiation should be core training components (Langlois et al., 2020; Wieckowski et al., 2021).

Fifth, policy frameworks should incorporate family support systems as essential components of care. Subsidies for therapy are not enough; families need emotional counselling, parental education, and peer-support networks that begin during the neonatal phase, not after a diagnosis has been stamped.

Finally, national and international collaborations should invest in longitudinal research that tracks early ASD trajectories from neonatal observations to diagnosis and intervention outcomes. Such data can inform context-specific, clinically effective, and culturally embedded models of care (Dounavi & Koldas, 2025; Horiuchi et al., 2023).

By centring families' lived experiences and acknowledging the symbolic and socioeconomic dimensions of early ASD detection, policymakers can move from reactive to proactive models of care. In doing so, they will improve diagnostic timing and restore a sense of agency and dignity to the families navigating this complex journey.

4. CONCLUSION AND IMPLICATIONS

This study has illuminated the complex interplay of symbolic interpretation, emotional processing, cultural context, and socioeconomic realities that shape how families respond to early neonatal indicators of Autism Spectrum Disorder (ASD). Rather than being isolated medical events, early behavioural signs in neonates are embedded in a rich matrix of meaning-making, where parental intuition, cultural narratives, and community discourses converge to influence perceptions and actions. The study reinforces that early intervention does not begin in the clinic but in the social spaces where behaviour is interpreted and caregiving decisions are made.

The findings demonstrate that symbolic interpretations often delay clinical engagement, not out of negligence, but because of deeply rooted belief systems and a lack of culturally aligned knowledge dissemination. Emotional responses, particularly maternal anxiety and paternal restraint, are shaped by these interpretations and compounded by the lack of institutional emotional support. Meanwhile, direct, indirect, and opportunity-related economic barriers amplify the difficulty of accessing early diagnostic services, particularly for families in low-income and rural settings. These interconnected dimensions form a barrier system that inhibits early detection and comprehensive support.

Cultural and community environments serve both as scaffolds and barriers to early ASD care. In settings where behavioural anomalies are interpreted through religious or moral lenses, medical narratives often lose their potency. Yet within these same communities, parents find support, solidarity, and guidance. This duality necessitates nuanced public health strategies that engage, not confront, local knowledge systems. Medical practitioners and policymakers must recognise the symbolic and social dimensions of early ASD responses and incorporate them into the design of communication and care delivery systems.

From a policy standpoint, the study calls for a radical rethinking of neonatal ASD screening and family support frameworks. Interventions must combine clinical vigilance with cultural sensitivity, economic accessibility, and psychological support. Public health initiatives must invest in symbolic reform alongside service expansion, creating awareness campaigns that inform and transform how communities understand and respond to early developmental diversity. Without such integration, even the most advanced screening tools may remain underutilised, misunderstood, or mistrusted.

Improving early ASD detection and care requires more than advancing diagnostic tools or expanding clinical networks. It demands that we listen to families, not just their behaviour reports, but the meanings, emotions, and trade-offs underlying those reports. By doing so, we can co-create care systems that are clinically effective, socially legitimate, culturally resonant, and emotionally humane. This transformation is possible and necessary for equitable and inclusive child development policies, particularly in the global south.

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