

# Cultural Beliefs and their Influence on Autism Spectrum Disorder Awareness in Kisii County

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## ABSTRACT

**Purpose:** This study examines how local cultural beliefs in Kisii County, Kenya, shape awareness, understanding, and help-seeking behaviors regarding Autism Spectrum Disorder (ASD). Given limited research in rural Kenyan settings, I aim to explore both traditional narratives and biomedical perspectives, and how they influence recognition and diagnosis of ASD.

**Methods:** I conducted a qualitative study using semi-structured interviews and focus group discussions among caregivers of children with ASD, community leaders, traditional healers, and health professionals in Kisii County. Using purposive sampling, I recruited 35 participants. Transcripts were analyzed via thematic analysis.

**Results:** Three major themes emerged: (1) supernatural attributions (e.g., curses, witchcraft, ancestral spirits) as causes of ASD; (2) stigma and social exclusion arising from these beliefs; (3) pluralistic treatment pathways, including traditional healers, prayer, and limited engagement with biomedical services. A lack of formal ASD knowledge, coupled with cultural interpretations, contributed to delays in diagnosis and under-utilization of available health services.

**Conclusion:** Cultural beliefs in Kisii County significantly affect ASD awareness, contributing to stigma and barriers to early diagnosis. To improve ASD recognition and care, culturally sensitive education and community engagement strategies are needed, involving both biomedical practitioners and traditional/spiritual leaders.

**Keywords:** Autism Spectrum Disorder, cultural beliefs, Kenya, Kisii County, traditional healing, awareness

## INTRODUCTION

### Overview of Autism Spectrum Disorder (ASD)

Autism Spectrum Disorder (ASD) is a neuro-developmental disorder characterized by persistent deficits in social communication and interaction, alongside restricted, repetitive patterns of behavior, interests, or activities, American Psychiatric Association (2022). The spectrum includes a wide range of presentations, from individuals with significant intellectual and language impairment ("classic autism") to those with higher functioning (e.g., formerly Asperger's syndrome) and those with broader autistic traits.

Historically, ASD was divided into sub-types—autistic disorder, Asperger's disorder, and pervasive developmental disorder-not otherwise specified (PDD-NOS). With American Psychiatric Association (2022), these are subsumed under a single diagnosis of ASD, but clinically and in the community, these differences persist: lower-functioning versus higher-functioning autism, nonverbal versus verbal, presence or absence of intellectual disability, and differing sensory or cognitive profiles.

### Cultural Beliefs and ASD in the Global Context

Growing evidence shows that cultural context profoundly shapes how societies interpret, respond to, and manage ASD. In high-income, western settings, ASD is more likely to be understood through a biomedical lens; diagnostic services, early intervention, and support structures are more available. In contrast, in many low- and

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middle-income countries (LMICs), awareness is limited, and alternative explanatory frameworks prevail (Greer, Sood & Metcalfe, 2022).

In some African settings, studies have documented belief in supernatural causes (witchcraft, curses, evil spirits) for ASD and other developmental disabilities (Gona et al., 2015). In Kenya, in particular, caregivers and professionals have expressed such preternatural explanations as well as biomedical ones (e.g., genetic factors, perinatal complications) side by side.

### **ASD in Kenya: Awareness, Stigma, and Diagnostic Barriers**

Despite increasing recognition, ASD remains poorly understood in many parts of Kenya. A study of pre-primary school teachers in western Kenya showed that 41.5% had never heard of autism; among those who had, some perceived it as spiritual affliction/demon possession (Saida, M., Ayodo, G., AmimoF., Itotia, S., Obinju, C. & Romuald, J. S., 2023).

Caregivers also report significant emotional and social burden. A qualitative study of Kenyan caregivers revealed that initial acceptance of diagnosis is often difficult, and cultural beliefs (e.g., ancestral punishment, supernatural causes) strongly influence how families make sense of ASD, (Cloete & Obaigwa 2019).

Furthermore, recent research highlights that cultural and socioeconomic factors contribute to delays in ASD diagnosis in Kenya. For example, a study in Kenyan tertiary hospitals found that caregivers who attribute symptoms to spiritual or cultural causes are more likely to use traditional/spiritual pathways, and that such pathways are associated with later diagnosis, (Muthiga et al. 2025)

### **The Case for Studying Kisii County**

While coastal Kenya (e.g., Mombasa, Kilifi) has been the site of some ASD cultural-belief research (Gona et al., 2015; Greer et al., 2022), there is little literature on inland, rural counties such as Kisii. Kisii County is home to predominantly Gusii (Abagusii) people, with distinct cultural practices, norms, and belief systems that may influence ASD awareness differently than along the coast. Understanding these local beliefs is vital for tailored awareness campaigns, reducing stigma, and improving care pathways in this context.

### **Current Study**

This study addresses the gap in literature by exploring the cultural beliefs surrounding ASD in Kisii County, Kenya, and assessing how these beliefs influence awareness, stigma, and help-seeking. Specifically, we seek to answer the following questions:

1. What cultural explanations (causal models) do caregivers and community members in Kisii County hold about ASD?
2. How do these beliefs affect the recognition of symptoms and timing of diagnosis?
3. What treatment pathways (traditional, spiritual, biomedical) are used, and how are decisions made?
4. What are the barriers to ASD awareness, and how might they be addressed within the local cultural context?

## **METHODS**

### **Study Design**

The study employed a qualitative phenomenological design to explore lived experiences, beliefs, and attitudes of community stakeholders in Kisii County. Phenomenology allows in-depth understanding of how individuals make sense of ASD within their cultural framework.

## Participants

Participants were purposively sampled to include a variety of voices:

**Caregivers** of children with ASD (n = 15), including mothers, fathers, and extended family.

**Community leaders/traditional healers** (n = 10), such as elders, herbalists, and spiritual leaders.

**Health professionals** (n = 10), including pediatric clinicians, nurses, and special-education teachers.

In total, 35 participants took part.

## Setting

Kisii County is located in southwestern Kenya, predominantly inhabited by the Gusii ethnic group, who maintain rich traditional beliefs, including ancestral veneration and spiritual causality. Healthcare services include county hospitals, health centers, and clinics, but specialized ASD services are limited.

## Procedures

### Ethical approvals

I obtained ethical clearance from the Research and Innovation Board, Kisii University and informed consent from all participants. For caregivers, I secured consent for both interview and audio recording.

### Data collection

Semi-structured interviews (one-on-one) with caregivers and healers. Questions covered beliefs about causes of ASD, first symptom recognition, reactions to diagnosis, stigma, and help-seeking paths.

Focus Group Discussions (FGDs) with community leaders (2 FGDs of 5 each) to explore shared cultural narratives and collective attitudes.

Key Informant Interviews (KII) with health professionals.

**Translation:** Interviews were conducted in Kisii dialect or Kiswahili, depending on participants' preference. Audio recordings were translated and transcribed into English.

**Quality control:** Member checking was done by presenting preliminary themes to a subset of participants (caregivers and leaders) for validation.

## Data Analysis

I used **thematic analysis**, following Braun & Clarke's six-phase framework:

**Familiarization** – reading and re-reading transcripts.

**Generating initial codes** – coding segments related to beliefs, experiences, and help-seeking.

**Searching for themes** – clustering codes into potential themes.

**Reviewing themes** – refining themes using the data-sets and member-checking feedback.

**Defining and naming themes** – creating thematic definitions and detailed descriptions.

**Writing up** – integrating quotations, analysis, and interpretation in a coherent narrative.

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I used NVivo to manage codes, ensure rigor, and track analytic decisions. To enhance trustworthiness, I employed investigator triangulation: two researchers coded independently, then reconciled differences.

## RESULTS

Analysis of the interviews and discussions yielded three overarching themes: (1) supernatural causal attributions; (2) stigma and social exclusion; and (3) pluralistic help-seeking and barriers to biomedical engagement.

### 1. Supernatural Causal Attributions

Many participants described ASD as being caused by forces beyond the physical realm. Sub-themes included:

**Curses and ancestral punishment:** Several caregivers believed their child's autism was a result of ancestral displeasure or a curse from a past wrong. One mother said, "It's like my grandparents are not happy with something in our family—so this came as a punishment."

**Witchcraft / evil spirits:** Traditional healers noted that some community members think autistic behaviors arise from bewitchment. One elder commented, "People think these children are 'possessed' or that someone did a charm against the family."

**Spiritual / religious interpretations:** Spiritual leaders reported that families often interpret autism in religious frameworks. A pastor explained, "They think it's a demon, so they bring the child to prayer, holy water, or deliverance sessions."

These supernatural narratives strongly shape how caregivers interpret early symptoms (e.g., delayed speech, repetitive behavior), often delaying biomedical interpretation.

### 2. Stigma and Social Exclusion

These beliefs contribute to deep stigma:

**Blame on the mother or family:** Some caregivers reported being blamed for the child's condition. In one FGD, an elder said, "People say the mother sinned, or married from a wrong clan; that's why the child is like this."

**Secrecy and shame:** Several families avoid disclosing the diagnosis to their wider social network due to fear of social judgment or exclusion. A father noted, "We don't tell our neighbors because they think it's something evil, so we keep quiet."

**Isolation of the child:** Children with ASD are often excluded from community gatherings, school, and family events, perceived as "different" or "not in control."

### 3. Pluralistic Help-Seeking and Barriers to Biomedical Engagement

Caregivers navigate multiple pathways:

**Traditional healers and spiritual care:** Many rely first on traditional healers or spiritual leaders, seeking cures through herbal remedies, prayers, or rituals. A mother explained, "We tried the herbalist to cleanse the spirit, then the church, then hospital."

**Biomedical services underused:** Although some caregivers eventually seek medical help, there is often a long delay. Health professionals reported late presentation: "By the time they come, they have tried many other things, so it's hard to explain diagnosis."

**Barriers to access:** Reasons for delayed or limited biomedical engagement included: cost of transport, lack of ASD-specific services locally, limited awareness among health workers, and fear of diagnosis.

## DISCUSSION

### Interpretation of Findings

This study reveals that cultural beliefs deeply influence how ASD is understood, experienced, and acted upon. The prevalence of supernatural causal models parallels findings from other regions of Kenya (e.g., coastal studies). In coastal Kenya, Greer Sood, & Metcalfe (2022) identified themes of stigma, lack of awareness, and government responsibility among Swahili communities. Similarly, Gona et al. (2015) found that parents and professionals attributed ASD to evil spirits, curses, or witchcraft.

The pluralistic help-seeking patterns we observed are consistent with prior work, showing that caregivers often use both traditional and biomedical systems. However, in Kisii County, delays in diagnosis due to cultural attributions may be exacerbated by limited local ASD-related resources.

### Implications for Awareness and Intervention

Given the strong role of supernatural beliefs, any awareness campaign or intervention must be culturally sensitive. Key recommendations include:

**Community engagement:** Partner with traditional healers, elders, and spiritual leaders to disseminate accurate information about ASD. These trusted figures can help reframe beliefs without dismissing cultural systems.

**Culturally adapted psychoeducation:** Develop education materials in EkeGisii and Kiswahili languages, using local metaphors, stories, or proverbs that resonate with community beliefs.

**Training for health workers:** Equip local clinicians, speech and language pathologists, nurses, and teachers with training to recognize ASD, communicate diagnosis in culturally sensitive ways, and support families who may feel blamed or ashamed.

**Policy and service development:** Advocate for county-level ASD services, including screening, early intervention, and affordable transport, to reduce reliance on distant clinics.

### Comparison to Other Kenyan Contexts

Our findings align with and expand on previous studies. For example, recent research in Nairobi tertiary hospitals documented that spiritual/traditional pathways contribute to a three-year delay in ASD diagnosis (Muthiga, et al. 2025) This underscores that cultural barriers are not limited to rural or coastal regions but pervade across Kenya's diverse settings.

Additionally, the low awareness among pre-primary teachers in western Kenya (where many had never heard of autism), Saida, M., Ayodo, G., AmimoF., Itotia, S., Obinju, C. & Romuald, J. S., (2023) suggest that educational systems may not be adequately prepared to support early recognition, a challenge likely mirrored in Kisii.

## LIMITATIONS

**Sample size and generalizability:** Our sample ( $n = 35$ ) is relatively small and context-specific; results may not generalize to other Kenyan counties or ethnic groups.

**Self-reporting bias:** Participants may under-report or over-report beliefs due to social desirability.

**Resource constraints:** Lack of comprehensive ASD services limited ability to follow up on how help-seeking translated into long-term outcomes.

## CONCLUSION

Cultural beliefs in Kisii County significantly shape awareness, understanding, and response to Autism Spectrum Disorder. Supernatural attributions, stigma, and mixed help-seeking behaviors delay diagnosis and limit optimal care. Addressing these challenges requires culturally tailored strategies—engaging traditional and spiritual leaders, training health workers, and building local ASD services—to foster greater acceptance, early detection, and support. Policymakers and stakeholders must recognize culture not merely as a barrier, but as a partner in promoting neurodevelopmental health.

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