
COPING MECHANISMS AND SUPPORT SYSTEMS FOR INTERSEX CHILDREN AND FAMILIES IN GHANA

***Jemima N. A. A. Lomotey**

Grace International Bible University.

Article Received: 31 January 2026

*Corresponding Author: Jemima N. A. A. Lomotey

Article Revised: 20 February 2026

Grace International Bible University.

Published on: 13 March 2026

DOI: <https://doi-doi.org/101555/ijrpa.8164>

ABSTRACT

The birth of an intersex child, characterized by variations in sex characteristics that do not fit typical binary definitions of male or female, presents profound challenges for families in Ghanaian cultural contexts where gender norms are deeply entrenched and intersex variations remain largely invisible. Parents of intersex children face complex decisions about medical interventions, disclosure to family and community, and the upbringing of their child, all within a context of limited information, inadequate healthcare guidance, and pervasive stigma. For intersex children themselves, growing up in environments that pathologize their bodies and deny their existence carries significant psychological and social risks. Yet, despite these challenges, some families navigate these difficulties successfully, developing coping mechanisms and accessing support that enable them to promote their children's well-being. This study examines the coping mechanisms employed by families of intersex children in Ghana and the support systems available to them, aiming to understand how families manage the challenges they face and what resources facilitate positive outcomes. Employing a qualitative phenomenological design, the study conducts in-depth interviews with parents of intersex children, intersex adolescents and adults reflecting on their childhood experiences, healthcare providers, and community stakeholders. Drawing on family stress and coping theory and ecological systems theory, the study seeks to identify the individual, family, and community-level factors that contribute to effective coping and to document the existing sources of support, both formal and informal. By providing empirically grounded insights into the experiences of intersex children and families in Ghana, the study aims to inform the development of culturally appropriate interventions, support services, and policies that promote the health, dignity, and well-being of intersex persons and their families.

KEYWORDS: Intersex, coping mechanisms, support systems, families, children, stigma, Ghana.

1. INTRODUCTION

The arrival of a newborn child is typically a moment of joy and celebration in Ghanaian families, marked by rituals, naming ceremonies, and the integration of a new member into kinship networks. However, for families whose infant is born with intersex variations atypical chromosomal, gonadal, or anatomical sex characteristics this moment can be overshadowed by confusion, fear, and uncertainty. In a cultural context where gender is understood as an unambiguous binary and where social identity is deeply tied to gendered roles and expectations, the birth of an intersex child presents challenges for which most families are entirely unprepared.

Intersex variations, affecting an estimated 1.7% of the population (Fausto-Sterling, 2000), are naturally occurring human variations that have been documented across cultures and historical periods. Yet in contemporary Ghanaian society, as in much of the world, these variations are largely invisible in public discourse, absent from educational curricula, and unaddressed in healthcare training and policy (Lomotey, 2024). When an intersex child is born, families typically encounter healthcare providers who may lack knowledge about intersex variations, who may frame the child's body as a medical emergency requiring immediate intervention, and who may offer little guidance about the long-term implications of decisions made in those first days and weeks.

The challenges facing families of intersex children are multifaceted and extend across medical, psychological, social, and cultural domains. Medically, families must navigate complex decisions about diagnostic investigations, surgical interventions, and hormonal treatments, often with inadequate information and under pressure to make rapid decisions (Roen, 2019). Psychologically, parents may experience shock, grief, guilt, and anxiety about their child's future, while intersex children themselves, as they grow, must grapple with understanding their bodies in the absence of accurate information and in the face of societal messages that pathologize difference. Socially, families must decide whether and how to disclose their child's variation to extended family, neighbours, and community members, balancing the desire for support against the risk of stigma and rejection. Culturally, they must reconcile their child's existence with deeply held beliefs about gender, normalcy, and the moral order.

Despite these profound challenges, some families develop effective coping mechanisms and access support systems that enable them to navigate these difficulties and promote their children's well-being. Understanding how families cope, what resources they draw upon, and what forms of support are most helpful is essential for developing interventions that can assist other families facing similar circumstances. Yet in Ghana, as in most African contexts, there has been no systematic research on the experiences of families of intersex children, their coping strategies, or the support systems available to them.

This study seeks to address this gap by providing the first comprehensive examination of coping mechanisms and support systems for intersex children and families in Ghana. Using a qualitative phenomenological approach, the study will explore the lived experiences of parents, intersex individuals, healthcare providers, and community stakeholders, illuminating how families navigate the challenges they face and what resources facilitate positive adaptation. The findings will inform the development of culturally appropriate support services, educational materials for families and healthcare providers, and policies that promote the rights and well-being of intersex children and their families.

2. STATEMENT OF THE PROBLEM

Families of intersex children in Ghana face a convergence of challenges that place them at risk for adverse psychological, social, and health outcomes, yet there are no established support systems or evidence-based interventions to assist them. The absence of research on these families' experiences and needs leaves a critical gap in understanding how to promote positive outcomes for intersex children and their families.

The immediate postpartum period, when an intersex variation is typically identified, represents a moment of acute crisis for families. Parents report receiving inadequate information from healthcare providers, feeling pressured to consent to surgical interventions they do not fully understand, and being advised to maintain secrecy about their child's variation (Roan, 2019). These experiences can have lasting consequences, with parents carrying unresolved grief and guilt, and children growing up in families marked by secrecy and shame. In Ghana, where healthcare infrastructure is limited and specialized services are scarce, these challenges are likely compounded. There are no national guidelines for the care of intersex infants, no requirements for informed consent before surgical interventions, and no training for healthcare providers on respectful, evidence-based care.

Beyond the medical domain, families face profound social challenges. In Ghanaian cultural contexts, where extended family networks are central to social life and where community

opinion carries significant weight, decisions about disclosure are particularly consequential (Nukunya, 2016). Families must weigh the potential benefits of seeking support from relatives against the risk of stigma, rejection, and gossip. Many families choose secrecy, but this decision carries its own costs, isolating them from potential sources of support and creating a burden of concealment that can strain family relationships and psychological well-being.

For intersex children themselves, growing up in this context presents significant developmental challenges. Children who become aware of their difference, whether through medical experiences, family secrecy, or social interactions, may struggle with identity formation, self-esteem, and social belonging. They may be subjected to bullying, exclusion, and ridicule by peers. They may receive no information about their bodies from parents or healthcare providers, leaving them to navigate adolescence and emerging sexuality without guidance. These experiences place intersex children at risk for adverse mental health outcomes, including depression, anxiety, and suicidal ideation, as documented in research from other contexts (Rosenwohl-Mack et al., 2020).

Yet despite these challenges, some families navigate this difficult terrain successfully. They find ways to cope with the emotional demands of their situation, make decisions that protect their children's well-being, and access sources of support that sustain them. Understanding how these families cope, what distinguishes them from families who struggle more severely, and what resources they draw upon is essential for developing interventions that can support all families facing these circumstances.

The existing literature on coping and support for families of intersex children is extremely limited. Most research on intersex issues has focused on medical management, psychological outcomes for intersex adults, or advocacy for human rights, with relatively little attention to the experiences of families during childhood and the mechanisms through which they navigate challenges. Research from Western contexts suggests that access to accurate information, connection with other families, supportive healthcare providers, and family acceptance are important resources (Roen, 2019), but the applicability of these findings to Ghanaian contexts cannot be assumed.

In Ghana, there are no organizations providing support to families of intersex children, no peer support networks, no educational materials designed for families, and no trained professionals offering specialized counselling. The absence of these resources means that families cope in isolation, relying on their own resources and whatever informal support they can access. Understanding how families manage in this context of limited formal support, and

what informal resources they draw upon, is essential for identifying opportunities for intervention.

This study seeks to address these gaps by documenting the coping mechanisms employed by families of intersex children in Ghana and the support systems, both formal and informal, that are available to them. By providing empirically grounded insights into these families' experiences and needs, the study aims to inform the development of culturally appropriate interventions and support services that can promote the well-being of intersex children and their families.

3. PURPOSE OF THE STUDY

The purpose of this study is to examine the coping mechanisms employed by families of intersex children in Ghana and the support systems available to them, using a qualitative phenomenological approach to understand the lived experiences of parents, intersex individuals, healthcare providers, and community stakeholders.

4. OBJECTIVES OF THE STUDY

4.1 General Objective

The general objective of the study is to investigate the coping mechanisms and support systems for intersex children and families in Ghana, providing empirical evidence to inform the development of culturally appropriate interventions and support services.

4.2 Specific Objectives

The specific objectives of the study are to:

- Explore the experiences of parents of intersex children in Ghana from the time of discovery through their child's development.
- Identify the coping mechanisms employed by families to manage the medical, psychological, and social challenges associated with having an intersex child.
- Examine the sources of support, both formal and informal, accessed by families of intersex children.
- Explore the experiences of intersex adolescents and adults reflecting on their childhood and family experiences.
- Investigate the role of healthcare providers in supporting or hindering family coping.

5. THEORETICAL LITERATURE

The investigation of coping mechanisms and support systems for intersex children and families in Ghana requires a theoretical framework that can account for both the stressors families face and the resources they draw upon in responding to those stressors. This study draws on two complementary theoretical perspectives: Family Stress and Coping Theory and Ecological Systems Theory. These frameworks provide complementary lenses for understanding how families navigate challenges and how the broader context shapes their experiences and resources.

5.1 Family Stress and Coping Theory

Family Stress and Coping Theory, originating in the work of Hill (1949) and subsequently developed by McCubbin and Patterson (1983) and others, provides a framework for understanding how families respond to stressful events and the factors that influence their adaptation. The theory conceptualizes family stress as a dynamic process involving the interaction between stressful events, family resources, and family perceptions.

Hill's (1949) original ABC-X model identified three key factors that determine whether a stressful event leads to crisis: A (the stressor event), B (the family's resources for meeting the demands of the event), and C (the family's definition or perception of the event). The interaction of these factors produces X, the outcome or crisis. This model highlights that the same stressful event can have different effects on different families depending on their resources and how they interpret the event.

McCubbin and Patterson (1983) extended this model in their Double ABC-X model, which incorporates the accumulation of stressors over time and the family's efforts to adapt. The model recognizes that families facing ongoing challenges, such as those associated with raising an intersex child, experience a pile-up of stressors rather than a single discrete event. It also emphasizes the role of coping strategies, which are the specific efforts families make to manage demands, and social support, which is a key resource for coping.

Applying this framework to families of intersex children, the stressor event (A) may be the discovery of their child's intersex variation, but this is typically followed by a pile-up of subsequent stressors: medical appointments and decisions, concerns about disclosure, experiences of stigma, and ongoing worries about the child's future. Family resources (B) include both internal resources, such as family cohesion, adaptability, and communication skills, and external resources, such as social support from extended family, friends, and community, as well as access to information and knowledgeable healthcare providers. Family perceptions (C) include how parents understand their child's variation, whether they view it

as a tragedy, a medical problem, or simply a natural variation, and their beliefs about their ability to cope.

Coping strategies are the specific behaviors and cognitive processes families use to manage demands. These may include seeking information, seeking social support, reframing the situation in more positive terms, maintaining family routines, and managing emotions. The effectiveness of different coping strategies may vary depending on the context and the fit between the strategy and the demands being faced.

This study will use the Family Stress and Coping framework to guide exploration of how families of intersex children in Ghana experience stressors, what resources they draw upon, what coping strategies they employ, and what factors distinguish families who adapt successfully from those who struggle.

5.2 Ecological Systems Theory

Ecological Systems Theory, developed by Bronfenbrenner (1979, 2005), provides a complementary framework that situates family experiences within the multiple layers of context that shape development and adaptation. The theory conceptualizes the environment as a series of nested systems that interact to influence individual and family functioning.

The microsystem refers to the immediate environment in which the individual or family directly interacts. For an intersex child, this includes the family, school, and healthcare settings. For parents, it includes their relationships with each other, with the child, with extended family, and with healthcare providers. The quality of interactions within these microsystems is crucial for well-being.

The mesosystem refers to the interactions between different microsystems. For example, the relationship between the family and the healthcare system, or between the family and the school, can either support or undermine adaptation. When healthcare providers communicate respectfully and provide adequate information, this positive mesosystem interaction supports family coping. When schools respond insensitively to an intersex child, this negative interaction creates additional stress.

The exosystem refers to settings that do not directly contain the family, but which affect their experiences. This includes healthcare policies, educational curricula, media representations, and the work settings of parents. For example, the absence of national guidelines for intersex healthcare creates an exosystemic context that leaves families vulnerable to harmful practices.

The macrosystem refers to the broader cultural and societal values, beliefs, and norms that permeate all other levels. In the Ghanaian context, the macrosystem includes cultural beliefs

about gender, religious teachings about the body and morality, and societal attitudes towards difference. These cultural frameworks shape how intersex variations are understood, how families interpret their experiences, and what responses they encounter from others.

The chronosystem refers to the dimension of time, recognizing that individuals, families, and contexts change over time. For intersex children and families, the challenges and resources they encounter may differ at different developmental stages, such as infancy, childhood, adolescence, and adulthood.

Applying Ecological Systems Theory to this study directs attention to the multiple levels of context that shape families' experiences and coping. It highlights that supporting families requires intervention not only at the individual and family level but also at the levels of healthcare systems, educational institutions, policy, and cultural beliefs. It also emphasizes that families' experiences cannot be understood in isolation from the broader context in which they are embedded.

The integration of Family Stress and Coping Theory and Ecological Systems Theory provides a comprehensive framework for this study. Family Stress and Coping Theory illuminates the processes through which families respond to challenges and the factors that influence adaptation. Ecological Systems Theory situates these processes within the multiple layers of context that shape families' experiences and resources. Together, these frameworks guide the investigation of how families of intersex children in Ghana cope with the challenges they face and what forms of support, at multiple levels of the ecology, can facilitate positive outcomes.

6. EMPIRICAL LITERATURE

Empirical research on coping mechanisms and support systems for intersex children and families is extremely limited, particularly in African contexts. This section reviews the available literature from international contexts, identifies relevant research from related areas, and highlights the gaps this study seeks to address.

Research from Western contexts has documented the profound distress parents experience when their child is identified as intersex. Duguid and colleagues (2020), in a qualitative study of parents of intersex children in the United States, found that parents described the moment of discovery as traumatic, characterized by confusion, fear, and a sense of crisis. Parents reported receiving inadequate information from healthcare providers, being presented with limited options, and feeling pressure to make rapid decisions about surgery.

Streuli and colleagues (2013) examined the impact of professional counselling on parents' decision-making, finding that the way information was presented significantly influenced

parents' choices. Parents who were presented with surgery as the only option, or as an urgent necessity, were more likely to consent to early intervention, while those who received balanced information and were encouraged to take time were more likely to delay surgery. These findings highlight the critical role of healthcare providers in shaping family experiences and decisions.

Research has also documented the emotional responses of parents, including grief for the "normal" child they expected, guilt about their child's variation, and anxiety about the future (Roen, 2019). These emotional responses may be compounded by secrecy, as parents are often advised not to disclose their child's variation to others, leaving them to cope in isolation.

The limited research on family coping strategies for intersex children suggests that information seeking, connection with other families, and developing a positive narrative about their child's variation are important coping resources. Crissman and colleagues (2011) found that parents who sought out information about intersex variations, connected with support groups, and developed a framework for understanding their child's variation as a natural form of human diversity reported better adjustment.

Reframing, or developing a more positive interpretation of the situation, emerged as an important coping strategy in research by Liao and colleagues (2019). Parents who were able to move from viewing their child's variation as a tragedy to viewing it as a manageable aspect of their child's identity reported less distress and greater confidence in their ability to support their child.

Maintaining family routines and normalizing the child's experience were also identified as coping strategies. Parents who made conscious efforts to treat their intersex child the same as other children, to avoid overprotectiveness, and to create a family environment where the child felt accepted reported better outcomes for both themselves and their children (Roen, 2019).

7. METHODOLOGY

7.1 Research Design

This study adopted a qualitative phenomenological design to examine coping mechanisms and support systems for intersex children and families in Ghana. The phenomenological approach was appropriate for this study because it enabled in-depth exploration of the lived experiences of participants and the meanings they attach to those experiences (Creswell & Poth, 2018). Phenomenology seeks to understand the essence of a phenomenon as

experienced by those who live it, making it particularly suitable for investigating how families navigate the complex and largely unexplored territory of raising an intersex child in the Ghanaian context.

7.2 Research Approach

The study was guided by an interpretivist research philosophy, which recognizes that knowledge is socially constructed through lived experiences and that multiple realities exist based on individuals' subjective interpretations (Lincoln & Guba, 1985). This approach was appropriate given the study's aim to understand the deeply personal and culturally embedded experiences of intersex individuals and their families. The focus was on capturing the richness and complexity of participants' narratives rather than on producing generalizable statistical findings.

7.3 Study Setting

The study was conducted in Ghana, focusing on the Greater Accra Region, Ashanti Region, and Volta Region. These regions were selected to capture diversity in Ghana's cultural, ethnic, and healthcare landscapes. Greater Accra, as the capital region, has the highest concentration of healthcare facilities and specialist services. Ashanti Region represents a major cultural centre with strong traditional institutions. Volta Region offers perspectives from different ethnic and linguistic backgrounds. This regional diversity was intended to capture variation in experiences across different healthcare access contexts and cultural settings.

7.4 Study Population

The study population comprised four groups: parents of intersex children (including both mothers and fathers), intersex adolescents and adults aged 16 years and above who could reflect on their childhood experiences, healthcare providers with experience caring for intersex patients, and key community stakeholders including religious leaders, teachers, and traditional leaders who might encounter intersex children and families in their roles.

7.5 Sampling Technique

Purposive sampling was employed to select participants who could provide rich information about the phenomenon under study (Patton, 2015). Given the sensitivity of the topic and the invisibility of the intersex population in Ghana, multiple recruitment strategies were necessary.

Parents of intersex children were recruited through healthcare providers who agreed to facilitate contact, through community-based organizations working on health and rights issues, and through snowball sampling where initial participants referred others. Intersex

adolescents and adults were recruited through the same channels, as well as through online platforms where some intersex individuals had begun to connect. Healthcare providers were recruited from major hospitals in the three regions, including paediatricians, endocrinologists, nurses, and counsellors. Community stakeholders were identified through community networks and included religious leaders from Christian and Muslim communities, teachers from schools that had enrolled intersex children, and traditional leaders from communities where intersex births had occurred.

7.6 Sample Size and Justification

Sample size in qualitative research is guided by the principle of saturation, the point at which additional interviews no longer yield new insights (Guest et al., 2006). The study targeted approximately 12–15 parents, 8–10 intersex individuals, 10–12 healthcare providers, and 8–10 community stakeholders, for a total of 38–47 interviews. Recruitment continued until thematic saturation was achieved, resulting in 42 interviews: 14 parents (8 mothers, 6 fathers), 9 intersex individuals (aged 16–45), 11 healthcare providers, and 8 community stakeholders.

7.7 Data Collection Method

Data were collected through in-depth, semi-structured interviews. This method was appropriate because it allowed participants to share their experiences in their own words while ensuring that key topics were covered across all interviews (Kvale & Brinkmann, 2015). Interview guides were developed separately for each participant group, with open-ended questions designed to explore experiences, coping mechanisms, support systems, and recommendations.

For parents, the interview guide explored: the discovery of their child's variation, their emotional responses, decisions about medical care, disclosure to family and community, experiences with healthcare providers, coping strategies, sources of support, and their child's current situation. For intersex individuals, the guide explored: growing up awareness of their bodies, family communication, medical experiences, social experiences including stigma, coping strategies, support accessed, and recommendations for helping other intersex children. For healthcare providers, the guide explored: training and knowledge, clinical experiences with intersex patients, communication with families, perceptions of family needs, and recommendations for improving care. For community stakeholders, the guide explored: awareness of intersex issues, community responses when intersex children are identified, role of cultural and religious beliefs, and potential community resources.

Interviews were conducted by the researcher and trained research assistants with experience in qualitative methods and sensitive topics. Interviews took place in locations chosen by participants, including private spaces in their homes, private rooms in healthcare facilities, or community centres. Interviews lasted between 45 minutes and two hours, were audio-recorded with consent, and were transcribed verbatim. For interviews conducted in local languages (Twi, Ewe, Ga), transcripts were translated into English for analysis, with careful attention to preserving meaning and cultural nuance.

7.8 Data Collection Instruments

Semi-structured interview guides were developed for each participant group, informed by the theoretical frameworks and the study objectives. The guides were reviewed by experts in qualitative research and gender studies, and pilot tested with one participant from each group to refine wording and flow. The parent guide included sections on: background and family context, discovery experience, medical journey, disclosure decisions, family and community responses, coping strategies, support accessed, child's well-being, and recommendations. The intersex individual guide included sections on: background, growing up awareness, family relationships, medical experiences, social experiences, identity and well-being, coping and support, and recommendations. The healthcare provider guide included sections on: professional background, training on intersex issues, clinical experiences, communication practices, perceptions of family needs, institutional resources, and recommendations. The community stakeholder guide included sections on: role and community context, awareness of intersex, community responses encountered, cultural and religious beliefs, resources available, and recommendations.

7.9 Trustworthiness and Rigor

Trustworthiness was established through several strategies recommended by Lincoln and Guba (1985). Credibility was enhanced through prolonged engagement with the topic, triangulation across multiple participant groups, and member checking, where preliminary findings were shared with some participants to verify interpretations. Transferability was addressed through thick description of the context and participants, enabling readers to assess applicability to other settings. Dependability and confirmability were established through maintaining a detailed audit trail of all research decisions and analyses, and through peer debriefing with colleagues not involved in the research. Reflexivity was practiced throughout, with researchers maintaining journals to document their own assumptions, reactions, and potential influences on the research process.

7.10 Data Analysis Procedure

Data were analyzed using thematic analysis following the procedures outlined by Braun and Clarke (2006). Analysis proceeded through six phases. In phase one, familiarization, all transcripts were read multiple times to gain immersion in the data. In phase two, generating initial codes, meaningful segments of data were identified and labelled using NVivo software. In phase three, searching for themes, codes were grouped into potential themes based on patterns and relationships. In phase four, reviewing themes, themes were checked against coded extracts and the entire dataset to ensure they captured the essential meanings. In phase five, defining and naming themes, each theme was refined and clearly defined. In phase six, producing the report, themes were described and illustrated with representative quotations. Analysis was iterative, moving between data and emerging themes, and was attentive to both patterns across participants and unique or divergent experiences. Themes were developed separately for each participant group and then integrated to identify overarching patterns across the entire dataset.

8. RESULTS

Thematic analysis of 42 interviews revealed four overarching themes: the crisis of discovery and early experiences, navigating medical systems, coping with stigma and secrecy, and sources of support and resilience. Each theme encompasses multiple sub-themes representing the range of experiences across participants.

8.1 Theme One: The Crisis of Discovery and Early Experiences

This theme captures participants' experiences at the time their child's intersex variation was identified, typically at birth, and the immediate aftermath. Three sub-themes emerged: shock and confusion, inadequate information, and pressure for decisions.

Shock and Confusion: All parents described the moment of discovery as deeply shocking and disorienting. The expected joy of childbirth was replaced by confusion and fear. One mother described her experience:

"When they handed me my baby, the nurse's face was strange. She kept looking and looking. Then she took the baby away and brought a doctor. They whispered. Finally, the doctor said there was a problem with the baby's private parts. I didn't understand. What problem? Is my baby sick? Is my baby going to die? Nobody explained properly." (Mother of 8-year-old intersex child)

Another father recounted the confusion surrounding his child's gender:

"They told us, 'It's a baby,' not a boy or a girl. We asked, 'Boy or girl?' They said, 'We don't know yet. We need tests.' We were devastated. How can you not know? In our culture, everything depends on knowing the name, the ceremony, how people treat you. We went home without knowing what our child was." (Father of 5-year-old intersex child)

Inadequate Information: Parents consistently reported receiving insufficient information from healthcare providers. They were told their child had a "problem" or "abnormality" but received no clear explanation of what intersex meant or what the implications were for their child's health and development.

"The doctor used big words I didn't understand. Something about hormones and chromosomes. I asked him to explain in simple language, but he seemed busy, in a hurry. He gave us a referral to another hospital and said they would explain more there. But at the next hospital, it was the same thing. We were passed from doctor to doctor, always confused." (Mother of 12-year-old intersex child)

Pressure for Decisions: Many parents described being pressured to make rapid decisions about surgery, often within days of the child's birth. They were told that early surgery was necessary for the child to be "normal" and that delay would cause problems.

"They said we had to choose to make the child a boy or a girl. And they said we had to do surgery quickly, before the child would know anything about it. They made it sound like an emergency. We signed the papers because we were scared, and because we wanted our child to be normal. Now I wonder if we did the right thing." (Father of 15-year-old intersex child)

8.2 Theme Two: Navigating Medical Systems

This theme captures participants' ongoing experiences with healthcare, including interactions with multiple providers, decisions about treatments, and the long-term consequences of medical interventions. Three sub-themes emerged: fragmented care, lack of follow-up, and physical and psychological consequences.

Fragmented Care: Families described being referred from one provider to another, with no coordination or continuity. They encountered providers who had never seen an intersex child before and who offered conflicting advice.

"We saw so many doctors. Paediatricians, surgeons, endocrinologists, urologists. Each one looked at our child like a puzzle to solve. No one explained the big picture. No one told us what to expect as our child grew. It was like we were collecting pieces of information from different places, trying to put them together ourselves." (Mother of 10-year-old intersex child)

Healthcare providers acknowledged these gaps. One paediatrician stated:

"The truth is, we don't have a system for these children. There's no protocol, no multidisciplinary team. Most of us learned nothing about intersex in medical school. We do our best, but our best is not good enough. Families fall through the cracks." (Paediatrician, 15 years experience)

Lack of Follow-Up: Many families reported that after initial interventions, they received little or no follow-up care. They were left to manage on their own, with no guidance about what to expect as their child developed.

"After the surgery, they sent us home. They said bring the child back for check-ups, but we didn't have money, and the hospital was far. So we didn't go. Now my child is a teenager, and we have new problems hormones, puberty, questions we can't answer. There's no one to help us." (Mother of 14-year-old intersex child)

Physical and Psychological Consequences: Intersex individuals described living with the physical and psychological consequences of early interventions. These included scarring, loss of sensation, incontinence, and complicated feelings about procedures performed without their consent.

"I have scars all over. I don't even know what all the surgeries were for. I have pain sometimes. And I have this anger that people cut me, changed me, before I could say anything. They didn't know what I would want. They didn't ask." (Intersex adult, 28)

8.3 Theme Three: Coping with Stigma and Secrecy

This theme captures how families managed the social challenges of having an intersex child, including decisions about disclosure, experiences of stigma, and the psychological burden of secrecy. Three sub-themes emerged: the burden of secrecy, encounters with stigma, and managing disclosure.

The Burden of Secrecy: Most families maintained strict secrecy about their child's variation, often on the advice of healthcare providers. This secrecy imposed a heavy psychological burden.

"We never told anyone. Not our parents, not our siblings, not our friends. We carried this secret alone. It was heavy. Sometimes I wanted to talk to my mother, to ask for help, but I was afraid of how she would react. So I said nothing, and I carried it alone." (Mother of 7-year-old intersex child)

For intersex individuals, growing up with family secrecy meant discovering their variation later, often accidentally, and struggling with feelings of betrayal.

"I found out when I was 19. I found medical records in my mother's room. I asked her about them, and she broke down. She told me everything they had hidden from me my whole life. I felt so betrayed. My whole identity was built on a lie." (Intersex adult, 24)

Encounters with Stigma: When families did disclose, or when others discovered, stigma was a common response. Participants described rejection, gossip, and cruel treatment.

"When my mother-in-law found out, she said the child was a curse, that we had done something wrong. She told the whole family. After that, we were outcasts. People crossed the street to avoid us. At funerals and weddings, no one would sit with us." (Father of 9-year-old intersex child)

Intersex individuals described stigma in schools and communities:

"School was hell. When I was little, my mother told the teachers, and they told the other children not to be friends with me. I ate alone every day. Later, in secondary school, someone found out somehow, and the teasing started. They called me names, said I wasn't a real boy. I wanted to die." (Intersex adolescent, 17)

Managing Disclosure: Families developed strategies for managing disclosure, weighing the risks and benefits of telling others. Some chose complete secrecy. Others told carefully selected individuals.

"We decided to tell only my sister. She has been our rock. She helps us, she loves the child, she keeps our secret. One person we can trust is better than no one." (Mother of 6-year-old intersex child)

Some intersex individuals, particularly younger adults, were beginning to challenge the culture of secrecy.

"I decided I'm done hiding. I tell people now, carefully, when I trust them. Some accept me, some don't. But I'm done living in shame. I didn't choose this body, but it's mine, and I'm not hiding anymore." (Intersex adult, 26)

8.4 Theme Four: Sources of Support and Resilience

This theme captures the resources families drew upon to cope with their challenges and the factors that promoted resilience. Three sub-themes emerged: family and partner support, supportive healthcare providers, and internal resources and faith.

Family and Partner Support: For families who were able to disclose to supportive relatives, this support was invaluable. Partners supporting each other was particularly important.

"My husband and I, we decided early that we would face this together. We talk about everything. When I'm down, he lifts me up. When he's worried, I comfort him. We are a team. Without that, I don't think we could have survived." (Mother of 11-year-old intersex child)

A few grandparents and extended family members provided exceptional support:

"My mother was amazing. When we told her, she cried, but then she said, 'This child is my grandchild, and I will love this child no matter what.' She helped us raise him, she protected him from gossip. She gave us strength." (Father of 13-year-old intersex child)

Supportive Healthcare Providers: While rare, encounters with supportive, knowledgeable healthcare providers made a significant difference. Participants described providers who took time, explained clearly, and treated them with respect.

"There was one doctor, a woman, who was different. She sat with us for an hour. She drew pictures. She said, 'Your child is healthy. There is no emergency. Take time, learn, ask questions.' She gave us information. She made us feel like we were not alone." (Mother of 8-year-old intersex child)

Internal Resources and Faith: Many participants drew on internal resources, including faith, determination, and reframing their situation in more positive terms.

"My faith keeps me going. I pray every day. I believe God made my child, and God doesn't make mistakes. This child is not a mistake. This child is a gift, different maybe, but a gift." (Mother of 10-year-old intersex child)

Some parents described a journey toward acceptance and even celebration of their child's uniqueness.

"I used to cry every night. Now, I look at my child, so beautiful, so smart, so kind. This child is perfect. The world says something is wrong, but I say the world is wrong. My child is perfect as they are." (Mother of 7-year-old intersex child)

8.5 Summary of Themes

Table 1 provides a summary of the key themes and sub-themes emerging from the analysis.

Table 1: Summary of Themes on Coping Mechanisms and Support Systems.

Overarching Theme	Sub-Themes
The Crisis of Discovery and Early Experiences	Shock and confusion; Inadequate information; Pressure for decisions
Navigating Medical Systems	Fragmented care; Lack of follow-up; Physical and psychological consequences
Coping with Stigma and Secrecy	The burden of secrecy; Encounters with stigma; Managing disclosure
Sources of Support and Resilience	Family and partner support; Supportive healthcare providers; Internal resources and faith

9. DISCUSSION

This study examined coping mechanisms and support systems for intersex children and families in Ghana, revealing profound challenges alongside remarkable resilience. The findings illuminate the experiences of families navigating a context of invisibility, inadequate healthcare, and pervasive stigma, while also identifying the resources that enable some families to cope effectively.

9.1 The Crisis Context and Its Implications

The finding that discovery of an intersex variation represents a profound crisis for families, characterized by shock, confusion, and pressure for rapid decisions, aligns with research from other contexts (Duguid et al., 2020; Roen, 2019). However, the Ghanaian context adds distinctive dimensions. The cultural importance of gender for identity, naming, and social belonging intensifies the crisis when a child's gender cannot be immediately assigned. The inadequate information and pressure for decisions described by participants reflect not only individual provider failings but systemic gaps in healthcare infrastructure, training, and policy.

From a Family Stress and Coping perspective (McCubbin & Patterson, 1983), these early experiences represent a pile-up of stressors that can overwhelm families' resources and perceptions. Families who lack information, who are pressured into decisions they do not understand, and who are left without follow-up support are at risk for poor long-term adaptation.

9.2 Medical Systems as Sources of Stress and Support

The finding that medical systems are primarily sources of additional stress rather than support represents a significant failure. Fragmented care, lack of follow-up, and the physical and psychological consequences of early interventions echo findings from international research (Jones et al., 2016; Rosenwohl-Mack et al., 2020). However, the Ghanaian context presents additional challenges related to resource constraints, geographic barriers to care, and the absence of any protocols or guidelines.

Ecological Systems Theory (Bronfenbrenner, 1979) illuminates how these medical system failures operate at multiple levels. At the microsystem level, individual interactions with providers are often negative. At the exosystem level, the absence of policies, training, and coordination creates conditions that virtually guarantee inadequate care. At the macrosystem level, cultural pathologization of intersex bodies shapes how providers understand and respond to intersex infants.

The rare positive encounters with supportive providers, described by some participants, demonstrate what is possible when the microsystem functions differently. These providers communicated clearly, provided balanced information, and treated families with respect. Their example offers a model for how healthcare could and should be delivered.

9.3 Stigma, Secrecy, and Their Costs

The pervasive stigma and secrecy documented in this study align with Goffman's (1963) analysis of stigma management. Families' decisions to maintain secrecy reflect rational responses to a hostile social environment, but these decisions carry heavy costs. The burden of secrecy isolates families from potential sources of support, creates ongoing psychological strain, and ultimately leaves intersex individuals to discover their histories in ways that can feel like betrayal.

The finding that some families were able to disclose to carefully selected individuals, and that these disclosures sometimes yielded valuable support, suggests that complete secrecy is not the only option. Supporting families in making thoughtful decisions about disclosure, and in identifying trustworthy individuals, could help reduce the burden of secrecy while managing stigma risks.

9.4 Resources for Resilience

Despite the profound challenges documented, the study also revealed resources for resilience. Partner support emerged as particularly important, consistent with research on couple coping (Duguid et al., 2020). Families who communicated openly, shared decision-making, and provided mutual emotional support reported better coping. Interventions that strengthen couple relationships and communication could build on this resource.

The rare but invaluable supportive healthcare providers demonstrate the difference that informed, compassionate care can make. Investing in training for healthcare providers, developing guidelines for respectful care, and establishing mechanisms for continuity and follow-up could transform healthcare from a source of stress to a source of support.

The internal resources participants drew upon, including faith, determination, and reframing, illustrate the cognitive strategies that contribute to coping. From a Family Stress and Coping perspective, these perceptions and appraisals are critical determinants of adaptation. Supporting families in developing positive narratives about their child and their situation could enhance coping.

9.5 Implications for Intervention

The findings suggest multiple levels at which intervention is needed. At the family level, interventions could include providing accurate information, facilitating peer support

connections, strengthening couple communication, and supporting positive narrative development. At the healthcare system level, interventions could include developing national guidelines, training providers, establishing multidisciplinary teams, and ensuring informed consent before any interventions. At the community level, interventions could include awareness campaigns, engaging religious and traditional leaders, and creating pathways for families to access support without facing stigma. At the policy level, interventions could include legal recognition of intersex persons, prohibitions on unnecessary surgeries, and protection from discrimination.

10. CONCLUSION

This study examined coping mechanisms and support systems for intersex children and families in Ghana, revealing a landscape of profound challenges alongside remarkable resilience. Families face a crisis at discovery characterized by shock, inadequate information, and pressure for decisions. Medical systems, rather than providing support, compound stress through fragmented care, lack of follow-up, and interventions with lasting physical and psychological consequences. Pervasive stigma drives families into secrecy, isolating them from potential support and burdening them with concealment.

Yet despite these challenges, families demonstrate remarkable resilience. They draw on partner support, carefully manage disclosure, cherish the rare supportive healthcare provider, and find strength in faith and internal resources. These resilience resources offer foundations upon which interventions can build.

The study contributes to theoretical understanding by applying Family Stress and Coping Theory and Ecological Systems Theory in a novel context, demonstrating their relevance while revealing culturally specific dynamics, particularly the role of extended family, community stigma, and faith as coping resources. It provides the first empirical evidence on the experiences of intersex children and families in Ghana, filling a significant gap in the literature. The integration of multiple perspectives parents, intersex individuals, healthcare providers, and community stakeholders provides a comprehensive picture of both the challenges families face and the resources they draw upon, revealing multiple points where intervention could make a difference.

11. RECOMMENDATIONS

Based on the findings of this study, the following recommendations are proposed for government, healthcare institutions, civil society, and future researchers.

Develop Family Support Services: The profound isolation documented in this study calls for the development of family support services. The Ministry of Health and civil society organizations should establish accessible, confidential support services for families of intersex children, including accurate information materials, counselling, and peer support groups. These services should be available from the moment of discovery and continue throughout the child's development.

Reform Healthcare Practices: The harmful medical practices documented in this study require urgent reform. The Ministry of Health should develop national guidelines for the respectful, evidence-based care of intersex infants and children, prohibiting medically unnecessary surgeries without informed consent. Healthcare professional training curricula should include comprehensive education on intersex variations, emphasizing human rights, ethical care, and the importance of involving families in informed decision-making.

Train Healthcare Providers: The lack of knowledgeable providers documented in this study requires investment in training. The Ghana College of Physicians and Surgeons, nursing and midwifery councils, and medical schools should incorporate intersex health into curricula and continuing professional development. Training should include both medical management and communication skills for supporting families.

Establish Multidisciplinary Care Teams: The fragmented care documented in this study could be addressed through establishing multidisciplinary teams at major hospitals. These teams should include paediatricians, endocrinologists, surgeons, mental health professionals, and social workers who can provide coordinated, comprehensive care and support to families over time.

Address Stigma Through Community Engagement: The pervasive stigma documented in this study requires community-level intervention. The National Commission for Civic Education, in collaboration with civil society, should develop and implement community awareness programmes that provide accurate information about intersex variations, challenge pathologizing beliefs, and promote acceptance. Engaging religious and traditional leaders as allies in this effort is essential.

Support Peer Connections: The value of connection with other families, though rare in this study, suggests that facilitating peer support could be beneficial. Organizations working on health and rights issues should explore creating safe spaces, whether in-person or virtual, where families of intersex children can connect, share experiences, and support each other.

Legal Recognition and Protection: The vulnerability of intersex individuals and families documented in this study calls for legal reform. The Government of Ghana should consider

legal recognition of intersex persons, prohibitions on medically unnecessary surgeries on infants and children, and protection from discrimination based on sex characteristics.

Conduct Further Research: This study represents an initial step, and further research is urgently needed. Future research should explore the experiences of intersex children at different developmental stages, evaluate the effectiveness of interventions, examine the perspectives of extended family members, and investigate the potential for community-based support models.

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