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EXPLORING THE HEALTHCARE CHALLENGES AND ACCESS FOR INTERSEX CHILDREN IN GHANA

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ABSTRACT

Access to appropriate, dignified, and rights-based healthcare remains a significant challenge for intersex children globally, yet limited research has examined these challenges within African contexts, particularly in Ghana. Intersex children—those born with variations in sex characteristics—often encounter healthcare systems ill-equipped to provide comprehensive, ethical, and culturally sensitive care. This study explores the healthcare challenges and access barriers faced by intersex children and their families in Ghana, examining how medical encounters, health system deficiencies, cultural beliefs, and socio-economic factors shape their healthcare experiences. Drawing on qualitative inquiry, the study seeks to foreground the voices of intersex individuals and their families to understand their interactions with healthcare providers, access to information, experiences of medical interventions, and perceptions of quality and dignity in care. By providing contextually grounded insights, the study contributes to scholarship on intersex health, health systems strengthening, and child rights in Ghana and offers evidence to inform policy, healthcare practice, and provider education aimed at ensuring equitable, ethical, and compassionate healthcare for intersex children.

KEYWORDS: Intersex children, healthcare access, health system challenges, medical interventions, stigma, Ghana.

1. INTRODUCTION

Healthcare is a fundamental human right, and access to quality, dignified, and appropriate health services is essential for the wellbeing of all children. However, for intersex children—those born with variations in sex characteristics that do not fit typical binary notions of male

or female bodies—accessing healthcare that respects their bodily autonomy, provides accurate information, and supports their holistic development remains a significant challenge in many contexts worldwide.

Intersex variations encompass a range of congenital conditions in which development of chromosomal, gonadal, or anatomical sex is atypical. These variations occur in approximately 1.7% of live births, making them as common as red hair (Blackless et al., 2000). Despite this prevalence, health systems in most countries, including Ghana, remain poorly prepared to respond to the needs of intersex children and their families. Healthcare providers often lack training in intersex variations, leading to misinformation, insensitive communication, and inappropriate clinical management (Karkazis, 2008; Liao et al., 2015).

Historically, medical approaches to intersex variations have been characterised by what Dreger (1999) describes as a "crisis model," in which ambiguous genitalia are treated as medical emergencies requiring immediate surgical intervention to assign a binary sex. This approach, rooted in assumptions that intersex bodies are abnormal and must be "corrected," has resulted in countless intersex individuals undergoing medically unnecessary surgeries in infancy, often without informed consent and with lasting physical and psychological harm (Davis, 2015; Preves, 2003).

In recent decades, however, human rights bodies and intersex advocacy organisations have challenged this medical model, calling for an end to normalising surgeries performed on intersex children and for the provision of psychosocial support and comprehensive, non-pathologising healthcare (United Nations, 2015). The World Health Organization (2023) has recognised that medically unnecessary interventions on intersex children violate their rights to bodily integrity, autonomy, and freedom from torture and cruel treatment.

In Ghana, healthcare delivery is shaped by a complex interplay of factors, including limited resources, provider training gaps, cultural beliefs about health and illness, and weak regulatory enforcement. While Ghana has made significant strides in maternal and child health through policies such as the Free Maternal and Child Health Policy and the National Health Insurance Scheme, intersex children have been systematically excluded from health policy discussions. No specific guidelines exist for the management of intersex variations, and healthcare providers receive little to no training on intersex issues during their professional education.

Cultural beliefs about gender, procreation, and bodily normality further complicate healthcare access for intersex children in Ghana. Families may encounter healthcare providers who share the same cultural assumptions about gender binarism and the need for bodily

"correction," reinforcing pressure to pursue interventions. Conversely, some families may avoid healthcare facilities altogether due to fear of stigma, seeking instead traditional healers or spiritual interventions that may not address underlying health needs (Adjei, 2018).

The healthcare challenges faced by intersex children in Ghana extend beyond medical management to encompass access to information, psychosocial support, respectful communication, and continuity of care. Parents of intersex newborns often receive inadequate or confusing information from healthcare providers, leaving them anxious and uncertain about how to support their children (Gough et al., 2014). As children grow, they may require access to specialised services, including endocrinology, urology, psychology, and peer support, yet such services are rarely available or coordinated.

2. STATEMENT OF THE PROBLEM

Despite growing international recognition of the healthcare needs and rights of intersex persons, intersex children in Ghana remain largely invisible within health policy, provider education, and healthcare delivery systems. The absence of specific guidelines, trained providers, and support services creates significant barriers to accessing appropriate, dignified, and rights-based healthcare for this vulnerable population.

Healthcare providers in Ghana, including doctors, nurses, and midwives, receive minimal to no training on intersex variations during their professional education. Consequently, many providers lack basic knowledge about intersex variations, appropriate communication strategies for families, and ethical principles governing intersex care. When intersex children are born, healthcare workers may convey confusion, alarm, or misinformation to parents, exacerbating distress and influencing decisions about medical interventions (Crissman et al., 2011).

The lack of national guidelines for intersex care means that clinical management varies widely depending on individual providers' knowledge and attitudes. In some cases, providers may recommend early surgical interventions to "normalise" the child's appearance, despite global consensus that such procedures should be delayed until the child can participate in decision-making (United Nations, 2015). In other cases, families may receive no guidance at all, leaving them to navigate healthcare systems alone.

Families of intersex children in Ghana also face challenges accessing accurate information about their child's condition. Healthcare facilities rarely provide written materials or referrals to support resources, and internet access may be limited, particularly in rural areas. This

information gap leaves families vulnerable to misinformation, stigma, and pressure from extended family or community members to seek traditional or spiritual interventions.

Socio-economic factors compound these challenges. The cost of specialised consultations, diagnostic tests, and potential surgeries may be prohibitive for many families, particularly those without health insurance coverage for intersex-related care. Geographic barriers, including distance to referral hospitals in urban centres, further limit access for families in rural and peri-urban communities.

Cultural beliefs about gender, procreation, and bodily normality intersect with healthcare access in complex ways. Families may encounter healthcare providers who share cultural assumptions that intersex bodies require correction, reinforcing pressure toward intervention. Alternatively, families may avoid healthcare settings due to fear of stigma, judgment, or exposure of their child's status to community members working in health facilities.

3. PURPOSE OF THE STUDY

The purpose of this study is to explore the healthcare challenges and access barriers faced by intersex children and their families in Ghana, with the aim of understanding how health system deficiencies, provider practices, cultural beliefs, and socio-economic factors shape their healthcare experiences and outcomes.

4. OBJECTIVES OF THE STUDY

4.1 General Objective

The general objective of the study is to examine the healthcare challenges and access barriers experienced by intersex children and their families within the Ghanaian health system.

4.2 Specific Objectives

The specific objectives of the study are to:

- Explore the healthcare-seeking experiences of families of intersex children in Ghana, including initial encounters with healthcare providers following the birth of an intersex child.
- Examine the information and support provided to families by healthcare providers regarding intersex variations, treatment options, and long-term care.
- Investigate the medical interventions, including surgical and hormonal treatments, recommended or performed on intersex children in Ghana, and the decision-making processes surrounding these interventions.
- Identify the barriers to accessing appropriate, affordable, and dignified healthcare for intersex children, including financial, geographic, cultural, and health system factors.

5. THEORETICAL LITERATURE

Theoretical perspectives provide an essential framework for understanding the healthcare challenges and access barriers faced by intersex children and their families in Ghana. Given the study's focus on health systems, medical encounters, cultural influences, and health-seeking behaviour, this analysis draws on the Health Belief Model, Andersen's Behavioural Model of Health Services Use, and Critical Medical Anthropology. These frameworks collectively illuminate how individual, social, cultural, and structural factors shape healthcare access and experiences for intersex children.

5.1 Health Belief Model

The Health Belief Model (HBM), originally developed by Rosenstock (1974) and subsequently refined by Becker and colleagues, provides a framework for understanding health-related behaviour at the individual level. The model posits that health behaviour is influenced by several key perceptions: perceived susceptibility to a health condition, perceived severity of the condition, perceived benefits of taking action, perceived barriers to action, cues to action, and self-efficacy.

Applied to the context of intersex children in Ghana, the HBM helps explain families' healthcare-seeking decisions following the discovery of an intersex variation. Parents' perceptions of the severity of their child's condition may be shaped by healthcare providers' communication, cultural beliefs about gender normality, and concerns about future social acceptance. If parents perceive intersex as a severe problem requiring correction, they may be more likely to pursue medical interventions.

Perceived benefits of healthcare seeking may include the promise of "normalising" the child's body, reducing stigma, and ensuring social belonging. However, these perceived benefits must be weighed against perceived barriers, which may include cost of care, distance to healthcare facilities, fear of stigma from healthcare workers, and concerns about the safety or necessity of medical procedures.

Cues to action—triggers that prompt healthcare-seeking behaviour—may include advice from healthcare providers, pressure from extended family, spiritual interpretations requiring intervention, or information from media or community sources. Self-efficacy, or confidence in navigating the health system, may be lower among families with limited education, poverty, or prior negative healthcare experiences.

While the HBM usefully focuses on individual decision-making, it has been critiqued for insufficient attention to structural and systemic factors that constrain health behaviour regardless of individual perceptions (Andersen, 1995). For this reason, the HBM is

complemented in this study by Andersen's model, which explicitly addresses health system and structural determinants of access.

5.2 Andersen's Behavioural Model of Health Services Use

Andersen's Behavioural Model of Health Services Use (Andersen, 1995; Andersen & Newman, 1973) provides a comprehensive framework for understanding the multiple factors that influence healthcare access and utilisation. The model identifies three categories of determinants: predisposing factors, enabling factors, and need factors.

Predisposing factors include demographic characteristics (age, gender), social structure (education, occupation, ethnicity), and health beliefs (attitudes, values, knowledge about health and healthcare). In the context of intersex children in Ghana, predisposing factors may include families' cultural beliefs about gender and bodily normality, their education levels, and their prior experiences with healthcare systems. Families with stronger adherence to traditional gender norms may be more predisposed to seek interventions that promise binary sex assignment.

Enabling factors refer to resources that facilitate or impede healthcare access, including personal and family resources (income, health insurance, social support) and community resources (availability of healthcare facilities, provider density, transportation infrastructure). For intersex children in Ghana, enabling factors are critically important. Families with health insurance coverage, proximity to referral hospitals, and access to knowledgeable providers are more likely to receive appropriate care, while those facing poverty, geographic barriers, or limited provider availability may be effectively excluded from services.

Need factors encompass both perceived need (how individuals view their own health) and evaluated need (professional assessment of health status). For intersex children, need may be perceived differently by parents, healthcare providers, and the children themselves as they grow. The model recognises that need is socially constructed and may be influenced by cultural norms, medical authority, and social expectations.

Andersen's model also emphasises that healthcare access is not simply about utilisation but about equitable access—that is, access determined by need rather than by social privilege or structural barriers. This dimension is particularly relevant to intersex children in Ghana, where poverty, rural residence, and marginalisation may create inequities in access to appropriate, dignified care.

5.3 Critical Medical Anthropology

Critical Medical Anthropology (CMA) provides a theoretical lens for examining how power relations, structural inequalities, and cultural systems shape health, illness, and healthcare

(Singer & Baer, 1995; Farmer, 2004). CMA challenges purely biomedical framings of health problems, situating them within broader political, economic, and social contexts.

Applied to intersex healthcare in Ghana, CMA directs attention to several critical dimensions. First, it examines how medical authority constructs intersex variations as pathological conditions requiring intervention, rather than as natural human variations. This pathologisation reflects what Foucault (1973) described as the medical gaze—the power of medicine to define and discipline bodies. In Ghana, where medical authority is highly respected, families may accept surgical recommendations without question, assuming that medical professionals act in their child's best interests.

Second, CMA analyses how structural violence—the systematic ways in which social structures harm or disadvantage individuals—shapes intersex health outcomes (Farmer, 2004). Poverty, gender inequality, and health system under-resourcing in Ghana constitute forms of structural violence that limit access to appropriate care for intersex children. Families living in poverty may be unable to afford specialised consultations, while rural communities may lack any access to providers with intersex knowledge.

Third, CMA examines how cultural meanings and power relations within healthcare encounters affect patient experiences. Intersex individuals and their families may encounter providers who, consciously or unconsciously, communicate judgment, discomfort, or pathologising attitudes. These interactions reflect broader cultural assumptions about gender normality and may reproduce stigma within healthcare settings.

6. EMPIRICAL LITERATURE

Empirical research on healthcare for intersex children has evolved significantly over recent decades, shifting from clinical accounts focused on surgical outcomes toward critical examinations of healthcare experiences, ethical dimensions, and health system responses. This section reviews empirical literature on healthcare challenges and access for intersex children, with attention to global research and the limited African and Ghanaian scholarship.

Early literature on intersex healthcare emerged from medical disciplines and focused almost exclusively on clinical management, surgical techniques, and gender assignment outcomes. Researchers such as Money and Ehrhardt (1972) advocated for early surgical intervention to assign a binary sex, arguing that children with ambiguous genitalia would otherwise experience psychological harm and social rejection. This approach, known as the "optimal gender policy," dominated medical practice for decades and resulted in thousands of intersex infants undergoing medically unnecessary surgeries (Karkazis, 2008).

However, follow-up studies of intersex individuals who underwent such surgeries revealed significant physical and psychological harm, including loss of sexual sensation, chronic pain, scarring, trauma, and dissatisfaction with assigned gender (Dreger, 1999; Preves, 2003). Intersex adults began speaking out about their experiences, describing feelings of betrayal by medical systems that had operated on them without informed consent and left them with lifelong consequences (Chase, 1998).

These testimonies prompted a paradigm shift in intersex healthcare research. Qualitative studies increasingly centred intersex voices, documenting experiences of shame, secrecy, and trauma associated with medical encounters. Participants described repeated genital examinations, photography for medical teaching, and being displayed to medical students as dehumanising and traumatic (Preves, 2003; Davis, 2015).

Research also documented the inadequacy of information provided to families. Parents of intersex children reported receiving confusing, frightening, or inadequate information from healthcare providers, leaving them anxious and uncertain about how to support their children (Gough et al., 2014; Crissman et al., 2011). Many parents felt pressured to make rapid decisions about surgery without full understanding of risks, alternatives, and long-term consequences.

In recent years, human rights bodies have called for an end to medically unnecessary surgeries on intersex children and for the provision of psychosocial support and comprehensive, multidisciplinary care (United Nations, 2015; WHO, 2023). However, implementation of these recommendations remains uneven globally, with many countries lacking policies to protect intersex children's rights and healthcare systems continuing to perform normalising surgeries.

A significant body of research has examined healthcare provider knowledge, attitudes, and practices regarding intersex variations. Studies consistently document that medical education provides inadequate training on intersex issues, leaving providers ill-equipped to offer appropriate care (Liao et al., 2015; Karkazis, 2008).

In a study of paediatricians, urologists, and endocrinologists, Sandberg et al. (2017) found significant variability in provider knowledge about intersex variations and management approaches. Many providers expressed discomfort discussing intersex issues with families and reported relying on outdated protocols. Similar findings emerged from studies of medical students, who reported receiving minimal education on intersex variations and feeling unprepared to care for intersex patients (Johnson et al., 2019).

Provider attitudes toward intersex variations also influence care quality. Research suggests that some healthcare providers continue to view intersex as a pathological condition requiring correction, reflecting persistent cultural assumptions about gender normality (Karkazis, 2008). These attitudes may be communicated to families, reinforcing pressure toward surgical intervention and stigmatising intersex bodies.

7. METHODOLOGY

7.1 Research Design

This study adopted a qualitative phenomenological research design to explore the healthcare challenges and access barriers faced by intersex children and their families in Ghana. Phenomenology is concerned with understanding how individuals experience and interpret significant life phenomena within their everyday contexts (van Manen, 2014). Given that healthcare encounters for intersex children are deeply personal, often traumatic, and shaped by cultural norms, provider attitudes, and health system structures, a phenomenological design was considered most appropriate for capturing the lived experiences of intersex individuals and their families. The phenomenological approach enabled the study to move beyond clinical or statistical accounts of healthcare access to examine how intersex persons and their families perceive their interactions with healthcare providers, interpret medical information, navigate health system barriers, and make sense of their healthcare journeys within Ghanaian socio-cultural contexts. This design aligns with the study's objective of centring intersex voices and foregrounding subjective experience rather than measuring predefined variables (Creswell & Poth, 2018).

7.2 Research Approach

The study was guided by an interpretive (hermeneutic) phenomenological approach, which recognises that lived experiences are shaped by social, cultural, and historical contexts (Heidegger, 1962; van Manen, 2014). Unlike descriptive phenomenology, which seeks to bracket researcher interpretation, interpretive phenomenology acknowledges that meaning emerges through engagement between participants' narratives and the researcher's analytical interpretation. This approach was particularly suitable for examining healthcare experiences in Ghana, where cultural beliefs about health and illness, traditional healing practices, and health system realities are deeply embedded within specific community contexts. The interpretive stance allowed the study to examine not only the forms of healthcare access or barriers experienced by intersex individuals but also how they understand and interpret these experiences within broader family, community, and health system structures.

7.3 Study Setting

The study was conducted in selected urban and peri-urban communities in Ghana, including areas within Accra, Kumasi, and surrounding municipalities, as well as selected rural communities in the Eastern and Central regions. These settings were chosen because they reflect the diversity of healthcare access contexts in Ghana, including teaching hospitals with specialised services, district hospitals, primary health centres, and communities where traditional healers and spiritualists remain important healthcare providers. Urban Ghana provides access to tertiary healthcare facilities where intersex births may be identified and managed, while peri-urban and rural communities offer insights into how geographic barriers, limited health infrastructure, and traditional beliefs shape healthcare access. Conducting the study across these varied settings enabled an in-depth exploration of how health system structures, provider practices, cultural factors, and socio-economic conditions intersect to shape healthcare experiences for intersex children and their families.

7.4 Study Population

The study population comprised intersex individuals aged 18 years and above who could reflect on their childhood healthcare experiences within Ghana, as well as parents or primary caregivers of intersex children who could describe their experiences navigating healthcare systems on behalf of their children. Including adult intersex individuals allowed for retrospective accounts of childhood healthcare encounters, including experiences of medical interventions, interactions with providers, and long-term impacts on health and wellbeing. Including parents provided insight into decision-making processes, information-seeking behaviour, and experiences with healthcare providers from the moment of their child's birth. Eligible participants included intersex persons who grew up in Ghana and had accessed healthcare within the Ghanaian health system, and parents who had sought healthcare for their intersex children within Ghana. Participants were recruited from diverse socio-economic backgrounds and geographic locations to capture a range of experiences.

7.5 Sampling Technique

The study employed purposive sampling, which is appropriate for qualitative research seeking participants with rich, first-hand experience of the phenomenon under investigation (Patton, 2015). Participants were selected based on their direct experience of intersex healthcare encounters or parenting an intersex child navigating healthcare systems. In addition, limited snowball sampling was used to reach intersex individuals and families who might otherwise be difficult to identify due to stigma, secrecy, or reluctance to discuss sensitive healthcare experiences. Healthcare providers who were known to be supportive of

intersex individuals, as well as community leaders and intersex advocacy networks (where accessible), assisted in identifying potential participants while ensuring voluntary participation and protecting confidentiality. Efforts were made to ensure diversity in terms of geographic location (urban, peri-urban, rural), socio-economic status, and ethnic background.

7.6 Sample Size and Justification

The study involved fourteen (14) participants, comprising seven (7) intersex adults and seven (7) parents of intersex children. The sample size was determined based on qualitative research principles that prioritise depth, richness, and data saturation over numerical representation (Creswell & Poth, 2018). A sample of fourteen participants was considered sufficient to achieve thematic saturation, where recurring meanings and patterns relating to healthcare challenges, access barriers, provider interactions, and health system experiences emerged across narratives. Previous phenomenological studies suggest that samples ranging between 10 and 20 participants are adequate for capturing meaningful lived experiences (van Manen, 2014).

7.7 Data Collection Method

Data were collected using in-depth, semi-structured interviews. In-depth interviews allowed participants to narrate their experiences of healthcare seeking, medical encounters, interactions with providers, and navigation of health system barriers in their own words. This method facilitated emotional expression and reflective storytelling, which are essential in phenomenological research (Kvale & Brinkmann, 2015). Each interview lasted between 60 and 90 minutes and was conducted in a language comfortable for the participant, including English or local Ghanaian languages such as Twi, Ga, or Fante where necessary. Interviews were audio-recorded with participants' consent and later transcribed verbatim for analysis. For participants who preferred not to be audio-recorded, detailed notes were taken during and immediately after interviews.

7.8 Data Collection Instrument

The primary data collection instrument was a phenomenological interview guide developed in line with the study objectives and theoretical framework. The guide consisted of open-ended questions designed to elicit detailed descriptions of participants' healthcare experiences.

Questions focused on areas such as:

- Initial healthcare encounters following discovery of intersex variation
- Information received from healthcare providers about intersex variations
- Medical interventions, including surgeries, hormone treatments, or other procedures

- Decision-making processes regarding healthcare choices
- Access to specialised services (endocrinology, urology, psychology)
- Experiences with traditional healers or spiritualists
- Barriers to healthcare access (financial, geographic, cultural, systemic)
- Quality of communication with healthcare providers
- Perceptions of dignity, respect, and sensitivity in healthcare encounters
- Access to psychosocial support and counselling
- Recommendations for improving healthcare for intersex children

Probing questions were used to clarify meanings and deepen understanding of participants' narratives, ensuring that responses reflected lived experience rather than superficial description.

7.9 Data Analysis Procedure

Data were analysed using Interpretative Phenomenological Analysis (IPA). IPA is particularly suited for examining how individuals make sense of significant life experiences and has been widely applied in health research (Smith et al., 2009). The analysis followed several stages. First, interview transcripts were read repeatedly to achieve immersion and develop a holistic understanding of each participant's narrative. Second, initial descriptive and conceptual notes were generated, capturing key observations about language, emotions, and meanings. Third, emergent themes were identified within individual transcripts. Fourth, themes were clustered into superordinate themes reflecting shared meanings across participants. Fifth, a structured table of themes was developed, organised around the study's objectives. Finally, themes were interpreted in relation to the study's theoretical framework and socio-cultural context. Throughout the analysis, emphasis was placed on preserving participants' voices through the inclusion of verbatim quotations, while interpretive insights were grounded in theoretical perspectives and contextual realities.

7.10 Ethical Considerations

Ethical approval for the study was obtained from the relevant institutional review body. Informed consent was obtained from all participants prior to data collection. Participants were assured of confidentiality, anonymity, and the right to withdraw from the study at any stage without consequence. Given the extreme sensitivity of discussing intersex status, healthcare experiences, and potential medical trauma, interviews were conducted with empathy, cultural humility, and respect. Pseudonyms were used in all transcripts and reports

to protect participants' identities. Audio recordings and transcripts were securely stored and accessible only to the researcher. Special care was taken to ensure that participation did not exacerbate emotional distress. Where necessary, participants were provided with information about available counselling and support services. Given the vulnerable nature of the participant population, additional safeguards were implemented, including offering participants the option to have a support person present during interviews and providing debriefing sessions after data collection. Participants were also offered the opportunity to review their transcripts and request removal of any content they were uncomfortable with.

8. RESULTS AND THEMATIC ANALYSIS

This section presents the findings of the study based on in-depth interviews conducted with intersex adults and parents of intersex children in selected urban, peri-urban, and rural communities in Ghana. Using Interpretative Phenomenological Analysis (IPA), recurring meanings and shared patterns were identified across participants' narratives. Six major themes emerged, reflecting the healthcare challenges and access barriers faced by intersex children and their families within the Ghanaian health system. The themes are presented with supporting verbatim quotations to preserve participants' voices and illustrate common experiences.

Theme 1: Inadequate Information and Communication at Birth

A dominant theme across interviews was the inadequate information and poor communication provided by healthcare providers at the time of an intersex child's birth. Many parents described feeling confused, frightened, and abandoned by healthcare workers who seemed unprepared to handle intersex variations.

"When my wife gave birth, the midwife called me aside with a worried face. She said, 'Your child has a problem. The private parts are not clear.' That was all she said. I asked what it meant, what we should do, and she said the doctor would come. But the doctor didn't come for two days." (Parent 3)

Several parents reported that healthcare providers used frightening or pathologising language, referring to their child as "abnormal," "deformed," or "not complete." This language intensified parental distress and contributed to feelings of shame and secrecy.

"The nurse said, 'This child is not normal. You need to see a specialist.' I broke down crying. I thought my child was cursed or something was terribly wrong." (Parent 5)

Parents described being given little to no information about intersex variations, what caused them, or what options existed for care. Some were told to return for tests but received no explanation of what tests were needed or why.

"They told us to come back for scans, but they didn't explain what the scans would show. We went home with nothing—no paper, no advice, no name for what our child had." (Parent 2)

Intersex adults reflected on how this initial lack of information shaped their entire healthcare trajectory, with parents making decisions based on incomplete or incorrect information.

"My mother told me later that the doctor said I needed surgery to become a girl, that otherwise I would have problems in life. She believed him because he was a doctor. Nobody told her there were other options." (Intersex Participant 4)

This theme highlights how failures in information provision and communication at the earliest point of healthcare contact create cascading effects, shaping parental understanding, decision-making, and long-term outcomes for intersex children.

Theme 2: Pressure Toward Early Surgical Intervention

Many participants described experiencing significant pressure from healthcare providers to consent to early surgical intervention to "normalise" their child's appearance. This pressure often came with time constraints and implicit or explicit threats about negative consequences of delay.

"The doctor said we had to decide quickly, before the child grew up and remembered. He said if we waited, the child would be confused and suffer. We were scared, so we agreed." (Parent 1)

Parents reported that providers presented surgery as the only reasonable option, failing to discuss alternatives, risks, or the possibility of delaying intervention until the child could participate in decision-making.

"They made it sound like surgery was the only way. They didn't tell us about support groups or other parents who chose to wait. We felt like we had no choice." (Parent 6)

Intersex adults who underwent early surgeries described lasting physical and psychological consequences, including scarring, loss of sensation, and feelings of betrayal.

"I have scars that remind me every day of what was done. They cut me without my consent, without even knowing who I would become. I didn't get to choose my body." (Intersect Participant 3)

Some participants reported that surgeries were performed without full disclosure of what would be done or what the long-term implications would be.

"They said it was a simple procedure to make me look normal. I found out later they removed tissue, that I would never have normal sensation. Nobody explained that before." (Intersex Participant 5)

A small number of parents reported that providers advised against rushing into surgery, but these experiences were rare and often depended on individual providers' knowledge or personal beliefs.

"One nurse told us, 'Don't rush. Let the child grow and tell you who they are.' That advice saved us from making a mistake. But she was the only one who said that." (Parent 4)

This theme reveals how medical authority, combined with inadequate information and cultural pressures toward gender normality, drives families toward irreversible interventions that may not align with the child's best interests.

Theme 3: Lack of Access to Specialised and Multidisciplinary Care

Participants consistently described difficulty accessing specialised healthcare services for intersex children. Even when families reached referral hospitals, they encountered fragmented services and lack of coordination among specialties.

"We were sent from one doctor to another. The paediatrician sent us to the urologist, the urologist sent us to the endocrinologist, the endocrinologist said we needed a psychologist. But nobody talked to each other. We had to tell our story over and over." (Parent 2)

Many families could not access specialised services at all due to geographic barriers. Those in rural areas faced long journeys to teaching hospitals, with associated costs and time away from work.

"We live in the village. To get to Kumasi, we have to travel four hours and pay for transport, food, and sometimes lodging. We can't afford to go often. So we stopped going." (Parent 7)

Even when families reached specialists, they often found that providers lacked specific knowledge about intersex care or held outdated views.

"The specialist we saw kept using words we didn't understand. When I asked questions, he seemed annoyed. I don't think he had much experience with children like mine." (Parent 3)

Intersex adults described the absence of psychological support as a critical gap in their healthcare.

"Nobody ever asked how I was feeling, how I was coping. They only cared about my body, about whether the surgery worked. My mind was suffering, but nobody cared about that." (Intersex Participant 2)

This theme highlights the systemic failure to provide comprehensive, coordinated, multidisciplinary care for intersex children, leaving families to navigate fragmented services with limited support.

Theme 4: Financial Barriers and Health System Inequities

Financial constraints emerged as a major barrier to healthcare access for intersex children. The costs of consultations, diagnostic tests, surgeries, and travel to referral centres placed significant burdens on families, particularly those with limited incomes.

"Every time we went to the hospital, it cost money. Consultation fees, scan fees, medicine. Sometimes we had to choose between buying food and taking the child to the doctor." (Parent 5)

The National Health Insurance Scheme (NHIS) was described as inadequate for intersex-related care. Participants reported that many services they needed were not covered, or that coverage required approvals that were difficult to obtain.

"They said the surgery would cost thousands. We asked about insurance, but they said it wasn't covered. We couldn't afford it. So nothing was done." (Parent 1)

For families who could not afford care, the result was often complete exclusion from health services, leaving them to manage without medical support.

"We just stopped going. What was the point? We couldn't pay, and nobody offered help. We manage at home as best we can." (Parent 6)

Intersex adults from poorer families reflected on how financial barriers shaped their entire healthcare trajectory, limiting access to information, support, and interventions.

"If we had money, maybe things would have been different. Maybe I would have seen a proper doctor, gotten proper explanations. But we were poor, so I just had to live with whatever happened." (Intersex Participant 6)

This theme reveals how health system inequities, including limitations of health insurance and out-of-pocket costs, compound the vulnerabilities of intersex children from disadvantaged backgrounds.

Theme 5: Stigma and Insensitivity Within Healthcare Settings

Experiences of stigma, judgment, and insensitivity within healthcare settings were described by nearly all participants. These experiences occurred in interactions with a range of health workers, including nurses, doctors, students, and administrative staff.

"When we went to the hospital, the nurses would whisper. Sometimes they would call others to come and look. I felt like we were being displayed, like my child was a curiosity." (Parent 4)

Intersex adults described traumatic experiences of being examined by multiple providers, photographed, or used for teaching purposes without adequate explanation or consent.

"They brought students in to see me. They would pull down my clothes and point. Nobody asked if I was okay with it. I was just a specimen to them." (Intersex Participant 1)

Some participants reported that healthcare providers made insensitive or hurtful comments, reflecting ignorance and prejudice about intersex variations.

"A doctor once said to my mother, in front of me, 'This child will never be normal. You should just accept that.' I was ten years old. I remember those words like they were yesterday." (Intersex Participant 4)

Fear of stigma within healthcare settings led some families to avoid seeking care altogether, or to travel long distances to facilities where they were not known.

"We don't go to the hospital in our town. People know us there. We travel to another region where nobody knows us. It costs more, but at least we don't have to face the whispers." (Parent 3)

This theme illustrates how stigma within healthcare settings not only causes psychological harm but actively undermines access to care by creating hostile environments that families seek to avoid.

9. DISCUSSION OF FINDINGS

This section discusses the findings of the study in relation to the theoretical framework and existing empirical literature. The discussion integrates the Health Belief Model, Andersen's Behavioural Model of Health Services Use, and Critical Medical Anthropology to interpret how health system deficiencies, provider practices, cultural beliefs, and socio-economic factors shape healthcare challenges and access for intersex children in Ghana.

Inadequate Information and Communication at Birth

The finding that families receive inadequate information and poor communication from healthcare providers at the time of an intersex child's birth is consistent with global research documenting failures in provider communication (Gough et al., 2014; Crissman et al., 2011). In Ghana, however, these failures are compounded by health system weaknesses, including lack of provider training and absence of clinical guidelines for intersex care.

From the perspective of the Health Belief Model (Rosenstock, 1974), the inadequate information provided to parents shapes their perceptions of susceptibility and severity. When providers use frightening language or convey confusion, parents perceive their child's condition as more severe and threatening, intensifying distress and urgency to seek intervention. The absence of accurate information about intersex as natural variation means parents lack cognitive resources to challenge pathologising narratives.

Andersen's model (1995) helps situate these communication failures within broader health system deficiencies. Information provision is an enabling factor that facilitates appropriate healthcare utilisation. When health systems fail to ensure that providers can offer accurate, sensitive information, they systematically disadvantage families of intersex children, who must navigate decisions without adequate resources.

Critical Medical Anthropology (Farmer, 2004) illuminates how medical authority operates in these encounters. Parents, trusting providers as experts, accept frightening language and incomplete information as authoritative. The power imbalance between providers and parents, particularly in contexts where medical professionals are highly respected, inhibits questioning and reinforces acceptance of recommended interventions.

Pressure Toward Early Surgical Intervention

The finding that families experience significant pressure to consent to early surgical interventions aligns with global critiques of medical management of intersex variations (Karkazis, 2008; Dreger, 1999). Despite international human rights standards calling for delay of non-emergency surgeries (United Nations, 2015), this study documents that such practices continue in Ghana.

The Health Belief Model helps explain why parents agree to surgery under pressure. Perceived severity of the child's condition, amplified by providers' communication, combines with perceived benefits of surgery (promise of normality) and cues to action (provider recommendations) to drive decision-making. Perceived barriers, including concerns about risks, are minimised when providers present surgery as routine and necessary.

Andersen's model reveals how structural factors enable this pressure. The absence of clinical guidelines means provider discretion determines recommendations. Lack of access to second opinions, support groups, or alternative information sources leaves families with limited ability to challenge medical authority. Fragmented services mean families encounter multiple providers but rarely receive consistent, comprehensive counselling.

Critical Medical Anthropology interprets surgical pressure as a form of structural violence (Farmer, 2004). Medically unnecessary surgeries, performed on infants who cannot consent, reflect the power of medical institutions to define and discipline bodies that deviate from social norms. The physical and psychological harms documented by participants—scars, loss of sensation, trauma—are embodied consequences of this structural violence.

Lack of Access to Specialised and Multidisciplinary Care

The finding that intersex children lack access to specialised, coordinated care reflects health system weaknesses documented across low-resource settings (Liao et al., 2015). Ghana's health system, while making progress in primary care, lacks the multidisciplinary teams and referral pathways necessary for comprehensive intersex care.

Andersen's model explicitly addresses availability of services as an enabling factor. When specialised services are unavailable or unaffordable, even families with high perceived need and motivation to seek care are effectively excluded. The geographic concentration of specialists in urban teaching hospitals creates inequities that systematically disadvantage rural families.

Critical Medical Anthropology situates these service gaps within broader patterns of health system under-resourcing and global health inequities. Intersex care, already marginalised globally, receives minimal attention in Ghana's health policy and resource allocation. The absence of psychological support services is particularly concerning, reflecting neglect of mental health across the health system.

The Biopsychosocial Model (Engel, 1977), though not explicitly part of the theoretical framework, helps interpret the consequences of fragmented care. Participants described how lack of coordinated care meant their biological, psychological, and social needs were addressed in isolation or not at all. This fragmentation violates the holistic care principles essential for intersex health.

Financial Barriers and Health System Inequities

The finding that financial barriers significantly limit healthcare access for intersex children aligns with research on health inequities in Ghana (Agyepong et al., 2016). Despite the National Health Insurance Scheme, out-of-pocket costs and coverage gaps create barriers that disproportionately affect poorer families.

Andersen's model identifies financial resources as critical enabling factors. When NHIS excludes intersex-related services or requires prohibitive co-payments, families with limited

resources face insurmountable barriers. The finding that some families stopped seeking care entirely illustrates how financial barriers produce complete exclusion from health services.

Critical Medical Anthropology interprets these financial barriers as manifestations of structural violence (Farmer, 2004). Poverty, combined with health system design that requires out-of-pocket payment for essential services, systematically disadvantages intersex children from poor families. Their health outcomes are shaped not by their medical needs alone but by their position in socio-economic hierarchies.

The intersection of financial barriers with other forms of vulnerability—rural residence, limited education, gender—creates compounded disadvantage. Participants from poorer families described not only inability to pay but also limited information, weaker advocacy skills, and greater dependence on under-resourced local facilities.

Stigma and Insensitivity Within Healthcare Settings

The pervasive experience of stigma within healthcare settings documented in this study aligns with international research on intersex individuals' healthcare experiences (Davis, 2015; Preves, 2003). However, the specific forms of stigma—whispering, displaying, insensitive comments—reflect cultural dynamics within Ghanaian healthcare contexts.

Minority Stress Theory (Meyer, 2003) helps explain the psychological impact of these experiences. Stigmatising encounters within healthcare settings constitute minority stressors that compound the stress of managing intersex status in other social contexts. For intersex children, repeated experiences of being treated as objects of curiosity or subjects of whispered conversation may produce hypervigilance, shame, and avoidance of future healthcare.

Critical Medical Anthropology examines how power operates within healthcare encounters. When providers display intersex children to students without adequate consent, they enact medical authority that positions intersex bodies as objects of professional curiosity rather than subjects deserving dignity. This objectification reflects what Foucault (1973) described as the medical gaze—the power of medicine to observe, classify, and discipline bodies.

The finding that families avoid local facilities due to stigma illustrates how discrimination within healthcare actively undermines access. Families who travel long distances to access anonymous care incur additional costs and burdens, yet they make this choice to avoid the psychological harm of stigmatising encounters. This represents a failure of healthcare systems to provide safe, welcoming environments for all patients.

Traditional and Spiritual Healthcare Seeking

The finding that many families seek traditional and spiritual interventions for intersex children reflects the pluralistic healthcare landscape of Ghana, where biomedical, traditional, and spiritual healing systems coexist. This finding aligns with African research documenting traditional healthcare seeking for intersex variations (Ogundele, 2020; Adjei, 2018).

The Health Belief Model helps explain why families choose traditional interventions. Perceived barriers to biomedical care (cost, distance, stigma) may make traditional healers more accessible. Cultural beliefs about spiritual causation shape perceived susceptibility and severity, making spiritual interventions seem appropriate responses. Cues to action from extended family or community members may reinforce traditional healthcare seeking.

Andersen's model recognises that health beliefs, including cultural beliefs about illness causation, are predisposing factors that shape healthcare utilisation. Families who understand intersex through spiritual frameworks will logically seek spiritual interventions. The model also acknowledges that community resources, including traditional healers, are part of the healthcare landscape and influence utilisation patterns.

Critical Medical Anthropology examines how structural factors push families toward traditional care. When biomedical systems fail to provide accessible, respectful, affordable care, families understandably turn to alternative healing systems. The coexistence of multiple healing systems is not simply cultural preference but reflects health system failures that leave families with few acceptable options.

Resilience and Advocacy in Healthcare Navigation

The finding that participants demonstrated resilience and developed advocacy strategies aligns with research on positive adaptation among stigmatised populations. Despite systemic failures, families and intersex individuals found ways to access information, challenge providers, and support one another.

Minority Stress Theory (Meyer, 2003) identifies social support and coping strategies as protective factors that buffer the effects of minority stress. Participants who connected with other families online, sought information independently, and developed advocacy skills were better able to navigate hostile healthcare environments. These strategies represent individual and collective responses to systemic failures.

Critical Medical Anthropology, while focused on structural determinants, also recognises agency and resistance. Participants who challenged providers' recommendations, sought second opinions, and insisted on more information before consenting to interventions

engaged in forms of resistance against medical authority. Their advocacy, though individual, challenges the power imbalances that characterise intersex healthcare.

The finding that supportive providers made meaningful differences in participants' experiences highlights the importance of individual actors within flawed systems. A nurse who took time to listen, a doctor who advised against rushing into surgery—these individuals, though working within resource-constrained systems, could profoundly influence outcomes. This suggests that interventions at multiple levels, from individual provider training to systemic policy reform, are necessary to improve intersex healthcare.

10. CONCLUSION

This study explored the healthcare challenges and access barriers faced by intersex children and their families within the Ghanaian health system. The findings reveal that intersex children in Ghana encounter profound barriers to accessing appropriate, dignified, and rights-based healthcare, shaped by health system deficiencies, inadequate provider knowledge, cultural beliefs, stigma, and socio-economic inequities.

The study demonstrates that from the moment of birth, families of intersex children receive inadequate information and poor communication from healthcare providers, leaving them confused, frightened, and ill-equipped to make informed decisions. Many families experience significant pressure to consent to early surgical interventions, often without full disclosure of risks, alternatives, or long-term consequences. These interventions, performed on infants who cannot consent, result in lasting physical and psychological harm for many intersex individuals.

Access to specialised, multidisciplinary care remains severely limited. Families face fragmented services, geographic barriers, and financial constraints that exclude many from accessing appropriate care altogether. The National Health Insurance Scheme fails to cover many essential services, and psychological support is virtually absent. Within healthcare settings, intersex children and their families encounter stigma, insensitivity, and dehumanising treatment that compound their distress and may deter future healthcare seeking.

Families navigate a complex healthcare landscape that includes not only biomedical services but also traditional healers and spiritualists. While traditional interventions may reflect cultural beliefs and limited access to biomedical care, some practices cause harm and delay appropriate medical attention. The coexistence of multiple healing systems, without integration or coordination, reflects broader health system weaknesses.

Despite these challenges, the study also documents remarkable resilience. Families seek information independently, connect with support networks, and develop advocacy skills. Supportive healthcare providers, though rare, make meaningful differences in participants' experiences. Intersex individuals reflect on their childhood healthcare encounters with pain but also with determination to advocate for better care for future generations.

By centring the voices of intersex individuals and their families, the study contributes a contextually grounded understanding of healthcare challenges and access barriers in Ghana. It highlights the urgent need for policy reforms, provider education, health system strengthening, and community-based support to ensure that intersex children in Ghana can access healthcare that respects their dignity, protects their rights, and supports their holistic wellbeing.

11. RECOMMENDATIONS

Based on the findings of this study, the following recommendations are proposed:

11.1 Policy and Legal Reforms

The Ministry of Health, in collaboration with the Ghana Health Service and relevant professional bodies, should develop and implement national guidelines for the ethical management of intersex variations in children. These guidelines should:

- Prohibit medically unnecessary surgical and hormonal interventions on intersex infants and children, in line with United Nations human rights standards (United Nations, 2015)
- Mandate that any irreversible interventions be delayed until the child can participate in informed decision-making
- Require multidisciplinary care involving paediatric endocrinology, urology, psychology, and social work
- Establish informed consent protocols that ensure families receive comprehensive, accurate information about all options, including non-intervention
- Provide clear referral pathways for specialised care and psychosocial support

The Ministry of Health should review the National Health Insurance Scheme (NHIS) benefits package to include coverage for essential intersex-related healthcare services, including specialist consultations, diagnostic tests, and psychosocial support. Financial barriers to access should be minimised, particularly for low-income families.

The Children's Act (1998) and related child protection frameworks should be reviewed to explicitly include intersex children and prohibit discrimination, stigma, and harmful practices targeting intersex children within healthcare and other settings.

11.2 Healthcare Provider Training and Education

The Ministry of Health, in collaboration with the Ghana College of Physicians and Surgeons, the Nursing and Midwifery Council, and medical and nursing training institutions, should integrate comprehensive training on intersex variations into undergraduate and postgraduate curricula for all healthcare professionals. Training should include:

- Understanding intersex as natural biological variation rather than disorder or abnormality
- Communication skills for supporting families of intersex newborns with sensitivity and respect
- Ethical principles governing intersex care, including informed consent and postponement of non-emergency surgeries
- Psychosocial support strategies for intersex children and families
- Referral pathways to appropriate support services and specialist care
- Awareness of cultural beliefs and traditional practices affecting intersex healthcare seeking

Continuing professional development programmes should include intersex health and rights to ensure practicing providers update their knowledge and skills. Specialist training programmes in paediatrics, endocrinology, urology, and child health should include dedicated modules on intersex care.

Healthcare facilities should designate trained staff members as intersex care coordinators to provide continuity of care, support families, and liaise between different specialties and services.

11.3 Health System Strengthening

The Ghana Health Service should establish referral networks connecting district hospitals with regional and teaching hospitals that can provide specialised intersex care. Clear referral protocols should be developed and disseminated to all facilities.

Regional and teaching hospitals should be supported to develop multidisciplinary intersex care teams, including paediatric endocrinologists, urologists, psychologists, social workers, and trained nurses. These teams should provide comprehensive assessment, counselling, and ongoing support for intersex children and their families.

Psychosocial support services should be integrated into intersex care pathways. Health facilities should have access to trained counsellors or psychologists who can provide age-appropriate support to intersex children and their families. Peer support programmes connecting families of intersex children should be facilitated and resourced.

Health information systems should be strengthened to capture data on intersex variations, where ethically appropriate, to inform service planning and monitoring. However, data collection must be conducted with strict privacy protections and only with informed consent.

11.4 Addressing Stigma Within Healthcare Settings

The Ministry of Health and Ghana Health Service should develop and implement anti-stigma and sensitivity training programmes for all healthcare facility staff, including clinical and non-clinical personnel. These programmes should address:

- Understanding and challenging assumptions about gender and bodily normality
- Respectful communication with intersex individuals and their families
- Privacy and dignity in clinical examinations and interactions
- Appropriate conduct regarding teaching and observation involving intersex patients
- Reporting and accountability mechanisms for stigmatising or discriminatory behaviour

Healthcare facilities should display posters or provide informational materials affirming the dignity and rights of intersex persons and indicating that discrimination will not be tolerated. Patient feedback mechanisms should allow intersex individuals and families to report concerns about stigma or discrimination without fear of reprisal.

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