Cultural and Moral Beliefs/Practices Towards Children With Congenital Anomalies Among the Idoma of Benue State.

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Abstract

This seminar discusses the cultural and moral beliefs/practices that with respect to the plights of children with disabilities. The author explored cultural/moral beliefs and practices towards children with congenital anomalies in general terms, using a qualitative study design, involving interviews and focused group discussion. The findings included superstitions and misconceptions including demonic spirits and wrongdoin as well as curses that were widely believed to be associated with the causes of congenital anomaly. These beliefs constituted the foundation of the societal perception, attitudes and practices towards children born with congenital anomalies, characterised by heightened levels of stigmatization, discrimination and denials. There were also remedial but harmful cultural and moral practices relating to congenital anomalies among the studied population. The study concludes there were lots of misconception and wrongful cultural practices with regards to congenital anomalies among the Idoma people of Benue State. It is recommended that rigorous awareness raising is needed for communities to support people with congenital anomalies, involvement of non-governmental organisations (NGOs), formation of support groups, introducing holistic interventions that address issues of cultural and moral beliefs and continuous training for frontline workers to keep in touch with current best practices, policies and laws around congenital anomalies.

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1. Introduction

Disabled people all over the world are confronted with a range of explanations for disability, which can have an impact on many aspects of their lives. In many African countries a range of beliefs and attitudes underpin the explanations, including assumptions, misconceptions, traditional or religious beliefs and beliefs about the natural and supernatural worlds. These misconceptions and myths attached to disability are mainly expounded through moral and cultural lenses. An observation by Miles (112) attests that disability in the Holy Bible, particularly in the book of Exodus is attributed to the sins of parents. In Africa, disability is generally attributed to witchcraft and such cultural and religious interpretations have a bearing on how children with disabilities are treated (Mukushi, 54). The caregivers of children with disabilities bear much of the burden that children with disabilities face and as such, they are left with a plethora of challenges. In some cases, the parents violate the rights of children in trying to correct the disability using cultural or moral means.

Various schools of thought try to explain the causes, management and other issues relating to congenital. These different hypotheses known as approaches or models to congenital anomaly include the traditional/moral model, the social model, the charity model and the medical model, to mention the few (Mugumbate and Mtetwa 594). In this context, explanations on the causes of disability are linked to traditional beliefs and morality, that is, the gods, ancestors, God, evil spirits, or wrongdoing (Mugumbate & Mtetwa 595). Resultantly, this view influences the attitudes and practices directed towards people with congenital anomalies (Miles 116). In the moral model, disability is seen as having meaning about the person's or the family's character, deeds, thoughts, and karma. Indigenous knowledge systems and beliefs on the causes of congenital anomaly are key in determining the attitudes of the society towards people with congenital anomalies (Miles 116). Most cultural (traditional) beliefs consider congenital anomalies to be a result of supernatural forces or incongruous deeds like incest or marital incontinence (Haihambo and Lightfoot 7). Various scholars including Haihambo and Lightfoot (7) and Mupedziswa (26) reported that a majority of people in Africa believe that witchcraft, punishment from God, avenging spirits, or promiscuity on the part of one or both parents can cause disability. It is important to note that these traditional beliefs play a role on how communities support and respond to the needs of people with disabilities.

Traditional beliefs about the causes of disability remain prevalent across sub-Saharan Africa. One set of explanations is linked to traditional animism. This carries beliefs that disabilities are punishments for bad deeds, or the result of witchcraft. Christian fatalism holds that disability is God's will. Medical determinist beliefs accept the explanations of modern medicine about the causes of disabilities. This approach often views disability as something to be treated or ameliorated. But individuals often combine different beliefs about the causes of disability. For example, they may suggest a medical explanation in addition to traditional animism.

Beliefs are sometimes based on the types of impairment and how or when the disability was acquired. Individuals or groups may hold beliefs that differ from those of wider society. And beliefs can vary across a region or within a country. Socio-economic issues can also affect attitudes towards disability. People with disabilities in rural areas may experience more harmful practices than in urban areas. It is also important to remember that stigma is not only associated with disability. It is often related to gender too – many women who are disabled are doubly disadvantaged. Stigma is experienced across a range of disabilities. For example, recent research showed that people with mental health conditions face mistaken beliefs that their illnesses cannot be treated, or they are accused of witchcraft.

The implications can be wide ranging. Studies found that people were being directed to traditional healers rather than medical treatment. The knowledge of traditional and moral beliefs and practices towards disability is of vital importance twards planning and implementing programmes for individuals with disability that will make a real difference in their lives and the lives of the communities in which they live.

Given this situational background, this study sought to assess the cultural and moral beliefs/practices towards children with congenital anomalies among the Idoma people of Benue State, focusing on the cultural/moral approach, which views congenital anomaly with cultural and moral lenses.

2. Methodology

Qualitative research design using interviews of key informants and focus group discussions (FGDs) was used for the study. Using purposive sampling, the researcher interviewed 42 participants.

2.1 Participants

The participants were drawn from two out of the nine local areas in Benue South (Zone C) senatorial district of Benue State, which is the homeland of the Idoma people of Benue State. The participants consisted of key-informant group (KIG) comprised 12 participants (6 chiefs – all males, and 6 elders: 3 each male and female), and focused group discussion (FGD) groups of 30 participants (12 traditional birth attendants, TBAs, and 18 others) distributed equally into two separate discussion groups.

2.2 Procedure

Participants were given an explanation regarding the study purpose and methods, and participated only after giving their informed consent, and they were informed of their right to anonymity and could withdraw from the study at any time. The data were collected with in-depth interview and focused group discussion, guided by semi-structured questionnaire conducted by the researcher. The interviews were recorded, and short notes were completed immediately after the interview. The interviewees and researcher confirmed the correctness of the interviewer's notes. The interview durations varied from 30 to 60 min. Similar exercise held for the focused group discussions.

2.3 Data Analysis

The study was carried out with a qualitative approach by content analysis. This is an appropriate method for obtaining condensed and broad descriptions of a phenomenon (Elo and Kyngas 112; Hsieh and Shannon 1284). The method of Graneheim and Lundman (109) was used in the present study. This method has four stages: choosing a unit of analysis (whole interviews); detecting the meaning units and referring to a keyword or phrase (a code in relation to context); condensation, or the process of shortening with preserving the core; and abstraction, or descriptions and interpretations on a higher logical level and creation of categories. The audio files were transcribed verbatim for the data analysis. The transcripts were then read several times and their meaning units were specified and condensed with a description close to the text. After that, a list of codes was provided and reviewed semantically. Then, by determining the similarities and differences in the meanings, similar codes were assigned at a more abstract level using a reduction and induction method. Thereafter, the researcher defined some acceptable subcategories and categories.

3. Results

The participants responded on five thematic aspects namely, (1) traditional belief system, (2) knowledge on congenital anomalies, (3) belief on the causes of congenital anomalies, (4) challenges of congenital anomalies and attitudes towards the sufferers and the families, and (5) solutions or remedies for congenital anomalies. Based on the findings, some main themes iwere dentified, as outlined below:

3.1 Morality

Idoma cultural and moral worldview on morality is largely rooted in religious beliefs and practices. Participants narrated that are two main belief systems in Idoma namely, the indigenous Idoma Traditional Religion (ITR) and Christian Religion beliefs; the latter came due to colonisation experience. In the ITR, there is belief that there is a supreme God who is the creator of all things, and who has the ultimate powers to life and existence. The ITR is closely linked to the worship of ancestors, chracterised by the belief that there are other spirits - àlekwu (avenging spirits) which *àdalekwu* (chief priest) can converse with. Ancestors are deceased family members that create an invisible family, who have an impact on the lives of the living. Likewise traditional healers or clannish heads (traditional chiefs) can converse with ancestors. It is pertinent to note that a good number of Idoma practice dual religion – ITR and Christian Religion.

3.2 Beliefs and Causes of Congenital Anomalies

With respect to the causes of congenital anomalies, there were varied response of beliefs and opinions by the participants. When asked about the causes of congenital anomalies, participants' responses varied from "I have no knowledge, I don't know exactly the causes", to "sins/spiritual redistributive consequences". Others related congenital anomalies to *fate* and *nature*, remarking that some babies were "born like that", or "You can get out of your mother's womb as a disabled child." [FGD]. All participants believed that there are certainly some types of anomalies that are caused by supernatural forces. Widely held views were that congenital anomalies and disability might be caused by avenging spirits, witchcraft and or punishment from either God or the ancestors.

Attribution to *one-self* was largely believed to be responsible for congenital anomalies. According to the chiefs and the elders, in some instances, the ancestors (*âlēkwu*) were consulted through a soothsayer or an oracle, to unravel the cause of the anomaly. Most times, the parents, often the mother, are implicated in such areas as "parental misdeeds" or "inappropriate relations", which appeared to be connected closely to non-observation or non-adherence to family/community cultural values or the flouting of social conventions, including committing adultery. Words reserved for the type of improper relations, although often seemed to overlap and were used inter-changeably, included, "àjà", "likpo tonu" and "otanyila", and were used variously to imply infidelity, flirting, unfaithfulness, adultery or extra-marital relations.

Some of the participants believed that congenital anomaly results ". . . when a pregnant mother gives birth to her baby and during that period the husband cheats on his wife and the father comes back and touches the child. . ." [FGD]. One participant explained that the TBAs attending to the child's birth would be the first to accuse, upon sighting a newly born child with a congenital anomaly. The fathers were usually implicated "second" or where the innocence of the mother had been proven.

Laughing at an individual with congenital anomaly was also believed to be another causative factor responsible for giving birth to a child with congenital anomaly. A TBAs narrated that a woman laughed at a dwarf and was told by the dwarf that:

> "if the baby she was carrying on her back was the last one then he will be tall but if she was still going to give birth to more children then she will laugh a lot more at home. . . the woman gave birth to three dwarfs." [FGD]

Another participant narrated that "The first albino children that I saw, are from Ehatokpe Okpiko. They told us that their mother laughed at, and despised other albino children before she got pregnant. This taught the people of Okpikô community not to discriminate against people with ablinos or other disabilities".

Other factors believed to be responsible for congenital anomalies included "witchcraft", "demons and evil spirits", as well as "evil eyes". The actions of witchcraft were believed to be invoked in the circumstance of offence by others. A curse or spell was cast as retribution for a past transgression, with congenital anomalyor disability viewed as the negative consequence:

> ". . . other people can put a spell on the mother or in that family, so when the parents give birth, they give birth to helpless children. . . the child instead gives trouble to the parents." [FGD]

The person with a deformity was sometimes described as having been placed under or on a seat for demons or ghosts. Although, the perception of "evil spirit" and "wicked people" as causes of the congenital anomalies was popular among the participants, this did not exclude the possibility of other causes. For example, it was recognised that certain types of disability may be attributable to sickness or unexplained reasons, whilst others to a preternatural power:

> "There is disability . . . that one is born with and there is another that one gets through sickness and there is another through witchcraft. . ." [FGD]

Another reason for congenital anomaly was what was referred to as "borrowed pregnancy", which described how the parents would have visited a shrine to seek help them have a baby. In this circumstance, references were made to mythical creatures and evil spirits:

> ". . .others who are also born . . . cannot be understood whether they are human or animal-like . . . since the pregnancy was forced or borrowed from the spirit world or the gods." [FGD]

Some congenital anomalies were attributed to fate, nature, or the will of God, described as part of "God's plan", as was expressed by one participant who expressed "I think some people are born like that since the father and the mother are usually fine. So, I think God created them like that." [FGD]

This view was reinforced by a story of a miracle whereby a malformed child was somehow miraculously healed, after a failed search for a cure:

> ". . .he was born disabled, and the mother sought for help from everywhere until she gave up hope and left it in the hands of the God. Suddenly, one day, the child started walking by himself and everybody was surprised." [FGD]

"Birth complications" and birth difficulties as well as carelessness during delivery were also cited causes. A TBA remarked: "For example, if head of the newborn is not compressed and molded immediately after birth by the mother or attending TBA, the baby would go on to develop oblong or long-shaped head later". However, a minority of the participants highlighted that congenital anomaly may be caused by prenatal health issues on the mother as well as genetic factors.

3.3 Attitude and Practices Towards Individuals with Congenital Anomalies

Responders varied in their expressions regarding their attitudes and perceptions pertaining to congenital anomalies (Table 1). In the KIG, the majority (41.7%) of the respondents disagreed that the notion that children with congenital anomalies were inferior, but rather always felt sorry when seeing someone with congenital anomalies (66.7%). The popular view was that congenital anomalies adversely affect the child relationship with his\her peer based on the opinion of 58.3% of them. Many of the interviewees agreed that congenital anomalies have negative impact on the self-esteem of the child.

One of the TBAs narrated how a woman who had a child with spina bifida associated with hydrocephaly and bilateral clubfoot,

> "was very frightened, shocked, and thought she did something wrong, and broke down when she saw her child. She cried for several days as she was always confronting challenges in her life, still grieving and thinking about the fate of her child". [FGD]

Another woman remarked that mothers whose children had cleft lip and palate expressed always expressed sadness and disappointment, so much so that they often hide their children from people.The main areas of concern as expressed by the FGD group can be considered as follows:

3.3.1 Reaction to Burden of Care and Stress

Participants related the burden of care to "support demands" and "harm prevention". Support demand challenges concerned personal maintenance or upkeep of the affected child and family in terms of medicare, self-care, feeding, clothing, hygiene, and mobility. Concerns were expressed about the mobility and comfort of some individuals with motor problems, with a lack of suitable equipment, such as wheelchairs, and the physical pain endured by some. Stories of support demands was told about a 7-year-old girl who had poor motor control and problems with continence, and who was dependent on others for bathing:

> "she always sits in a particular spot and even defaecates and urinates on her body….and has to be washed bathed….and removed from where she has been washed and carried by two people and put back to the bed because she is not able to move on her own." [FGD]

3.3.2 Stigmatisation and Barriers to Inclusion

Participants said that children with congenital anomalies and their families do suffer social barriers, such as stigmatising attitudes and actions expressed during social interactions. They remarked that congenital anomalies were associated with shame and stigma from the larger society, including the extended family, manifested as limited acceptance or outright non-acceptance of the children. They stressed that staring and gazing were the most common forms of stigmatisation, although sometimes over sympathising was also common, which made parents feel that their child was not normal. For example, some participants posited that words such as pity and sympathy often used to describe the general community's perception of such a child, was not helpful for feeling and being included by the parents. They observed that the parents' concerns related to the difficulty in addressing people's reactions towards their index children, and that such attitudes could lead to the affected families feeling blamed, shamed, and stigmatised or experiencing overt discrimination and rejection.

It was unanimously upheld that stigmatisation inevitably leads to exclusion and isolation from the local social networks. Some participants believed that many mothers purposely avoided social gatherings, preferring to remain at home, where they or their children would less likely face discrimination. This was especially the case of severely disabled children, especially girls, who were seen by parents as frail, needing somebody to look after them even in adulthood, or were seen as vulnerable, finding it more difficult to live alone.

According to some participants, the malformed child and its parents could also suffer stigmatisation from family members, friends, and relatives, making some mothers to feel they do not belong and leave them feeling hopeless and powerless in family relationships. One of the respondents remarked that "neighbours could refuse to carry the child and making jest of him/her. In-laws would refuse to carry such a baby, blaming the condition of the child on the mother; The mothers are often shunned and isolated by in-laws because they had a child who was viewed as less than "perfect."" One of the respondents described a case where the parents of a child with cleft lip and palate "did everything possible to prevent friends from seeing their affected child, that their relatives were ashamed of their affected child, and they have been treated like an outcast by neighbours, relatives, and friends because of their affected children."

It was the general opinion that "Mothers are commonly blamed for their children's disability". A woman narrated a situation in which "One mother vented her frustration over her mother-in-law's taunt that she was the cause of her child's disability and was not a 'good' daughter-in-law because she did not have a healthy baby" According to the narration,

> "'My mother-in-law blamed me for not having a healthy child. Society blames the mother. In the beginning, my mother and my aunts told me to admit him to disabled centers and to leave him till he became independent, but I refused'". [FGD]

Another woman described additional bad experiences of societal responses to a child with a defect: "I know a mother of a child with congenital anomaly whose husband refused to care for his deformed baby and other children after the birth of the affected baby. The husband's family warned him not to marry the wife because of where she came from. Since the birth of the index child, they have made life miserable for her (the mother). Her mother-in-law was very angry with her for having this child, accusing her of being the first to give birth to 'a child like this' in their family. Sometimes the husband is sad and becomes moody about this baby. This makes the wife sad also. The father of the baby later abandoned the mother and the baby with the cleft lip and palate." Participants also expressed the view that some affected mothers may experience feelings of shame and of receiving negative attitudes from their extended family. A mother of a child with cleft of the lip and palate was quoted as saying: “I had to hide the baby inside the house. The naming ceremony has been postponed indefinitely because of the defect.” “I was never comfortable taken my baby out.” “I had to stay away from home the day the baby was being named because of shame.” [FGD]

Other concerns had to do with people with cognitive and behavioural or even severe physical (motor) problems, who had difficulties in accessing opportunities such as going to school and enjoying peer group plays and would rather stay within the confines of the homestead instead of being part of the surrounding community. Some of the participants remarked that the stigma associated with people with anomalies extended to the family members, and to people who tried to render help; the belief was that the helper would also “. . .give birth to such a child” [FGD].

Additionally, people with congenital anomalies suffer denials or deprivation of privileges. For instance, marriage proposals were hardly offered to individuals with disabilities by “normal individuals” because it was not socially acceptable, because of cultural fear that disabled individuals would transmit the defect to their children, apart from the ensuing stigma.

3.3.3 Discrimination

Congenital Anomalies evoked varied social reactions at the family, community and the institutional level considerations. Participants highlighted that some people avoid close interaction with the immediate family members of children with congenital anomalies or disabilities. They reported that such family members were hardly not invited to most social gatherings and in those few incidences they were invited, the treatment they received clearly showed that they were not appreciated. One participant said:

> “People think if they come near disabled children, they will be infected. Disability in is considered as punishment from God or from the ancestors, so people do not want to show sympathy, as they believe the disability is well-deserved...”

The participants reiterated that of all the challenges malformed children face, discrimination was the most grievous one, as it triggers a lot of emotional suffering for the caregivers and children. One caregiver said the following as she was becoming emotional:

> “When you are carrying a child with disability even people who know you and the child keep staring at you like they do not know you, like you are carrying faeces...”

Table 1. Perception and Attitude Towards Congenital Anomalies

Item	Respondents							
	Strongly agree		Mildly agree		Mildly disagree		Strongly disagree	
	#	%	#	%	#	%	#	%
Children with congenital anomalies are inferior	3	25.0	2	16.7	2	16.7	5	41.7
You always feel sorry when seeing someone with congenital anomalies	8	66.7	3	25.0	0	0.0	1	8.3
You are afraid of disabled people	4	33.3	1	8.3	2	16.7	5	41.7
A disabled child should not marry.	3	25.0	2	16.7	1	8.3	6	50.0
A child who has no congenital malformation should not marry a person with congenital malformation	7	58.3	2	16.7	0	0.0	3	25.0
People with congenital malformation should not have children.	2	16.7	2	16.7	1	8.3	7	58.3
Persons with congenital malformation could be employed in your company	4	33.3	5	41.7	0	0.0	3	25.0
People with congenital malformation should not be allowed to be in the council of elders	9	75.0	0	0.0	0	0.0	3	25.0
Families having malformed people should completely hide them in seclusion.	5	41.7	0	0.0	1	8.3	6	50.0
Congenital malformation affects the parents’ relationship with each other	7	58.3	1	8.3	1	8.3	3	25.0
Disabled persons should associate with the other members of the community	4	33.3	3	25.0	0	0.0	5	41.7

Persons with congenital disability should not be allowed to use public services like public transport	2	16.7	2	16.7	2	16.7	6	50.0
Disabled children should not attend school	3	25.0	1	8.3	1	8.3	7	58.3
There should be separate schools for disabled children.	6	50.0	2	16.7	1	8.3	3	25.0
The society does not help families of children with congenital anomalies to adapt	3	25.0	1	8.3	4	33.3	4	33.3
The society and individuals must help children with anomalies	7	58.3	3	25.0	2	16.7	0	0.0
Persons with congenital anomalies and their families should be treated as outcasts	3	25.0	1	8.3	3	25.0	5	41.7
Congenital anomalies adversely affect the child's relationship with his/her peer	7	58.3	2	16.7	2	16.7	1	8.3
Congenital anomalies have negative impact on the self-esteem of the child and that of the parents/families	9	75.0	2	16.7	0	0.0	1	8.3
Disabled children should participate not in sports	4	33.3	2	16.7	1	8.3	5	41.7
Relatives like disabled child very much.	3	25.0	0	0.0	2	16.7	7	58.3
Newborns with congenital anomalies should be allowed to survive if the anomalies is discovered at birth	5	41.7	1	8.3	1	8.3	5	41.7
According to Idoma tradition, persons with congenital anomalies can become a traditional chief	11	91.7	0	0.0	1	8.3	11	91.7
According to Idoma tradition, persons with congenital anomalies have equal right to family inheritance	8	66.7	0	0.0	2	16.7	2	16.7

Participants said that there were some traditional remedies meant to end the disability. According to some participants, the traditional ways of therapy include applying traditional medicines and consulting traditional healers. Other participants believed that many of the congenital anomalies have some form of treatment, usually using herbs or by offering prayers to appease the ancestors (âlēkwu) or the gods. Each anomaly has its own prescribed herbs for treatment. For example, pepper leaves, rice husk, and cassava leaves are used to treat and cure àkpâ (hydrocephalus). However, it is believed that some severe congenital physical deformities in newborns are not compatible with a useful in life. Such infants are either abandoned to die by withholding food or actively killing them, are taken away by "masquerades" (êkwu) or "hyena" (odumu) and buried alive. In a similar way, when a mother has a series of still births, it is the same child returning or reincarnating. The corpse of the infant is therefore mutilated with a razor blade either to enable identification if the ''same'' child returns with subsequent pregnancies or to discourage the reincarnation of the same child. Emphasis is placed on the observance of cultural and family/community values, as well as non-flouting of social conventions as a means of preventing congenital anomalies occurrence.

At the time of the ''announcement'' of the pregnancy, a ceremony that occurs around five months' gestation, the husband or compound head visits the local soothsayer to receive news from the ancestors about the outcome of the pregnancy. The soothsayer can foretell whether the child will be the reincarnation of a particular ancestor, the importance of the child to the family's future, the child's wishes about where to be born and occasionally, the sex of the child. If the soothsayer finds that the ancestors are angry with the family, he can advise them on what is needed for pacification, failing which, the ancestors may threaten to send an ɔ̀y'ánjɛ̀nū.

The key informants described ways for determining whether a child is a spirit child after birth. These include the identification of physical abnormalities such as very large or very small heads (hydrocephalus, micro and anencephaly), feet pointing in the wrong direction (talipes), lumps in the back (spina bifida), teeth at birth, dislocated or broken limbs. The child of a mother who had a very difficult pregnancy or who dies at birth; a child of a mother who engages in intercourse in an open place; or a child whose birth is followed by a series of tragic events within the compound is also likely to be an ɔ̀y'ánjɛ̀nū. In addition, ây'ánjɛ̀nū (pleural) are believed to cry constantly and become particularly upset if they are stared at. Informants described how, even at an early age when most children cannot control the movement of their necks, spirit children can turn away to avoid a gaze.

When the presence of a spirit child is suspected, the compound head may sprinkle ash outside the room in which the child sleeps. The presence of small footprints in the ash the next morning is diagnostic of a spirit child. Others report having heard the chattering of rafters during the night which is the result of the spirit child roaming for food when everyone else in the compound is asleep. Once a spirit child has been identified, a soothsayer is called in and sacrifices are performed around the ancestral rooms of the compound. The soothsayer remains in a room with the child where their spirits battle and they come to an agreement; the ɔ̀y'ánjɛ̀nū must leave this world. The child is then force-fed a portion of bitter herbs, which in ‘‘really bad’’ spirit children causes instant death. If the child survives the potion, he or she is left out in the bush far enough away from home so that they cannot crawl back. The mother is allowed to go and get the child after two nights. If after being alone for two nights, the child is still alive, it is believed that there was either a misdiagnosis or that the bad spirit left the child’s body. No one knew of a child who had survived, the child is buried without a funeral ceremony and the family has to perform a series of sacrifices in order to be cleansed.

Asked what the solution congenital anomalies should be generally, and how the treatment of the negative connotation associated congenital anomalies should be treated, the participants were unequivocal in their suggestions which included the following:

3.3.4 Support Systems Involvement

Support systems are individuals and entities that offer emotional, physical, mental and spiritual support to caregivers and children with disabilities. Participants emphasised that societies and communities should have systems that support caregivers. These support systems should come in many forms like non-formal, for example, family and friends and formal for example, professional rehabilitation programs by government and its partners. Many participants agreed that although the most important source of support comes from the immediate family of the child with a disability, close relatives and friends often distance themselves the moment they realise that there is a child with a disability in the family.

It was suggested that volunteers receive donations, stipends and handouts, advice and social support from other members of society and various organisations. The church also emerged as another source of support for caregivers of children with disabilities. However, caregivers seemed to have divided notions towards how helpful the social support that comes from churches really is to them. Psychologically, they all believed the church is instrumental in that part especially from teachings and counselling from pastors and elders. Socially, the case was not the same. Caregivers highlighted that the same people who segregate against them in communities are the same people who come in church uniforms.

3.3.5 Coping Strategies Support Systems Involvement

Participants advocated that caregivers should employed different coping mechanisms to curb the challenges they are facing. They believed that when the caregiver’s strong religious and cultural belief systems can influence the coping mechanisms as propounded by (Miles, 2006).

3.3.6 Counselling Support Systems Involvement

Participants prescribed the embracing and utilisation of counselling from experts to enable them cope with the reality of coping with congenital anomaly-induced stress. They believed that counselling gives caregivers a different view of disability as well as acceptance to having a child with a disability.

3.3.7 Seeking Faith Healing Support Systems Involvement

Participants were unanimous in recommending seeking divine intervention since they believed that the affected children are in the condition they are because of witchcraft and supernatural forces”. Because of this belief, they advocated that joining the Pentecostal churches, in the hope to attract prophetic power to cure the children will be beneficial.

3.3.8 Avoiding Unfriendly and Intimidating Environments Support Systems Involvement

Participants would rather admonish caregivers to avoid intimidating environments, areas and places where they receive silly comments from strangers and members of extended families, even if that means stop visiting members of the extended family, avoid going to public places during busy days, and generally shutting themselves out of the entire social life of the community.

4. Discussion

This study revealed that the Idoma worldview is basically a religious worldview like any other African society, meaning there is the belief in the existence of two worlds. In the Idoma worldview, "Ôwôicho", God is transcendental, all excelling, supreme. He is also looked upon as "Ôwô no fie ôwôdodu" (omniscent). The Idoma worldview or value system was anchored mainly on the indigenous traditional religion, which consisted of three essential aspects, namely, *Ôwôicho* (the Supreme God), *âjē* (the outstanding earth), and *alekwu* (ancestral spirits). The Idoma people viewed *Ôwôicho*, (God) as the Supreme Being and the Creator of all things, both the visible (universe) and the invisible worlds (spirtual) worlds, and to whom all things belong. *Ôwôicho* created everything therein in the universe including human beings, and they look up to Him for provision and sustenance. Conversely, *Ôwôicho* depends on the visible world for manifestations. For instance, if an individual is said to be blessed by Him because of the individual's good, this can only be known through such benevolence from *Ôwôicho*, which connotes physical manifestations of the power of God's providence and sustenance.

The participants believed that *Ôwôicho* is transcendental, all excelling, and supreme (*Ôwô no fie òwòdodu*), but, since He is too physically removed from the world, due to the physical distance between the people and God, there must be an intermediary between the Him and them. Hence, the people thought it necessary to look up to a substitute which acts as an intermediary between them and the Supreme Being. This intermediary is the *âjē* (literally meaning "*land*") through which God transmitted His force; and it is *Òche* who is invested with god-like attributes and made the ruler of the community to superintend as the chief priest of the *âjē*. Thus, the Òche as the Chief Priest oversees nearly all the religious rites in the community.

Òche is referred to as the *adalekwu* (father of the dead/spirit). In Idoma belief, the dead members of the kindred group were paradoxically alive. In other words, death in the corporeal sense did not remove the dead from kindred membership as such. Rather, certain classes of the ancestors were considered vital and living members of the community. Consequently, they were endowed with certain rights and responsibilities. The *Òche*, in his priestly capacity and role, was considered a vital link between the *alekwu* and the living community.

"*Alekwu*" literally means spirits [of the dead] or ancestors in Idoma, the worship of which forms the basis for the indigenous Idoma traditional belief system or indigenous traditional religion [ITR]. Thus, the Idoma religious belief in the life hereafter could be seen in the belief in *alekwu*, ancestral spirits. When an Idoma person dies after living a morally sound life, died at a ripe old age and have been giving complete funeral rites, he or she transmigrates and joins the communion of ancestors. Of all spiritual realities, ancestors are the closest to the Idoma people through which they offer worship to *Ôwôicho*, God the Supreme Being. Ancestors, contrary to the postulations of the pioneer scholars of African Traditional Religion, are not worshipped but venerated and they are channels through which the Idoma person and mind can reach out to *Ôwôicho*, God the Supreme. *Alekwu*, ancestors are referred to as the living-dead because of the physical ceasation of life and the continuation of life in the spiritual realm. This of course buttress the fact that the Idoma people believe in the immortality of the soul and the existence of life after our physical stay in the universe.

According to Quarcoopome (43), ancestors are central in the traditional religious beliefs of the different African societies. They ancestors are believed to have acquired extra-human power in the afterlife. They can intervene in the lives of the living members of society. They act as intermediaries. They are the unseen presidents at family and community meetings. They are the custodian of morality of the Idoma communities, and they are venerated and not worshipped. They are venerated but not worshipped. It was a misconception from the pioneer scholars and researchers that they are worshipped. Of all spiritual realities they are the closest to man and they act as intermediaries. Worship and prayers are offered to the Supreme Being through them. They are remembered periodically at festivals. They are the closest to man and they act as intermediaries between God and man. They are the custodian of morality, and they enforce morality through rewards and punishments. They are the unseen chairmen of family meetings. They are concerned about a sane society. They are the police men of traditional African Societies. Ancestors are remembered in diverse ways. They are persons that have lived morally sound lives. As a result of the good lives, they have lived those living physically remember them by giving names of their children to them. Giving names to children of ancestors is a sign of appreciation to them for living a good life and encourage those living to do the same. These names convey religious meanings. There is a relationship because they are the custodians of morality. They are interested in a morally sound society. They are the ones that enforce morality in society, the worldview of the Idomas as it relates to the universe could believe in them as the enforcers of morality. (Daniel 149)

Allam (120) and Daniel (144) were definite when they posited that the African society observe a worldview of dualism of existence which is physical and spiritual, the former being rooted in the culture and traditional religion. In support of the above views about the philosophical foundation of Idoma Traditional Religion, Mbiti (118) and Makumba (166) note that Africans are 'notoriously religious' and religion has such a grip on their entire life that it is not always easy to isolate it. Consequently, he maintains that an understanding of the people requires knowledge of their religion. This applies even to their thinking because:

> "Philosophy of one kind or another is behind the thinking and acting of every people, and a study of traditional religions brings us into those areas of African life where, through word and action, we may be able to discern the philosophy behind". Makumba (166)

Makumba, citing Mbiti, insists that religion "has dominated the thinking of the African peoples to such an extent that it has shaped their cultures, their social life, their political organisations, and economic activities... religion is closely bound up with the traditional way of African life, while at the same". (66-67) Religion, therefore, according to this position, occupies a special place in African ontology for it defines the world of the African man and woman. People apply their religion to their social, emotional, economic, intellectual, and spiritual life. According to Anyebe (580), it is for this reason that religion has been understood to give African peoples, including the Idomas, a way of understanding the world in which they live and is responsible for cultivating the whole person. And under the influence of religion, the great ideas of the people concerning moral life, cultural achievements, social organization and institutions, political systems and the building of their past civilizations were enunciated. The expression of this thought and ideas are to be found in proverbs, riddles, sayings and culture of the people. These are the ones in which the wisdom of the people is enshrined and many of them are also religious. According to Banja, culture influences the belief system and worldview of the society in many ways, including the causes of illness or disability, and what a person does when she/he is ill or disabled is another cultural artefact (96). This worldview underlies the perception and attitudes towards congenital anomalies.

In general, the findings in this research elucidated negative perceptions underlying the various versions of the myths and cultural beliefs about the causes of congenital anomalies, which is consistent with the report by Mukushi et. al. (103), Although the widely held views that avenging spirits, witchcraft and/or punishment from either God or the ancestors for wrongdoing such as "disobeying a taboo" and the flouting of social conventions might be responsible for congenital anomalies /disability could be regarded as a misconception, there is an ethical sense in it which ensures respect and observance for societal norms and family moral values. In this sense, the fear of having a child with congenital anomalies could make families to avoid acts that are considered immoral and capable of invoking curses, and the society will be good for it. Again, it is important to note, however, that these belief system about the causes of disability are the basis of how communities treat individuals with disabilities together with their families (Miles 653).

While some of the participants demonstrated poor understanding of congenital anomalies and their causes, a few others had little knowledge on congenital anomalies and their causes, which were centred on myths, or superstitions as expressed by similar findings in Ghana (Bello et al. 5), Kenya [Dellicour et al. 47], and Iran [Masoumeh et al. 44), indicating the societies' shared-deep rooted cultural beliefs and perceptions on congenital anomalies as mainly mysterious circumstances associated with supernatural impressions. Some previous studies held that this may reflect the influences of differences in religions, tradition, norms as well as education and exposure relating to congenital anomalies across societies (Taboo 462; Obu 5; Prajapati 33; Fida 1367; Ekwere 27; Eluwa 29; Gill 1016; Mashuda 6; Rozendaal 885; Saleh 173). Misdeeds of family members was regarded the main cause of a congenital anomaly. Ogechi and Ruto reported that the family can be punished for doing something wrong with a disabled child (78). In such circumstances, it was common to blame the mother, as propounded by Teferra (82). According to Omiegbe, when the mistake of the family member is thought to be very bad, a child is born deaf or mute to keep them from telling the family secrets (70).

Blaming the women as the complicit, although not exclusively so, for children's congenital anomalies in traditional stories of the immoral behaviour, possibly commensurate with their generally viewed lower status in African society and their roIes as caregivers and managers of the homestead, as noted by (Bunning et al 1863). The perceived improper relations which was explained to invoke a "curse", or punishment from dead ancestors ("âlēkwu") which afflicted the perpetrator through the birth of a malformed child, as well as "inappropriate relations" which also extended to sickness in the child, are all beliefs anchored on cultural or traditional worldview. This also applies to the view of improper behaviour towards someone with a disability being perceived as a different type of transgression capable of bringing forth a curse that would affect an unborn child. For example, laughing at someone because of their condition or appearance was thought to affect the perpetrator's own offspring eventually.

The narrative of supernatural causes of congenital anomalies such as witchcraft, and/or parental (mother's) improper relationships as enunciated agrees with other studies done in other Sub-Saharan African nations, such as Kenya (Monk and Lee 109), Zimbabwe (Mupedziswa & Jackson 29) and Botswana (Dart 135). Attributing the child's condition to some form of malevolent, preternatural force, by reference to demons, evil spirits and witchcraft, contributed to the view of disability as both undesirable and unacceptable, and have some strong, negative connotations capable of relegating people with congenital anomalies to the lower esteem (Raman 48). Whilst they had these views, they also believed that supernatural forces still cause some types of disabilities. Needless to emphasise, therefore, the strongly held belief about the relationship between illness/disability and supernatural forces, based on the people`s traditional and religious belief system. Haihambo and Lightfoot (10) observed that disabilities in most instances are interpreted culturally and likewise the solutions are found within the cultural spectrum. However, even if the idea behind the traditional remedy is done with goodwill, it is a risk to the child`s health considering hygienic issues and complications that may results from taking the remedy in its concentrated form.

The various harsh social reactions exhibited in this study towards congenital anomalies was against the backdrop of perceived challenges of living with and caring for someone with a disability and indeed living with a disability, as well as social acceptance and inclusiveness, which are typically related to the burden of care and stress, and discrimination and stigmatisation, respectively. As observed by Nimbalkar et al (5), some people even deliberately avoid close interaction with the immediate family members of children with congenital anomalies or disabilities, leading to social exclusion. Yeo (588) puts it more succinctly when he posited that that children with disabilities are discriminated against from birth, and this goes on for a lifetime. One could attribute discrimination against congenital anomalies to the general community perception on disability. Social exclusion includes denying children with disabilities services enshrined in the constitution, including deliberate negligence of provisions by facilities to cater for some disabilities, which constitutes a clear violation of their rights. Mukushi (103) remarked that most government institutions (schools, district offices, etc.) are not disability friendly, as they do not have ramps for wheelchairs and the toilets are not built to disability specifications. A combination of these system shortfalls and the traditional and religious perceptions influencing officials operating in institutions, children with disabilities often find themselves continuously struggling to access services.

Mbah-Ndam (250) explained that congenital anomalies are regarded as punishment from the gods or bad omens, and hence affected people are rejected or abandoned. Like Groce (7) suggests that if change is to take place, it should start with making local people understand that their opinions are not applicable worldwide and may need to be reviewed. It was admitted in this study by the participants that people with congenital anomalies are often referred to in a derogatory manner; neglected in terms of basic human needs and excluded from socialisation activities both at family and community level. Not only were interactions with the affected child described as showing a lack of human warmth and regard, thereby assigning the child to a sub-human class, the families of persons with disabilities also experienced stigma, isolation, and rejection, and often lived with stigmatised grief. Individuals with congenital anomalies sometimes received pity from their communities, but generally not a sense of inclusion or acceptance.

The implication of associating congenital anomalies with a sense of worthlessness or uselessness is that there is little sense of a need to invest in persons with disabilities, particularly in family or community settings. According to Kermanshahi, many parents will rather prefer the institutionalisation of children with disabilities, for example, a special school where there are experts and facilities to take care of this child or where nobody will laugh at and tease the child as all children will have a disability, thereby shifting their caregiving responsibilities to the state or private sector to remove the shame placed on them placed by their communities (317-326). However, the implication suggests that parents and communities lack the necessary skills and support to raise children with disabilities in their respective communities, or that they feel their children will have a better life raised in an environment that accepts their children. These admittance stands in sharp contrast to Groce's observation that that a community with positive practices towards people with congenital anomalies may provide positive models of intervention that are likely to be in line with universally accepted standards. (7) Thus, it can be deduced that when communities hold negative notions about congenital anomalies, these may provide negative models for intervention.

Certainly, discussing the ethical aspects of stigmatisation is important. Stigmatisation refers to the process of labeling and devaluing a person or a group based on certain characteristics, behaviours, or attributes that are perceived as different from societal norms. Stigmatisation raises various ethical concerns, particularly regarding the treatment and inclusion of individuals who are stigmatised. Ethical principles, such as respect, equality, justice, and autonomy, should guide our actions in addressing and preventing stigmatisation. It's crucial to foster a more inclusive and compassionate society that values the diversity of its members.

Stigmatisation of persons with disabilities raises significant ethical concerns as it often contradicts key moral principles such as respect, autonomy, dignity, justice and equality, Non-maleficence and beneficence. The perception of the nature and causes of congenital anomalies could explain how these conditions are managed traditionally. For instance, the proposition to seek faith healing can be ascribed to the religious aspect of belief in the cause of congenital anomalies, as noted by Chitereka (91) who observed that disability generally is religiously interpreted. Whilst this interpretation has its own effects (Miles 654), joining the apostolic sect in search of cure is also dangerous to the child, as it violates his autonomy of choice. Some caregivers confidently said that they do not adhere to prescriptions and advice from medical staff because of their apostolic beliefs. This endangers the child as withdrawal from daily routines that are medically proven may worsen the disability.

From the perspective of ethical consideration, ethical responsibility involves promoting awareness and education about the rights and capabilities of individuals with disabilities. Society has a duty to reduce ignorance and foster empathy. It will be of utmost ethical importance to support legal protections against discrimination and stigmatisation of people with disabilities. Laws and policies should be in place to safeguard their rights and ensure equal access to opportunities. Finally, ethical organisations and institutions have a social responsibility to create inclusive environments and practices that respect the abilities and potential of individuals with disabilities.

According to some participants, the traditional ways of therapy include applying traditional medicines and consulting traditional healers. While participants claimed in some instances it had worked, it is important not to ignore the risk and dangers it poses to children. Children are at risk of overdose of traditional medicines and sundry complications. This however is testimony to the fact that traditional and cultural beliefs pose a risk to children with disabilities, mainly because they lack autonomy since they cannot make their own choices regarding how they want to seek help and services, instead the community and parental beliefs are key.

Some of the ways the index child with congenital anomaly is treated lacks moral flavour, making some participants to prescribe avoiding unfriendly and intimidating environments. However, avoiding emotional suffering by avoiding provocative comments also affects children with disabilities, as they grow up lonely and being “the cause” of family shame and feeling of sin (Chitereka 92).

5. Conclusions

The seminar concludes that one of the major challenges caregivers of children with congenital anomalies are facing is discrimination. Lack of acceptance of congenital anomalies as an inevitable and natural occurrence by community members cause discrimination. Evidence suggests that the religious and cultural beliefs on the causes of disability influence discrimination. Congenital anomaly is associated with spiritual or supernatural forces hence the treatment of people with congenital anomalies in general is also guided by religion and cultural/moral beliefs and practices. Understanding the cultural and moral beliefs/practices towards children with congenital anomalies is vital for providing them with appropriate care, support, and opportunities. Moral and traditional understanding of congenital anomalies also influences coping mechanisms caregivers of children with congenital anomalies employ.

6. Recommendations

To lessen the effects of different moral and cultural practices and beliefs, there should be efforts from the government, NGOs, the religious organisations and communities in redefining congenital anomaly and in adopting the medical model of congenital anomaly. There is need to conduct awareness raising campaigns in communities on disability. The aim should be on making the community appreciate different pre-natal, natal and post-natal causes of disabilities. It is also important to raise awareness on available services at government institutions like health institutions and social welfare organisations. A deep understanding of different disabilities and how they are managed will go a long way in shifting perceptions and beliefs towards congenital anomaly and hence improve the manner in which children with congenital anomalies are treated. It has been observed that current programmes are mainly concerned with the rehabilitation of the child in some countries, unfortunately the caregivers and families are left out in these. However, the wellbeing of the caregiver is directly related to the quality of support they provide to children. Strategies like organising counselling sessions for the caregivers and parents, and capacity building workshops on disability for caregivers could be useful. It is also necessary to create a system that allows and encourages continuous professional development for the frontline service providers so that they keep up to date with new policies and new practices and that they continually develop and sharpen their expertise, thus improving the provision of care for children with congenital anomalies.

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