

RESEARCH

Open Access



Beliefs and perceptions towards congenital anomalies in Dilla town, Gedeo Zone, Southern Ethiopia; a qualitative study

Addisu Getnet^{1*}, Zerihun Figa¹, Desalegn Tarekegn¹, Rediet Gido¹ and Getanew Aschalew Tesfa²

Abstract

Introduction Morbidity and mortality associated with congenital anomalies are higher in low-income countries. People's knowledge, beliefs, and attitudes towards congenital anomalies vary from community to community. In some communities, it is believed to be untreatable and the burden remains devastating. Studies addressing the societal perspectives were scarce, therefore this study aimed to explore beliefs and perceptions in the community about congenital anomalies.

Methodology This study was conducted in Southern Ethiopia, Dilla town from September to November 2023. A qualitative study with a community-based exploratory study design was implemented. A total of 33 participants who were selected conveniently among permanent residents of Dilla town were included. Data were collected using face-to-face in-depth interviews and focus group discussions. The collected data were transcribed verbatim and translated into the English language. Data analysis was implemented thematically using Open Code 4.03 software. Finally, the result was presented descriptively based on the themes that emerged. Trustworthiness was ensured throughout the data analysis.

Result In this study, most participants poorly understood congenital anomalies. God's punishment, curse, parents' sin, magical practices and evil spirits, illness, lack of pregnancy care and contraceptive pills were the believed causes of congenital anomalies. The burden of congenital anomalies dismantles the social, economic, and psychological dimensions of the life of parents. In addition, the study identified attitudinal variations and doubts about treatment outcomes and prevention strategies of congenital anomalies.

Conclusion This study highlights that people's perceived knowledge, beliefs, and awareness of congenital malformations were limited to socio-cultural and religious roots. Understanding beliefs and perceived knowledge would be significant in planning risk-reduction strategies. Hence health education, behavioral change communications, and information dissemination strategies should be strengthened at each community level.

Keywords Community, Perception, Congenital anomaly, Southern Ethiopia

*Correspondence:

Addisu Getnet
Addisuge@du.edu.et

¹Department of Midwifery, College of Health Sciences and Medicine, Dilla University, Dilla, Ethiopia

²School of Public Health, College Of Health Sciences and Medicine, Dilla University, Dilla, Ethiopia



© The Author(s) 2024. **Open Access** This article is licensed under a Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License, which permits any non-commercial use, sharing, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if you modified the licensed material. You do not have permission under this licence to share adapted material derived from this article or parts of it. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit <http://creativecommons.org/licenses/by-nc-nd/4.0/>.

Introduction

Congenital anomalies (CAs) refer to structural or functional abnormalities, including metabolic disorders that arise during intrauterine development. These anomalies can be detected prenatally, at birth, or later in life [1, 2]. Although the exact cause of CAs is not known, genetic, nutritional, infectious, and environmental factors have a significant contribution to the occurrence. CAs cause serious morbidity, mortality, and long-term disability in children. Some CAs can be prevented through vaccination, supplementation of folic acid or iodine through fortification of foods, and adequate care before and during a pregnancy [1, 3, 4]. Globally, 240,000 newborns die within 28 days of birth due to CAs. Around 8% of child death under the age of 5 years is caused by CAs [3, 5]. In east Africa, the proportion of structural CAs is 4.54 per 1000 live births [6]. In Ethiopia, 21% of stillbirths and 4.08% of neonatal deaths are associated with CAs [7, 8].

People's perception of CAs varies from society to society. Social, cultural, and biomedical-sourced beliefs on CAs are prevalent in many low- and middle-income countries. Superstitious beliefs towards CAs are held in different settings and are posing challenges for parents [9, 10]. Many people think that CAs is the result of punishment sent from God for a parent's sin. Others also perceived that CAs occur if a woman eats culturally forbidden food during pregnancy [11, 12]. Similarly, others believe that CAs occur when a mother faces a life-threatening condition in the antepartum period. A study done in Kenya revealed that women think that CAs may have resulted when a woman engaged in sexual relations outside of her marriage and unfaithfulness [11, 13, 14]. People in Brazil think that CAs result from tobacco smoking, drugs, alcohol, and serious genital infections [15]. Study participants in the Amhara region believed that the causes of CAs are parents' sin, history of use of contraceptive pills, exposure for fertilizers (used for crop development), and use of un-prescribed drugs during pregnancy [16].

Medical and surgical treatments can be effective for certain types of health conditions, but due to limited awareness among parents and communities, many children were not receiving the necessary medical and surgical care [3, 17, 18]. Children born with CAs are often neglected either because their families feel ashamed and keep them hidden from society or because their parents are unaware of where to seek proper care [11, 19]. The experience of raising a child with a congenital anomaly can have a significant psychosocial impact on individuals. Women who have a child with a CA often experience emotional distress, self-blame, and a sense of unacceptance. Mothers of children with congenital defects are frequently stigmatized and held accountable for their child's condition [20–22]. Caring for children with special

needs causes parents much suffering. For children in hospitals, the financial burden of receiving treatments poses grave obstacles [17, 23, 24].

Understanding societal views, beliefs, and perceptions towards CAs is essential for implementing public health interventions. It is also helpful to strengthen preventive strategies that can reduce the occurrence of CAs and minimize their negative impact [16, 25, 26]. In Ethiopia, where multicultural communities are present, only limited evidence is available in Amhara region, northern Ethiopia. In southern Ethiopia, there are different ethnic groups that have distinct socio cultural identities and practices. Hence, a variation in the socio cultural beliefs and practices among the Amhara and the southern regions would justify the need to conduct similar study in the southern region of the country. Therefore, this study aimed to explore the community's beliefs and perceptions towards CAs in Gedeo zone, southern Ethiopia. The results of this study would be crucial in gaining a deeper insight into the level of awareness within the community regarding CAs.

Methods and materials

Study area and period

The study was conducted in Dilla town, South Ethiopia, from September to November 2023. Dilla is located 356 km away from Addis Ababa, the capital city of Ethiopia, and 86 km away from Hawassa, the capital of Sidama regional state. Dilla is the capital of the Gedeo zone, which is one of the trading and cash crop centers in southern Ethiopia. The area is 135 km², which accommodates 102,624 people, among whom 50,286 (48.9%) are males and 52,338 (51.1%) are females. The town has 9 kebeles under 3 sub-cities. There are two (1 public teaching and 1 private primary) hospitals, 2 health centers, and 16 medium private clinics in the town. Dilla University is also found in the town and provides academic, research, and community services for the surrounding societies. According to EDHS 2016, under five mortality was estimated to be 88/1000 live births, and infant mortality was 65/1000 live births. In the study catchment, the leading causes of neonatal mortality are neonatal sepsis, low birth weight, birth asphyxia, jaundice, and congenital malformations [27, 28].

Study design

A qualitative study with a community-based exploratory study design was implemented to explore beliefs and perceptions in the community towards CAs.

Source population

All residents of Dilla town.

Study population

The study populations comprised residents of Dilla town who were available during the data collection period.

Inclusion and exclusion criteria

All residents of Dilla Town were included in the study. Community members who resided in Dilla town for less than 6 months were excluded from the study. Also, those who were under 18 years old were excluded.

Participant selection and sampling procedure

Study participants were selected from residents of Dilla town. Participants were selected using community centered convenience sampling, where participants are chosen because they are easily accessible to the researchers. Those individuals who were easily accessible in their villages were approached door to door individually. For the in-depth interview, 21 participants were recruited and underwent interviews. In addition, the researchers recruited focus group discussion participants who could provide detailed information from different backgrounds. A total of 12 discussants were recruited for the focus group discussion in two groups each with six participants. Before conducting interviews, participants were informed about the purpose, risks, benefits, and rights of participants. Informed consent was obtained from participants. The interview continued until the data saturation was achieved and a total of 33 participants were included in the study for both interviews and focus group discussions.

Data collection method and procedures

Data were collected using face-to-face, in-depth interviews, which were guided by an interview guide. An interview guide was prepared in English and translated into Amharic and local Gede'uffa languages. An interview guide was prepared by a team of researchers based on the scientific merit of the qualitative study and the objective of the study. The researchers reviewed different literature to develop the tool. The data collection was conducted by Amharic (the working language of the country) and Gede'uffa (the local language of the Gedeo Zone). In-depth interview participants were approached in the community door to door. Focus group discussions with two rounds each with 6 participants were involved. Selected Focus group discussions participants were taken to a suitable place where they could speak freely and comfortably. Both male and female participants were involved in the Focus group discussions. The moderator controls the discussion to cascade without dominance. All responses of respondents were recorded using an audio recorder. Once the interview began, the interviewer was deeply probing the interviewee to widen the flow of ideas. Before conducting actual data collection, a

pilot interview was conducted to test the interview guide. Data was collected by those collectors who had a master's degree in maternity and neonatal nursing and were trained in qualitative data collection methods.

Trustworthiness

To ensure trustworthiness, the criteria of credibility, transferability, dependability, and conformability were considered in each step of data analysis. Credibility was ensured through prolonged engagement with the data and building trust with participants. Field notes were taken in each step of data collection, and peer debriefing was made to confirm valid findings that can improve quality. Transferability was ensured through thick descriptions of findings gained from different data collection methods with sufficient details. Dependability was considered to assure the study procedure replicated with consistent results. Careful data collection techniques were implemented, and an audit trail from the outside reviewer was considered. Confirmability was ensured by following scientific data collection, analysis, and reporting procedures to make the process free of bias. Audio recording and transcription files were kept safe and confidential with backup drives on password-protected computers and emails. Files can be accessed through a formal request from the authors.

Data processing and analysis

The data collected from the in-depth interview and Focus group discussions were transcribed verbatim and translated into English. Translations and transcriptions were cross-checked for accuracy and consistency. Data analysis was implemented thematically using Open Code 4.03 software. The translated data were entered into open-code software after careful reading line by line. Inductive coding was applied. Responses of individual translations were read line by line and represented by codes. All responses in the sentences and paragraphs were coded, and a list of codes was identified. Code definitions and dictionaries were prepared for the final refined codes. Categories/subthemes were developed from interconnected codes. The final refined themes were named and described. Finally, the thematic analysis result is displayed based on the ideas and concepts described in each theme. Similar repeated responses were identified and coded in the same group. The codes were categorized, and themes were merged. Themes were generated from several combined codes. Finally, the researchers wrote up the descriptive summaries presented to the final themes, explaining the perceptions and beliefs towards congenital anomalies.

Table 1 Socio demographic characteristics of participants

Variables	Category	Frequency	Percentage (%)
Sex	Male	24	72.72
	Female	9	27.27
Age	< 20	2	6.06
	20–35	21	63.63
	> 35	12	36.36
Marital status	Married	18	54.54
	Single	11	33.33
	Others ^a	4	12.12
Occupational status	Housewife	8	24.24
	Government Employer	14	42.42
	Merchant	6	18.18
	Student	2	6.06
	Others ^b	3	9.09
Education level	No formal education	3	9.09
	Primary	7	21.21
	Secondary	9	27.27
	College and above	14	42.42
Religion	Orthodox	17	51.51
	Protestant	10	30.30
	Muslim	6	18.18

^a divorced ^b daily labor

Result

Socio-demographic characteristics of participants

The majority of the respondents were males 24(72.72%). The age of respondents ranged from 19 to 58 with the median age of 33 years. More than half of the respondents were married (51.51%). More than half of the participants were orthodox by religion (51.5%). (Table 1)

The final result of the thematic analysis of the qualitative data unveiled four compelling themes: perceived knowledge and experience, causes of congenital anomalies, burden of congenital anomalies, and attitudes and beliefs towards congenital anomalies. All the findings in each theme are described as follows:

Theme 1- perceived knowledge and experience about congenital anomalies

The majority of participants described CAs as a child being born with an illness, dysfunction, or a missing body part. They perceived malformations confined to hands, legs, and eyes.

“If some part of the body is missed or malformed from the normal structure it is a congenital anomaly: such as a child with paralyzed legs, undifferentiated fingers or defective eyes” (IDI, a 34-year-old male respondent).

Participants were asked about exposure to CAs. Most had not observed any anomalies firsthand and relied on information from other people, mass media, and social media. They felt that community-based health education

and information dissemination programs were lacking. These inadequate information access and provision could emanate from gaining poor public and governmental attentions. Some expressed potential frustration if they had a child with anomalies.

“I have never seen a child born with congenital anomaly but I hear from my neighbor about a child born with a very large head which is full of water” (IDI, a 26-year-old female respondent).

“I don’t know about it, I didn’t see any newborn which is malformed. I might feel frustrated and afraid to touch the child if I see a newborn with a defective body part” (IDI, a 24-year-old female).

Theme- Two: causes of congenital anomalies

The participants identified cultural, medical, traumatic, and nutritional factors as potential causes of CAs. Although the exact cause remains uncertain, cultural influences are believed to play a significant role. Additionally, the participants highlighted the impact of parental adherence to sociocultural norms on the newborn’s health outcome. They believe that curses and social disappointment would result in the birth of an anomalous newborn to the family.

“A congenital anomaly is believed to be a mark of a curse or societal disapproval. If the couple disappoints or disrespects their family, the family may sadly curse them, which is believed to potentially bring about the birth of a baby with malformations.” (FGD, a 41-year-old male).

“There is a time when Abba Gadda (community leaders) move around to visit and bless the society. If a woman puts on culturally inappropriate dressings during the Abba Gadda visit time she could have an unhealthy newborn.”(IDI, a 23 year male respondent).

Participants were asked whether CAs have relation with religious concerns. However, some participants explained that there was no religious basis for the development of CAs. Others believe that congenital anomalies are a symbol of sin in their community and that parents who violate religious codes will have a congenitally deformed kid.

“God would provide a congenitally malformed child as a punishment for sinned parents who broke religious orders” (IDI, a 31-year-old female respondent).

From the cultural perspective, there is also a belief in linking CAs with magical and evil practices. Some participants explained that magical practices applied at the individual level or to the family would harm sibling outcomes.

“If someone applies magic to a pregnant woman, it could result in the abortion of her fetus or the birth of a child with deformities. It is also believed that if a pregnant woman lived near an evil-eyed person (Buda), she might

give birth to a child with deformities.” (FGD, a 34-year-old male).

Participants in this study explained that health and safety during pregnancy could be related to the development of CAs. Disease, lack of pregnancy care, and nutritional deficiencies were believed to cause fetal malformation. In addition, some participants stated that the cause of CAs is believed to have a genetic base.

“In my view illness during pregnancy could result in congenital anomalies, for example, if the pregnant woman was affected by serious illness during her gestation, the fetal body parts might be affected and born unhealthy”(IDI, a 23-year-old female participant).

“The cause of the congenital anomaly is unknown but a problem in the diet pattern of the pregnant women would result in birth defect for instance if a pregnant woman didn't get a balanced diet her fetus might be affected by an illness that could disable fetal body parts” (FGD, a 32 years male).

Some participants in this study explained that birth control contraceptive pills would have a contribution to the occurrence of CAs.

“In my view contraceptive pills used to prevent pregnancy might cause fetal malformation in the next pregnancy. Even those post-pills used within 72 hours of sexual intercourse would increase the chance of congenital anomalies” (IDI, a 34-year-old male respondent).

Theme – 3 burden of congenital anomalies

Participants were asked to explain the burden of CAs; however, most participants explained the multidimensional burden of CAs. Participants expressed the high burden of having a congenitally anomalous child from social, psychological, and economic perspectives.

“For a woman who gave birth to a congenitally malformed baby, it is difficult to attend social events. She hears gossip and negative stories from her neighbors about her child that could discomfort the mother. In the village, the woman is called the “mother of the anomalous child” which is morally traumatic” (FGD, a 33-year-old male FGD respondent).

“Parents were insulted about their child; they heard disgusting words and felt social isolation. People considered parents as criminals and sinned” (IDI, a 25 years female respondent).

Participants also explained that the burden of having a congenital anomaly child extends to the loss of marriage as the community believes that it could recur in subsequent pregnancies.

“If a woman once delivered a congenitally defective newborn and if she got divorced from her husband by any means, she might not have the chance to marry another husband because other men fear that she could

have another anomalous child in the next birth”(FGD, a 36-year male participant).

Most participants also expressed that the burden of congenital anomalies is higher, especially in-home care. Parents might need the support of another person to feed, and care for the anomalous child at home. The financial cost that will be expended for medical care is also difficult for parents.

“Even if the child survives for years, it is difficult to access education for the anomalous child, especially in illiterate societies” (IDI, a 34-year-old male respondent).

“Let me tell you one story: Once upon a time, a child in our village was born with a deformity, and her mother sought care at the local hospital. However, the local hospital directed the child to higher tertiary care, which was over 400 km away from her home. She visited the tertiary hospital, but the hospital provided an appointment for surgical repair. However, the mother didn't return to the date of the appointment because of a financial shortage. Unfortunately, the child is still partially deformed.” (IDI, a 24-year-old male participant).

Theme – 4 attitudes and beliefs towards management of congenital anomalies

Participants were asked about the treatment of CAs and their attitude to the treatment however different options and attitudes were raised. Some participants explained that the treatment is impossible and have poor attitude to treatment outcomes. In contrast, the others had a positive attitude towards modern care. Those participants who had exposure to CAs expressed that the attempt to manage them via modern medicine didn't get a satisfactory outcome. Participants also indicated that there is a belief that medical and surgical interventions would complicate the problem rather than heal the condition. Some participants also stated that if it is believed to be God's order no intervention can produce a positive prognosis. As stated by some respondents, there is also an attempt to manage the problem through traditional medicine and religious options.

“Most anomalous babies are considered as God's gift and parents are neglected to attempt medical care. Even those minor anomalies that can be treated are kept hidden at home. Some parents would try traditional practices or accept it as god's will. It is believed that god's order cannot be managed by modern medicine” (FGD, a 41-year-old male respondent).

“In our locality, there is an attempt to manage congenital anomaly cases through traditional and religious trials. The baby will be taken to the healer man and they apply topical herbal medications or allow the child to drink leave extracted traditional drugs but no significant change was observed with these practices. As another

option, people used to have religious prayers and Holy water (Tsebel) as a treatment option" (IDI, a 35-year male respondent).

Let me tell you one story;" Once upon a time in our locality, a child with a closed anal opening was delivered. The father of the newborn makes an incision to the anus of the newborn with a blade at home to have an opening for defecation. But the child died two days after the local incision was made" (IDI, a 31-year-old female respondent).

Most participants believed that the prevention of CAs depends on the awareness of the family. Participants were also asked whether there are medications taken to prevent the occurrence of CAs. However, most participants responded that they had no information about preventive medications. Some participants also indicated that CAs can be prevented to some extent in such a way that if proper nutrition and medical follow-up for pregnant women prevention would be possible.

"I don't know whether these problems can be prevented or not, even I have no information" (IDI, a 30 years female respondent).

"It can be prevented by refraining from traumatic labor work, having a proper pregnancy follow-up and adequate nutritional care. Above all, attachment to religious faith and prayer are saviors from any adverse health outcome in the family" (FGD, a 43-year-old male participant).

Discussion

Poor knowledge of congenital anomalies

In this study, most participants poorly understood CAs. Most of the participants in this study had a limited understanding of CAs, as their knowledge was primarily based on oral narratives and talks shared by their neighbors, relatives, and friends. Participants' understanding of CAs was limited to malformations affecting the limbs and eyes of a child. Most had no exposure to congenital anomalies and reported never having seen any abnormal conditions. They also mentioned that information about congenital anomalies is not widely shared in their community. This might be due to poor governmental attention to the problems and weak community-based health education programs. This finding is similar to studies done in Nigeria and India [29, 30]. Only a few participants have information about CAs which is sourced from academic disciplines and mass media. These findings are also in line with studies done in Pakistan and Saudi Arabia [31, 32].

Socio cultural based beliefs

The finding of this study explored different beliefs perceived to cause CAs. Participants' beliefs vary regarding the causes of CAs. Many participants indicated that the occurrence of CAs is considered a sign of curse and social disappointment. It is believed that those parents

who disappoint their families or community leaders become cursed and obtain a congenitally defective child. This implies that societal loyalty to the social and family structures would have an impact on fetal outcomes [18, 33]. The causes of CAs were also believed to be due to the breaking of religious codes. Some participants explained that CAs are God's punishment in response to parents' sin. These concerns could emanate from the participants' attachment to religious codes and thoughts. Similar findings were displayed from prior review reports [33–35]. Contrary to these, other participants explained that there was no religious root for the development of CAs. As a participant stated magical practices applied among unfaithful social interactions would result in the delivery of a congenitally defective child. Similarly, some participants were believed to relate the occurrence of CAs with the presence of an *Evil-eyed* person in the neighborhood of the pregnant woman. These variations to the believed causes were sourced from people's attachment to cultural practices. This finding is congruent with prior studies in northern Ethiopia and Nigeria [16, 36, 37].

Participants in this study indicated that medical conditions during pregnancy and care and follow-ups with the pregnant mother would determine the fetal outcomes. Medical illnesses that happen to the pregnant woman would cause congenital malformations [9, 11, 16]. In addition, some participants added that nutritional deficiencies that occur during pregnancy are believed to cause congenital birth defects in the fetus. Similarly, lack of self-care and traumatic workload for the pregnant mother were believed to cause birth defects. These findings are in line with prior studies from Kenya, the Philippines, and Iran [9, 11, 38]. In this study, few participants explained that CAs would have a genetic base. In contrast, the majority believed that congenital anomalies would not have hereditary concerns [9, 18, 33]. In this study, contraceptive pills were blamed for causing congenital defects in the upcoming pregnancy. Participants believe that birth control pills including emergency post pills would contribute to fetal malformations. This finding is in line with previous reports from Kenya and Northern Ethiopia [11, 16].

Socio-economic and psychological influences

In this study, the burden of CAs was explored according to respondents' views. The social psychological and economic challenges were described. Most respondents explained that parents who gave birth to congenitally malformed child suffer social isolation and stigma. These problems could be emanated from low awareness level of the community and poor social support strategies. This tells that the need for increasing public awareness and social responsiveness to reduce stigma associated with CAs [18]. In addition, respondents explained that

parents were ashamed to take their child to social ceremonies. Gossip and negative stories heard about their child would result in a psychological crisis for the parents of the anomalous child [39–41]. People considered these cases as a sign of sin and crime, therefore, parents might consider themselves criminals and sin committers [23, 42]. The medical cost that could be wasted to treat CAs creates great economic stress [43, 44]. Difficulties to care at home and the need for additional servants who can care at home could challenge families [18, 23]. As stated by the respondents the burden of CAs extends to loss of marriage and sophisticates the life of women because in some societies CAs are believed to have a hereditary base [18]. CAs were believed to recur in the next pregnancies and men fear women who have a history of congenitally defective children.

Negative attitudes and doubts of management

Respondents in this study had different views regarding the management and prevention of CAs. Some participants explained that medical interventions would have a significant effect in treating CAs. In contrast, some explained that medical interventions wouldn't have a significant prognosis for the health of the newborn. According to some respondents, these are believed to be God's punishment and no intervention can improve these defects. This finding is consistent with the study done in Madagascar, Africa [23, 45]. Others also explained that there were traditional treatment options including cultural and religious trials. The use of traditional medicines was practiced but no significant improvement was observed in the health of the child [33]. In addition, some believe that religious prayers and Holy water could have a role in managing congenital anomalies. Participants had also contrary views on the prevention of CAs. Some participants had no clue whether it was preventable or not [32, 46, 47]. Some explained that based on the degree of defect prevention might be possible. It is also described that pregnancy care including nutritional care could prevent the occurrence of CAs.

Strength and limitations

This qualitative study could be a pioneer in southern Ethiopia where the issue of congenital anomaly was poorly addressed. Also it may serve as a pilot to a more comprehensive cross sectional study. As a limitation, due to the qualitative nature of the study and the sampling methods were prone for bias. The inability to include participants who had CAs affected children is also another limitation of the study.

Conclusion

In conclusion, this study explores perceptions and beliefs about CAs in the community. Poor knowledge and awareness on CAs, a socioculturally based understanding of CAs, the psychosocial and economic burden of CAs, and poor attitude to treatment options are key findings in this study. The knowledge and awareness about CA is poor, and their little knowledge is not based on scientific facts rather it is highly attached with superstitious, cultural and religious based beliefs. These imply that there is poor health literacy and information scarcity in the community. Hence, this study emphasizes the need for awareness raising program and social support strategies. Therefore, health education and behavioral change communications should be promoted in different settings. Health care providers should provide health education focusing on CAs for pregnant women in the antenatal care settings. Health education programs shall be strengthened in the schools and social events where people collectively meet. Moreover, different stakeholders including ethnic and religious leaders have to be engaged in creating public awareness that will foster prevention, encourage community support for parents with children who have CAs, mitigate against stigma, and encourage increasing governmental investment in care of such children. It is also essential to develop healthcare policy for children with congenital abnormalities and their families. Further studies are also necessary to assess the populace's perception, knowledge, attitude and awareness about prevention, causes, and management of CA in Ethiopia.

Abbreviations

Congenital anomaly	any structural or functional organ defect present at birth
Beliefs	what the people accept and hold as right without proof
Perceptions	what the people feel or sense about congenital anomalies
CAS	Congenital anomaly
FGD	Focus group discussion
IDI	In-depth interview
IRB	Institutional review board
STI	Sexually transmitted infections

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12887-024-05257-1>.

Supplementary Material 1

Acknowledgements

Our deepest gratitude goes to the Health Professional Education Partnership Initiative (HEPI) for providing the financial support to conduct this research. Next, it's our pleasure to acknowledge Dilla University for facilitating cooperative jobs with HEPI and creating chances that allow completing this study. Lastly, we would like to acknowledge the data collectors, supervisors, and study participants for their support in conducting this study.

Author contributions

AG conceived and designed the study and wrote the manuscript draft. RG and DT participated in the acquisition and analysis of the study. ZF and GA participated in software management and review of the drafted manuscript. All authors approved the submitted version of the manuscript.

Funding

Health Professional Education Partnership Initiative (HEPI) provided the financial support to conduct the study.

Data availability

The data pertinent to the findings of this study is available from the corresponding author upon reasonable request.

Declarations

Ethical approval

Ethical approval was obtained from Dilla University College of Health Sciences IRB (Ref.no: duchm/irb/015/2023). Participants were informed about the purpose, risks, benefits, and rights of participants. Informed consent was obtained from participants. The privacy and confidentiality of participants was assured. The data obtained from respondents were kept safe and used for this study purpose only.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

Received: 12 February 2024 / Accepted: 18 November 2024

Published online: 11 January 2025

References

1. WHO. Mngement of birth defects and hemoglobin disorders: Report of a joint who-march of demise meeting geneva, switzerland 17–19 may 2006. 2006.
2. Malherbe H, Modell B, Blencowe H, Strong K, Aldous C. A review of key terminology and definitions used for birth defects globally. *J Community Genet.* 2023;14(3):241–62.
3. WHO. Congenital disorders. 2023; <https://www.who.int/news-room/fact-sheets/detail/birth-defects>
4. Behrman ER, Kliegman MR. B H, Jenson. Nelson_textbook of pediatrics 17th edition. 2003.
5. Villavicencio F, Perin J, Eilerts-Spinelli H, et al. Global, regional, and national causes of death in children and adolescents younger than 20 years: an open data portal with estimates for 2000–21. *Lancet Global Health.* 2024;12(1):e16–7.
6. Kassaw MW, Abebe AM, Abate BB, Kassie A, Zemariam AB. Proportion of structural congenital anomaly in eastern africa; a systematic review and meta-analysis. *J Pediatr Neonatal Care [Internet].* 2020;10(2):43–50.
7. Desalew A, Sintayehu Y, Teferi N, et al. Cause and predictors of neonatal mortality among neonates admitted to neonatal intensive care units of public hospitals in eastern Ethiopia: a facility-based prospective follow-up study. *BMC Pediatr.* 2020;20:1–11.
8. Madrid L, Alemu A, Seale AC, et al. Causes of stillbirth and death among children younger than 5 years in eastern hararghe, Ethiopia: a population-based post-mortem study. *Lancet Global Health.* 2023;11(7):e1032–40.
9. Felipe-Dimog EB, Tumalak M-AJR, Laurino MY et al. Beliefs on the causes of birth defects as perceived by mothers of children with birth defects in a tertiary care hospital in the Philippines. *J Community Genet.* 2022: 1–9.
10. Emordi VC, Osifo DO. Challenges of congenital malformations: an African perspective. *Annals Pediatr Surg.* 2018;14(1):1–7.
11. Stephanie Dellicour1, Phillips-Howard2, MD. 3. Exploring risk perception and attitudes to miscarriage and congenital anomaly in rural western kenya.
12. Christou A, Alam A, Hofiani SMS, et al. How community and healthcare provider perceptions, practices and experiences influence reporting, disclosure and data collection on stillbirth: findings of a qualitative study in Afghanistan. *Soc Sci Med.* 2019;236:112413.
13. Andrews EE, Williams JL, VandeCreek L, Allen JB. Experiences of parents of children with congenital limb differences with health care providers: a qualitative study. *Rehabil Psychol.* 2009;54(2):217.
14. Rosenthal E, Biesecker L, Biesecker B. Parental attitudes toward a diagnosis in children with unidentified multiple congenital anomaly syndromes. *Am J Med Genet.* 2001;103(2):106–14.
15. Garcias GdL, Schüler-Faccini L. The beliefs of mothers in southern Brazil regarding risk-factors associated with congenital abnormalities. *Genet Mol Biology.* 2004;27:147–53.
16. Taye M. Parents' perceived knowledge and beliefs on congenital malformations and their causes in the amhara region, Ethiopia. A qualitative study. *PLoS ONE.* 2021;16(11):e0257846.
17. McDougall L, Kennedy J, Coombs C, Penington A. The psychosocial impact of congenital hand and upper limb differences on children: a qualitative study. *J Hand Surg Eur Vol.* 2021;46(4):391–7.
18. Kimotho SG, Macharia FN. Social stigma and cultural beliefs associated with cleft lip and/or palate: parental perceptions of their experience in Kenya. *Humanit Social Sci Commun.* 2020;7(1):1–9.
19. Ahadome N. Factors associated with birth defects in children of teenage mothers in the agona east district of the central region, ghana. 2020, University of Ghana.
20. Ahiabe D. Adaptation experiences of family caregivers of children with congenital birth defects in the accra metropolis. University of Ghana; 2020.
21. Mazibuko TB, Ramukumba T, Ngwenya N. The lived experiences of mothers who have children with congenital abnormalities in the gert sibande district. *CURATIONIS J Democratic Nurs Organisation South Afr.* 2022;45(1):2250.
22. Likumbo N, de Villiers T, Kyriacos U. Malawian mothers' experiences of raising children living with albinism: a qualitative descriptive study. *Afr J Disabil (Online).* 2021;10:1–11.
23. Nayeri ND, Roddehghan Z, Mahmoodi F, Mahmoodi P. Being parent of a child with congenital heart disease, what does it mean? A qualitative research. *Bmc Psychol.* 2021;9:1–8.
24. Alqarawi N, Alhamidi SA, Alsadoun A, Alasqah I, Mahmud I. Challenges of having a child with congenital anomalies in Saudi Arabia: a qualitative exploration of mothers' experience. *Front Public Health.* 2023;11:1111171.
25. Emordi VC, Osifo DO. Challenges of congenital malformations: An african perspective.
26. Glinianaia SV, Morris JK, Best KE, et al. Long-term survival of children born with congenital anomalies: a systematic review and meta-analysis of population-based studies. *PLoS Med.* 2020;17(9):e1003356.
27. CSA. Demographic and health survey Ethiopia 2016. 2016.
28. Eshete A, Abiy S. When do newborns die? Timing and cause-specific neonatal death in neonatal intensive care unit at referral hospital in gedeo zone: A prospective cohort study. *International journal of pediatrics.* 2020; 2020(1): 8707652.
29. Kar A, Dhamdhare D, Medhekar A. Fruits of our past karma: a qualitative study on knowledge and attitudes about congenital anomalies among women in pune district, India. *J Community Genet.* 2023: 1–10.
30. Lawal TA, Yusuf B, Fatiregun AA. Knowledge of birth defects among nursing mothers in a developing country. *Afr Health Sci.* 2015;15(1):180–7.
31. Alshehri Y, Salem I, Alamri Z, et al. Knowledge and attitude towards hydrocephalus among healthcare providers and the general population in Saudi Arabia. *J Family Med Prim Care.* 2020;9(12):6240.
32. Yasmin S, Siddiqia A, Rockcliffe L, Miyan J. Knowledge of neural tube defects and prevention through folic acid use among women in faisalabad, punjab, Pakistan: a cross-sectional survey. *Int J Women's Health.* 2022: 425–34.
33. Hasanuddin H, Al-Jamaei AA, Van Cann EM et al. Cultural beliefs on cleft lip and/or cleft palate and their implications on management: a systematic review. *Cleft Palate Craniofac J.* 2023: 10556656231209823.
34. Kimotho SG, Macharia FN. Social stigma and cultural beliefs associated with cleft lip and/or palate: parental perceptions of their experience in Kenya. *Humanit Social Sci Commun.* 2020; 7(1).
35. Saluja H, Asnani S, Dadhich A, Shah S, Khandelwal P, Sachdeva S. Study of myths and beliefs among the parents of a child with cleft lip and palate. *Natl J Maxillofacial Surg.* 2023;14(1):68.
36. Kanmodi KK, Akinloye AG, Olukoya EO, Sulaiman AO, Adeniyi OR, Fagbule FO. Is cleft lip a spiritual thing?—a pilot study of beliefs and attitudes amongst some future primary health care workers in ibadan metropolis, Nigeria. *Int J Trop DISEASE Health.* 2017;22(4):1–7.
37. Oginni FO, Asuku ME, Oladele AO, Obuekwe ON, Nnabuko RE. Knowledge and cultural beliefs about the etiology and management of orofacial clefts in Nigeria's major ethnic groups. *Cleft Palate-Craniofacial J.* 2010;47(4):327–34.

38. Borjali M, Amini-Rarani M, Nosratabadi M. Nonmedical determinants of congenital heart diseases in children from the perspective of mothers: A qualitative study in iran. *Cardiology Research and Practice*. 2021; 2021.
39. Kyarimpa R, Muramuzi D, Muhwezi T. Care giver's experiences of having a child with hydrocephalus: A phenomenological study at ruharo mission hospital. *MedRxiv*. 2020: 2020.06. 25.20139683.
40. Lian X, Jia Y, Wang L, Wang Y, Li X, Jia H. Mothers caring experiences of children with congenital hand or foot abnormalities: a phenomenological study. *J Pediatr Nurs*. 2022;62:e164–9.
41. Tekola B, Kinfe M, Girma F, Hanlon C, Hoekstra RA. Perceptions and experiences of stigma among parents of children with developmental disorders in Ethiopia: a qualitative study. *Soc Sci Med*. 2020;256:113034.
42. Kar A, Dhamdhere D, Medhekar A. Fruits of our past karma: a qualitative study on knowledge about congenital anomalies among women in pune district, India. 2022.
43. Morsi AO, Yehia AM, Badran AS, Khattab NMA. Challenges and concerns faced by parents of a group of Egyptian children with cleft lip/palate: a qualitative study. *BMC Oral Health*. 2023;23(1):1011.
44. Aksenov LI, Fairchild RJ, Hobbs KT, Tejwani R, Wiener JS, Routh JC. Financial toxicity among individuals with spina bifida and their families: a qualitative study and conceptual model. *J Pediatr Urol*. 2022;18(3):290. e1-290. e8.
45. Mandrano NAJV, Tosa Y, Kuroki T, Sato N, Yoshimoto S. Beliefs and perceptions that impair cleft care treatment in Madagascar: a qualitative study during humanitarian mission. *J Cleft Lip Palate Craniofac Anomalies*. 2017;4(2):149.
46. Kari J. Folic acid awareness among female college students: neural tube defects prevention. *Saudi Med J*. 2008; 12(29).
47. Zeru T. Understanding awareness and consumption of folic acid among reproductive age women in bahirdar town, North West Ethiopia. A qualitative study.; 2020.

Publisher's note

Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.