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Making sense of the unexpected: neural tube defects in Ethiopia

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Abstract
Neural tube defects are severe birth defects with visible and devastating malformations in babies, and can lead to death before, during or soon after birth. Neural tube defects are preventable, and in many countries there has been an increasing 'responsibilization' of pregnant women in terms of taking folic acid before and during pregnancy to avoid these malformations in their babies. In low-income countries, many women are not in positions to plan pregnancies, access appropriate information and allocate scarce resources to avoid neural tube defects. Lack of compliance with biomedical management strategies remains a challenge in many places, and, in this paper, we turn the attention to local perspectives on neural tube defects in eastern Ethiopia, where there are high number of cases. Drawing on interviews and focus group discussions with mothers, community members, health workers and traditional birth attendants, we explore why the malformations of babies lead to stigma of their families and demonstrate how local forms of responsibilization impact the families of the babies born with neural tube defects.

Keywords Neural tube defects (NTDs) · Responsibilization · Spina bifida · Hydrocephaly · Anencephaly

1 Introduction

Neural tube defects (NTDs) remain common in many low- and middle-income countries. NTDs are visible birth defects with well-known biomedical causes that can be devastating, traumatizing, and stigmatizing for families. NTDs can take different forms, such as spina bifida, anencephaly, craniorachischisis (a combination of anencephaly with a contiguous bony defect of the cervical spine), and myelomeningocele. Hydrocephalus can also be a manifestation of NTDs (but not all hydrocephalus cases are caused by NTDs) [1, 2]. NTDs can result in severe disability or death, but are largely preventable through the periconceptional intake of folic acid in the form of tablets [3] or through food fortification [4, 5]. Such insights into the causes and prevention are, however, rarely available to parents and local communities in rural areas of low-income countries. With limited access to health care and education, people may understand the causes of NTDs very differently from biomedical perspectives [6], which combined with stigma towards those who give birth to children with such malformations can be a source of resistance against interventions. Despite the role of social and cultural dimensions, it is the biomedical aspects of NTDs that have been at the center of much research. This paper shifts the attention to people's experiences of NTDs in Ethiopia.

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In recent decades, there has been increasing attention to the topic of fetal death and to 'break the silence' around women's experiences of miscarriage [7, 8]. Much of the work has emerged out of feminist perspectives to bring to 'light the grief and devastation that some women and their families experience over the loss of their unborn child' ([9], p. 379). Such research has also provided insights into how women manage their pregnancies, where compliance with biomedical management and responsible behavior are often valued as confounding factors for the outcomes of pregnancies [9].

The emphasis on individuals and their way of managing health for themselves and their children is often referred to as 'responsibilization.' Responsibilization can to some extent be empowering as pregnant women are understood as agents who are responsible for themselves and the fetuses, but at the same time, they are also seen as the ones who can endanger the health of the fetus [10]. This gives opportunity to allocate blame to women for their and their children's poor health instead of, for example, questioning their access to health care [11]. Related to NTDs, there has been a growing emphasis on family planning and the use of folic acid even before conception to ensure that babies are born healthy [12]. The attention to women's behavior prior to conception extends the responsibilization into yet other parts of their lives but does not necessarily help reduce the prevalence of NTDs.

The Child Health and Mortality Prevention Surveillance (CHAMPS) was established in eastern Ethiopia in 2017 to identify causes of death among children below the age of five. Postmortem examinations are usually offered to families who reside in the study catchment area as part of the CHAMPS project [13, 14] and through this surveillance, it emerged that NTDs are very common and cause many stillbirths in the area. This consolidates existing knowledge about the high number of NTDs in Ethiopia [15]. There has been much biomedical research on the causes of NTDs, but little is known about how people understand and relate to babies with NTDs in rural areas of Ethiopia.

Despite the growing body of knowledge about the biomedical causes and conditions of NTDs, there are limited opportunities to treat these conditions in the Ethiopian healthcare context. Efforts to introduce folic acid through family planning have not been successful and there are limited opportunities for treatment of NTDs. Surgical closure within the first 48 h is the primary treatment for NTDs to minimize the risk of infection, further damage to the central nervous system, and the severity of hydrocephalus, which approximately 85% of children with NTDs will develop over time [16–18]. Unfortunately, in Ethiopia the necessary surgical intervention is often delayed due to several factors, including late diagnosis of NTDs due to a lack of available imaging investigations such as CT scans or MRIs, a high number of home deliveries, and delays in referring NTDs cases to hospitals equipped with a neurosurgery unit. Additionally, follow-up adherence is usually poor because of the long distance to the larger referral hospital, economic constraints faced by families, and the absence of a multidisciplinary approach to manage and monitor these cases [19]. Like in other low-income contexts, there is limited support to manage the challenges of raising babies with NTDs who are not stillborn [6, 20]. These circumstances impact how women's opportunities to take responsible actions to prevent NTDs.

Considering the disturbing appearance of babies born with anencephaly or craniorachischisis and the limited opportunities for prevention and treatment, NTDs do not only affect the babies but also their families who are associated with them. In this paper, we explore how mothers of children born with NTDs, health workers, traditional birth attendants, and other community members considered the underlying causes of NTDs. Through this examination of different perspectives on why some babies are born with malformations, the paper interrogates how mothers are being made responsible for NTDs in their local communities.

2 Methods

The research took place in the CHAMPS site in eastern Ethiopia that includes Kersa, Haramaya and Harar, which is a setting with high numbers of child mortality [21]. Even though the causes and means of prevention of NTDs are well established in medical science, the categorizations of the underlying causes bear little meaning in the local communities where we conducted the research. We therefore include hydrocephalus in this study as it may be a clinical manifestation of NTD, though not all children with hydrocephalus will be NTD cases, and there are many babies born with this condition in Ethiopia [22]. In this research, we sought to consider NTDs from the perspectives of people affected by them, which required flexibility in relation to biomedical classifications.

We explored what people in this area thought about the causes of NTDs, how they understood them and the social implications of giving birth to babies with such malformations. The group of researchers collected data through semi-structured interviews and focus group discussions following a question guide that the team had prepared. Considering that child death and malformation is a sensitive topic, we used purposive sampling to identify parents who had already participated in the CHAMPS project and whose babies had been born with NTDs. Seven mothers whose babies had died with an NTD participated in the study, and the low number relates to the difficulty of finding people willing to speak about this sensitive topic. Despite only being able to interview few women who themselves had given birth to babies with NTDs, they provide important insights into the local perspectives on the causes for NTDs. The questions to mothers centered around how they found out that their baby had an NTD, how they reacted, how family and others responded, their thoughts on possible reasons for this happening to them, and other questions related to the experience. Considering the sensitivity of the topic, the researchers used local terminology and put the women's narratives at the center, while being empathetic and without attempting to discredit their narratives by providing biomedical explanations.

In addition, we supplemented their perspectives with interviews and focus-group discussions with traditional birth attendants, health workers and other central community leaders and members. We used existing networks to recruit participants, including two women who lived locally and supported mothers giving birth at home, here referred to as traditional birth attendants. Also, seven health workers who worked at health centers and hospitals were included in the study and interviewed. Finally, three focus group discussions were conducted: two of them with women (16 in total) and one with ten men. The participants for the focus group discussions were selected to represent different areas of the three sites and people in different social positions, including leaders of community-based organizations and 'lead mothers' (mothers who are selected as role models for other women and lead local groups of 39 mothers). While the sample was relatively small, these interviews enabled us to build insight into ways of making sense of NTDs in this area as the questions explored their familiarity with the issue, experiences of seeing babies with malformations, and thoughts on causes.

Some interviews were conducted in the urban setting of Harar, but most of the data collection took place in rural areas of Haramaya and Kersa. Researchers interviewed participants in people's homes, at health centers and other locations where we could ensure that participants' confidentiality could be kept. The interviews began with researchers explaining the research and obtaining written informed consent for participation and the use of the data for publication from the participants to ascertain that they were willing to discuss NTDs with us. All informants have been given pseudonyms in this paper.

The data analysis was a collaborative process where each researcher transcribed and translated the materials s/he had collected, and then a smaller team of three researchers coded the data in NVivo. The coding was deductive and based on the main topics in the interview questions, but also allowed for inductive coding in the initial round of coding. Subsequently, we agreed upon the codes before the remaining materials were coded. This was followed up with a group discussion about how to write up the findings. The sample size did not allow us to identify differences in perceptions between the urban and rural settings, and the data were considered across the three sites. The different data sources, the interviews and focus groups, were compared to explore differences in perspectives depending on who were speaking, which revealed that women who had given birth to babies with NTDs understood the causes as very different from other people in the community. This and other patterns gave us a sense of how NTDs are understood in this part of Ethiopia, which we unpack in the following.

3 God's will

Many women give birth at home without any prior visit to health facilities and ultrasound is unavailable in most parts of eastern Ethiopia, which means that malformations only become apparent upon birth and are therefore surprising both for the mother and traditional birth attendants. The sight of new-born babies with spina bifida and especially anencephaly is unsettling for mothers and others. There is no local terminology for these malformations, but people would describe the appearance of NTDs very literally in Afan Oromo (the most common language in the study area). Spina bifida was referred to as '*duuyda uree*' which translates into English as 'back with hole,' whereas in cases of anencephaly people would say '*daa`ima mataa hin qabne*' which means 'the baby who has no head' in English. Hydrocephaly was spoken about as 'big head' ('*mataa guddaa*').

The terminology people used to describe babies with different kinds of NTDs points to the seriousness of such malformations. One mother, Darartu, shared her memories of giving birth to a baby with anencephaly: 'I have seen my baby after delivery. Other parts of his body were normal, but his head was open and not full in nature.' The discomfort of remembering the sight of her baby without a fully formed head was evident during our conversation with her. Also Kimiya, an elderly traditional birth attendant who had supported women giving birth for many years, explained that mothers reacted strongly upon seeing babies born with hydrocephalus: 'the mother who gives birth to babies with a big head is shocked when they see their baby.' The same applied to women who gave birth to children with spina bifida or anencephaly.

The appearance of babies born with NTDs were disturbing to those who gave birth to them and many of the mothers turned to God to try to make sense of these malformations. Menida was a mother who had given birth to a baby with a 'big head' (hydrocephaly) and 'two holes in the back' (spina bifida). The baby was stillborn and she explained: 'I don't know how to explain what happened to my baby. God knows everything. I have never heard about or seen something similar to what happened to my baby.' Many mothers lacked familiarity with biomedical explanations and Menida could not quite understand the reason for her baby being malformed: 'I guess nothing about why this happened except that is God's will. I have never thought that there is something wrong with me. This happened because of God's will.' Many of the mothers who experienced NTDs among their babies tried to make sense of these and other aspects of life by turning to their faith, as is common in this part of Ethiopia when facing hardship.

Traditional birth attendants (local women who, in most cases, had learned skills from their relatives or neighbors) also pointed to God to make sense of some babies being born with NTDs. For example, Kedo was in her fifties and had wide experience of supporting women during delivery. She had come across cases of NTDs and explained about a baby who had been born with a hole in its back (spina bifida) and passed away shortly after: 'It is by the will of God. This might happen when the baby was in womb of the mother. We can't know about the cause. This happens by the will of God, it is only God who creates a child with normal body. It is only God who can fill the gap on the baby's back.' Both mothers and traditional birth attendants found the delivery of babies with NTDs difficult to manage, but many found consolation in knowing that the outcome was determined by God.

Religious knowledge was central to explain the malformations and, in many cases, deaths of their babies. Explanations of God determining people's lives and deaths are also common in other countries [23, 24]. However, people did not only seek explanations through God but also considered other factors to be of importance in shaping the outcomes of births, which we turn to next.

4 Natural causes

There were different views of the causes for NTDs, and some pointed to natural causes. These kinds of explanations mainly emerged among health workers, traditional birth attendants and women who had themselves given birth to a baby with an NTD. Some health professionals, like Nediya who was a midwife, were aware of the biomedical causes for NTDs: 'We know that the problem comes from deficiencies.' At the same time, she was knew that people in her community saw the underlying causes for NTDs through another lens: 'Their perception is different from that of professionals' (Nediya, midwife). The idea that nutritional deficiencies were the cause of NTDs were, as the health professional pointed out, not widespread among people in the area.

Some women who had given birth to babies with NTDs sought to understand the causes of malformations in other ways. Zeytuna was a mother in Harar who given birth a to baby with a 'big head' (hydrocephaly) and reflected on why her baby was born with such a condition:

> Sometimes I think the problem is related to something that might happen naturally and sometimes I think that it might be due to my negligence specially in relation to specific activities I did. While I was pregnant, I used to carry my elder child and sometimes I think this might have caused the problem.

Zeytuna's perception differed from health workers, and she searched for an explanation by reflecting on what she could have done wrong during the pregnancy. There were also traditional birth attendants who thought that NTDs were related to physical incidents, such as Kimiya who had delivered several babies with hydrocephalus and explained that this happened because 'of physical strike during the mother's pregnancy.' Such strikes could be through violence, falling or other accidents, which was understood to contribute to the shaping of babies' bodies.

The uncertainty about what could cause these unfortunate events meant that people did not have a singular, consistent explanation for them. Even though they considered God to have the ultimate power in these matters, the lack of certain knowledge meant that people struggled to make sense of this phenomena as the following excerpt of a discussion among women in Kersa about the causes for NTDs illustrates:

> Researcher: What do people in the community say about the cause [of NTDs]?
> Muna: To be honest, I have heard nothing about the cause.
> Meftuha: I want to clarify a thing. Birds are not responsible for paralysis but for stillbirth. When it comes to paralysis it happens when she is hit by *showla*.

> Researcher: What is *showla*?
> Meftuha: It is a type of wind. If a mother is hit by this wind, it paralyses the child. And what causes a stillbirth is the bird. But what paralyses a child is not a bird, it is wind.
> Amin: Such a problem is not common in the community. It happens very rarely. I know about a child that was born without head. People say that it happened because God is not happy with them. The community doesn't know what causes such malformations they just say, "it is a curse from God."
> Fatuma: That is all they say, they can't explain the cause since they don't have the knowledge.

This discussion highlights how difficult it was for people to make sense of NTDs. Some recognized that they lacked knowledge about the causes of NTDs, but others tried to make sense of the disease in line with their understanding of the natural world where a specific kind of wind and particular birds were factors that could impact people's health.

These varying and contrasting views on the causes of NTDs and the suspicion of sin as a factor led to rumors about the parents of babies born with NTDs, but also to tension with health workers. Many people in these communities were skeptical of the local provision of biomedical health care and it is a relatively common practice to rely on traditional birth attendants, use herbal treatments and other attempts to heal before seeking help from local health centers [25]. For those who gave birth at health centers, there was sometimes suspicion of the health workers or others having caused the NTDs, as Nediya (midwife) explained:

> Because of lack of awareness, sometimes they blame us health professionals. Since they don't have formal education, their view is very different from ours. Some people say that we have killed their child unless someone was there watching the delivery. Usually, they come with a traditional birth attendant after their effort to deliver at home failed and, in such cases, they may blame the traditional birth attendant. They think as if the damage happened during delivery.

The appearance and death of many newborns with NTDs could, in different ways, generate tension between people in these communities.

Because of the severity of NTDs, as well as the social challenges the disease generated, several of those who had experienced giving birth or encountered babies with NTDs highlighted the importance of preventing this from happening again. For example, Menida, a mother who had lost a baby during childbirth explained that she did not have sex after the 7th month of her following pregnancy to protect the baby. Another approach was shared by a traditional birth attendant, Kimiya, who suggested that the mother should avoid 'work overload and falling during the pregnancy. The mother should also be careful of the sun because the sun can make the baby lose weight in the mother's womb.' With conflicting opinions about the causes and prevention of NTDs, people responded by trying to find plausible explanations and develop practices that would ensure giving birth to healthy babies in the future. However, those who were not directly affected themselves commonly explained NTDs in a different way, which we look at in the next section.

5 NTDs as punishment

Some people in the study site thought that the parents of babies were to blame for their NTDs. People's behavior was commonly used to explain why this happened to some families and not to others. Hamdiya, a lead mother in Kersa, suggested that people in the area 'believe that there is a reason for God to bring such a curse to the family. Some say that God is not happy with the family.' This assumption of a relationship between people's behavior and babies' malformations was common, which Zako, a 37-year-old farmer, suggested:

> If a mother is not compliant with what the society does and if she creates trouble in her neighborhood, the community may curse her. If she shows sign of being despotic and causes harm to poor families, or if she is not obedient to what elders say, the case [NTDs] will happen to her.

Such narratives suggested that God punished those who did not behave appropriately. Differently from the mothers who had given birth to babies with NTDs and referred to God's will as unknowable, these narratives pointed to God's will in relationship to immoral behavior.

Although the health and wellbeing of babies and children was portrayed as the responsibility of women, malformations were not only blamed on the behavior of mothers. Some explained that fathers or other family members could also cause NTDs through their behavior. Ayantu, a mother of five children, shared her view on how the responsibility for such outcomes was understood in her community:

> Many people believe that the husband or wife or their families have done something wrong which leads to the problem. They think that the problem is the result of their sin. The community says that the child is born with malformation because its family has sinned against God. Some say that the father is getting payment for what he has done. Elders advise that people shouldn't laugh at someone who has physical problems. If they do so, it can happen to their family.

There was a tendency to associate the causes of NTDs to bad behavior, and different relatives of the baby could be perceived as the culprit. This meant that parents and relatives of babies with NTDs were subject to, first, the challenge of giving birth to a baby with malformations and, in the case of survival caring for baby with serious health challenges, and second, to the suspicion of having done something to deserve to be punished in this way.

NTDs were often a source of rumors because of the perceptions that it was caused by inappropriate behaviors or sin. Nediya, a midwife, explained that people 'say that it is a curse and that this happened to her [the mother] because she is not kind to her husband or his mother.' This was confirmed by a mother of eight children and in her late 30s who suggested that giving the birth to a baby with any kind of NTD was a source of shame for the mother and that: 'people in the community talk about what have happened to her' because the 'community gets so curious about what the family has done to face such a tragedy.' These ideas that the families of babies with NTDs were being punished by God for misbehaving became an additional burden to carry.

As a result of the rumors and suspicion of wrongdoing, women who gave birth to a baby with NTDs did not speak openly about it. Several families had hidden the babies who survived the birth to avoid rumors: 'Such parents do not want to show their children. They ask health professionals not to show it to anyone' (Nediya, midwife). In some cases, parents kept babies with hydrocephaly or spina bifida inside their house for months after giving birth. When parents eventually took their babies outside, Hamdiya explained that 'people are shocked when they see the baby.' The uncertainty around the causes of NTDs and the stigma that the parents and their families could experience, meant that these malformations not only affected the babies themselves but that the rumors about sin and bad behavior influenced families' relationships in the community.

The lack of reliable knowledge about the causes for NTDs contributed to the different perspectives on how people's behavior could influence babies' health. To many, this meant that God's will was a direct response to bad behavior, pointing to a form of responsibilization of everyday practices and especially women's behavior, and not only how they took care of their health. This differs from the responsibilization that emerges from lack of compliance with biomedical management [26].

6 Discussion

This paper has touched upon some of the perceptions related to NTDs in eastern Ethiopia. We recognize that there are other forms of NTDs that we have not yet explored and that a larger sample of interviewees would enable us to better understand the differences in perceptions between spina bifida, anencephaly and other NTDs. Still, our findings made it clear that the understanding of NTDs in the study differ significantly from contemporary scientific consensus about low levels of folic acid at early stages of the pregnancy being the main cause of these malformations [3]. Some people provided explanations of NTDs related to violence or natural phenomena such as particular kinds of wind and birds. Health workers, especially in urban settings, drew on biomedical perspectives and some of them pointed to deficiencies of nutrients as a factor. Mothers of babies with NTDs suggested that arduous work or accidents during pregnancy could possibly have been the causes, but more commonly referred to the will of God as the reason for their destiny. They also emphasized God making choices they had no control over, whereas other people in the communities attempted to make causal connections between behavior and health outcomes by suggesting that God was punishing parents for having sinned or behaved badly.

The responsibilization of women has often been related to biomedical management during pregnancy [9]. While this can give women more responsibility and autonomy, there is also the risk of them being blamed for any issues to the health of the fetus or the newborn baby [10]. The case of NTDs differs because it imposes responsibility upon women prior to their pregnancy: Folic acid needs to be consumed before and very early in the conception to prevent NTDs as the neural tube is formed in the first 28 days of pregnancy [27]. In this part of Ethiopia, the mothers, however, had limited access to education and health care, and they had few opportunities for knowing about the value of folic acid or to access it. They lacked control over these conditions and therefore had limited opportunities to prevent NTDs.

Despite this, health workers and policy makers tend to suggest that mothers are to blame for not planning their pregnancies. Such perspectives are far removed from the realities of women's everyday lives in these areas and place responsibility on those who neither have access to information nor the means to center their attention on the risk of one specific disease. By allocating the blame to women who give birth, the attention is removed from the shortcomings of health care access [11]. In addition, people in these communities considered the moral behavior of women and their families to impact the health of new-born babies, which shows how a community-based form of responsibilization becomes an additional burden on women who have few means of protecting themselves against the malformations of their babies. In this sense, women who give birth to babies with malformations are subjected to a double responsibilization; first, from health workers and policy makers because women do not follow their guidance (which women may have little access to or reason to trust) and, second, from local communities who consider these outcomes in relation to individuals' behavior. Prevention of NTDs is a key step to reduce the responsibilization that leads to women being blamed, but this requires suitable and sustainable strategies being implemented through existing health structures in ways that do not leave it up to individuals to take measure to avoid NTDs.

Folic acid, a more stable and easily absorbed form of folate, provides significant, cost-effective, and safe protection against NTDs when taken by mothers during the periconceptional period. This can be achieved through vitamin supplement pills or through folic acid-fortified staple foods [28, 29]. During the study period, Ethiopia had a poorly implemented program for periconceptional vitamin supplementation aimed at high-risk women and lacked mandatory folic acid fortification policies. Research indicates that voluntary food fortification is much less effective in preventing NTDs compared to mandatory food fortification [30].

The findings in this paper, however, has attended to local perceptions of NTDs. These are likely to differ in other contexts. In addition, it is not only in relation to NTDs that there is limited knowledge about the causes of death, disease, or malformations. In studies of stillbirth from different low- and middle-income countries it has been shown that people often explain these events in relation to the will of God [23]. This paper, however, has shown that people's use of God's will as an explanation is only part of the picture and that people's own position in relation to the birth of babies with these conditions influenced how they understood and explained NTDs.

7 Conclusion

This paper has provided insights into how people in eastern Ethiopia try to make sense of NTDs. Efforts to reduce NTDs requires scientific knowledge, but this alone is not sufficient as people's understanding of the causes and the stigma associated with particular diseases can impact how people respond to interventions. The perspectives of people in this area differed substantially from contemporary scientific knowledge but attempts to reduce the cases of NTDs in Ethiopia and elsewhere cannot simply overlook such viewpoints or dismiss local perspectives as beliefs or superstition. Instead, it is necessary to explore how people relate to these diseases and include their perceptions as part of the solutions to this major public health issue. The limited efficiency of family planning suggest that other solutions are needed, such as fortifying food to reduce cases of NTDs [31]. Still, further research is needed on perceptions of other kinds of NTDs, how other people relate to those with such malformations and how children and adults live with the physical and social challenges of having this disease.

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Data availability The datasets generated during and/or analysed during the current study are not publicly available due to this being a very small qualitative research project but are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate All methods were performed in accordance with the relevant guidelines and regulations. Ethical clearance was obtained from Haramaya University, Ethiopia, and the London School of Hygiene and Tropical Medicine, United Kingdom. Informed consent was obtained from each individual respondent during data collection. Privacy and confidentiality were maintained throughout the study. All participants in this study provided informed consent to participate, in accordance with ethical guidelines and institutional review board approval.

Consent for publication All authors confirm that they have reviewed and approved the final version of this manuscript and consent to its publication.

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