

# Neural Tube Defects: Making Sense of the Unexpected

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## Background

- There is a high prevalence of Neural Tube Defects (NTDs) in Ethiopia.
- The Child Health and Mortality Prevention Surveillance (CHAMPS) project and its research in eastern Ethiopia has found that many of the stillbirths and neonatal death are caused by Neural Tube Defects.
- The appearance of some of the babies with Neural Tube Defects caused rumours among families and communities.
- There is little knowledge about how people in eastern Ethiopia understand the causes and outcomes of NTDs.



## Methods

- This qualitative research took place in Kersa, Haramaya and Harar in eastern Ethiopia.
- We approached parents who had already participated in the CHAMPS project and whose babies had been born with NTDs as well as traditional birth attendants, health workers and other community members who were familiar with the ongoing research in the area.
- Seven mothers whose babies had died of NTDs participated in the study. In addition, we interviewed two women who lived locally and supported mothers giving birth at health centres, here referred to as traditional birth attendants. Also, seven health workers who worked at health centres and hospitals were interviewed. Finally, three focus group discussions were conducted; two of them were with women (16 in total) and one with ten men.
- The data analysis process was a collaborative process where each researcher transcribed and translated the materials s/he had collected, and a smaller team of three researcher then coded the data in NVivo.

## Results

### Allah's will

The surprise and discomfort upon seeing new-born babies with spina bifida and especially anencephaly for the women who had given birth to children led many of them to turn to Allah to explain these malformations. Menida was a mother who had given birth to a baby with '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. Allah knows everything. I have never before heard about or seen something similar to what happened to my baby.' Menida did not have any knowledge about the NTDs or their causes: 'I guess nothing about why this happened except that is Allah's will. I have never thought that there is something is wrong with me. This happened because of Allah's will.' The disturbing appearance of babies with NTDs meant that mothers used their knowledge of the world, rather than scientific knowledge, to explain the malformations and, in many cases, deaths of their babies.

### Punishment for bad behaviour

Some people in these communities thought that there were good reasons why this happened to some families and not to others, and the causes of NTDs were often associated with parents' behaviour. Hamdiya Ali, a mother in Kersa, suggested that people in the area 'believe that there is a reason for Allah to bring such a curse to the family. Some say that Allah is not happy with the family.' The relationship between people's behaviour and babies' malformations was a common perception, which suggested that Allah's will is a direct response to people's behaviour. The stigma of the parents and their families meant that these malformations not only affected the babies, but that rumours about their assumed sins or bad behaviour influenced relationships within the wider community.

### Natural explanations

Some participants brought forward more mundane explanations of NTDs and pointed to practices during pregnancy. Traditional birth attendants, for example, explained that NTDs happened because of violence, falling or other accidents that could shape the bodies of babies while they were inside the womb. 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 Allah to have the ultimate power in these matters.

## Conclusion

- The views on the causes of NTDs presented here bear little resemblance to contemporary scientific views of lacking folic acid being the main cause.
- The understanding and explanation often depended on people's own position in relation to the birth of babies with NTDs.
- Ongoing attempts to reduce the cases of NTDs in Ethiopia and elsewhere cannot ignore forms of local perceptions of the causes even if they do not correspond to scientific knowledge as the stigma related to NTDs will influence how people respond to interventions.
- Further research on how people live with NTDs in Ethiopia is necessary both to reduce the number babies born with NTDs but also to find news ways to disseminate scientific knowledge about the underlying causes and prevention.

