Journal of Midwifery & Women's Health www.jmwh.org
Original Research

A Qualitative Study of Attitudes and Values Surrounding Stillbirth and Neonatal Mortality Among Grandmothers, Mothers, and Unmarried Girls in Rural Amhara and Oromiya Regions, Ethiopia: Unheard Souls in the Backyard

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Introduction: In Ethiopia, neonatal mortality and stillbirth are high and underreported. This study explored values related to neonatal mortality and stillbirth and the visibility of these deaths in rural Ethiopia among 3 generations of women.

Methods: We conducted a qualitative study in 6 rural districts of the Oromiya and Amhara regional states during May 2012. We included 30 focus groups representing grandmothers, married women (mothers), and unmarried girls in randomly selected *kebeles* (villages).

Results: Until the 40th day of life, neonates are considered to be strangers to the community (not human). Their deaths are not talked about; they are buried in the house or in the backyard. Mothers are forbidden to mourn their loss lest they offend God and bring on future neonatal losses. Women who repeatedly lose their neonates may be blamed, mistreated, and dishonored through divorce. Neonatal death and stillbirth are attributed to supernatural powers, although some women and girls associate these deaths with poverty and lack of education. The desire for increased visibility of neonatal death is mixed. Unlike the grandmothers and unmarried girls, most of the married women want death to be visible to draw the attention of policy makers. Women prefer home birth and consider themselves lucky to be able to give birth at home. At present, there is no national vital registration system.

Discussion: Neonatal death and stillbirth are hidden and the magnitude is likely underrepresented. The delayed recognition of personhood, attribution of death to supernatural causes, social repercussions for women who experience a pregnancy loss, preference for home birth, and lack of a vital registration system all contribute to the invisibility of perinatal deaths. Increasing the visibility of (and counting) these deaths may require multifaceted behavior-change interventions.
J Midwifery Womens Health 2014;59:S110–S117

Keywords: Ethiopia, neonatal death, stillbirth, bereavement, qualitative research

INTRODUCTION

Globally, 4 million neonates die each year, and a similar number are stillborn.[1] Indeed, neonatal mortality and stillbirth account for about 40% of deaths among children under 5 year of age each year. Most of these deaths occur in low- and middle-income countries.[1,2] Mortality rates, however, reflect only the officially registered deaths. Many neonatal deaths and almost all stillbirths are underreported.[3,4] The underreporting of neonatal death and stillbirth is neglected in the global health agenda.[5]

Underreporting occurs for a number of reasons, including the practice of isolating women and their newborns in the early postnatal period, an acceptance of newborn death as normal, and a perception that the newborn is not a person for a specified period of time.[6] Although parents' grief over the loss of their newborn or unborn child may be great, those who have never faced such loss often do not respect the needs of grieving parents[7,8] and may even blame the woman for the death.[6]

In Ethiopia, neonatal mortality is still high at 37 deaths per 1000 live births, and perinatal mortality is 46 deaths per 1000 pregnancies.[9] These mortality rates are higher among parents having lower levels of wealth and education.[9] The medical causes of neonatal death include birth asphyxia, sepsis, injury, preterm birth, and tetanus, among others.[10,11] However, community members often perceive that malevolent spirits are the cause.[12] Maternal health care is provided free of charge at primary health care centers. In the event of a complication and transport to a hospital, the family bears the cost of transport.[13,14] However, almost 90% of women give birth at home, despite the low cost and lower risk of newborn death and stillbirth in a health facility compared with the risk in a home birth.[9,15] Reluctance to give birth in a health facility may be due to previous negative experiences with health facilities and a preference for family caregivers and traditional birth attendants.[9,15–17]

Consecutive Ethiopian Demographic and Health Surveys note that perinatal mortality is underreported because of omission and mis reporting.[9,18,19] Although smaller studies indicate a higher magnitude of perinatal mortality compared with the Ethiopian Demographic and Health Surveys. In this

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 1526-9523/09/$36.00 doi:10.1111/jmwh.12156

Quick Points

- Invisibility of stillbirths and neonatal deaths is complex and deeply rooted in social constructs of personhood in high mortality settings such as Ethiopia.
- Blame and stigma, as well as the prevalence of home birth and the lack of a national vital registration system, contribute to the invisibility of stillbirths and neonatal death.
- The invisibility of stillbirth and perinatal death is a major barrier to the achievement of Millennium Development Goal 4 because it precludes adequate investment, health planning, and programming.
- Acknowledging stillbirth and neonatal death when it occurs requires both local and national response, including the development of a national vital registration system, health system policies, and behavior-change communication interventions.

article, we describe beliefs and values surrounding neonatal death and stillbirth among Ethiopian women of different generations. We focus on perceived causes of death, mourning and burial practices, and the social consequences for women who have experienced a stillbirth or neonatal death. We hope that the findings will contribute to interventions designed to increase the visibility and reporting of deaths and support for women who have experienced a stillbirth or neonatal death.

METHODS

Context

This exploratory, qualitative study was conducted within the context of the Maternal and Newborn Health in Ethiopia Partnership (MaNHEP). MaNHEP was designed as a 3.5-year learning project to demonstrate a community-level model of maternal and newborn health and to position the model for scale-up. Under the leadership of the Ethiopian Federal Ministry of Health (FMOH) and Amhara and Oromiya Regional Health Bureaus, MaNHEP was implemented by Emory University, in collaboration with Addis Ababa University, JSI Research and Training Institute, Inc., and University Research Co., LLC. MaNHEP took place in the West Gojjam Zone of the Amhara region and the North Shewa Zone of the Oromiya region.[20]

Sample

We first randomly selected one *kebele* (village) from each MaNHEP project area *woreda* (district) and 2 *kebeles* from the same *woreda* that were neither close to nor included in the MaNHEP project areas, for a total of 10 *kebeles*. The reason for including *kebeles* from both MaNHEP and non-MaNHEP areas was to explore the potential variation in responses, even though MaNHEP interventions did not target beliefs and values surrounding neonatal death. We then purposively sampled 3 categories of women across the *kebeles*: grandmothers (women who had given birth to at least one child, who in turn had given birth to at least one child), women who had any child under 5 years of age, and unmarried primary school-aged girls. This was to identify the beliefs, values, and experiences of women of different ages (and generations) with respect to childbirth and loss. Health extension workers—government employees responsible for providing primary health care at the *kebele* level—assisted with the identification of respondents. They contacted potential respondents a day before the planned focus group discussion in their respective *kebeles*. They also recruited the grandmother and women category of respondents through house-to-house visits and obtained informed consent. In addition, they recruited the unmarried girls through their school, usually just after the lunch hour. Girls who "could speak out" and were aged 15 years or older were recruited. Consent from the girls and assent from the school heads were obtained. The recruitment process was facilitated by the *woreda* health office heads, who were working with MaNHEP. Respondents were organized into homogeneous focus groups comprised of 6 to 10 members: grandmothers ($n = 10$ groups, total of $n = 63$ grandmothers), women who had any child under 5 years of age ($n = 10$ groups, total of $n = 74$ women), and unmarried primary school-aged girls ($n = 10$ groups, total of $n = 70$ girls).

Data Collection and Procedures

We prepared and pretested a focus group discussion guide that addressed the following content areas: 1) place of birth; 2) knowledge about signs of a healthy/unhealthy neonate and health care seeking for a sick neonate; 3) perceptions about stillbirth and neonatal death, as well as perceptions about the difference in abortion or miscarriage and stillbirth with respect to age of the fetus; 4) causes of stillbirth and neonatal death; 5) mourning and burial practices for stillborn and dead neonates; 6) treatment of women who have experienced a stillbirth or neonatal death in the community; and 7) visibility of stillbirth and neonatal death in the community as compared to adult death. In this study, a stillbirth is defined as the death of a fetus after the 28th week of gestational age, whereas abortion is defined as the loss of a fetus before the 28th week of gestational age. The guide was developed in the relevant local languages (Amharic and Oromiffa).

The principal investigator trained 2 experienced, master's degree-level female moderators and 2 note takers with health backgrounds, all fluent in the local language and culture. Working in pairs (one moderator and one note taker), these individuals first observed and then practiced conducting the focus group's discussion using the guide. During training, the principal investigator supervised each team while members conducted the discussions and debriefed with them at the

end of each day in order to standardize and improve data collection.

Each tape-recorded focus group discussion was conducted at a private place and time mutually convenient for participants. Before beginning a focus group discussion, participants were reminded of the purpose of the study. Their names and ages were recorded, but the names were only used to facilitate the discussions. The participants were encouraged to share their genuine ideas and to discuss them freely. During the discussion, the participants' nonverbal expressions were noted in addition to recording their verbal responses. After completing the discussion, the moderator summarized the discussion and key points with the participants to check for accuracy. On average, the focus group discussions lasted 90 minutes.

Analysis

Each note taker listened to her tapes and transcribed each tape verbatim in the local language. Each moderator translated each of her transcripts into English for analysis. The principal investigator listened to a sample of the tapes to assess and ensure the accuracy of the transcriptions.

Using Open Code software,[21] the principal investigator and coauthor on the study team independently read and coded each English transcript line by line. They discussed their codes and resolved any differences in coding. They further discussed their coding with a senior member of the study team. A final consensus agreement was reached on the coding.

Framework analysis was used to facilitate comparison within and among the 3 categories of women. In this process, similar codes were categorized, and the categories were used for identification, interpretation, and presentation of themes. Framework analysis enables researchers to track decisions, which ensures that links between the original data and findings are maintained and transparent. This adds to the rigor of the research process and enhances the validity of the findings.[22] The analysis itself was guided by a phenomenological perspective in which the focus is on the experience of the phenomenon under study (beliefs, values toward, and experience of newborns and their death in general).[23,24]

Ethical Considerations

This study was a component of MaNHEP, which received institutional review board approval from Emory University and Addis Ababa University, the Ethiopian FMOH, and the Amhara and Oromiya Regional Health Bureaus. Written informed consent was obtained using standard disclosure procedures. Individual identifiers were removed during transcription to maintain anonymity of information. Records are kept in a locked place that only was accessible to the principal investigator.

RESULTS

Participant Characteristics

In the combined 3 categories, there was a total of 207 participants. As expected, the 3 categories of participants differed, with the grandmothers being older and less educated than those in the young girl groups. The mean (SD) age of the grandmothers' group was 54.0 (9.5) years. None of the grandmother participants had received any schooling. The mean (SD) age of the women's group was 28.7 (6.4) years. All of these women were married, although few had received any schooling. Last of all, all of the young girls had attended some primary school (grades 4–8). Participants were predominantly Orthodox Christian.

Seven categories reflecting beliefs and values about stillbirth and neonatal death were identified: 1) the newborn is a stranger to the community; 2) newborn deaths and stillbirths are hidden; 3) burial practice is age-based; 4) stillbirth and neonatal death are mostly due to malevolent spirits; 5) home birth is the norm and facility birth is for complications; 6) women who experience a stillbirth or neonatal loss are blamed, neglected, and in the case of repeated loss, dishonored; and 7) response of women to repeated stillbirth and neonatal death. These are described in turn below and in Table 1.

Beliefs and Values Surrounding Stillbirth and Neonatal Death

A Stranger to the Community

All participants in each category remarked that stillborns and those who die in the early neonatal period are not considered to be human; rather, they are "strangers to families and neighbors" because they have never been seen or known by others. As one young Amhara girl noted, "If the neonate dies immediately after birth or [is] born dead, we cannot treat his/her death as a human loss or as that of an adult. Even if it is a term baby, we call it a missed baby." Moreover, almost all participants indicated that mourning the death of a newborn is not culturally acceptable. This stance with respect to mourning is handed down through the guidance and instructions of parents, in-laws, religious leaders, and elders. As one Amhara grandmother noted, "It is our tradition and culture. We do not mourn the death of a newborn like that of an adult, though they [the newborns] are the ones that grow up to be adults." Participants in both the grandmothers' and women's groups also indicated that they do not mourn a newborn's death *because they do not know the newborn*. Some participants further described stillborns and dead newborns as "mere blood" and noted that that it was useless to feel sad or mourn their death.

Newborn Deaths and Stillbirths are Hidden

Because stillborns and newborns who die soon after birth are not considered to be human and are not openly mourned, they are essentially hidden to the community—they are "invisible." The family and birth attendant handle the death. The participants in all categories expressed the belief that a woman should not be allowed to see her dead newborn or even know its burial place, partly to protect the woman from emotional and psychological harm and to prevent future harm to the woman. One woman said, "If the neonate is hopeless, the birth attendants will manage it secretly." A girl noted, "We should not mourn the death of a newborn, it is

Table 1. Framework Analysis Indicating Main Categories, Codes, and Focus Group Participants Who Fall into Each Category

		Participant Group		
Category	Code	Grandmothers (n = 10 groups)	Married Women/ Mothers (n = 10 groups)	Unmarried Girls (n = 10 groups)
1. A stranger to the community	Inhuman treatment	√	√	√
	New to the community	√	√	√
	Stranger	√	√	√
	Child life less valued	√	√	√
	Missed baby	√	√	√
	Cooling or suppressing the grief	√	X	X
	Mere blood	√	X	√
2. Newborn deaths and stillbirths are hidden.	Hidden	√	√	√
	Attained secretly	√	√	X
	No need of exaggeration	√	√	√
	Need to make it visible	X	ü	X
3. Burial practice is age-based.	In house or backyard (immediately after birth)	Amhara all	Amhara all	Amhara all
	In backyard (immediately after birth)	Oromiya all	Oromiya all	Oromiya all
	Backyard (up to 2 weeks of age)	√	√	√
	Outskirts of churchyard (2 weeks until baptized)	√	√	√
	Mourning for neonates not accepted	√	√	√
4. Stillbirth and neonatal death are mostly due to malevolent spirits.	Maternal evil spirits	√	√	X
	Equity in mortality	Grandmothers (all but few)	Mothers (all but few)	X
	Poor birth management	X	X (all but one)	√
	Old TBA mismanagement	X	X	√
	Poverty kills	X	X	√
	Illiteracy kills	X	X	√
5. Homebirth is the norm; facility birth is for complications.	Saints help in labor	√	√	X
	Fear of health facility	√	√	√
	Our culture, routine	√	√	√
	Perceived parental and neighbor support	√	√	√
	Ease of labor	√	√	√
	Risk of delayed labor	√	√	√
	Hope in health seeking following education	√	√	√
6. Women who experience a stillbirth or neonatal loss are blamed, neglected, and in the case of repeated loss, dishonored.	Differential treatment	√	√	√
	Divorce as a response	√	√	√
	Blamed	√	√	√
	Unaccepted	√	√	√
	Stigmatized	√	√	√
	Humiliated	√	√	√
	Sad	√	√	√
	Less valued	√	√	√

Continued

Table 1. Framework Analysis Indicating Main Categories, Codes, and Focus Group Participants Who Fall into Each Category

Category	Code	Participant Group: Grandmothers (n = 10 groups)	Married Women/ Mothers (n = 10 groups)	Unmarried Girls (n = 10 groups)
	Seen as a curse, a source of uncleanness	√	√	√
	Helpless, futile effort	√	√	√
	Bad luck	√	√	√
7. Women use different strategies to cope with stillbirth, neonatal death	Use of local remedy	√	√	√
	Magical work	√	√	√
	Contraceptive use	√	√	√
	Repeated pregnancy	√	√	√
	Self-blame	X	√	X
	Self-punishment, self-endangerment	X	√	√

Abbreviation: TBA, traditional birth attendant.

Note: The √ indicates that at least one participant within the type of group (eg, grandmothers) mentioned content related to the category code. In most cases, many participants did so. The X indicates that no participant within the type of group mentioned content related to the category code.
The "X" indicates that no participant within the type of group mentioned content related to the category code.

culturally forbidden because God will bring more and more sad events to the family."

However, there are some regional differences in beliefs about mourning. Amhara women indicated that, although the woman herself feels and grieves the loss of her newborn, her feelings are suppressed by community norms. One woman in the group who had lost her newborn shared, "My heart breaks every time I see the age mates of my child playing around … " Oromiya women, on the other hand, believed that a newborn death should be mourned like that of any adult and openly talked about in the community, although as one woman noted, there is pressure not to do so: "Even if you raise the issue of making neonatal death visible, the culture does not allow you." They argued that such visibility might make the magnitude of the problem known and draw the attention of policy makers, stimulating solutions and saving more newborns lives. Some women noted that newborns are the future (they build the nation). As one woman remarked, "Government shall advise the people in this area to change their culture, norm, tradition. It is these newborns that will grow to be adults."

Burial Practice is Age-Based

Participants in each category agreed that stillborns and newborns who died immediately after birth are buried at home—in the house (Amhara) or the backyard (Oromiya)—by the husband or birth attendant (someone present at the birth). Burial in a churchyard, however, varied by age of death. In the Amhara region, participants noted that newborns who die are buried in a churchyard only if they have been baptized—which usually happens at 40 days (males) and 80 days (females) of age. They are buried in the outskirts of the church if they are older than 10 days of age at the time of death but not baptized. In this case, a few close family members will attend the funeral to avoid public notice. The situation in Oromiya appears to be similar. One Oromiya grandmother said, "If a newborn dies immediately after birth or up to 2 weeks after birth, he/she will be buried in the backyard, but after 2 weeks of age, he/she will be buried outside the churchyard … unless baptized."

Stillbirth and Neonatal Death are Mostly due to Malevolent Spirits

All but the young girls associated the causes of stillbirth and neonatal death with malevolent spirits. As one Oromiya grandmother observed, "Families lose their newborn because of an evil spirit." (*Wukabi* is a type of malevolent spirit that, when offended, will attack the beholder or his/her family.) Amhara grandmothers and women further noted that a pregnant woman may be considered to be the cause of her own newborn's death because of the evil spirit that resides within her (the woman). In addition to malevolent spirits, the grandmothers and women in both regions agreed that a newborn's destiny is predetermined. That is, whether the malevolent spirit inhabits the woman and/or her family, this is considered to be destiny.

The young girls, on the other hand, associated newborn death with poverty, lack of education, maternal health problems during pregnancy, use of unskilled and old birth attendants, and/or improper care (eg, inattention leading to suffocation by bed covers, unsafe practices, or lack of health care seeking for a sick newborn). Yet, as one young Amhara girl remarked, "Even though the real cause of neonatal death is bleeding from the loosely tied umbilical cord due to poor management by birth attendants who are old, nobody in the community talks about this as a cause of neonatal death."

Home Birth is the Norm; Facility Birth is for Complications

In both regions, the grandmothers indicated that, although births usually occur at home with the help of family and/or neighbors, if the labor is prolonged the woman is usually taken to the nearest health facility for care. The women agreed that home birth is the norm in their community and is preferred

over health facility birth because of the comfort surrounding the home. As one woman described, "Home birth is common. Everyone gives birth at home unless the labor is tough. If the labor is delayed we will go to health facility." In addition to the comfort of home, other women commented that they felt that birth in a health facility would be scary; even if they really needed help they would be reluctant to go. They fear being left alone in a new environment because no one is allowed to accompany them to the labor ward. As one mother remarked, "I went to the health facility. I was admitted alone without any family around and was scared and cried." Still, for some women, having to give birth in a facility was considered to be bad fortune. As one Amhara woman observed, "If we are lucky we give birth at home, with the support of our neighbors and family, if not we will go to clinics …"

At the same time, some grandmothers and women noted that, following education provided by the health extension workers, more women now receive antenatal care, save money for complications, and give birth at health facilities. Some of the young girls also noted that women have started seeking health care from modern services for normal birth. The situation is changing.

Women who Experience a Stillbirth or Neonatal Loss are Blamed, Neglected, and in the Case of Repeated Loss, Dishonored

Nearly all participants observed that a woman who loses her newborn is often neglected and mistreated by the husband and his family, and that people do not understand that the woman is grieving and needs emotional and physical support, such as a woman who has given birth to a live-born neonate and needs attention and special care. Several women in the focus groups had personally experienced a loss shared that they had not been treated as though they had given birth to a live-born neonate. One grandmother said, "A woman who loses her neonate has to start work immediately and she is referred [to] as 'yewesha aras' in Amharic, which means that she is like a mother dog who walks around immediately after giving birth."

As described previously, a woman who experiences a stillbirth or neonatal death is often considered to be the cause of the loss. In particular, a woman who repeatedly loses her newborns is referred to as having *shotelay*, an evil or ancestral spirit inside her body that kills the newborn. One Amhara woman described the situation as follows: "A woman who loses her babies repeatedly is stigmatized. Her neighbors will insult and humiliate her. They will call her *woldo-bela* [child-killer, in Amharic], meaning a woman who kills her kids with her evil eye." One focus group participant described how she was actually chased out from her rented house by the landlord because she repeatedly experienced a pregnancy loss. Moreover, her landlord considered her to be a source of the curse and of uncleanness because her newborns were buried in the backyard. She shared her landlord's comment, "You have spoiled my compound, and I cannot have you any more in my compound."

In addition to neglect and blame, women who experience stillbirths or neonatal deaths may become divorced. Divorce as a response to repeated pregnancy loss does not appear to be common in the Oromiya region. However, in the Amhara region, the grandmothers observed (and supported) that it is customary to dissolve a marriage if a woman repeatedly gives birth to neonates who do not survive or are stillborn. They noted that if a husband desires to get divorced, this is acceptable in the community. One grandmother shared her own family's experience, "My brother was separated from his wife after she lost 5 newborns. Now he has 13 kids from the new wife but she [the previous wife] has none to date." The young girls also noted that the husband's family often pushes the husband to dissolve the marriage. They added that, because of this, some women put their lives in danger by running away from the *kebele* or by attempting suicide so as not to face humiliation. As one girl shared, "I know a girl who was in school and married off by her parents. After the marriage, she repeatedly lost her newborns and was divorced. Not to face the humiliation in the village she ran away to a city and now she is a commercial sex worker."

Women use different strategies to cope with repeated stillbirth and neonatal death

Women who experience one or more stillbirths or neonatal deaths use different strategies to cope with their loss and to minimize the social consequences (described above). They use traditional remedies such as taking herbal medicine or holy water and/or wearing necklaces made of parchment which had religious writing on it. As one Oromiya woman shared, "I myself had a stillbirth and they gave me a magical writing in a parchment to be used like a necklace during my next pregnancy. Then, when I gave birth, they took it from my neck and put it around the neck of the newborn before I made eye contact with the child. The child survived." If the remedies fail, women may resort to using a modern contraceptive to avoid another pregnancy. One grandmother noted, "After a woman has tried everything, if she continues to lose babies, then she will start a contraceptive in consultation with the husband. My daughter had this problem and now she is using it." Many women, however, are encouraged to conceive again quickly to replace the lost one.

DISCUSSION

The death of a stillborn or newborn is not discussed; it is hidden from all but the woman, her family or close neighbors, and her birth attendant. Women's personal feelings are suppressed because they are encouraged not to mourn the loss of one that is not yet human (and whose death was destined to be). In keeping with these beliefs and values, the birth attendant or husband usually buries stillborns, and newborns that die soon after birth, in the house or in the backyard. Only if a newborn survives at least to the age of baptism (becomes human) will it be buried in the churchyard upon death (become visible in the community). The hidden nature of pregnancy loss and age-based mourning practices are embedded in the social construction of personhood, a phenomenon observed in diverse cultural contexts that are characterized by a high infant mortality.[25–27]

Ethiopian women prefer to give birth at home and most do so. Home birth inadvertently contributes to invisibility, providing a space in which to hide a pregnancy loss from

the community. Lack of a national vital registration system also contributes to invisibility—stillborn and neonates who die soon after birth are not counted.[12,28] Indeed, two-thirds of all stillbirths and neonatal deaths are not reported in developing countries.[29] In these countries, home birth and dysfunctional registration systems contribute to the invisibility.[16,30] The participants in this study noted that women who have a stillbirth or lose their newborns are often blamed for the loss, and their postpartum care is neglected as if they had not given birth. Women who repeatedly lose their newborns may be stigmatized and even dishonored (eg, through divorce, in the Amhara region). Although the research on social consequences of stillbirth and newborn death is limited, some researchers have also found that women who experienced a stillbirth or newborn death may be vulnerable to social stigma, divorce, and sometimes physical harm—without bereavement support.[31,32]

Women who have a stillborn or lose their newborns use traditional remedies, and when these fail they may opt to forgo future conception by using modern contraception. However, women often continue to attempt to conceive and bear a liveborn neonate. Other researchers have documented this coping mechanism for stillbirth and neonatal loss.[33]

The 3 categories of participants were for the most part similar in their responses. There were 2 notable differences, however. First, the participants in the grandmothers' and the women's groups mostly attributed death to supernatural powers and destiny, whereas those in the young girls' groups generally attributed death to social and medical causes. Second, unlike the participants in the grandmothers' and young girls' groups, the women participants all believed that stillbirth and neonatal death should be made visible—in spite of social pressure to the contrary. They believed that doing so (making death visible) will help draw the attention of the government policy makers to the extent of the problem and encourage them to allocate resources to reduce perinatal deaths. That this belief was not shared by the young girls suggests that these beliefs, and values surrounding when a fetus becomes a human, are deeply rooted.[34]

Limitations

In this study, participants shared their understandings of community beliefs and values surrounding stillbirth and neonatal death. Some participants had also experienced a loss and shared their experiences. The study would have benefited by having more grandmothers and women who had personally experienced a stillbirth or neonatal death in the focus groups. We did not target these women because they are difficult to identify through the peripheral health posts due to the underreporting and also because the event (perinatal death) is common. We anticipated that participants would be able to reflect on their own experiences, as well as those of their daughters and other family members. We sampled 3 homogeneous categories of women/girls. This allowed us to begin to identify similarities and differences between shared beliefs and values across generations.[35] The strength of homogeneous groups is that they may facilitate participant openness. The disadvantage is that they are subject to response bias through within-group peer pressure to conform in terms of responses.[36]

Implications

The findings of this study are interrelated and have implications for public health policy and programming. At the national level, there is underreporting and a clear need for a vital registration system to assess the magnitude and distribution of perinatal deaths, both of which underpin investment in perinatal health programs. The women who participated in this study are astute in their recognition that making death visible is necessary to reduce mortality. Making death count is a prerequisite for addressing the problem and also to shifting cultural beliefs about the preventability of death and value of neonatal life. In its emphasis on achieving Millennium Development Goals 4 and 5, the Ethiopian government is in the process of developing a vital registration system and health system strengthening.

It is critically important to address the response of communities to women who experience pregnancy loss, particularly those who experience repeated loss. The national focus on Millennium Development Goals 4 and 5—along with national, regional, and local information, education, and communication campaigns that increase public understanding of the social and biological causes and preventability of perinatal death—may help decrease the blame and stigmatization of women. Such campaigns may also help enhance the value of women as persons, mothers, and community members and lead to women's improved self-care and health-care seeking and avoidance of potentially harmful behaviors (eg, repeated pregnancies or moving away from their community).

Clinicians caring for individual pregnant women can likewise emphasize these messages and encourage women to notify them in the event of miscarriage, abortion, or birth (irrespective of the outcome). They can also provide bereavement support and counsel women who experience a loss about the best (safest) time to conceive again, if desired, and ways to prevent conception in the interim (or for as long as desired). Finally, in settings where health care providers and facilities are able to offer at least basic emergency obstetric and newborn care, clinicians can encourage women to give birth with a skilled attendant in such a facility. Local institutional policies can be changed to facilitate this.

CONCLUSION

The invisibility of stillbirths and neonatal deaths is complex and deeply rooted in social constructs of personhood in high mortality settings such as Ethiopia. This invisibility is a major barrier to the achievement of Millennium Development Goal 4 because it precludes adequate investment, health planning, and programming. Development of a national vital registration system, health system policies, and behavior change communication interventions are needed for perinatal deaths and also maternal deaths to count.

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CONFLICT OF INTEREST

The authors have no conflicts of interest to disclose.

ACKNOWLEDGMENT

This study was funded by Emory University, Atlanta, Georgia, USA.

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