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Mothers' experiences with still birth: a dead fetus as a'tax' given to allah: qualitative phenomenological study

Abstract

Introduction: The months of excitement and expectation and planning magnifying the devastating incomprehension of giving birth to a baby bearing no signs of life. Stillbirth has been recognized as one of the most neglected areas of public health while millions of women are suffering from aftermath of its occurrence. Exploring root causes of malpractice, myth, attitude and misperception helps to focus on meaningful, contextual and evidenced based interventions. However there is no any documented research specifically addressing experience of mother with still birth in the study area.

Objective: The aim of this study is to explore mothers' lived experiences related to still birth Method and materials: Qualitative study design with hermeneutic phenomenological approach was conducted in Eastern Ethiopia, January 2019. The snow ball sampling technique was used to pick and interview four mothers who had delivered still birth in the last 12 months using local language. Nvivo version 11 software and steps of Colaizzi's were used for data analysis after members were checked the congruence of given report and thematized results.

Findings: the data were saturated at four in-depth interview and emerged themes were:: 'Shanfa': a fetus as a tax given to God, 'Allatti': a shadow of a bird as cause for fetal death, 'Mijawiru': getting offensive nick name, Feeling accused to happiness, 'Mana Kitaaba' as a prevention or treatment, powerlessness on self-determination, Challenge in getting facilities, being fatigue and ignorance, Oxygen Hunger in ambulance, and Partner support.

Conclusion and recommendations: There are lots of unspeakable myth and challenges that a specific mother are experiencing due to still birth. Some are helpful for better coping and some are hiding issue from getting proper attention and management. As part of global and national response to perinatal mortality, mothers experience need to be explored with multi-site, high tech investigation to identify problem and make proper planning to solve the challenges.

Keywords: still birth, lived experience, phenomenology, qualitative, perinatal loss, fetal death

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Dawit Tiruneh, Agezegn Asegid
Department of Midwifery, College of Health sciences, Debre Tabor University, Ethiopia

Correspondence: Dawit Tiruneh, Department of Midwifery, College of Health sciences, Debre Tabor University, Debre Tabor Town, South Gondar province, National state of Amhara, Ethiopia, Tel +251920806931, Email Dawit2h2005@gmail.com

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Abbreviations: CHAMPS, child health and mortality prevention surveillance; HP, health professionals; PMR, perinatal mortality; M, mother; NGO, non- governmental organizations; WHO, world health organization; UN, united nations, SNNPRS, southern nations and nationalities peoples regional state.

Background

Even though, there are global calls for actions to reduce mortalities and or morbidities, over 800 women are still dying from complications in pregnancy and childbirth every day. Of which, 99 percent occur in developing regions. Sub-Saharan Africans suffer from the highest maternal mortality ratio – 546 and followed by 182 per 100,000 live births in South Asia.[1] An estimated 2.6 million newborns were died in 2016 which accounted for 46 percent of all under-five deaths worldwide.[2] Moreover, globally, an estimated 2.6 million still births occur in each year in whichhalf of them occuring during labour and birth.[3] The causes of stillbirths and early neonatal deaths are closely linked, and it can be difficult to determine whether a death is attributable to one cause or the other. The rate encompasses both stillbirths and early neonatal deaths. In Ethiopia the estimated perinatal mortality rate by DHS was 33 from 1000 total births in 2016, while its distribution was varying across regions and city administration of the country.[4] Even though, the still birth rate is a sensitive marker of quality and equity of health care, it is still one of the most neglected areas of public health[5] and also majority of deaths were attributed to mechanical cause and low level of skilled attendance. As result scholars recommends improving access to obstetric care as corner stone to reduce perinatal mortality.[3,5,6]

Mother's experiencing still birth facing various challenges originating from self, intimate partner and social community. An estimated 4.2 million women are living with depression associated with a previous stillbirth. At the same time, parents are also experiencing various psychological symptoms that often persist long after the death of their baby which could be mitigated by respectful maternity services.[3] The grief of a stillbirth is unlike any other form of grief: the months of excitement and expectation and planning magnifying the devastating incomprehension of giving birth to a baby bearing

no signs of life. Moreover, 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 these deaths may require multifaceted behavior-change.[7]

Assumptions of the study

a. Perceived reasons that cause still birth are linked to community tradition and perceptions

b. Mothers are psychologically affected by poor community perceptions than losing their pregnancies.

c. Mothers who had experienced still birth may understand their lived experiences in different ways.

Having those assumptions by researchers and witness from literature makes this study more meaningful to the study area. Since, quality care at all levels of health system is critical in reducing maternal traumas and its effect on subsequent pregnancy outcomes. Little researches were done on parent's experience and grief related to still birth as a qualitative research in developing counties including Ethiopia and also no document research in the study area. As a result exploring root causes of malpractice, myth, attitude and misperception in health seeking behaviors that help to focus on meaningful, contextual and evidenced based interventions in the community. Policy makers design new systems which are specific and applicable for coping skills of parents.

Model

Understanding contextual factors of still birth through the "three delays" model of Thaddeus & Maine.[8] Thaddeus and Maine observed that many pregnant women reach health facilities in such a poor condition that they cannot be saved, and that the time taken to receive adequate care is the key factor in their deaths. These are: Delay in decision to seek care, Delays in reaching a medical facility, and Delay in receiving appropriate care at facility. The model helps us to see different variables and factors of perinatal mortality and this research suitable to the first delay of decision to seek care since most of mother's experiences are personal in nature.

Materials and method

Design: Qualitative study design with hermeneutic phenomenological approach was employed to interpret mothers' experiences after getting still birth. As method of analysis it helps to identify contextual meaning by familiarizing with data, generate codes, search and review themes, define and name themes, and producing report by Chesnay. Phenomenological methodology can reflect the essential themes that are able to characterize and describe the phenomenon of lived experiences of mothers with still birth. Explanatory research was used to made explanations of observed phenomena, problems, or behaviors. It helps us seek answers to reasons why mothers experienced still birth at different settings.

Settings: The study conducted in one tertiary university hospital, one primary health care unit or health center, and one kebele from rural community. The Interpretation of data was done with no regard to sociocultural norms, or preconceived ideas about the experience of the investigator.

Access and recruitment of study participants: Mothers were selected based on their experience with the phenomenon, interest to participate in the study and the ability to disclose their experience to the investigator. Mothers who had experienced still birth between 1 month and 12 months from Hararge region, Ethiopia were selected were purposely. Moreover, key informants at Tertiary and primary levels of care were recruited to supplement the data. Mothers who have had still birth within a month were excluded in this study.

Sampling techniques and sample size determinations: Two Health professionals who works at Health Center and Tertiary Hospital were purposely selected as a key informant for in-depth interview. A purposive snow ball sampling technique was used to recruit participants for this study. Since analysis goes parallel to data collection, the level of data saturation limited our study participants to only four. Documents were reviewed and observations were noticed and supplemented with field notes before determining points for data saturation.

Data collection method and techniques: Guiding tools and open ended probing questionnaires were used after reviewing previous literatures related to this study. Introductory assessments were made through reviewing documents before any attempt to get participants. Closed ended questionnaires were used to gather demographic data of participants.

Data quality assurance

Validity: Interview questions were originally prepared in English language to make it consistent with other literatures. Individual depth interviews with two key informants were conducted in Amharic language while two mothers with experience of still births were interviewed by Afaan Oromo language. Each conversation was transcribed in its original language and then translated back to English language for transcription. Member check was made before attempting of data analysis.

Truth worthiness: To increase its trustworthiness, participants were asked to validate the summarized information at the end of each interview.

Data analysis: Codes, nodes, child nodes, themes or patterns of analyses were made through Nvivo version 11 software for social science research. Detail description and interpretation of contexts to give meanings to their experiences through content and thematic analyses were made by the principal investigator.

Seven steps Colaizzi's method were used for data analysis.[9] Transcripts and translations were repeatedly read in order to understand the overall essence of data and relevant statements were identified. Pre-supposition about mothers' experiences were quoted. Codes and themes were created and identified by the principal investigator. Parallel to the overall process the research, writing memos and linking to identified code and quotations were noticed. More than fifty nodes and child nodes were emerged in early stage of analysis and condensed to eleven major themes for discussion and interpretation.

Ethical issues

Informed consent was obtained participants before initiation of Individual depth interviews. The purpose of the study was justified, making of confidentiality secret. Coding of recorded conversations for data analysis were made for each participant. Participation was based on their voluntary informed decisions after all possible benefits and risks were examined. Participants were neither directly benefited nor harmed as compared to non-selected ones. Participants have been informed about the right to refuse or withdraw from this study at any time.

Results

In this qualitative study, four participants were recruited and involved as human study subjects to explore mothers' lived experience

with still birth. The two key participants, who are maternal, Neonatal and child case team coordinators at governmental Health facilities and the rest two were from rural village, Kersa Woreda, Eastern Hararge, Ethiopia. Those mothers whose ages were 25 and 21 years have experienced two and one still birth respectively. Moreover, both mothers are waiting for successful pregnancy in their future life.

In this qualitative study, seven probing questions were used on community perception, emotions, consequences and reaction, health seeking behaviors before and after, reason of preferences of birth places and Health care services. Nodes with their child nodes were developed after critical analyses and interpretations were made by the principal investigator through the aid of Nvivo version 11 software.

Ten major themes were emerged. These are: 'Shanfa': a child as a Tax, 'Allatti': a shadow of a bird as cause, 'Mijawiru': getting offensive nick name, 'Mana Kitaaba' as a treatment or healer, Feeling accused to happiness, powerlessness for self-determination, Challenges in getting facilities, Being fatigue and ignorance, Oxygen hunger in ambulance, and Poor Partner support (Table 2).

a) Theme one: 'Shanfa': giving a fetus and a newborn as a tax given to god

The cause of still birth in this rural community is rooted with religious beliefs, customs or traditions in different ways. Participants' responded when they were asked about reasons for causing still birth is mentioned and quoted here below.

[Participant 0002HP]: said that "what I understood from the rural community about what they do say is 'Shanfa'. Shanfa is there. It means that still birth is considered to be a "tax" that was given to God. If a mother did not have still birth, the community perceived that her creator 'God' does not love her. They commonly make a link like this".

b) Theme two: 'Mijawiru': getting an offensive nick name

This nick name is given for a mother having frequent still births in the community. This is an Afan Oromo word which is commonly used either to insult them or wish others to get still birth during fighting each other.

[Participant 0003M]: expressed that "among community members, you know peoples are fighting each other. They call us 'Mijamen' for those we don't have children. They have used you as best example when they insult each other during fighting. 'Mijamiru', one no grown underneath--one with unsuccessful births".

c) Theme three: feeling accused to happiness

The community perceived that the first still birth is a good opportunity obtained from 'God' or 'Allah'. She gets still birth because she is loved by her creator 'God' or 'Allah'. The reverse is true if the incidence is frequent in this community.

[Participant 0001HP]: explained that "Mothers are expressing their emotion through crying entirely with non-expressive feelings which is more painful than others ever feel**.** Some have shouted on health professionals and some are interested in struggling with health care team". This participant who have no children yet with two still births expressed.

[Participant 0003M]: She voiced that "Is God with me? Is noble unfriendly about me from the whole community? Your friends have got children. But when you failed to get a child, you ask God whether any accuse of any life problem I have made or not". In contrary to those feel sadness, when it was for first time mother expression may not be worse.

[Participant 0002HP]: "Their faces do not reflect like a mother losing a child. That means it has two reasons: It is either God's willingness or families' beliefs or sins. I did not see their feelings or reactions on their faces".

d) Theme four: 'mana kitaaba': as a prevention or healer

The community perceived that still birth is prevented or treated by local healers. They did not associate the cause of still birth with that of obstetrics and medical conditions. They travel far for searching local healers and attend given recommendations carefully.

[Participant 0003M]: perceived that "when women get similar case they take to local healer **'**kitaaba'. When mothers lost a child, they send a mother to those healer and they become treated. Now I have already started treatment after I return from hospital. They indicated me to go far village and now I am on treatment there. It comes due to mothers' problem. When they take you to book knower, it stops. It is always happened there unless we go to book knower or healers".

e) Theme five: 'allatti': Shadow of a bird as cause to premature birth

Participants believed that the cause of still birth is associated with religious and traditional customs which may vary across communities. One Participant explained that the cause for her premature labor and still birth was the Shadow of 'Allatti'.

Participant 0004M]: understood that, "the community perceive as it is immaturity and the cause is the shadow of 'Allatti': a type of birds. They said a shadow of birds will kick the fetus. Then the fetus will die if the shadow kicks the fetus in the uterus. I do share the community's perception. But I don't think it is the cause".

f) Theme six: powerlessness on self-determination

Mothers with frequent still birth felt a strong sense of condemnation and powerlessness. They need reassurance from health care providers and community members. Supportive, open and trustworthy approaches from providers can minimize their level of trauma which help them feeling a sense of empowerment.

[Participant 0001HP]: "mothers are delayed by the decision making process for more than 24hrs of prolonged stay at home with traditional practices. This condition is common in peripheral areas which are not accessible for ambulance entrance for emergency conditions".

[Participant 0002HP]: Verbalized that "Every decision is made by her partner. His families are even come together and involved in decision making. Whatever he is providing safe care for his wife, it is must to get his families decision. He left her and married another wife. The community may condemn or stigmatize her by perceiving that she is the reason for still birth. They may perceived as she has something. This may traumatize and harm her psychologically. Her families are reassuring her".

[Participant 0004M]: "He has the same role to me like other husbands here. His decision is autonomous from accessing family planning to getting next the pregnancy".

g) Theme seven: challenges of getting facilities

Geographically marginalized communities are facing multilayered problems in rural communities. Health facilities are everything for people living with low socio economic status. They travel a long distance to access health facilities, as result some may arrive after they develop multi-organ damage at a stage of near miss and others are still dying either at home, travelling time to facilities or during labor and postpartum period.

[Participant 0001HP]: "Mothers from pocket areas are not benefited from our service packages and Infrastructure of roads should be accessible for Ambulance entry".

In this study there was a report that indicates delay in receiving appropriate care at all levels of care. Low level of awareness about ANC care service, misconception about birth outcomes of grand multiparous mothers, poor decision making, low economic status, poor infrastructure especially in remote areas, and congested health facilities were consistently reported issue of poor perinatal outcome.

[Participant 0002HP]: "…When husband is able to decide, there is also infrastructure challenge….. If labor is started earlier at home, there is distance between home and facility. They said that "you gave births at home with no complication. ….. there is issue of economy…… There are mothers who come here in labor ward with no ANC contact.. On the other hand, mothers who had no ANC contact said that "we had given births with no complication at home". But, when they feel different from their previous experiences, they came here to deliver the 9th or 10th pregnancy here".

[Participant 0001HP]: "In addition to parents' interest of getting a child from their sons, the community believed that mothers revive soon if the lost pregnancy is substituted by another one. If not, her husband needs to make divorce and get another marriage by associating that she is not allowed by 'Allah' to bear and have a child. Psychological and moral consequences are the worst of all which might be end up with divorce. This condition is most common in rural residents than urban".

h) Theme eight: fatigue and ignorance

Health professionals become fatigue due to high flow of self-referral clients to hospitals. This condition is aggravated by the existing proportion gap between health force and population density. In addition, bulky registration items for documentation purpose of a single laboring mother by itself is a time taking activity and make providers fatigue and ignorant. Participants honestly explained the situation as follows:

[Participant 0001HP]:"Health professionals are fatigue due to high client flow to governmental hospitals. This may be a reason for case ignorant which may be again a reason for miss management of cases. In private hospitals, they are focusing more about the profits rather than the quality of service delivery. A mother whose ANC follow up was here and came with pushing down pain made self-referral to private hospital for labor. She was in a stable condition here but was dead with her fetus in one private hospital recently. The incidence of still birth is becoming raised up. Even we health professionals are not working as much as we possibly can for mothers"

[Participant 0002HP]: "The hospital has made priority but there is imbalance between demand and supply. It is difficult to manage self-referral mothers for normal labor. It may disappoint them when it hands only special cases as a referral hospital. Whatever it is, client flow is increasing over time".

i) Theme nine: oxygen hunger in ambulance

I have been surprised when participants told me that two laboring mothers with fetal distress are referred to the next facility without health care providers and oxygen cylinder in a single ambulance at same time. A Participant who has more than eighteen years of work experience was getting somewhat nervous when she explained about causes for still birth.

[Participant 0002HP]: "We have enough ambulances. But two mothers are sent here at a time in one ambulance. It is okay (even better) instead of letting them stay in home. But ambulances must have life-saving materials just like others. Firstly, why do not a first aider come together by providing care? Secondly, ambulances have no single portable oxygen machine inside. If mothers are referred due to fetal distress with oxygen hunger, their condition becomes aggravated and worsened. Finally its outcome will be still birth. Therefore taking measurements like these are not as such complex".

[Participant 0003M]: "At that time, they said ambulance was broken. I was travelled by private vehicle. Then they brought me by Bajaj here from the health center".

Partner support

Communication established between husbands and their wives are crucial for developing trusting relationships which can facilitate increased male involvement to benefit pregnancy outcomes. In this study, partner support was a major gap observed in the community as it was voiced by all participants. Two participants replied as follows when they interviewed on the role of husbands in assisting their wives during child birth.

[Participant 0001HP]: "----Shy and laughing -- they do not want, smiling-- they do not want the presence of close families including their husbands to assist them during labor. We accept their presence if they wish. But if they become aggressive during some procedures like repairing episiotomy, we request their husbands or mothers to tell them and stay calm for accepting our procedures".

[Participant 0003M]:"Laughing…. what makes the husband bring here? The problem belongs to mothers. She is the one who get pregnant, the one with the problem. How do we think of a husband?

Discussion

'Shanfa', It means that still birth is considered as a *"Tax"* that is given to God. If a mother did not have still birth, the community perceived that her creator 'God' does not love her. Similarly, in two regions of Ethiopia(Amhara and Oromia), the occurrence of still births are attributed to supernatural powers.[10] As result mother may not be depressed about the condition for the first pregnancy. Positively this helps mothers to better cope up with condition of losing births. Among many factors perpetuating the incidence of still birth, the one playing great role is misconception about the cause and consequence of still birth. Even though it helps to cope-up in first occurrence it demotivate community to seek real health care service and investigate the root cause of the problem for the subsequent occurrence of still birth. Moreover, it minimizes male involvement and facilitate multi aspect effect on maternal conditions.

Mothers are influenced by their own previous experiences, remain very concerned and anxious about future.[11] In This study most mothers are living with rooted misperceptions in the community, which act as a barrier to not seek medical service for good perinatal outcomes. Their experiences are shared to others and translated into their parenting experiences. When women had once, they are feeling happiness because they assume they are loved by God. When it became frequent, emotional reactions and life transition was minimal changes. Finally, mothers accuses and ask their super natural power for stopping the case, avoid being example of bas insult in the community and help them to kiss their own child. Parents experience various psychological symptoms that often persist long after the death of their baby but could be mitigated by respectful maternity services.[3]

Physical distance and financial limitations were two major constraints that prevented community members from accessing

and using trained attendants and institutional deliveries.[12] Similarly distance, road conduciveness and poorly furnished facilities also reported from study participant as reason for occurrence of still birth. Similarly, in Gambia in accessing life-saving emergency obstetric care interventions revealed that long distances to the hospital and lack of appropriate means of transportation were found to be major problems affecting timely evacuation of women with obstetric complications.[13]

After mother reach the care facility, space for admission and follow-up after labour was not enough. Physical access to health services has been hampered by a rapidly growing population, inadequate financial and logistic support, gross shortage of skilled human resource for health, high staff attrition, and an ineffcient referral mechanism Poverty and ignorance have, in some instances, led to inappropriate health seeking delivery behavior and contributed to ill health.[14]

Mothers are not well recognized the need of support from their husbands for the reduction of still birth. The roles of husbands are not supportive in assisting positive pregnancy outcomes. All participants have similar explanations.

Even though, lack of partner support can actually increase the risk of negative psychological outcomes for mothers in particular.[15] In this study the involvement of husbands near to zero and lack of mother empowerments also negatively affecting the outcome of pregnancy. Unfortunately, mothers also agree with low power of decision making and husband involvements.[16–32]

Limitation of the study

Even though the data saturation obtained at four samples, it seems low for the design. Moreover, the nature of the study design allows subjective judgment of data saturation by principal investigator, which may introduce bias.

Conclusion

Misperceptions, decision making, accessibility, psychological effects, male support in the community are major observed gaps in this study. Despite frequent calls and actions for improving quality of lives of mothers and children as global agenda, understanding the complexity of women's lives in marginalized rural community have to be simplified according to the barriers what were developed by Thaddeus and Maine in 1994. This shift would enable policy makers and program implementers to redesign new approaches and strategies as a solution to explore traditional root causes for perinatal loss.

Recommendation

Working on the first delay model to bring behavioral changes on traditional practices and make modifications on indigenous local knowledges are best signals for partners, government officials and health care providers. We suggests to work on accessibility of health facilities through scaling up infrastructure of roads for Ambulance entry, educating males with them to enhance male involvement in supporting their wives. Cost for health services, transportations and caring of herself and the baby can influence poor mothers to prefer home delivery than facilities. These mothers need to be supported by income generating activities in their localities and creating awareness through community mobilization. Working on the sources of persistent gaps that contributes a lot for still birth needs a collective action.

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Ethics approval and consent to participate

As course requirements this study was supported by letter from Haramaya University, College of Health science and medicine, Department of Public health, and written informed consent was obtained from all study subjects.

Author's contributions

DT initiated the conception, designing of the study, data collection and analysis and interpretation of the data. AA participated in data collection, analysis and manuscript writing. Authors read and approved the final manuscript.

Conflicts of interest

No conflict of interest among authors and other parties.

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