



## What women want after experiencing a stillbirth: A focus group study

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## Cultural understandings of pregnancy




- 7 million women in Nigeria fills their pot with water every year (UN, 2016)
- This process is more than physiological because it guarantees access to power, status, resources and inheritance (Olueze, 2004)
- In a study, 79% of women said they were under intense pressure to have children (Fehintola et al., 2017)
- The role of women is defined by fertility

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## Losing the content of your pot



- Women lose the content of their pots at high rates in Nigeria
- In 2015, out of the 7 million women who attempted to fill their pot with water, more than 300,000 lost theirs to stillbirth (FMoH, 2016)
- It is not hard to imagine the cost of stillbirth for these women.
- Primary or secondary infertility leads to instability, relationship breakdowns and poor quality of life (Koster, 2003)


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## Clash of values



- Despite the real and potential impact of stillbirth, the society has a different idea
- In the traditional sense, losing the water is not the ultimate tragedy. The ultimate tragedy is the breaking of the pot, which is maternal mortality.
- This narrative has subjected survivors of stillbirth to a downward comparison where women are expected to be grateful for their own lives.
- Grieving over the loss is seen as a form of ingratitude
- Omi lo danu, agbe o fo – it is the water that is spilt, the pot is unbroken


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## The cracks and dents are not talked about



- The cultural interpretation of pregnancy and the loss of a baby has dumbed down the cracks or the dents that losing a baby has on the mother
- As long as the pot can still hold or store water, the cracks or the dents will not be fixed.
- The idea that an unbroken can still serve its purpose has contributed to the silence around the issue and has encouraged practices that deny women memory making, burials and burial in unmarked graves (Adebayo et al., 2018)
- Most women can only talk about the chaos surrounding their loss or the pregnancy itself, not how the child looks like

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## Categorisation of death: Good versus bad

- Burials are essential for closure and the dead are buried closer to home.
- Having contact with the body is a mark of respect
- U
- a
- ir
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*are not given this kind of burials are considered worthless and their survivors (Lawal et al., 2013)*




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## The present study



- I was interested in how women live with the cracks and dents of stillbirth in a context that does not see those dents as a problem
- I was interested in this issue because of my experience of how other cultures treat the experience of stillbirth
- Initially, the goal was to interview and collect diagrams, but this changed because of the preliminary findings

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## Loss and grief has strong cultural frameworks



- These memorabilia was donated by SANDS NZ
- All those interviewed in Nigeria declined these memorabilia because
  - It is against the culture and does not reflect the mother's readiness to heal
  - A woman cannot be a mother to a child that has passed. Mementoes will not facilitate discussion about it
- Women also discussed that they would not join a support group that brings mothers of stillborn babies together because
  - It is shameful to be there. It is a form of personal and social failure that should not be glorified
  - Conversations that attach personhood to the child or that brings the child to life is a form of pathologic grief
  - Women have little memories of the loss itself

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## Participatory focus group

- The findings of the interviews led me to conduct a participatory focus group
- The idea was to allow women to step back from the cultural expectations and talk about what they want for themselves
- All women had intrapartum stillbirth under the care of health professionals
- Out of the 20 women who were interviewed, only 7 agreed to a focus group
- All the seven who participated have surviving children.
  - They are more able to engage with the issue more openly because they have proved their motherhood by having surviving children
- The central question asked was “from your own experience, *how best can we support mothers faced with stillbirth?*”
- The discussions were recorded, thematically analyzed into three recommendations

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## Recommendation 1

- **The need for logical explanations about the death of the baby**
  - “It is more painful when you cannot attribute the death of your child to any cause and you are left with speculations and assumptions” (FGD)
  - “The government should do their best on what causes stillbirth and how it can be prevented. Doing this I believe will help women to adjust to the loss” (FGD)
  - “The nurses and doctors must be able to discuss things like why it happened so that we won’t repeat the same mistake in subsequent pregnancies. Prevention is better than cure” (FGD)

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## Recommendation 2

- **A strong desire for tailored individual and private counselling**
  - “The same way there is an emphasis on antenatal care, there must be an emphasis on post-stillbirth care” (FGD).
  - “Not all of us get support from our families and some of us don’t even have our relatives around us. There should be alternative support outside the home that includes counselling and there must be awareness of its usefulness” (FGD).
  - “The government can introduce programs that would make it possible for women to seek counselling after stillbirth” (FGD)

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## Recommendation 3

- **Bereavement needs can only be met through improved training for health professionals**
  - “Nurses should be prepared and well equipped with the necessary knowledge about stillbirth because most of these problems come from nurses at the hospital. My baby was alive when we got to the clinic, and I was shocked when I was told the baby died” (FGD)
  - “People take information from health professionals seriously. The advice from home may not resonate with some of us until we hear it directly from the health professionals” (FGD)
  - “The medical professionals should not restrict their care to the medical aspect alone. They need to know how to give counselling, show empathy and say words of encouragement because the pain of stillbirth is not a physical pain that requires just medical treatment” (FGD)

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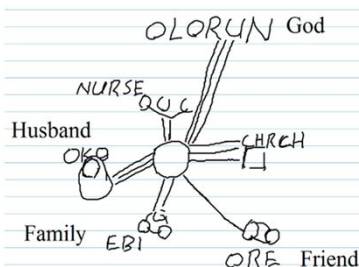


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## Sharp focus on health professionals



- One of the interesting findings was the damning assessment of health professionals bereavement care
- This is due to increasing public health awareness that childbirth is safer when attended by skilled birth attendants
- In 2015, 2.6 million women delivered the babies under the care of health professionals (UN, 2015)
- Women are increasingly putting their faith in the medical model of childbirth because its practice is evidence based and its explanations are logical
- Women expected more because of this and felt betrayed when standards and expectations are not met.

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## What led to the recommendations

- **Although culture strongly shapes the experience of grief, but maternal instincts is stronger than cultural prescriptions**
  - “Every woman wants to know what came out of her body”
  - ‘omo eni ku san ju omo eni sonu’,  
(it is better for someone’s child to die than to be missing).
  - “I thought they could have at least bury him with one of the dresses we brought for him, but they returned all the clothes without touching them. The nurses said there was no need to dress him”
  - “When we got home, I asked how and where the body was disposed, and they quickly replied, “God will not allow you to know the grave of your child”. That was the end of his story” (SK6)

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## Grim picture of health professionals caring abilities

- I did not hear her cry. She was taken away immediately after she was delivered. When I asked for her to be given to me, the nurse allayed my fear that my baby was okay and that there was nothing to be worried about... I was blindsided throughout the whole process (SK13)
- The nurse asked me “what would you do with it [the body of the stillborn infant] if we hand it over to you? It is not normal, it is not right, you will not like it (SK5)

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## Grim picture of health professionals caring abilities

- The doctor just said in front of everyone, “madam, you see that child inside you is no longer useful. We don’t need it anymore. You should worry about your own survival and forget about the child” (SK18)
- During the scan, the doctor’s body language suggested that something was wrong, but he said nothing to us. Later, he called my husband to the side, told him the baby had died and instructed him not to tell me... From the time I started suspecting that the baby had died till when I finally delivered was three days and those three days were the most dreadful experience of my life because I feared something terrible could happen to me as well (SK20)

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## Implication 1

- Culture influences stillbirth experience, but the cultural context of stillbirth grief includes health professionals own behaviours, guidelines and utterances
- We need clearer positions on contentious issues. It is not enough to offer women a choice to see or not too see

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## Implication 2

- **There is a real deficit of kind, compassionate, and skilled care**
  - The failure of compassionate care means mothers are doubly disenfranchised and erodes trust
  - It is important for professionals to recognise the efforts that went into the pregnancy journey
  - The need to pay more attention to compassion fatigue and burnout among childhealth professionals
  - There is a need for health professionals to display their understandings of the contextual ramifications of stillbirths in how they care for those faced with stillbirth

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The challenge is to provide care that is both respectful of current cultural norms yet manages to respond compassionately and actively to what is a shared human experience.

- Grieving as a mother whose child passed away is very tricky and challenging. On the one hand, you cannot move on too quickly because people expect a lengthy and genuine portrayal of soberness from you... your conduct should convince people that you are truly and deeply pained by the loss. On the other hand, you also cannot dwell on it for too long, because people expect you to be grateful for your own life... So, grieving a stillborn child is like a performance, the timing of your re-entrance into the society, the way you carry yourself and your countenance must genuinely reflect your sadness but also your gratitude... Performing this role is hard (A Nigerian mother).

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## Questions and discussions

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