

ETHICAL CHALLENGES IN MORTALITY ENQUIRIES USING VERBAL AUTOPSIES IN RURAL GHANA

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Introduction

- Accurate information on overall and cause-specific mortality is essential to prioritize the activities of health systems
- The use of VAs in collecting mortality data has been validated in different settings
- Little has been said about the ethical concerns

surrounding it



Problem statement

- Almost 15% of deaths of infants under 3 months of age are due to a belief in a concept called the *spirit child*
- Recounting the circumstances surrounding the death of an individual could lead to severe emotional distress
- VAs could clash with traditional norms
- Establishing this would lead to a more ethically acceptable procedure that could improve data quality



Study objectives

- General Objective:

- To explore the ethical issues arising from mortality enquiries using VAs in the Kassena-Nankana District

- Specific Objectives:

- To determine potential ethical issues in VA procedures
- To determine the cultural appropriateness of the VA tools
- To examine the management of ethical dilemmas

resulting from VAs



Methodology

- Study site: KNE and KNW - KNDs
 - Population of approximately 150,000 people who reside in about 30,500 households
- NDSS – That monitors vital population events
- Verbal autopsy – VAs conducted on all deaths using the INDEPTH standard verbal autopsy questionnaire
- Study Design: An exploratory study using mainly qualitative research techniques



Methodology cont

<i>Category of Respondent</i>	<i>Number of Interviews</i>
Field staff administering VA questionnaires	4
<i>Coders of VAs</i>	4
<i>Recent respondents of VAs (the past two weeks)</i>	10
<i>Opinion Leaders</i>	8



Results and Discussions



Risk of emotional distress

- Bonding between the respondent and the deceased
- *Lost of a breadwinner*
- *Death from a short illness or Road traffic accident*
- *Timing of the interview and duration of the interview*

• Because I lost my old lady and she came to remind me of her again and when she asked me the question and I was narrating to her, it was disturbing me in the heart and I wanted to stop her from asking me those questions...

• It makes me think about my mother because she is no more and she came to remind me of her that is why I am thinking that if she was alive it would have been nice because I can't go to market again. (Recent Respondent)

For the road traffic accidents when you get to that point, it is always pathetic because many are always crying. When you ask for the history, it is that part that t to shed tears. For instance, when they narrate it and you start to write, before you raise your head, they have already started crying but they don't hide accident issues, they always say it. (Data collector)



Sensitive questions

- Questions are sensitive but should be maintained

For instance if you ask that; was the deceased taking “wee” or drugs and so on, they feel that you came to insult the deceased. (Data collector)

Some of the questions are sensitive but if we mean to revise them then what it means is that essentially we are losing out on the sensitivity of the instrument and even at times the specificity. If we want to collect as much data as we can and as much relevant data that we can, then we can't run away from asking such sensitive questions. (Coder)

- Training of data collectors in softening the sensitive nature of the questions



Engaging relatives of the deceased

- No traditional procedures for researchers
 - Traditional sympathies

Let's take it that if it's a chief who died, you have to go to an elderly person who is always with the chief and can give you the information... So going to see those people you must send kola-nuts and drinks to greet them before you ask them and everybody will be happy. (Recent respondent)

That one, I think that if the centre can always give us something that we can give to them after interviewing just to say thank you as a way of sympathizing with them because in our local homes when you go to greet some one in the house you have to show some level of respect or concern. When the centre is able to do this the people will be ready to give the correct information (Data collector)

- Counseling of relatives of the deceased

- *Propose to giving gifts*



Respect for persons

- Seeking voluntary informed consent
- Respect for the culture of the people – Reincarnation in the case of the *spirit child*
 - *When I asked the mother, what she said was that she doesn't want to hear anything concerning that baby because when she was pregnant, she felt very ill even to the point of death so I shouldn't mention its name for it to return(Data collector)*
- Membership of the DSS being an implied permission to participate



Feedback to respondents

- Community versus/and individual feedback

...But that is not our business. In conducting VPMs, our business is to look for the cause of death period...

as at now, we do not go back to tell the families the causes of their relatives' deaths. Our business is to ask them about the causes of the deaths ... Some cases we can't confirm it exactly so we actually have no business to go back and say 100% this is the actual cause of a death that killed Mr. A or Mr. B.

(Coder)

VA provides information on general causes of death



Feedback to respondents

- Respondents to VAs demand feedback

- *It would have been nice because if they tell you and you know you can always prevent yourself from these diseases so that in future, such a thing will not happen to you because you might not know but those who came and conducted the interview will know so when they give you the feedback it will be better (Recent respondent)*

- *They expect us to come back and tell them because they always asked us all the time that we come to ask them and we don't come back to tell them what has killed the person or nothing. So we tell them we are supposed to write and send to the Doctor's (Data Collector)*



- Ancillary care to those respondents who will need it

Confidentiality of VA data

- Multiple respondents during VA interview

- *That one is not a problem. For instance if a man dies and you are interviewing his wife and the compound head is around you cannot sack him. He also sit and listen because you have already explained to him why you came. So where the woman can not provide certain information that you need, the compound head can chip in and say can you remember this or that happened? (Data Collector)*

- *The problem may arise when you give out information that has to do with excuse me to say stigmatized diseases, for instance if the cause of death is HIV/AIDS or a narrative that suggests a death was due to HIV/AIDS. These are where ethical issues may arise where repercussion could befall the family member's of the deceased. These are sensitive or medically sensitive information which we do not have a degree of control over because we are not in a hospital setting. (Coder)*

- Data collectors from the same community

- Sharing of data

- Absolute confidentiality not possible for criminal cases



Conclusions

- Ethical challenges exist in mortality enquiries
- Some critical decisions have to be taken in order to resolve them
- Resolving them have the potential of improving data quality



Recommendations

- Extensive and regular training in counseling for data collectors
- Separate interviews with everybody who was present during the deceased illness
- Respect for traditional culture of bereavement
- The use of a written consent form – include disclosure for legal purposes and opting for feedback



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Thank you for your
attention!

