Comments to WHO on “Annex 10: Verbal and social autopsy tool for stillbirth and neonatal death audits in the community” of “Making Every Baby Count: Audit and Review of Stillbirths and Neonatal Deaths”

By the Stillbirth Advocacy Working Group

Co-Chairs Susannah Hopkins Leisher (International Stillbirth Alliance) & Dr Hannah Blencowe (LSHTM)

8 October 2018

|  |  |  |
| --- | --- | --- |
| Page | Section | Comment (or suggested text in red) |
| 105 | Introduction of interviewer | * It’s key to train interviewers in how to speak to a mother whose child has died (or a caregiver who has cared for the bereaved parent, or other family member). Their words and actions may affect the mother differently from other people whom the interviewer may have interviewed in the past. The interviewer must show respect and compassion for the mother (or caregiver) and her grief, and refer to the deceased baby in a culturally appropriate, respectful manner. For bereaved parents, this interview could be one of the only times they are asked, invited, or encouraged to speak of their dead child at all, so the interview may take on additional importance. * Immediately after introducing yourself, explain that you are asking to interview the mother because of the death of her child, and offer your condolences on the family's loss. Only then, continue to the purpose of the visit. |
| INFORMED CONSENT FORM | | |
| 106 | Hello My name is and I am working with (AGENCY) a partner of the Ministry of Health We are conducting a survey in this district that asks about health issues of newborn babies. | An expression of condolences should be made in the first couple of sentences. For example: "I was told that you [or your family, if not speaking to the parent] recently experienced the death of your baby [before birth/soon after birth]. I would like to offer my sincere condolences to you and your family on the death of your baby." |
|  | I am asking you to take part in this survey because I am trying to learn more about stillbirths and the causes of death among newborn babies. | * Replace "stillbirths" with "stillborn babies" or "babies who were stillborn" throughout the document. This helps to humanize these babies. * Since stillbirth is not a cause of death but a time of death, this should be revised as "learn more about the causes of deaths among babies both before birth--stillborn babies—and after birth— newborn deaths." |
|  | The government and its stakeholders have been improving access to health care and the provision of health services in this district. The information that you provide will help us understand health challenges faced by newborns. | “will help us understand health challenges faced by babies before they are born, as well as newborns.” |
|  | You should be aware that your answers about the deceased may say something about your own health | “You should be aware that your answers about your baby who died…" |
|  | I am visiting you today because we were informed about the death of (your baby). | Add “I am sorry for your loss.” |
|  | This information will help the government and its stakeholders to understand better ways through which they can improve neonatal health services | “antenatal and neonatal”, not “neonatal” |
| 107 | Interviewer copy | Same edits as in Interviewee copy, above |
| SECTION 1. INTERVIEW AND DEMOGRAPHIC INFORMATION | | |
| 108 | NAME OF DECEASED BABY | This is excellent. Please ensure that the question is asked of stillborn babies. Instruct the interviewer to use the baby's name as relevant in subsequent questions. |
| SECTION 2. BASIC INFORMATION ABOUT THE RESPONDENT | | |
| 109 | Did you live with the deceased baby in the period leading to his/her death? | Is it clear that for stillborn babies, this refers to living with the pregnant mother? |
| SECTION 3. INFORMATION ON THE DECEASED AND DATE/PLACE OF DEATH | | |
| 110 | What was the name of the baby who died?  RECORD THE NAME OF THE BABY AND USE THROUGHOUT THE INTERVIEW | Yes. Please add emphasis that this is regardless of whether stillborn or neonatal death. |
|  | 3.5 In what day, month and year did the baby die? RECORD “98” IF DON’T KNOW DAY OR MONTH RECORD “9998” IF DON’T KNOW YEAR | For stillborn babies, this may be confusing. Do you want to allow for death dates prior to birthdates? Probably not, so maybe skip for stillborn babies? |
|  | 3.6 How old was the baby when he/she died?  ENTER NEONATAL DEATH AGE IN MINUTES, HOURS OR DAYS  IF THE BABY WAS STILLBORN, ENTER “00” FOR MINUTES | Later, you indicate that you will only be including stillbirths if 7+ months’ gestational age. While in LMIC, it is most likely to be the case that stillborn babies will be over 7 months’ gestational age, it still may be good to check here by asking for the actual age in gestational months/weeks here. Then "end" if less than 7. Or are you assuming that if reporting from LMIC, all stillborn babies are less than 7? Then how will you exclude miscarriages? |
|  | 3.9 Where did the baby die? | Poorly worded for stillborn babies. Technically, the answer is “in the mother's womb”. What do you want to know for stillborn babies? Technically the question would be: Where was mother when baby was stillborn? but this is the same as location of delivery. Maybe skip for stillbirth, if this question is asked later? |
|  | 3.9.1 What was the name of the health-care facility where the baby died? | Or, if stillborn, where he/she was born? |
| 111 | 3.9.2 Was the baby taken to any (other) health-care facility for treatment prior to his/her death? | Skip for stillborn babies |
|  | 3.9.3 What was the name of the health-care facilities where he/she received treatment? | Skip for stillborn babies. Asking these irrelevant questions of mothers with a stillborn baby can be painful for a mother, when her baby did not survive birth, and so could not have received treatment. |
|  | Instructions to interviewer: Allow the respondent to tell you about the illness in his or her own words | For stillborn babies, there may have been no illness. Instead it is the pregnancy and the birth itself that is the story. Asking about illness can inspire feelings of guilt in the mother, who may have had a perfect pregnancy with no apparent cause of stillbirth. |
| RESPONDENT’S ACCOUNT OF ILLNESS/EVENTS LEADING TO DEATH | | |
|  | Could you tell me about the illness that led to the baby’s death? | Need to replace this entire box with a different one for stillborn babies, that asks about the pregnancy and birth, including quality of care. Different probes also required. |
|  | Do you feel the death could have been avoided somehow? Please explain: | Crucial set of questions for stillborn babies as well. |
| 112 | ASK THE RESPONDENT: What do you think was the primary or basic cause of death? | Retain for stillborn babies. |
|  | ASK THE RESPONDENT: In addition to this primary cause, do you think there are any additional or secondary causes of death? | Retain for stillborn babies. |
| SECTION 4. PREGNANCY HISTORY AND CARE | | |
| 113 | Overall | For stillborn babies, you may want to ask these questions prior to the narrative on events leading to death. |
|  | I would like to ask you some questions concerning the mother and symptoms that the deceased had/showed at birth and shortly after. Some of these questions may not appear to be directly related to the baby’s death. | * your baby's (not THE baby's); your baby who died (or NAME) (not “the deceased”) * Take care with phrasing—do not say "and shortly thereafter" if stillborn baby. |
|  | Please bear with me and answer all the questions. They will help us to get a clear picture of all possible symptoms that the deceased had. | “your baby who died” (or NAME)—do not use the term "the deceased", which is dehumanizing. |
|  | 4.2 Did the mother receive any antenatal care during the pregnancy? | Need to ask about ultrasound scan. Prenatal care is widely variable across settings. |
|  | 4.3 How many antenatal visits did the woman have during the pregnancy?  IF RESPONDENT DOESN’T KNOW, ASK IF SHE HAD ATTENDED AT LEAST 4 VISITS | Since prenatal care is widely variable, it is important to understand whether women were educated on kick counts during their pregnancy |
|  | 4.4 How many weeks or months pregnant was the woman at her first antenatal visit?  ENTER IN WEEKS OR MONTHS | Also need to know the date of the last prenatal visit/ultrasound scan, which will help to assess whether signs of distress were noted |
| 114 | 4.4.2 Before the woman became pregnant with this pregnancy, how many times per week was she drinking alcoholic beverages? | The questions in this section are highly skewed toward maternal behavior. This is problematic for two reasons – first, quality of care is a major driver of maternal, fetal and neonatal outcomes; second and equally important – the interviewer is likely to come across as blaming the mother for her baby’s death. Asking a lengthy series of questions about actions she took during pregnancy, without paying equal attention to factors beyond her control, will translate to the mother as blaming. |
| 115 | It is common for women during and after pregnancy to feel down or depressed.  During the last 3 months of pregnancy but  before labour, how often did (you – if mother is the respondent; or the mother – if other respondent) have little interest or pleasure in | Unsure whether this is the right time frame if baby was stillborn during the last trimester. |
| 116 | 4.16.2 During the last 3 months of pregnancy but before labour, how often were (you – if mother is the respondent; or the mother – if other respondent) down, depressed or hopeless? | As above |
|  | 4.18 How many of these previous births were stillbirths?  BORN DEAD AFTER 7 MONTHS OF PREGNANCY | * There should be a place to ask about earlier losses. This validates those losses even if they will not be investigated in depth. Also, you have asked all these questions without knowing whether the present baby, the focus of this questionnaire, actually made it through 7 months of pregnancy. What if the baby died earlier? You will have included him/her anyway. This will throw off stillbirth estimates. Will you exclude the whole interview if baby was stillborn <7 months? * Also, replace “stillbirths” with “babies who were stillborn” |
|  | 4.20 Was the baby born before expected? | This should be “due date” or expected delivery date. “Expected” is unnecessarily ambiguous. |
|  | 4.21.3 | There is no option here for losses prior to 7 months; need to add |
| 117 | 5.1.1 How soon after labour started did she receive assistance with labour and delivery? | You need to start with a question about onset of labor. Many women do not recognize signs of labor. Many other women will go to their doctor for a routine visit and be admitted for labor induction. This is a common practice. This series should start with a question: “Did you enter labor naturally or were you induced?” Then, “What were the first signs that indicated you were in labour?”; then “What was the amount of time between this and when the baby was delivered?” ; then “Did you seek assistance during delivery?”; then “Who assisted…?”; then “How long after those first signs of labour did you seek assistance?”  Keep in mind that many women will start labor at one place and end at another. They may go from a lower level of care to higher level, or from a traditional birth attendant to a skilled birth attendant. Questions need to be built to allow for these situations. |
| 118 | 5.11 Did a birth attendant listen for fetal heart sounds during labour with an electric device (Doppler) or cone-shaped stethoscope placed on the abdomen? | Painful question for mother of baby who died prior to labor. Please ensure proper use of skip pattern to avoid asking this if baby died prior to labor. Therefore, need a question early on about "died before, during, or after birth, or do not know" |
|  | 5.11.1 Were fetal heart sounds present? | As above. |
|  | 5.11.2 Was an ultrasound scan done just before labour started or during labour? | As above. |
| 119 | 5.11. 3 Did the scan show any fetal heart beats? | As above. |
| 120 | 5.22 Was anything applied to the umbilical cord stump after birth? | Unnecessary question for stillbirths, painful to be asked this. |
|  | 5.22.1 What was applied to the umbilical cord stump after birth | As above. |
| 121 | 5.29 Did the baby ever cry after birth, even a little? | Insensitive question for stillborn babies. Suggests that this questionnaire is aimed at neonatal deaths. However, it could be helpful to clarify if there is any doubt over whether stillborn or neonatal death, of course. Perhaps rephrase: "I understand that it seems your baby was stillborn. But sometimes it is unclear exactly when baby died. It is important for us to understand the timing of your baby's death. Can you recall whether your baby ever cried after birth, even a little?" Maybe also ask in this way of movement and heartbeat? |
|  | 5.30 How many minutes after birth did the baby first cry? | As above. |
|  | 5.30.1 Did the baby stop being able to cry? | As above. |
|  | 5.30.2 How long before death did the baby stop crying? | As above. |
|  | 5.31 Did the baby breathe after birth, even a little?  PROBE FOR PRESENCE OF ANY CHEST MOVEMENT; CIRCLE ‘YES” EVEN IF ONLY SMALL OR IRREGULAR MOVEMENTS WERE PRESENT | As above. |
|  | 5.32 Was the baby given assistance to breathe?  MULTIPLE ANSWERS ARE ALLOWED; READ ALL OPTIONS | As above. |
|  | 5.32.1 Was the baby given any oxygen? | As above, or skip for stillborn babies. |
| 122 | 5.33 Did the baby ever move, even a little? | As with "cry" questions. |
|  | 5.33.2 Did the baby have any heartbeats? | As with "cry" questions. |
| 123 | 5.46 Did the mother receive any counselling by a health worker before discharge? | This question is relevant for mothers of stillborn babies also, but would be skipped with the current skip pattern. |
|  | 5.47 What was the mother counselled on? | Relevant for mothers of stillborn babies also (with different response options), but would be skipped with the current skip pattern. |
|  | 5.48 Was the mother given vitamin A just before or after delivery? | Relevant for mother or only for breastfeeding? |
| 127 | 6.28 How long after the first symptom was recognized did the baby die?  ENTER IN HOURS OR DAYS | This series of questions is great for neonatal deaths. Can you add a series of questions for stillborn babies? Perhaps this could be based on PSANZ cause of death categories? Or ICD-PM for stillbirths categories? |
| SECTION 7. HISTORY OF INJURIES/ACCIDENTS | | |
| 128 | overall | As with section 6, this needs a counterpart for stillborn babies. |
| SECTION 8. TREATMENT AND HEALTH SERVICE USE FOR THE FINAL ILLNESS | | |
| 129 | 8.5.1 As far as you know, was anyone aware that the baby needed medical help before the baby died? | These questions may also have a stillbirth counterpart, eg if fetal distress was recognized, was it treated? Yet will be skipped for stillborn babies with the current skip pattern. |
| 132 | 8.16 How much time passed between when the baby arrived at the first place of care and  treatment was given? | These questions are very relevant for mother trying to get to facility for difficult delivery if stillbirth occurs just before or during birth, yet would be skipped with the current skip pattern (all of section 8 indeed?) for a stillborn baby. |
| 133 | 8.23 Altogether, how much did you pay for transport during the illness that led to death? | Cost questions are so relevant for stillborn babies also, yet would be skipped with the current skip pattern. It may be that two separate modules are required, one for stillbirth and one for neonatal death. |
| SECTION 9. DATA ABSTRACTED FROM RECORDS | | |
| 134 | 9.1 Do you have a death certificate for the deceased? | “baby who died” (or NAME) |
| 135 | 9.7 LAST VISIT ...........................GRAMS | Skip for stillborn babies. |
|  | THANK RESPONDENT FOR THEIR COOPERATION | * Once again, offer condolences for the death of the baby. * In HIC we might provide contact info for bereavement support services. Is there any responsibility or option in LMIC? This is likely very context-specific. |