1 **'Moving towards understanding', acceptability of investigations following stillbirth in sub-Saharan**

2 **Africa: a grounded theory study**

3

4 **Running title:** Acceptability of investigations after stillbirth

5

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Abstract

Objective: To explore the views of women, partners, families, health workers and community leaders of potential investigations to determine the cause(s) of stillbirth, in Malawi, Tanzania and Zambia.

Design: Grounded theory.

Setting: Tertiary facilities and community settings in Blantyre, Malawi, Mwanza, Tanzania and Mansa, Zambia.

Sample: Purposive and theoretical sampling was used to recruit 124 participants: 33 women, 18 partners, 19 family members, 29 health workers and 25 community leaders, across three countries.

Methods: Semi-structured interviews were conducted using a topic guide for focus. Analysis was completed using constant comparative analysis. Sampling ceased at data saturation.

Results: Women wanted to know the cause of stillbirth, but this was tempered by their fear of the implications of this knowledge; in particular, the potential for them to be blamed for the death of their baby. There were also concerns of the potential consequences of denying tradition and culture. Non-invasive investigations were most likely to be accepted on the basis of causing less ‘harm’ to the baby. Parents decision-making was influenced by type of investigation, family and cultural influences and financial cost.

Conclusions: Parents want to understand the cause of death, but face emotional, cultural and economic barriers to this. Offering investigations will require these barriers to be addressed, services to be available and a no-blame culture developed to improve outcomes. Community awareness, education and support for parents in making decisions are vital prior to implementing investigations in these settings.

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48 **Keywords:** Stillbirth, autopsy, investigations, post-mortem, sub-Saharan Africa.

49 **Tweetable abstract:** Investigations to understand the cause of stillbirth may be acceptable to
50 parents and communities.

51

52 **Introduction**

53 Women who have experienced stillbirth have expressed the need to understand the reasons for their
54 baby's death[1, 2]. Of the 820,000 stillbirths per year in sub-Saharan Africa[3] at least a quarter are
55 unexplained[1, 4]. The limited availability of post-mortem investigations leaves women and families
56 without the answers they require to process their grief. The absence of investigations and a cause for
57 stillbirth can impact on women's psychological wellbeing and on the ability for health professionals to
58 provide appropriate targeted care in future pregnancies[5]. In addition, failure to understand the cause
59 of stillbirth leaves women open to stigma and blame[6]. Receiving and understanding autopsy results
60 has been associated with better emotional outcomes for women as they are able to gain closure and
61 are absolved of blame[7, 8].

62 Reducing stillbirth is a health priority driven by Sustainable Development Goal (SDG) 3, and global
63 policy, including Every Newborn Action Plan[9] and the Global Strategy for Women's Children's and
64 Adolescents' Health[10]; which aim to reduce the stillbirth rate to fewer than 12 per 1000 live births and
65 end preventable stillbirths by 2030. However, without understanding the reasons for stillbirth, these
66 goals will be difficult to reach. This is a particular issue in sub-Saharan Africa which continues to have
67 rising rates of stillbirth and the highest stillbirth burden globally[3].

68 There is limited access to investigations in LMICs, such as Malawi, Tanzania and Zambia, despite the
69 high burden of stillbirth in the Region[3]. Where investigations may be available, the financial cost is
70 met by the parents. In many cases, clinical records and verbal autopsy are the only means of
71 determining cause, but these rely on clinician judgement and are subject to misclassification[1, 4, 11]. Full

72 autopsy investigations require highly trained staff and additional costs, which may make them
73 unviable in some LMICs, where resources are already stretched[11]. Even if available, cultural
74 expectations, practices and beliefs may prevent women from accessing these services[5]. Moreover, the
75 costs of autopsy may prove prohibitive to parents. Non-invasive or minimally-invasive autopsy may be
76 more culturally acceptable to parents[5] and place a lesser burden on health systems. Such
77 investigations include biopsy, placental examination and histology, imaging including MRI or CT and
78 verbal autopsy[11-14]. Some methods, such as MRI or CT imaging have been reported to be as effective
79 as conventional post-mortem[13]. The aim of this study was to explore the views of women, partners,
80 families and stakeholders in relation to the type of investigations that would be culturally acceptable,
81 if any, and how the consent process should be approached.

82

83 **Methods**

84 A Straussian grounded theory approach was taken[15]; this allowed for the understanding of
85 participants' views and experiences though social interaction. Participants were recruited primarily
86 from similar public tertiary facilities in Blantyre, Mwanza and Mansa in Malawi, Tanzania and Zambia
87 respectively. Tertiary facilities were selected as the majority of women experiencing complications
88 resulting in stillbirth will have been transferred to this level of care during pregnancy or labour. This
89 included women from semi-urban and rural areas to allow for a variety of views. Furthermore, these
90 sites were partners in a programme of work aimed at preventing and managing stillbirth, funded by
91 NIHR (16/137/53). Community Engagement and Involvement (CEI) groups, consisting of women who
92 had themselves experienced stillbirth, further identified local women, families and stakeholders in the
93 community for potential recruitment to the study. Women were included if they were over 18 years,
94 had capacity to consent and had experienced a stillbirth at 28 weeks gestation or later, as per the
95 World Health Organisation (WHO) definition[3], as adopted by the included countries. Women were
96 identified by health workers, who made the initial approach, and collected consent to contact forms

97 from women interested in taking part. Women who agreed to contact were then approached by the
98 researcher. Partners and family members of consenting women were approached by the researcher
99 if women gave permission for this. Community leaders were identified by CEI group members in the
100 community. Those interested in participating were introduced to the researcher by a CEI member.
101 Health workers opted into the study using contact details on advertisements in the clinical
102 environment. Sampling commenced with purposive sampling of three participants of each of the
103 following groups: women who had experienced a stillbirth, partners and family members of women
104 experiencing stillbirth, health workers working in maternity wards and community leaders. Theoretical
105 sampling continued until data saturation was confirmed, when no new themes emerged from the
106 data[16]. Participants were recruited by Lugina Africa Midwives Research Network (LAMRN)[17] trained
107 researchers, with experience in taking informed consent and qualitative interviewing. Health workers
108 were recruited via posters and information inviting them to participate in the study.

109 Interviews were conducted in a mutually convenient setting; home, facility or community building,
110 and audio recorded with consent. Women, partners and family members were interviewed in local
111 language, with health professionals and community leaders choosing their preferred language.
112 Interviews were respondent led, with topic guides used to maintain focus. A description of potential
113 investigations, including biopsy, skin swab, placental investigation and post-mortem was provided by
114 the interviewing research assistant using a standardised format (supplementary table 1).
115 Demographic data were collected as part of the interview to enable contextualisation of the data. A
116 summary of the interview was confirmed with participants by the researcher, confirming validity.

117 Constant comparative analysis of the data guided by Strauss and Corbin[15] was completed by in-country
118 researchers (by country) and synthesised/integrated by UK leads. Transcribed interviews underwent
119 translation and back-translation to ensure accuracy. Transcripts were read in their entirety for
120 familiarity and open, axial and selective coding completed in line with the Strauss and Corbin approach
121 [15]. Open coding allowed for the identification of key concepts, axial coding involved linking of concepts

into initial sub-categories according to their commonalities, and selective coding facilitated the formalising of these relationships into theoretical categories, identifying a core category. Discussion between the research team and the CEI groups confirmed interpretation.

Community Engagement and Involvement (CEI)

CEI groups in each country were integrated into the research from the design stage. They provided additional input commenting on study documents, providing support in introducing potential participants to researchers and reviewing study findings, adding confirmability.

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Results

Interviews were conducted with 124 participants: 33 women, 18 male partners, 19 family members, 29 health workers and 25 community leaders, across the three countries. Demographic data are presented in table 1. The majority of women participants were multigravida, with 16 participants experiencing antepartum, and 17 intrapartum stillbirth. This reflects the position in sub-Saharan Africa where approximately half of stillbirths occur during labour [3]. All women experienced stillbirth after 28 weeks gestation, as per WHO definition. Participant views were similar across all settings, regardless of parity and gestation, and are presented together under the following key themes; '*needing to know versus fear of knowing*', '*minimal harm',* and '*negotiating the decision*' leading to a core category of '*moving towards understanding*'. This core category represents the needs and willingness of parents and health professionals to know the causes of stillbirth and parents' preparedness to accept

146 investigations. However, this was tempered by tradition and culture, which crosscut all themes acting

147 as a barrier to progress in understanding the causes of stillbirth.

148

149 *Needing to know versus fear of knowing*

150 The majority of women and partners would welcome investigations to determine the cause of death

151 of their baby, frequently citing understanding as potentially improving the outcomes of future

152 pregnancies.

153 *'Absolutely. I would agree so that I know what caused my baby's death. If at all in future, I plan*

154 *to have another baby then I need to take precautions.' (Woman 7, antenatal stillbirth,*

155 *Tanzania)*

156 Some women considered possible benefits for others, demonstrating altruism despite their own

157 difficulties.

158 *'Because the problem that I may face, it may also happen to another woman. So, it may help*

159 *them to see that the same thing has happened to another.' (Woman 6, intrapartum stillbirth,*

160 *Malawi)*

161 This was echoed by community leaders who believed there were benefits to the community in

162 reducing stillbirth and health workers who believed practice could be advanced with this knowledge.

163 However, some women felt there would be no benefit, and potentially harm, in knowing the cause.

164 *'It won't bring it back to life. The baby died between me and the nurses. Maybe I killed it.*

165 *Knowing that it died out of my carelessness would devastate me.' (Woman 12, intrapartum*

166 *stillbirth, Tanzania)*

167 The element of blame attribution resulting from investigations was a potential concern for many.

168 Some family members believed that knowing the cause would place the blame on health workers,

169 vindicating the family. Conversely, community leaders felt that knowing the cause may reduce conflict
170 between women, families and health workers.

171 *'It means to remove the conflict [and] misunderstanding between the mother and the nurses*
172 *to know the cause of the death, because when the investigations are done means the source*
173 *and the cause of death will be known.' (Religious leader 4, Tanzania)*

174 The potential for the women to receive blame and stigma remained, with dissonance between the
175 potential for investigations exonerating the women and others 'finding her out'.

176 *'If the mother caused the stillbirth, this will be a learning lesson for her.' (Traditional leader 4,*
177 *Tanzania)*

178

179 *Minimal harm*

180 There was an overall acceptance of the concept of investigations, but some techniques were more
181 acceptable than others (see table 2). Although the infant was viewed as a body, rather than a person,
182 many parents and family members were reluctant to accept invasive measures, particularly those
183 involving cutting, on the basis that it may 'hurt' the baby. Non-invasive techniques, such as skin swabs,
184 and placental investigations were acceptable to almost all participants, whilst a needle biopsy was
185 also acceptable to most (see table 3). Community leaders felt it appropriate for parents to be guided
186 by health professionals' knowledge in their choice of investigation type and were more supportive of
187 invasive investigations, such as post-mortem. Health professionals were supportive of a range of
188 investigations, should they be available, but understood they would not be acceptable to all women.
189 However, health workers knowledge of investigations varied, and some did not feel equipped to give
190 explanations.

191 *'I think if we are trained more about these options then I would be free to explain them. I don't*
192 *know anything about them.' (Health worker 3, Tanzania)*

193 Cultural beliefs were strong and reinforced by family members, who appeared less likely to support
194 investigations.

195 *'The main influence is our culture. Stillbirths are associated to a bad spirit or curse from the*
196 *family, as a result, any medical investigation is regarded as trying to annoy the spirit and it can*
197 *strike again.' (Family member 1, Zambia)*

198 As well as feeling protective of their baby in terms of potential harm, trust in the facility and staff was
199 important in the acceptability of investigations. Invasive procedures were most likely to be refused as
200 women were suspicious about the destination of samples taken from their baby, based on their
201 understanding of local practices.

202 *'I cannot allow any procedures that involve cutting the baby…. Who knows where they take*
203 *those pieces they get from babies? Such procedures are against our culture and beliefs. We*
204 *have heard of many stories of health workers selling body parts of human beings to ritualists.*
205 *I cannot allow my baby to be subjected to such procedures.' (Woman 2, intrapartum stillbirth,*
206 *Zambia)*

207

208 *Negotiating the decision*

209 All participants felt that the health worker caring for the woman should be the one to make the
210 approach for consent to investigations. In making the decision itself, the majority of participants saw
211 the couple as the sole or main decision makers. Health workers felt they should hold open
212 conversations about potential investigations, but concerns regarding cultural influences, women's
213 emotional position, potential blame and their own knowledge impacted upon their confidence in
214 doing this.

215 *'The mother's reaction upon hearing of her baby's death will prevent me from telling her about*
216 *the post-mortem…They have emotions. They may even accuse us of killing the baby. I think if*

217 *we are trained more about these options then I would be free to explain them. I don't know*
218 *anything about them.' (Health worker 3, Tanzania)*

219 In making the decision, women also had to negotiate cultural influences and beliefs, which were often
220 related to future pregnancy success, making women fearful of denying them.

221 *'According to our tradition, when I give birth to a stillborn baby, the baby should be buried in*
222 *less than 24hrs. If the hospital is to start investigations, they are supposed to put the baby in*
223 *the mortuary which is not allowed in our tradition. If that is done, it means that I will never*
224 *have any other child.' (Woman 8, antenatal stillbirth, Zambia)*

225 Families often reinforced these beliefs, and in some cases were instrumental in making decisions in
226 areas where wider family involvement was expected. This affected the autonomy of the couple to
227 decide and some parents felt the inclusion of family in decision making could be an issue as they may
228 be less supportive of investigations.

229 *'Family members can be a hindrance to this investigation, as they will think it is time wastage*
230 *and wasting of money because anyway, you cannot bring back the baby.' (Partner 3, Tanzania)*

231 Partners accepted they had little knowledge of investigations and would be guided by health
232 professionals in making the decision.

233 *I will be listening to the doctor… because I have no knowledge about it. The doctor is the one*
234 *who directs you (Partner 8, Tanzania)*

235 In making the decision, women were also mindful of the potential cost of the investigations and the
236 fact that they may need to rely on others for financial support. This was particularly evident in
237 Tanzania.

238 *'My sister, being informed, she wanted a post-mortem to be done on the baby's heart and*
239 *other organs, but I told her that we could not afford the charges.' (Family member 9, Tanzania)*

240 The impact of potential cost was echoed by health workers in Malawi.

241 *'After the baby is born, sometimes we offer them to do histology of the placenta, like you take*
242 *a biopsy and do a tissue diagnosis, but it's not a free service. So far I haven't come across*
243 *anyone who can afford them.' (Health worker 8, Malawi)*

244

245 **Discussion**

246 ***Main Findings***

247 This study has highlighted that most woman and partners want to understand the cause of the death
248 of their baby. The main driving force for this is the desire to protect against stillbirth in future
249 pregnancies. Some women, community leaders and health workers also understood the potential
250 wider societal benefit from this knowledge. Parents in this study are open to a range of investigations
251 from autopsy to non-invasive options. However, this is tempered by the need to comply with cultural
252 practices and beliefs, which form a potential barrier to parents' acceptance of the offer of tests to
253 discover why their baby died. These beliefs were often strongly reinforced by family members, who
254 may act as a barrier to acceptance of investigations. Conversely, community leaders representing both
255 traditional and religious groups appeared to be generally supportive of investigations and of the
256 parents alone making decisions around this.

257 Women in this study shared similar concerns to women in high income settings, including prevention
258 of further harm to the infant[7, 18] and concerns of inappropriate use of infant organs. Although culture
259 varied across the three countries, all participants were aware of local cultural norms and the potential
260 influence on their choices. One practical application of culture was the requirement to bury the infant
261 within 24 hours of birth, and many would not accept investigations which would necessitate delay.
262 Other cultural beliefs focussed on potential future 'bad luck' or further stillbirth if the baby is
263 'disturbed'. Fear for women of additional blame as a result of investigations is a unique finding in this

264 study. Whilst women in high-income settings have reported that investigations alleviate anxiety[19],
265 some participants in this study believed findings may expose women to further stigma and blame, by
266 highlighting impacts of their pregnancy behaviour. A further important practical concern was financial
267 outlay, with many parents unable to afford investigations even if they were available. Investigations
268 related to the infant following stillbirth were very rare in these countries and some participants,
269 including health workers, were unaware of the potential advantages and limitations of autopsy or
270 non-invasive examination.

271

272 ***Strengths and Limitations***

273 This is one of the first studies to explore the potential acceptability of investigations in sub-Saharan
274 Africa. The inclusion of partners, family, health professionals and community leaders has ensured
275 contextual and comprehensive understanding, identifying areas to be considered, prior to potential
276 implementation of wider investigations. As a grounded theory study, the findings are not generalisable
277 but are likely to be transferable to other similar settings. The presentation of the findings to country
278 stakeholder groups, CEI groups and in dissemination events (including health workers, women,
279 families etc) established confirmability.

280 It is possible that some participants found it difficult to explore their views of investigations which are
281 not routinely offered in these settings. This was mitigated by ensuring the research assistants were
282 trained in describing the different approaches and the use of a standardised narrative to ensure all
283 participants received the same information about each investigation.

284

285 ***Interpretation***

286 The dissonance between parents wanting to understand the cause of death and cultural constraints
287 was evident. The possibility of investigations was a positive concept for many who wanted to be able

288 to move forward and actively protect against future pregnancy loss, which is particularly important as
289 prior stillbirth is an important risk factor for future pregnancy loss. Importantly, women in this study
290 appeared less tolerant of a fatalistic acceptance of stillbirth than has been reported previously[20],
291 indicating women may be becoming more actively engaged in their health. This understanding
292 suggests that offering women choices in investigations may encourage them to be invested in their
293 future health and empower them to make decisions around care[21]. Such health empowerment is vital
294 in improving maternal and neonatal outcomes and reducing stillbirth[22]. However, tradition and culture
295 were likely to negatively influence women's decisions around investigations, regulating behaviour and
296 choice[23]. These cultural norms prevent women from exercising choice around care of their stillborn
297 baby and removes their ability to pursue clinical explanations. Women bound by cultural constraints
298 are therefore unlikely to gain closure for the death, particularly in light of the limited community
299 support available for bereaved parents[2, 24].
300
301 The suggestion that understanding of cause of death may alleviate or determine blame requires
302 consideration. Blame is associated with higher rates of psychological distress[19] and reducing this would
303 be beneficial[6]. However, it is unclear how the outcome of investigations would be interpreted and
304 whether this would, in fact, reduce the blame burden for many. Women may still suffer stigma and
305 blame where the reasons for the death are not fully understood[6]. In this study, some believed the
306 results of investigations may shift the blame to health workers, absolving women of wrongdoing.
307 However, this may have an impact on health workers wellbeing and potentially how they care for
308 women[25]. Health workers frequently experience blame for stillbirth, with little support[1], and
309 increasing this may impact on how investigations are offered, becoming counterproductive. Prior to
310 implementing investigations, it is important to consider how a no-blame culture for women and health
311 professionals could be developed in these settings, to ensure transparent discussions for individuals
312 around the cause of stillbirth and future planning of care.
313

314 The availability of investigations requires consideration at local and national level, to ensure women
315 are offered appropriate and effective choices. Health workers acknowledge the usefulness of post-
316 mortem, but this is not acceptable to all, both emotionally and financially. A compromise may be
317 effective non-invasive and potentially cheaper alternatives such as histopathological examination of
318 the placenta[5, 13]. The financial cost of stillbirth is considerable and reducing stillbirth through
319 knowledge and treatment of cause will help to reduce this cost[26, 27]. Consideration of free
320 investigations for women experiencing stillbirth may be a positive forward move in addressing and
321 preventing stillbirth whilst providing psychological closure and destigmatising treatment of women.
322 This may also empower women to make decisions without reliance on family for financial support.
323
324 Discussion of autopsy or investigation following stillbirth is sensitive and can be difficult for health
325 workers and women to address[8]. In settings where investigations are not common practice, particular
326 care needs to be taken to ensure practitioners understanding of this unfamiliar concept. Participants
327 in this study implicitly believed that any investigation would provide a definitive answer to cause of
328 death. Hence, it is vital that discussions around investigations enable adequate understanding of the
329 benefits and limitations, to prevent potential further emotional trauma for women[18]. Parents also
330 require clear information of the investigation on the body of their baby, given their continuing need
331 to 'protect' the infant[7]. Health workers will need to be equipped with the necessary skills and
332 understanding of any investigations to be able to effectively discuss with women, as evidence suggests
333 they often lack training and skills in this area[8]. Furthermore, health workers will be subject to similar
334 cultural norms which they will need to negotiate in facilitating these conversations in an open and
335 non-judgemental way.
336

337 **Conclusion**

338 Whilst women want to understand the cause(s) of their baby's death, emotional, cultural and
339 economic barriers exist. Non- or minimally-invasive investigations may be the most acceptable options

340 in these settings. However, certain considerations require addressing if introducing new investigations
341 into already stretched health systems. To gain the widest reach and potentially improve care for
342 women in subsequent pregnancies, facilitating factors would include: community support, education
343 of health workers, parents and communities, and affordability. Community leaders would be well
344 placed to provide support for parents pursing investigations, along with sensitisation of the
345 community as a whole. Health workers would require adequate training and understanding of the
346 types of available investigations, including their limitations, to be able to provide parents with the
347 information they require to provide truly informed consent. The economic cost of investigations would
348 also need to be considered in determining provision, to enable equity of access. It is important that
349 where investigations are offered, women's choice is paramount in accepting or declining these and
350 women should not face further stigma as a result of their decisions.
351

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357

358 **Disclosure of interests**

359 None declared. Completed disclosure of interest forms are available to view online as supporting
360 information.
361

362 **Contribution to authorship**

363 CB and TL designed the study, with input into protocol development from AH, SV, BV. All authors
364 contributed to specific country analysis (CB, VAD, TL, KT, KL, DK, HS, FK, CP) with CB, VAD and TL
365 synthesising the overall findings. All authors interpreted the data. CB drafted the first version of the

article. All authors (VAD, TL, KT, KL, DK, HS, FK, CP, AH, SV, BV) commented on drafts of the article and have read and approved the final version for publication.

Details of ethics approval

Ethical approval was gained from University of Manchester ethics committee (ref: 2019-7451-11496, 24/07/19), College of Medicine Research and Ethics Committee, Malawi (ref: P.09/19/2793, 22/11/19), the Catholic University of Health and Allied Sciences (CUHAS)/Bugando Medical Centre (BMC) Joint Ethical and Review Committee, Tanzania (ref: CREC/399/2019, 12/09/19), and National Health Research Authority and Ethics and Science Converge Institutional Review Board (ERES Converge IRB), Zambia (ref: 2019-Aug-020, 07/10/19).

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