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Community Understanding of Stillbirths and Neonatal Deaths in Cambodia: Family Education and Communication is Vital to Improve Outcomes

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ABSTRACT

Introduction

Globally, the proportion of childhood deaths in the neonatal period is increasing. Despite improvements in maternal health, Cambodia continues to fall behind neighbouring countries in reducing neonatal mortality. The aim of this study is to explore community attitudes towards stillbirths and neonatal deaths by exploring the understanding of these terms, and the causes of them.

Methods

A qualitative study using focus group discussions in randomly selected villages in Preah Vihear province, Cambodia. Data were analysed iteratively until saturation was reached, using thematic content analysis. Investigators' triangulation was used throughout analysis.

Results

Six focus group discussions, involving 55 villagers, were conducted in three villages in November 2020. Participants were able to define stillbirth and neonatal death. However, their depth of understanding was limited. Participants described social determinants causing delays in obtaining timely healthcare for pregnant women. Participants with personal experience of stillbirth or neonatal death could cope and manage their grief by accepting their fate and moving on to other responsibilities, such as earning a living. Both parents were found to be equally responsible for preventing adverse outcomes of pregnancy. However, a lack of communication and silent expectations between partners was hindering prevention.

Conclusions

Community understanding of the definitions of stillbirth and neonatal death is good, although their understanding of what occurred in real-life is limited. Whilst traditional medicine has become less popular, some traditional beliefs are still deeply held, with potentially fatal consequences for the baby. Community education remains a crucial public health measure. However, perinatal education alone is unlikely to be enough. Encouraging family members to actively communicate their knowledge amongst themselves could further improve healthcare seeking behaviours. Better communication could also enhance the family's ability to cope with grief. This could avoid adverse pregnancy outcomes, and reduce the risk of stillbirth and neonatal death.

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Introduction

Globally the proportion of childhood deaths that occur in the neonatal period is increasing [1]. Cambodia met targets in reducing child mortality and improving maternal health by investing in health systems [2, 3]. However, according to the Sustainable Development Goals, Cambodia continues to fall behind neighbouring countries in reducing neonatal mortality and further improvements are called for [4].

The Saving Babies Lives (SBL) Programme has been developed in partnership with the Kingdom of Cambodia Ministry of Health (MoH) and Angkor Hospital for Children, and is conducted in Preah Vihear (PVH) province. The SBL programme aims to develop a package of interventions to reduce neonatal mortality in rural Cambodia and similar low-resource settings [5].

Verbal autopsy (VA) data collected as part of the SBL programme found that stillbirth rate was higher than expected. A potential explanation is that neonatal deaths and stillbirths were being miscategorised. Many studies describe factors associated with neonatal death and stillbirth, and barriers to health seeking behaviour for neonates in rural Cambodia [6–8]. However, no studies have described community members' perceptions of the definition or causes of stillbirth and neonatal death. Understanding community perceptions of perinatal deaths could potentially improve understanding of stillbirths and neonatal deaths in Cambodia.

Studies that involve dialogue with community members can provide insights into both clinical care and community care [9–11] because they provide platforms for communities to address social and healthcare needs from their perspectives [5, 12, 13]. This qualitative study aimed to describe community attitudes towards stillbirths and neonatal deaths in rural Cambodia by exploring the community's understanding of these terms, the difference between the two, and the causes of them.

Methods

This qualitative study was nested within the SBL programme. Three out of 293 villages were randomly selected in Preah Vihear province and two focus group discussions (FGDs) were conducted per village; a male and a female group **(Table 1)**. The FGDs were conducted in Khmer and were audio-recorded. The topic guide contained four categories: understanding the terms stillbirth and neonatal death, community beliefs about stillbirths and neonatal death, attitudes and practices, and exploring blame **(appendix 1)**. Audio data were transcribed and translated into English language into Microsoft Word and analysed in the qualitative data management software package, "the RQDA package" built in R programs version 3.6.1[14].

FGDs were conducted in November 2020, during the Covid-19 pandemic and so all relevant MOH guidance was followed. This included limiting group size to15with facemasks and alcohol handwash, in a well-ventilated space with participants arranged in a circle, either on the floor or on chairs depending on preference.

To maintain confidentiality, FGDs were conducted either outside or under the house of VHSGs, and participant names were not recorded on transcripts. Audio-recordings and all documents were stored securely on our server and only accessible by authorised study staff. Participants were offered a choice of providing consent as either voice, signature, or thumbprint.

Data analysis

Thematic content analysis was used with an inductive approach. Emerging themes were discussed and agreed upon by the study team. To validate the data and to add greater depth to the credibility of the data, triangulation was used. The process included cross-checking transcriptions, cross-coding, and interpretation.

Facilitators' Positionality

The facilitators' backgrounds are in public health, nursing and community health. Both have experience in facilitating FGDs in hospital and community settings. Prior to data collection, the facilitators underwent extensive preparations including piloting the FGDs to familiarise themselves with topic guides and to ensure questions were understandable and natural. The SBL team supported permissions from relevant authorities and recruitment of participants. For each FGD there were two facilitators and one assistant. During data collection, the two facilitators alternated between note-taker and facilitator. Feedback and any issues encountered were discussed immediately after each FGD. Any statements and reflections were carefully discussed and documented on contact summary forms.

Results

In total, 55 villagers from three randomly selected villages in Preah Vihear province participated in the study (**Table1**).

Table 1: Summary and demographic information of focus group discussion (FGD) on 55 participants, 2020

	Male (%)		Female (%)
Total number of participants	18 (33.0)		37 (67.0)
FGD- Village 1	5 (28.0)		13 (72.0)
FGD- Village 2	6 (43.0)		8 (57.0)
FGD- Village 3	8 (35.0)		15 (65.0)
Median age of participants (25^{th} -75^{th})	45 (37.5-61)		37 (25.8-45.0)
Median number of children per participant (25^{th} -75^{th})	3 (2-4)		3 (2-4)
FGD-Village 1	4 (2-5)		2 (1-3)
FGD-Village 2	3.5 (3-4)		3 (1.8-4.3)
FGD-Village 3	3 (2-3)		3 (2-3.5)
Status:			
Mother	-		29
Father	15		-
Grandmother	-		6
Grandfather	3		-
Pregnancy	-		1
	Village-1	Village-2	Village-3
Village's population (2020)	715	852	594
Distance from provincial capital (km)	94	22	25
Distance from health centre (km)	4	8	10

All participants described having direct or indirect experience of stillbirth or neonatal death. The timeframe of these experiences ranged from within the last year to around ten years ago. Some had personal experience of stillbirth or neonatal death in their own family, and some had observed the experience in their neighbours or relatives. Five themes were found in the study, each interrelated: understanding the terms (neonatal death and stillbirth), causes, blame, prevention and treatment. These five themes were broken down into six sub-themes: roles and responsibilities, attitudes and emotions, family relationships and communication (**Figure 1**).

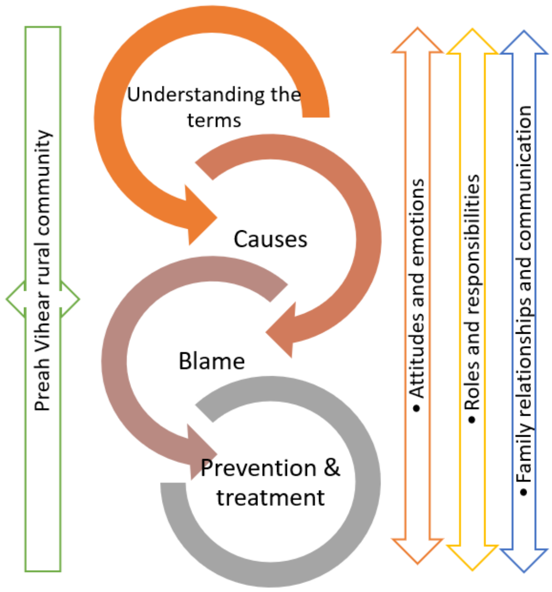

Figure 1: Summary of themes and how they interrelate. Five themes were found in the study: understanding of terms, causes, blame, prevention and treatment. Each theme follows the other dependently. Six sub-themes (roles and responsibilities, attitudes and emotions, family relationships and communication) appeared throughout

1. *Understand the terms Stillbirth and Neonatal Death*

The terms stillbirth and neonatal death are self-explanatory words when translated into the Khmer language, which allowed participants to easily differentiate between the two terms. Stillbirth in Khmer is "Kon Slab Kong Pours", which means "baby dies inside womb"; whilst neonatal death is "Tearourk Koert Hoy Slab", meaning "baby dies after birth" (**quote 1.1, 1.1a, Table 2**). Yet, participants could not themselves identify if a baby is a stillbirth or neonatal death; they only knew if the health professional informed them (**quote 1.1b, Table 2**).

Participants associated stillbirths with mothers, and neonatal deaths with babies. Views differed between participants who had experienced stillbirths themselves, compared to those who had not. Participants who lacked personal experience of stillbirths, said stillbirths often happened when women are physically unwell during pregnancy, whilst neonatal deaths generally occurred when babies are physically weak. For example, babies may not have received enough nutrients from their mothers (**quote 1.2, Table 2**). On the other hand, participants with personal experience of stillbirth, said that they had not encountered any unusual feelings during pregnancy.

2. *Causes, blame, prevention and treatment*

2.1. Causes

Participants described similar causes of stillbirths and neonatal deaths. Causes named were based on living situations, traditional beliefs, and not following medical advice such as spirits, fate, poverty, lack of antenatal visits, improper hygiene, lack of nutrition, overwork, lack of self-care, lack of education, and pregnant women not seeking medical care when they got sick. The causes can be categorised into three types of blame: blame on persons, blame on situations, and blame on supernatural.

2.2. Blame on persons (self, family members)

Participants blamed themselves and other family members in causing stillbirth and neonatal death. Participants who had experienced stillbirth or neonatal death blamed themselves as parents for not taking care of the pregnant woman. Female participants blamed themselves as mothers for not taking adequate care of their bodies when pregnant, whilst some male participants strongly blamed themselves as husbands for not taking care of their pregnant wife (**quote 2.1 & 2.1a, Table 2**). Participants also accused other family members for not bringing pregnant women to the hospital quickly enough (**quote 2.1b, Table 2**).

2.3. Blame on situations (poverty, limited education, infrastructure

Structural causes such as poverty and illiteracy were also described as contributors to stillbirths and neonatal deaths. Participants described a lack of education leaving them with no job option but to continue physical labour. Due to poverty, pregnant women had to choose between working or starving. Participants recognised pregnant women's dilemma of putting themselves at risk by working too hard in pregnancy or not earning money for basic needs (**quote 2.2 & 2.2a, Table 2**). Participants also described how improper and unsafe infrastructure, such as poorly built houses, could contribute to stillbirth and neonatal death (**quote 2.2b, Table 2**).

2.4. Blame on supernatural (spirit, fate)

Stillbirths and neonatal deaths were described as the result of something unexplainable or unsolvable by modern medicine. Participants tended to blame traditional beliefs, fate or dark magic if a stillbirth or neonatal death occurred unexpectedly. Traditional beliefs include the circle of life, bad spirits (Preay), or anger from ancestors (**quote 2.3 & 2.3a, Table 2**).

2.5. Prevention and Treatment

Participants felt that illnesses related to stillbirths and neonatal deaths occurred for two reasons: biological disturbance and supernatural spirits, and they took precautions accordingly. This included following pregnancy health advice such as attending antenatal visits, eating adequate nutritious food, maintaining hygiene, not overworking, and also food avoidance, not lifting hands up high, and not riding on a tractor on bumpy roads. Pregnant women took traditional medicines (TM) and followed some traditional rituals as well as following modern medicine.

2.6. Traditional medicine and beliefs

Various types of traditional medicines were used for prevention, inducing delivery and increasing milk production. Traditional medicines described had different forms, such as drinking plant roots boiled in water or fermented in rice wine (**quote 2.5, Table 2**). Some traditional practices are no longer followed, whilst some are still followed such as "Bon, Sron" [pray], "Sen" [spirit offering], "Sdos and Plom" [spitting betel nuts on infected areas], and "Jong Ksear" [tight small bag of TM on baby's wrist or neck] (**quote 2.5& 2.5a, Table 2**).

2.7. Modern medicine

Preferences have shifted from traditional medicine to modern medicine. Participants agreed that their treatment choices lean much more towards modern medicine than previously (**quote 2.4, Table 2**). They strongly believed in the quality of modern medicine stating that if babies had been born at the health centre, they would not have died (**quote 2.6&2.6a, Table 2**). They only used Kruu Khmer (traditional healer) if healthcare professionals could not treat their children.

3. *Attitudes and emotions*

Participants conveyed different attitudes and emotions towards neonatal death or stillbirths, particularly related to grief and coping.

3.1. Grief for the baby and worry about the mother

All groups described a stronger emotional response to a neonatal death compared to a stillbirth. Unlike for stillbirths, with a neonatal death they were able to see and/or hear the baby (**quote 3.1, Table 2**). However, participants expressed greater concern for mothers who had experienced stillbirths than those who had experienced neonatal death. Stillbirths were thought to cause mothers more harm than neonatal deaths; a stillborn baby could not help itself push out for delivery. A neonatal death created less worry for the mother as the baby was already out (**quote 3.1a &3.1b, Table 2**).

3.2. Coping mechanisms: acceptance and avoidance

Participants that had personal experience of a stillbirth or neonatal death described different coping mechanisms to deal with their emotions and grief, which can be categorised into acceptance and avoidance.

Parents accepted the possibility that their actions may have caused the neonatal death or stillbirth, even though they said they did everything they could to prevent it. Participants also accepted that fate was one of the reasons for neonatal death or stillbirth. They agreed that death is a part of destiny and some babies were just born and die to complete their circle of life (**quote 3.2&3.2a, Table 2**). Some participants demonstrated avoidance, by answering "I don't know", when wanting to avoid rather than participate in the conversation (**quote 3.3 &3.3a, Table 2**).

4. *Roles and Responsibilities*

Participants agreed that each family member has different roles and responsibilities during pregnancy and the neonatal period. For men, their responsibilities were described as supporting the family by working in the field, earning money, and doing household chores (**quote 4.1 & 4.1a, Table 2**). Taking care of babies was the mothers' responsibility because mothers are physically closer to newborns. Grandparents play major decision-making roles during the perinatal period, especially for young parents. When babies were sick, decisions such as whether to withdraw or continue care, were made by grandparents (**quote 4.2 &4.2a Table 2**).

5. *Family relationship-communication*

Throughout all the FGDs, participants were able to describe good practices to be done before, during, and after delivery. Yet, there seemed to be a lack of communication within the family and silent expectations were occurring between partners (**quote 5.1 & 5.1a, Table 2**). Male participants expected their wives to follow all of the Peth's (health professional's) advice, whilst female participants expected their husbands to look after them, take them to antenatal visits, and help with the household chores.

Discussion

Although participants were able to define stillbirth and neonatal death, their ability to differentiate between the two terms did not parallel their level of understanding. In real life situations, participants rely on health professionals to tell them if the baby was a stillbirth or neonatal death.

The causes of stillbirths and neonatal deaths were attributed to social determinants that contributed to a lack of good health in pregnancy and to a delay in obtaining timely care [5, 15] (**Figure 2**). This finding is similar to studies conducted in Cambodia and Mexico, with contributing factors including poverty, inability to attend regular health check-ups, no access to clean water, and not getting nutritious food [15] (**Figure 2**). Delays to seeking care occur when participants face a dilemma between working up until delivery to earn money or to be closer to a health facility.

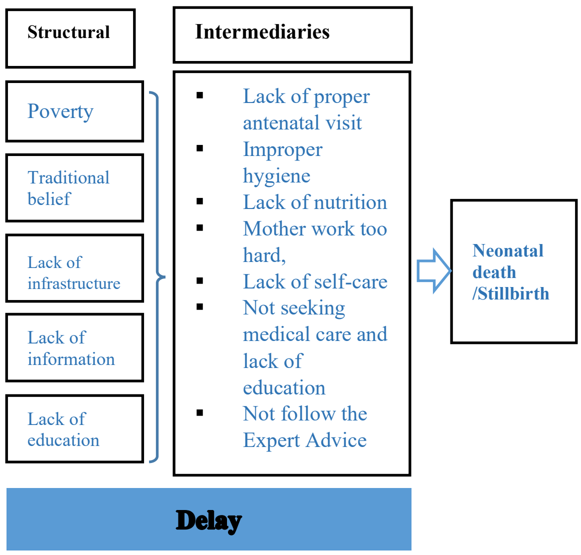

Figure 2: Social determinants/ Pathways that lead to neonatal death/stillbirth: adapted from [5, 15]

Table 2: Key quotes from the six focus group discussions (FGDs) by themes

Theme	Quote number	Quote	Participant

1. Understand Stillbirth and Neonatal Death			
Understanding the terms	1.1	Well, stillbirths are when the baby who was already born dead. .. baby was so sticky. Even the placenta was also very sticky." (P-9)	FGD-1-F
	1.1a	Well, for the neonatal death is died outside the mother's tummy. (P-4)	FGD-1-F
	1.1b	It depends on Peth. Peth is the one who know and let us know if the baby is stillbirth or neonatal death. (P-6)	FGD-6-M
Differentiate the terms	1.2	… stillbirth occur when mother has a big problem … F: how about neonatal death, what happened then? When the baby is not healthy[weak]" (P-5)	FGD-1-F
	1.2a	"I would say stillbirth is when the mother of that baby is weak and also the baby inside does not have enough nutrition and energy to push itself out". (P-5)	FGD-2-M
2. Causes, blame, prevention and treatment			
Blame on a person	2.1	I will be responsible [should be blamed] because I am a husband…P1: Because as the husband, he drinks alcohol (P-5) …	FGD-2- M
	2.1a	Might be our fault because we don't take care of our baby well that can lead to death. (P-14)	FGD-1-F
	2.1b	…, but her husband seemed to not encouraged her to go to heath centre/hospital. Her husband and her parents followed her not to got to health centre/hospital just because she didn't want to go… Until the next morning. [it's late] (P-1).	FGD-2-M
Blame on situations	2.2	… a lot of reasons and those have to do with money. Some choose to not going to deliver at the health centre was because they don't have the money. (P-4)	FGD-2- M
	2.2a	"There is a lot of work to do in the field, and family not enough money. To do the health check-up, one needs to be in town which is far from the village. Thus, mothers need to work hard in the field to get the money to go for a check-up". (P-1)	FGD-2-M
	2.2b	… she used toilet [that] was not a well-built. The brittle [wooden] floor was broken and when she steps on it, she got slip and fell down. Then she was feeling unwell…..she went to the health centre. The baby was born and died after three days (P-5).	FGD-4-M
Blame on supernatural	2.3	Well, Preay [ghost] is staying in the body of the mothers and then they would eat all the spirit and then cause mothers to have the illness and die (P-10)	FGD-1- F
	2.3a	Well, indeed, some baby was just born for about a week or so and then die. That was because the baby's destiny was meant to be like that. To born and to die. (P-1)	FGD-3- F
Prevention and Treatment			
Treatment	2.4	P1: We go to Peth first, P2: We go to see Peth first and if it does not work, we then go to see Kruu Khmer. P8: When we go Peth but we don't know the reason that causes the baby sick, we then go to see Kruu Khmer (P1-2-8)	FGD-4- F
Traditional medicine	2.5	Some recommend to eat and drink seven eels soak in white wine to give birth easily ----laughing-----To give birth easily like eels because the eel is easy to move" (P-1 our belief is 100% different from the previous time" (P-4)	FGD-2-M
	2.5b	"Yes, and sometimes, Peth [health professional] cannot help curing that issue. Only after Sen and Bon Sron [Pray] then the health issue is gone." (P-7)	FGD-6- M
Modern medicine	2.6	"…We go to Peth first," (P-1-2) "Delivering at HC, can help as it is safer. There are more equipment and modern care" (P-2)	FGD-4- F
	2.6a	"I said, if the baby was born in the Health centre, the baby would have been fine because the baby seemed healthy. The baby weight was 4 kg!" (P-11-12)	FGD-1- F
3. Attitudes and emotions			
Grieving for the baby and worried about the mother	3.1	"To me is the neonatal death is more painful as we can see the baby's face and we can feel their presence already." ……. But for the stillbirth, if the baby dies, we did not see the baby so it is less of the grief" (P-8)	FGD -2- M
	3.1a	"To me, both are equally sad. But I am more concern about the mother. If it is neonatal death, is better for the mother. Baby was already out." (P-4)	FGD -3-M
Coping mechanisms:			
Acceptance	3.2	"No, we like to think such cases as faith. That's a destiny that brought us together and if it means to me just this short period [of time]. …. In Buddhism, we believe in reincarnation. Sometimes, one dies and rebirth just to complete their circle of life."	FGD-1- F
	3.2a	"Well, some babies were just born and die. No one wants the baby to die. Mother have worked so hard to make sure to help the baby [but baby still died]." (P-10) "P2: I don't know... I have never known and heard of such things. If I know I will tell you."	[SSI -1-addition]
Avoidance	3.3	"Don't know the causes. Death is death" (P-5)	FGD-2- M
	3.3a		FGD-2- M
4. Role and Responsibility			

Parent's roles and responsibilities	4.1	"Well, their [fathers] jobs are to make sure that the farm is well. They should grow vegetable making sure we have money to buy food. Their jobs are to help reduce the [economic] burden." (P-3)	FGD -1- F
	4.1a	"Peth (HCW) always advises us … to do health check-ups during pregnancy. I haven't joined a lot of sessions. It is a women's job to take care of." … "Men don't have wombs" (P1-4)	FGD -6-M
Grandparents	4.2	"Well, I was not there [at the hospital] ... I suspected they requested the nurse to bring the baby home, but I cannot say because I was not there. The Peth did not allow the baby to come yet." (P-A)	SSI -1- addition]
	4.2a	"For my child, she was in her 7th-month pregnancy. She was bleeding unusually. …Then we went to see Peth. …Then we have to do the operation. I decided to sign the consent for the doctor to do the operation... it's been 5 years already. My granddaughter is alive and well." (P-1)	FGD -4- F
5. Family relationship-communication			
	5.1	"The same as others. Husband doesn't take care of his wife and his wife is afraid to tell her husband. And other couples are not in good relationships…" (P-1)	FGD -2-M
	5.1a	"But I got to say, most of the things that happened with my wife during the daytime, if she does not tell, I would not know. She would be the one who let us know what? [They could just say] "Oh, honey, today, I went to see Peth, or Tomorrow is the appointment date, please bring me to the health centre?" (P-2)	FGD -6-M

Participants in rural Cambodia were more accepting of the high incidence of stillbirth and neonatal death than described in other settings [15, 17, 18]. Cambodians might be more used to these terms because we found that, participants had seen and experienced at least one stillbirth or neonatal death in their lifetime. Those experiences influence most Cambodians to accept the belief that life depends on faith and destiny. They face the uncertainty that their babies may be born dead regardless of all precautions they have taken [7, 8]. Hence, their choices lean toward going to work for money rather than seeking health care. It is important to understand that issues of stillbirth and neonatal death are complex and require intersectional policies and actions to increase effective access to health services [5, 7, 15]. National policy should consider prioritising actions in the poorest communities to improve living conditions and better access to health care.

Parents' expressions of grief and coping were much less intense compared to studies done in the UK and Spain [15, 17, 18]. In these high-income settings, the amount of grief expressed was profound with parents describing experiences of post-traumatic stress disorder, emotional shock, pain, suffering, loneliness, and loss of hope. In contrast, in our study, participants with personal experience of this grief, were not affected by discussing the terms and experiences of stillbirth or neonatal death. Through the FGDs, we found that the timeframe of the event did not affect the ways of the community handling with grief. Even parents with recent stillbirths or neonatal deaths, seemed to cope with grief well. The difference in findings could be because these studies were conducted in developed countries where living conditions are incomparable to Cambodia. Participants were able to tolerate and manage their grief by accepting the fact that death is inevitable. They were able to cope by accepting the situation and moving on to other responsibilities such as earning a living. This does not mean that their level of grief is any less than those felt in developed countries, it was just that they were too busy to express their feelings. Therefore, it would be interesting to study more about coping strategies that parents in low-income settings have around stillbirth and neonatal death. This could help to increase mental well-being of parents who experience stillbirth or neonatal death in countries with limited resources.

Currently, modern medicine is seen as highly effective and something that all participants thought that pregnant women should follow. Modern medicine at health facilities has become the first choice of treatment, with traditional medicine and practice complementing this. It became clear in this study that treatment choices for perinatal care were made based on available services rather than faith or traditional practice. The shift towards modern medicine could be explained by the increased availability and accessibility of Cambodia's healthcare services in rural areas [8, 16]. Previously, people went to the Kruu Khmer (traditional healer) because modern medicine was not easily reachable or affordable.

Each family member plays an important role in preventing stillbirth and neonatal death. Good communication is essential so that they can share knowledge regarding perinatal care [5, 19–21]. Though parents are aware that they are responsible for looking after pregnant women and unborn babies, it appeared that they did not communicate to each other about specific perinatal care. There was a silent expectation amongst partners. Therefore, part of the perinatal education should include the importance of communication between family members in order to better support each other to prevent stillbirth and neonatal death if it does happen[22, 23].

Conclusion and Recommendation

We found that community understanding of the definitions of stillbirth and neonatal death is good, although their understanding of what occurred in real-life is limited. Whilst traditional medicine has become less popular, some traditional beliefs are still deeply held, with potentially fatal consequences for the baby. Community education remains a crucial public health measure.

However, perinatal education alone is unlikely to be enough. Encouraging family members to actively communicate their knowledge amongst themselves could further improve healthcare seeking behaviours. Better communication could also enhance the family's ability to cope with grief. This could avoid adverse pregnancy outcomes, and reduce the risk of stillbirth and neonatal death

Acknowledgement

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Conflict of interest

The Author(s) declare(s) that there is no conflict of interest.

Approvals

The study was approved by the Cambodian National Ethics Committee for Health Research (NECHR, ref. 083) and Oxford Tropical Research Ethics Committee (OxTREC, ref. 515-20).

Authors' contributions

S.Pol and **C.Soputhy**: collected and analysed data and wrote the article. **C.Turner, K.Patel, S.Pol, K.Lo**: designed the study, analysed data. **C.Turner, K.Patel, S.Pol, C.Soputhy, K.Lo, and D.Leng**: analysed data and reviewed the study. **C.Turner, K.Patel, S.Pol, C. Soputhy, K.Lo, D.Leng**: critically reviewed the manuscript. **D.Leng, S.Pol and C.Soputhy**: collected data. All authors read and approved the final version of the manuscript

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