"I should have seen her face at least once": Parent's and healthcare providers' experiences and practices of care after stillbirth in Kabul province, Afghanistan

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Abstract

Objective

This study aimed to explore bereaved parents' and healthcare providers experiences of care after stillbirth.

Study design

Qualitative in-depth interviews with 55 women, men, female elders, and healthcare providers and key informants in Kabul province, Afghanistan between October-November 2017.

Results

Inadequate and poor communication and insensitive practices including avoiding or delaying disclosing the death by healthcare providers were recurring concerns. There was a disconnect between parents' desires and healthcare providers perceptions. The absence of shared decision-making on birth options, seeing and holding the baby, and memory-making, manifested as profound regret. Health providers reported hospitals were not equipped to separate women who had a stillbirth and acknowledged that psychological support would be beneficial. However, the lack of trained personnel and resource constraints prevented provision of support.

Conclusion

Findings can inform future provision of perinatal bereavement care. Given resource constraints, communication training can be considered with longer term goals to develop context-appropriate bereavement care guidelines.

Keywords: Stillbirth, perinatal death, bereavement care, health services research, qualitative methods, Afghanistan

Introduction

Stillbirth is a devastating and traumatic loss for parents and families and associated with long-term psychological and social consequences[1, 2]. The psychological and emotional impacts of stillbirth are well documented and include post-traumatic stress, anxiety and depression[3-6]. Parent's wellbeing is further affected by the care and treatment received after a stillbirth from healthcare providers[7, 8]. The practices and behaviours of care providers during their interactions with parents at each point around their stillbirth, from diagnosis through to the birth and post-natal period, can affect how and if families cope with the death and the extent of psychological trauma[9]. These impacts are being increasingly recognised with many studies now describing and investigating these experiences to improve care and minimise the psychosocial effects[10-12].

Stillbirth can cause prolonged grief comparable to the loss of any child, but is complicated and intensified because of the lack of an equivalent recognition and acceptance of this grief by society and healthcare providers[7]. Evidence from studies conducted in several low- and middle-income countries (LMIC) suggests that stigmatisation around stillbirth due to sociocultural beliefs and societal pressure means women and men often cannot openly grieve their loss [13]. There are few studies from LMICs examining the experiences of parents of the care received just before or following stillbirth, yet these countries account for 98% of the global burden of stillbirths[14].Two recent systematic reviews have examined the experiences of care received after stillbirth including one focused on studies from LMICs, although most included studies were from middle-income countries with only five from low-income countries [13, 15].

Afghanistan is a high stillbirth burden country with a stillbirth rate of 27 per 1000 births – almost nine times greater than rates in high-income settings[14]. Despite this large burden there is little known about the experiences of parents of stillborn infants or the healthcare staff who provide care to these mothers following a stillbirth. Our previous research in Kabul province found that parents and the wider community recognised and valued babies who are stillborn[16] but whether this is reflected in the provision of care by healthcare workers at health facilities or at the community level is not known.

Health systems have a pivotal role to play in supporting families following a stillbirth[12]. Appropriate and respectful perinatal bereavement care is core to these efforts. Bereavement care comprises both the formal and informal care provided to parents and families in the time following a diagnosis of stillbirth and into the post-natal period[17]. The aim of this care is to facilitate parents' recovery and minimise the psychosocial impact of the loss by ensuring respectful, compassionate,

patient-centred care that is respectful of the diversity of parent's grief. Standards and clinical guidelines for the provision of bereavement care following stillbirth were recently developed for a few high-income countries[18, 19]. In Australia, clinical practice guidelines for Respective and Supportive Perinatal Bereavement Care were developed to improve the quality of bereavement care and outlined several recommendations based on current evidence combined with extensive stakeholders consultation[20]. These guidelines comprise 49 recommendations around the five central goals of bereavement care including: i) good communication; ii) shared decision-making, iii) recognition of parenthood; iv) effective support; and v) organisational response.

Equivalent guidelines for bereavement care do not exist for LMIC settings primarily due to the absence of adequate evidence on the effectiveness of support strategies or best practice following perinatal death[21]. Although many of the recommendations from existing guidelines may be transferable and applicable to low-income contexts, they require adaptation for different countries and socio-cultural contexts. In 2020, through extensive stakeholder consultation including a global survey with health workers across high-, low- and middle-income countries, a global consensus was reached on eight core, evidence-based principles for a bereavement care package after stillbirth[22]. Understanding the challenges related to ensuring implementation of these principles and the provision of perinatal bereavement care in low income settings is needed.

The situation and experiences of parents and care providers across different countries and cultures can vary due to varying socio-cultural perspectives of grief and death, perceptions and meanings associated with stillbirth and pregnancy loss, as well as prevailing health system constraints and capacity of healthcare providers. Given the scarcity of studies from low-income settings, in this paper we sought to explore bereaved parents' and healthcare providers experiences and perceptions of care provided and received following stillbirth in Afghanistan to identify opportunities for improving practices and to provide guidance on the future provision of bereavement care.

Materials & Methods

Study design

The data for the current analysis are from a qualitative study conducted in Kabul province Afghanistan in 2017 that have not been presented in previous publications[16, 23]. In this study, we employed semi-structured in-depth interviews to elicit the perceptions and experiences of stillbirth from both parents and healthcare providers perspectives. The current analyses focus on individuals' experiences of the care they received or provided just prior to and after the delivery that resulted in

a stillbirth focusing on elements related to perinatal bereavement care. A related paper investigated possible pathways leading to stillbirth[23].

Study setting

The study was undertaken in urban and rural districts of Kabul province, Afghanistan. Study sites included three high-volume referral maternity hospitals in the capital, and two lower-level health facilities and surrounding communities in two rural districts ~25-30 kilometres west and north of Kabul city.

Participants and recruitment

Study participants comprised of mothers (n=21) and fathers (n=9) who had experienced a recent stillbirth and female community elders (n=3), various healthcare providers (n=20) ranging from Community Health Workers (CHW) at the community level to hospital managers in tertiary health facilities, and selected government health officials (n=2). We used purposive sampling to recruit participants either through health facilities or from the community-level through CHWs and contacts of our local interviewers. Our methods to identify and recruit women who had a stillbirth varied throughout the data collection due to several challenges related to contacting women including missing contact telephone numbers in medical records, women not owning mobile phones, frequently changing phone numbers etc. Therefore, we used multiple methods to recruit women who gave birth to a stillborn. We identified women through hospital medical records and contacted them by telephone if numbers were available and working, or through direct notification from hospitals when a stillbirth occurred over the field work period, or through our local interviewers' networks. Fathers were recruited either through identified mothers or interviewers' networks. In rural districts, CHWs assisted with identifying participants including female elders. Selection of participants in a management position in facilities and government officials was done in consultation with local researchers.

Data collection

The study data collection team included three (2 female and 1 male) experienced Afghan qualitative interviewers with background training in the social sciences who participated in three days of training provided by the study team. The first author, a foreign female public health researcher, also conducted interviews in English with eight selected key informants (e.g. medical doctors, chiefs of wards, hospital directors, government health officials). The remaining interviews (47 of 55) were carried out by the Afghan interviewers and conducted in Dari or Pashto (the two official local

languages). We developed semi-structured in-depth interview guides for each participant type which explored their perceptions, understandings, experiences and practices related to stillbirth[23]. Interviews were held in private locations agreed upon by participants usually at health facilities or in their homes and were conducted by an interviewer of the same gender as the participant for socio-cultural reasons. It was challenging to ensure women's interviews were conducted alone and in three cases the mothers-in-law of women were present in the interview while in a further three interviews other female relatives were present. After providing information about the study and obtaining informed consent, interviews were conducted in the participants' preferred language and audio recorded where permission was obtained. Only half (10 of 21) of interviews with women were audio-recorded due to privacy concerns of women or because it was prevented by their mother-in-law. For these cases, interviewers took notes which were expanded after the interview. Interviews ranged in length from 30 to 60 minutes. Following each interview, interviewers also completed a debrief form to document non-verbal observations during the interview about the participant or the interview environment, any new topics that arose, and any challenges. Interviews were transcribed verbatim in the language conducted and Dari and Pashto transcripts were translated to English by independent Afghan translators fluent in English. Translations were checked for accuracy by the interviewers and local researchers. Discussions among the research team were held to clarify any discrepancies and understand contextual meaning. Recruitment of mothers, fathers, and healthcare providers continued until we had an adequate range of responses and no new themes were emerging[24]. Identification of female elders was time intensive, and we were unable to recruit sufficient respondents in the time period of the data collection.

Data analysis

We conducted a thematic analysis of the data[25]. Our analysis focused on how parents perceived the care received just prior to, during, and after delivery in relation to the pregnancy that was a stillbirth and also how healthcare providers described and perceived the care they provided to women. Analysis began with multiple readings of all transcripts and was followed by generating a code list. Codes were initially based on the interview guide topics and new codes were added as additional concepts emerged. Codes were then categorised and grouped into meaningful categories relevant to the study objective. Theme development was primarily deductive and informed by the available literature on best practice in perinatal bereavement care taking into consideration context [9, 17, 20]. Themes were revised and refined after discussion among team members. We used N-vivo 11 software to organise and facilitate data management and analysis. Obtaining the viewpoints of various participant groups assisted with triangulating findings and allowed us to compare the

experiences and care practices as perceived from different perspectives to obtain a comprehensive picture of the experiences of care around stillbirth. We examined the variations that existed across respondents identifying similarities and differences between narrative perceptions.

Results

Several recurring themes emerged surrounding the experiences and perceptions of care from diagnosis through to the early post-natal period. We mapped the identified themes under the framework on goals for respectful & supportive perinatal bereavement care adapted from Boyle et al.[20]. The main themes of our analytical framework were: i) communication and information provision, ii) decision-making practices, iii) parenthood and personhood, and iv) availability of support (Figure 1).

COMMUNICATION AND INFORMATION PROVISION

Delay or avoid communicating stillbirth diagnosis

Many of the women we interviewed explained how they had not been told that their baby was stillborn or had died immediately after birth; some were not even directly told or communicated about this by a healthcare provider at all, finding out through other family members or relatives. Some women with an antepartum stillbirth were aware their baby had died prior to arriving at the hospital. However, it was not common practice for healthcare providers to prepare or inform women or their husbands of the death or what they might expect in the next stages of the birth or the post-natal period.

Several respondents recounted that following the birth, healthcare providers would quickly take the stillborn baby away handing it to a family member (outside the birthing room) without mentioning anything to the mother. It was common for healthcare providers to avoid disclosing the death to the mother, at least not immediately. One mother recalls how she was waiting for her newborn after she gave birth,

> '…when my baby was born the doctors prepared its place and I was waiting (wondering) why didn't they put my child there. I waited for a long time and then I saw the baby was under the table. I waited for half an hour. They did not tell me because they were afraid of *joora* [placenta].'
>
> -Mother#06

Another woman waited for several days not knowing what happened to her baby and was finally informed by her husband who received the news while waiting outside the health facility. Although this particular mother's baby was an early neonatal death, her baby was alive for only a few hours. She had undergone surgery and was in the hospital for three days before she was informed about the death,

> 'They didn't tell me anything about it, because I had high blood pressure and (thought) I might go into shock. I was in the hospital for three days, but I didn't know anything about my baby…That was my last day in the hospital and when I found about it, there was no one with me… I was in the hospital and the doctors didn't tell me anything, but my husband did.'
>
> -Mother#20

Healthcare providers explained that they were protecting women by concealing the death initially, which they thought would benefit the mothers' wellbeing,

> 'No, we don't talk about it (her stillbirth) in front of the mother; we only tell her companion [the person accompanying her to the hospital - usually mother-in-law] about it and we don't mention it in front of the mother. Even if she delivers the baby, we use medical terms in front of her so that she doesn't know about it, because the status of the mother might not be good and it could cause the death of the mother.'
>
> -Obs/Gynae resident doctor_facility#03

However, women reported that non-disclosure caused further distress as they found out through other avenues. One woman recalls how she found out about her stillborn baby while still in the hospital through a phone call from a relative who had heard the news from the person accompanying her at the hospital,

> 'When the dead baby was delivered, they hid this news and I didn't know that it died. But one of our relatives called me for the mourning [to give condolences].'
>
> - Mother#19

Women also spoke of how healthcare providers avoided them altogether after the birth. Women perceived this behaviour as suggestive that the doctors had made a mistake and were responsible for the death of their child and were afraid of blame,

> 'I later found out in the hospital…but the doctor hid herself. When I delivered the baby she didn't visit me again, because she killed my child.'

-Mother #19

Fathers, who were usually waiting outside of the hospital as they are not permitted inside, were also not informed immediately that their baby had died. One father described how he was told by his mother who had accompanied his wife inside of the hospital,

> 'After the child was born, my mother said it was a boy. I was just given this much information, and no one came out (to tell us) then. When they came out after one hour and we asked, they said the child had died we have no idea why.'
>
> -Father#03

It was not only healthcare professionals that avoided telling parents they had lost their baby – this was also common among family members and untrained birth attendants during home births. One mother who gave birth at home to a stillborn relayed how her mother-in-law delayed telling her husband,

> 'First, they didn't tell my husband about the baby's death. He asked my mother-in-law, why didn't the baby open its eyes? Later, my mother-in-law told him that it died.'
>
> -Mother#04

Inadequate information and discussion on what happened

Many parents described not having an opportunity to discuss what had happened with the responsible care provider after their stillbirth and were frequently left without any reason or understanding of what had happened, or what might have contributed to the loss of their baby. Although several participants reported having asked healthcare providers for an explanation, they did not receive any information and had not persisted to follow up. It was apparent from respondent's narratives that there was a sense of disempowerment among parents to question doctors. Most explained that healthcare providers informed them their child was dead and were then discharged. When one father was asked about what he was told afterwards about the reasons for their child's death, he stated:

> 'They [health providers] said nothing, they just kept us for half an hour then let us go home and we carried the dead baby home.'
>
> -Father#06

This same husband explained how his wife had also asked the doctors about why their baby died, but no reason was provided, with the doctors' response appearing to downplay the loss,

> *Respondent:* They [the doctors] were asked for the reason, no one gave us the answer though. We were not allowed to enter (the hospital).
> *Interviewer:* No, but your mother was inside. Hadn't your wife asked?
> *Respondent:* They had asked them [the doctors] this question, but no one gave them the answer. Then we asked my wife, how did this happen? She said it was all because of the carelessness of the doctors. Since it is your first time, these problems are usual, said the doctors. Don't worry about it. After the child was born, they had put it on her mother's chest and said it was a boy. Then we didn't know what happened. They came and told us our child was dead.
>
> -Father#06

Not only were families not provided with any information about why their baby died, but there was no communication about future prevention or risk. Several women in our study had experienced multiple pregnancy losses and wanted risk reduction information to avoid future pregnancy loss. One mother complained that,

> '…They [the doctors] don't tell you about your problems; whether it was due to the anaemia, they only prescribe you lots of medicines. If they find out about the cause, that's fine; otherwise, they only charge fees to you.'
>
> -Mother#14

In contrast to some parents' recounts, healthcare providers claimed they were sympathetic and communicative with parents when revealing a stillbirth diagnosis, as this midwife explained,

> 'She [the mother] is certainly very upset. We try to get her to understand that her child is dead and that she can become expectant with another child again. We answer all her questions as she is upset. We say we did everything we could to save her child.'
>
> -Midwife#04_Facility#03

The differences between what healthcare providers reported regarding the information communicated to parents compared to parent's recount of events, suggests substantial variation in

practice and perceptions. Some providers stated that their staff should give sufficient information to parents, as this midwife explained,

> 'The parents should be given the information and reason of the death of their baby - why it died? We are providing enough information and the reason for the death to the mother and her female family members of the baby, but we never talk to the male member of her family. But some of the hospitals talk with a male member of the family as well and give them enough information about that. However, here in our hospital, we just give the information to the mothers and their female relatives, because the mother should know the reason why her baby is dying or is born dead.'
>
> -Midwife_Facility#01

DECISION-MAKING PRACTICES

No consultation on birth options

Based on parents' responses there appeared to be very little communication from healthcare providers with women or accompanying family of the options for the birth of their antenatally detected stillborn infants. Although permission was sought to conduct caesarean sections, it was not explained the reason for it. This mother recollects that '*When I was checked-up, I was told that the baby is lost, and I needed to do the surgical operation. Then they asked for permission from my mother-in-law and the surgical operation was conducted.'* [Mother#11]. Similarly, fathers who could not enter the hospital and had even less information on their wife's situation, agreeing to whatever healthcare providers requested, as one father explained: '*They haven't told me anything, they just asked me to sign the paper and (said) your baby has already gone, and we need to do surgery to take out the baby.*' [Father#08].

In some cases, parents did not even know their baby had died at the time consent was sought for the caesarean section, nor were they informed there was any concern or that their child was at risk, as this father explains about his experience,

> 'She [his wife] was examined there (at the hospital) and we were not told anything; then we were given a letter to (go to) [-name of tertiary hospital omitted-] Hospital, and we went to that hospital. She was admitted there for one night. In the morning, the doctor obtained our thumb prints and asked whether you agree for her operation, according them it was not possible without operation; at this time, we were not told about the

death of the baby. I gave my thumb print and allowed them to do the operation; after the operation the child was born dead. Neither we asked nor did they [the doctors] say anything (to us). The operation went well, but the child was lost.' - Father#05

Inadequate time and opportunity for memory making

Some women in our study had the opportunity to hold their baby, whereas others did not. What was apparent was that both mothers and fathers in our study had a strong desire to see and hold their stillborn baby; and those who did not, expressed intense regret and sadness during the interview,

'I wished to see her once. When we had got her out of the hospital, I hugged her. As my mind had not worked on the spot I could not see her face. Later, I was more regretful, as after we reached home, the baby had already been buried. For a few days it was coming to my mind that, 'I should have seen her face at least once'.''

- Father#05

This father recalled how his wife had wanted to see their stillborn baby but was not able to due to the practice of burial as soon as possible after death,

'She has asked (to see and hold the baby), but it was too late; I had taken the baby and buried it after the evening prayer. If we had waited there it might be too late. She still reminds me (of) that situation and becomes so sad.'

- Father#02

Many parents lamented that they did not have as much time or opportunity to spend with their baby as they wanted either because of the initial shock of the loss at the time, or because of social requirement of an immediate burial. One mother who had not seen or held her baby stated -'*When I got out of the delivery room and my mother-in-law brought the baby to me. I was so upset, and I didn't see the baby as it was given to me*.' [Mother#04]. When asked why she didn't hold it, she replied that, '*I couldn't stand and I was so upset too and it* [the baby] *wasn't left (with me) for a while, but my husband was so looking for it...*'

Both mothers and fathers expressed regret about not having enough time to hold their baby. One father said, '*Yes, I hugged him, but my brother was sitting in the car and took it* [the baby]

…and there was no chance for me to hug him again…'[Father#04]. A mother describes her only desire after birth: '*I wanted to hold it in my arms and didn't let (them take her from me) her to be buried. I wanted no one to take her from me*.' [Mother#17]. Almost all women that did not see their baby wished they had. One mother when asked if she desired to hold her baby and why, said '*Definitely…In fact, it is a child for the mother, and she wants to take care of it and bring it up*.' [Mother #20]. Another stated she wanted to hold it '*Because I loved it. I carried it in my womb for nine months. I tried a lot to bring this baby into the world.*' [Mother#21].

Respondents also commented that other family members also expressed a desire to see the baby. One female elder said that,

> 'Yes, not only the mother…Everyone wished to see the baby and the mother also wished to hold the baby in her lap, but she was sick and couldn't hold it.'
>
> -Female elder#01

In contrast, a mother whose fifth child was stillborn did not wish to hold her baby, but did express a desire to see it,

> *Interviewer:* Did not you wish to hug the baby?
> *Respondent:* No… I requested my sister to show me the baby, well, so I can understand how the loss of a baby looks like. Then I saw the baby who had hands, feet, and his mouth was open. He was a large baby. It did not affect me so much.
>
> -Mother#01

Disconnect between care providers' practices & parents' desires

Healthcare providers and birth attendants reported that it was best for women who had a stillbirth not to see their baby and avoided giving the baby to them to hold. Many did this with good intentions as there was a widespread perception that the mother would be harmed further from the distress caused if she saw her baby, and that it would exacerbate any medical condition or complication and would negatively affect her emotional wellbeing. There was no discussion between healthcare providers and parents around whether they wanted to hold or see their stillborn. Instead, many healthcare providers made assumptions about what they thought parents wanted or what they thought was best. Many believed mothers did not want to hold their stillborn baby as this interview with a senior healthcare provider indicates,

Interviewer: According to the experience you have, is the mother interested to hold her stillborn child?

Respondent: No, she is not.

-Obs/Gynae Trainer_#02_Facility#01

Another doctor also stated with certainty that, 'They (mothers) might see their babies, but they don't want to hold them…' [Obs/Gynae doctor_facility#02]. In contrast, other healthcare providers including two midwives, stated that they always show the mother her child whether it was stillborn or died soon after birth, but do not necessarily give her the baby to hold,

'Yes, we give the baby to their family members and show it to the mother as well. Once the baby is born then we clean it and submit it to their family members.'

-Midwife#01_facility#01

Another doctors' response suggested women were interested to hold their baby, but this decision was made by the health provider and largely determined by the health status of the mother,

Interviewer: Doesn't the mother ask that she wants to see her baby and take her in her arms?

Respondent: Of course, yes. Then we tell her that its [the baby] condition was not good at all and we send it to the newborn babies' ward. It depends upon the status of the patient, because the patient might be in a bad situation and it will be worse if we tell her. We don't tell the mother at that time - we tell her when she recovers gradually.

-Obs/Gynae doctor_Facility#03

This statement from a neonatal ward chief demonstrates how mothers do express interest to see their baby, yet providers avoid giving it to her,

'Of course, she sees it [the baby], but we directly don't give it to her… First, they want to see, yes. Yes, sometimes (they ask to see it) when we deliver the baby sometimes there is missed abortion (miscarriage) and the baby is for example, less than 20 weeks and they don't have everything developed, but they still want to see…'

-Neonatal ward chief_facility#01

At the community-level, there were similar perceptions around allowing the mother to hold her stillborn. Female elders who often attend home births confirmed these practices, *'…We show her the baby. But we don't show the baby to the most, but we show it to some women…'* [Female elder_#01]. A CHW stated,

> 'They just inform the mother about the death of her baby; if it was completely ok and not mis-shaped, but (they) never give it [the baby] to her to hold because she will feel sad….I don't know exactly (why), but people say the mother will get deeply sad if she sees the dead baby.'
>
> - CHW#03

There were also several underlying perceptions about the consequences of showing the baby to the mother including how seeing the stillborn will affect her, as one mother explains,

> '…they do not show her (the mother) the stillborn baby because they are afraid the mother will cry very badly, and it will cause the mother to not have more children...'
>
> -Mother#06.

Importance and value of mementos

The value of having a memento to remember their baby was raised by several participants. One mother had a photo of her stillborn and her recollection illustrates the significance of having this option,

> 'When I got out of the delivery room and my mother-in-law brought the baby to me, I was so upset I didn't see the baby as it was given to me. Then it was taken to my mother-in-law. My cousin took its picture. I sometimes look at it and become so sad; I told my husband that day to print this picture in large size and bring it to me.'
>
> -Mother#04

Fathers similarly conveyed a desire for a memento. One father expressed regret at not having taken a photo of his baby and losing the opportunity due to the distraction of events surrounding the death,

> 'Yes, the mother and I wanted to see the baby. Later, I wished that I was able to take a photo in my mobile and show it to the mother, but I have already lost that chance.'

-Father#08

PARENTHOOD AND PERSONHOOD

Acknowledgement and respect

Parents recollected in detail the events leading up to and after the stillbirth and the actions and words of healthcare providers. Although many women said they were treated well and health providers showed sympathy and expressed their condolences, there were several occasions that were not positive. A lack of acknowledgement of personhood and the relationship parents had developed with their baby was apparent in some healthcare providers behaviours and comments to parents. One mother described how her baby was given to her husband,

> '…I was transfused two bags of blood too because I was in the worst condition…The doctors put it (the baby) in a plastic bag and gave it to my husband...'
>
> -Mother#07

The insensitivity of some healthcare providers was also evident in this mother's recollection of her birth when she had requested staff for her baby,

> '…My mother-in-law said that the baby was large, she told me, 'do not allow the doctor to throw the baby out'. I told the support staff of the hospital to give me my baby, she said [in a sarcastic tone], 'do I give you his placenta as well?'; I said, NO. Then she put the baby in the plastic and gave it to me.'
>
> -Mother#01

However, many healthcare providers acknowledged the loss of the baby and treated both the mother and her stillborn baby with respect, as one healthcare provided stated,

> '…The patient's companion brings a piece of cloth for the dead child and the child is handed over to him with all the respect. He takes it home and then buries it.'
>
> -Obs/Gyne Trainer#02_Facility#01

But it was evident from some healthcare providers comments that some did not perceive a stillborn to be as significant as a live baby,

'When the baby is born dead, it will be wrapped in a white piece of fabric and will be submitted to the family, but it cannot be as important as a live baby.'

-Obs/Gyne doctor#02_Facility #02

While others had very different views as illustrated by this doctor's comment,

'…even we are not respecting the stillborn baby, once we show it to the mother carrying it, we take it as something rubbish and put it somewhere. We haven't respected it as a human being, because there is a big load of work for us and we cannot respect it. So, we put the dead baby aside, especially the macerated (one), but not in the place which is specified for the newborn baby.'

-Obs/Gynae doctor#01_Facility#02

AVAILABIILTY OF SUPPORT

Lack of bereavement support and training

Health facilities and healthcare providers in our study were not equipped or trained to provide any form of support immediately after the birth or in the post-natal period for women or their families following a stillbirth. There were no formal structures to enable the provision of perinatal bereavement care or facilities to refer women to receive such support. When a neonatal ward chief was asked about any support services for mothers or if there was any capacity for it, she said, 'No. Nothing! Just sometimes we prescribe some medicines for the milk – breast milk - so that it stops...' [Chief of Emergency_Facility#02].

Healthcare providers explained that they themselves tried to console parents however they could, although there were variations in practices and behaviours as evidenced by parent's accounts of these interactions. Women were discharged and left to cope on their own, relying on their husbands or family members for support, as one mother explained, 'I was very distressed, cried a lot and shared my grief with my husband, mother-in-law and my mother.'[Mother#15]

Many doctors and midwives reported trying their best to console and counsel women who had a stillbirth,

'… in addition to being doctors, we are Muslims, thanks to God. We behave well with the mother who gives birth to a live child too. It is not like we behave badly with her. Health care services should be provided for every mother. If a mother has been psychologically

hurt, we sympathize with her and tell her that God may give her live children, as many as she wants. We try to psychologically relieve her.'

-Obs/Gynae trainer_facility#01

A manager at one health facility described how healthcare providers *should* be communicating with women in her hospital despite some of these experiences not being reflected in parents accounts,

'…they (the doctors) should talk with her very kindly; they encourage them in their future life and give them a good consultation for not repeating the same case in the future. While a dead baby (is) born, the doctors don't blame the mothers (or say) that you had that problem and you have birthed a dead baby, but they bring the scientific reasons and advise them. Then they also add that it was God willing, we tried our best, but we couldn't rescue your baby and they also mention the previous situation of the baby which was not well and had a problem before it reached to the hospital, or if it has gone by the doctors they also mention it as a reason.'

-Chief of Neonatal Ward_facility#02

Some healthcare providers acknowledged that a pregnancy loss was devastating and were aware of the psychological impacts, '*She* [the mother] *is mentally affected very much and we try to strengthen her morale and do everything as she wishes because she is distressed.*' Midwives recognised that the loss was also upsetting for husbands and other family members too,

'Yes, when a stillbirth happens the mother becomes very upset and so do her companion and husband. As the mother takes efforts for nine months, when it is born dead, she is extremely affected…'

-Midwife#04_facility#03

It was evident that many healthcare providers acknowledged the loss and stated that they did not treat women who had a stillbirth any differently to those who had a live birth,

'….They [mothers who had a stillbirth] should be treated the same because their arms are empty; they need more care and sympathy…,'

-Obs/Gynae doctor_facility#02

Some healthcare providers also advised accompanying family members to treat the mother well at home to minimise any emotional and psychological effects,

> 'We ask the patient's companion to behave well with the patient as she has lost her child. We tell him/her to keep her happy as she will be concerned and upset after this delivery and will get a mental problem.'
>
> -Midwife#04_facility#03

Lack of separate wards

In the health facilities through which the study was conducted, there was no provision of separate wards for women whose baby had died, and they were in the same room as all women. These field notes by one of our interviews illustrates how distressing this can be,

> '…all the patients were resting in their own beds. Some of the patients were happy and laughing because they have delivered the baby and it was in their arms. The only woman who was so sad and worried and her eyes were swollen was the one that I had the interview with. She was so sad because her has lost her baby during the delivery, but she still wanted to have an interview. She said that the doctor has killed her baby.'
>
> -Notes by interviewer about Mother_#19

Healthcare providers agreed that separation was needed and would be beneficial, but hospitals were already over-crowded, with very few private spaces. They acknowledged that seeing mothers with their live infants would be difficult:

> '…Because we don't have that much space that we should separate things…Yeah (it would be good to separate them) because sometimes they see other mothers breastfeeding, or it's a little...psychologically she is depressed, but we don't have the space…'
>
> -Chief of Emergency_Facility#02

Early discharge practices

Another concern related to the constraints of health facilities and overcrowding were around discharge practices. Mothers of stillborn infants or newborns that died soon after birth were

discharged on the same day if there were no complications, as this healthcare provider explains,

> '…First the companion is told, then the dead baby is taken by them. If the mother delivers the baby normally, she should stay in the hospital for six hours and complete her period. If she has gone through the surgical operation she should stay for the specific time [3 days] in this case too.'
>
> -Obs/Gynae resident doctor_Facility#03

However, accounts from parents differed with some indicating they were discharged from hospital even within an hour after birth,

> '…it was around 9 o'clock in the morning when the child was born. It was around ten or half past ten [in the morning] when we left here for our house.'
>
> -Father#03

Another mother said,

> '…I was discharged on same day… A patient is discharged early if a baby is miscarried or stillborn. The doctors say they don't discharge the patient if she is critical.'
>
> -Mother#11

No support person

Parents reported that some facilities would not only prohibit fathers inside but would not allow anyone to accompany the mother which meant women did not have a support person during or after their birth. One father recounted that, '*Yes, because it (the hospital) has all the facilities and men are not allowed to get in. My mother who was accompanying her was also not allowed to enter…*' [Father#03].

Discussion

In this study we have described the experiences and perceptions of care received from parents just prior to and after stillbirth and of healthcare providers in the provision of this care, in the context of Afghanistan. The inclusion of both parents and caregivers' perspectives highlighted a disconnect between parent's desires and providers' perceptions of what families may want or need. We also found a large variation in practices by care providers and birth attendants and also in parent's

wishes. Some parents reported positive experiences, whereas others experienced very negative and insensitive practices and communication by healthcare providers - the effects of which could potentially be long-lasting and detrimental[1]. At the core of most concerns surrounding negative experiences was the lack of information and appropriate communication about the loss, recognition of parenthood and personhood of the stillborn, and the missed opportunities for memory making. Healthcare providers, for the most part, had good intentions, but were also constrained by health system processes, lack of support services and training, to give the support needed.

Healthcare providers interactions with parents was of critical importance and women in our study vividly recalled the details of what was said and how their stillborn baby was handled. Similar recollections have been documented in other studies[15, 26, 27]. Healthcare providers frequently avoided or delayed disclosing the stillbirth to the mother as a means of protecting mother's health and her mental state. This perception indicates to some extent their understanding of the magnitude and impact of the perinatal loss, but also an absence of awareness of the potential negative impacts this can have. Pullen et al. investigated how stillbirth notification was delivered to parents by caregivers and found that it could negatively impact their grieving process[28]. It was not only healthcare professionals that avoided telling parents they had lost their baby – this was also common among family members and untrained birth attendants during home births, suggesting there may be underlying societal attitudes around disclosing or communicating distressing news as a means to protect from further pain. It will be important to sensitise maternity care providers at all levels in Afghanistan to ensure they are conscious of their interactions and are sensitive and empathic in their communication with bereaved parents.

It was evident from our findings that some healthcare providers also avoided women in the hospital following a stillbirth which led women to conclude that they were at fault and responsible for the death of their child. Our previous study indicated that there was much fear among healthcare providers about being blamed for a perinatal death which may underly these avoidance behaviours [16]. It has been highlighted previously that when parents perceive health providers are not being forthright and transparent this can create mistrust[26, 29]. Similar avoidance behaviours by medical professionals were also reported by parents in the UK[10]. Lack of empathy and information from healthcare providers was also a complaint identified by mothers in Malawi[30]. Globally, dissatisfaction with communication from healthcare professionals was one of the most common concerns from parents who have had a stillbirth[9, 31]. A systematic review identified that ensuring communication and support for families from diagnosis through childbirth and post-birth was critical

and underpinned meaningful care[9]. If health personnel were better equipped with strategies and communication skills to approach women with compassion and sensitivity during these difficult encounters, it may be possible to overcome some of these issues. Increasing awareness in the community and among healthcare professionals around the causes of stillbirth would be one way of minimising the issue of blame that might prevail.

Some healthcare providers in this study were aware of the psychological impacts of stillbirth on parents and what appropriate care or communication might look like; however, there was substantial variation in practices. Parents were generally not consulted with about decisions in their medical care or interventions after stillbirth, nor were they provided with information on birth options. A study in the UK[10]found similar variations in care, inadequate communication and the lack of involvement of parents in decision-making regarding birth options in particular. Similarly a study in Nigeria found that women were not consulted or involved in any decision-making regarding their stillborn baby[32] and in India, women who had a stillbirth described paternalistic decision-making by health providers[33], indicating these practices are widespread. One of the principles in the global consensus on bereavement care recommends providers to support women and families to make shared, informed, and supported decisions about birth options and this can be encouraged in the Afghan setting as well[22].

There were similar concerns when it came to memory making and the opportunity for parents to see or hold their baby. There was a disconnect between mothers' and healthcare providers perceptions; healthcare providers did not seem to be aware that their perception of what they felt was best for the mother was not necessarily what the mother/family wants; nor did they consider asking women or their husbands what they wanted or what the possible options were at any stage. Similar divides between parents and healthcare providers were noted in a study in Somaliland where women expressed a desire to see and hold their baby but here they were not permitted, even after they asked[34]. The power imbalance that exists in provider-patient relationships may underscore the interactions we observed and may also explain why parents do not question or make requests of medical providers. In Afghanistan, where large inequities exist and often the very poor are using public health facilities, this may be even more evident and therefore makes it all the more imperative to ensure that healthcare providers initiate these conversations with parents.

Several studies have investigated the mental health effects of giving parents the opportunity to see and hold their baby, but the evidence remains unclear around whether this has positive or negative

744 impact and currently the recommendation is to offer the option to parents[17]. Few studies have
745 examined this in low-income settings, yet the different perceptions of stillbirth and perinatal loss
746 that exist across different contexts would suggest there may be variable views and preferences. In
747 some contexts there are taboos around seeing or holding a stillborn infant and therefore it is
748 important to consider the cultural context and provide parents the option together with adequate
749 time to make the decision[35]. Our study participants – both mothers and fathers - expressed a
750 desire for seeing, holding and having a memento of their stillborn child; although in this context, a
751 stillborn baby was recognised and valued and not generally hidden[16]. In other settings where
752 miscarriage or stillbirth may not be openly discussed or may be associated with stigma or social
753 exclusion, differing views might exist. In a Nigerian study, over two-thirds of women reported that
754 they wanted the opportunity to see their stillborn baby, however, fewer were interested in holding
755 or taking photographs[36]. In our study, it was apparent that parents did not have sufficient time to
756 process what was happening and many were regretful about things they would have liked to have
757 done with their child before it was taken away. Ideally, giving information to parents in advance of
758 some of the decisions they might have to make would prepare them and provide more time to
759 consider the options.
760
761 Several health system constraints made it challenging to ensure appropriate and respectful
762 bereavement care for women following stillbirth. Some were structural – resulting from physical
763 limitations of health facilities, while others were partly due to healthcare providers' behaviours and
764 perceptions, and the absence of training or guidelines to provide bereavement care. A review by Ellis
765 et al. found that health care providers acknowledged that their own knowledge, emotions and
766 system barriers were challenges to the provision of effective care after stillbirth[15]. Perinatal loss is
767 a challenging and stressful event for health providers and they also need to be supported and
768 equipped with relevant skills to manage the range of responses. Addressing health system barriers
769 to provide respectful care has been was a consistent finding in studies in LMICs to improving
770 bereavement care following stillbirth[13] and it is critical that action be taken to address these in
771 Afghanistan – not only to minimise long term psychosocial and economic consequences, but to
772 facilitate improved access to health facilities overall during pregnancy and childbirth and reduce the
773 burden of stillbirth. Existing perinatal bereavement care guidelines emphasise that such care should
774 be personalised and there is no single approach for all parents and circumstances. The key
775 recommendation is acknowledgement and validation of parent's grief. The global consensus on
776 perinatal bereavement care advises the provision of adequate postnatal care to address parents'
777 physical, psychological and practical needs and establishing a point of contact for ongoing support

and provision of information for future pregnancy planning[22]. Without appropriate and meaningful care, psychosocial support or counselling after stillbirth, the long term psychological impacts including grief related depression, anxiety, post-traumatic stress can persist up to four years and the social and economic consequences on families and societies can be immense[1, 2, 37]. In addition, women that conceive again after stillbirth are at an increased psychological distress in subsequent pregnancies[1], thus making it imperative to ensure ongoing care and support.

A key strength of this study is that it provides evidence for Afghanistan in which care following stillbirth has not been previously investigated and therefore contributes important knowledge to guide improvements in perinatal bereavement care practices. Capturing healthcare provider's views and practices alongside parents identifies behaviours and perceptions are not well represented in the literature for LMICs. A limitation of our research is that data collection was confined to only one of Afghanistan's 34 provinces and the most progressive and with the greatest access to healthcare facilities. We were also limited to rural districts with good security, access to health facilities and active CHWs, all of which may limit the generalisability of our findings. The difficulties in conducting interviews alone with women may have affected the responses they provided and should be considered when interpreting the findings. Further research is needed to understand experiences from different parts of the country and among a range of different ethnic groups.

Recommendations

There are several opportunities to improve the experiences of care of women and their families around stillbirth in Afghanistan. In such a resource constrained setting where health services are already under immense pressure with staff shortages and are overburdened with patients, introducing some minor changes that can improve the experience of parents can be a small first step. At a minimum, the care and communication that occurs between healthcare providers and parents within health facilities could be addressed. Improving the interactions of staff with patients can make substantial difference and avoid causing unnecessary distress and long-term psychological impact.

Increasing awareness of healthcare providers on the variation of parents' perspectives and needs after stillbirth through education and training and implementing measures to ensure specific questions or discussions take place could be one strategy to improve bereavement care practices. The feasibility of training health providers on shared decision-making and skills on providing clear information using a basic package of perinatal bereavement training could be explored. Even in high-

income countries, training in perinatal bereavement care is rare[38, 39]; however, with increasing attention on the importance of improving bereavement care and the interaction between care providers and parents, and several guidelines now available and a global consensus on core principles for bereavement care[22]. The availability of mental health services and trained professionals in Afghanistan is extremely limited although some psychosocial counselling training has been provided to existing healthcare professionals in the country[40]. However, a counselling for Reproductive, Maternal, Newborn and Child Health and Family Planning (RMNCH/FP) training package provided to doctors, nurses and midwives exists, and includes material on bereavement counselling for maternal and newborn deaths [41]; this can be updated or adapted with recommendations from the global consensus on perinatal bereavement care or other existing guidelines[22, 29]. Midwives may be most suitable and best placed to target for such training at the facility level. At the community level, CHWs or community midwives could be engaged and provided with some basic training and counselling skills on perinatal bereavement care to follow up families who have experienced stillbirth and also to connect and refer women to further care if needed. If feasible, another strategy could be to incorporate a checklist for healthcare providers to use with women that experience a perinatal death in health facilities that prompts providers to ensure certain measures are taken, for example, providing women adequate information and the opportunity to ask questions, giving them the option to see and hold their baby, asking if they would like a photo taken etc. These could be incorporated into existing monitoring checklists used by health facilities.

Structural limitations including the lack of separate maternity wards for women who have had a perinatal loss may be challenging to address in the context of Afghanistan given the constraints on health facilities, but separation is important for women's mental wellbeing and consideration should be given to how this could be accommodated. There are also limitations around allowing men inside many maternity hospitals and the need to bury the deceased immediately which pose additional challenges for affording parents the opportunity to spend time with their child. One possibility for this to occur could be to have a separate dedicated room in health facilities away from the maternity ward for parents to spend time with their stillborn baby and a healthcare provider trained in counselling and bereavement care to discuss options and give advice for post-birth care and wellbeing. To begin with, this may be feasible to implement at tertiary, provincial and district health facilities. This might also help to address the early discharge practices that were reported in our study to allow women more time to process the death and make a decision about if and when they want to see their baby.

In the medium to longer term, the adaptation and revision of RMNCAH clinical guidelines to incorporate updated guidelines for perinatal bereavement care with recommendations directed at both healthcare providers and health services can be developed. These can revolve around the five broad goals of best practice of perinatal bereavement care[20] and the global consensus on the core evidence-based principles for a bereavement care package[22]. However, future research is needed to understand in more depth Afghan parents' wishes following stillbirth and the feasibility and acceptability of implementing and integrating such guidelines into existing practices.

Conclusion

Our study findings are similar to what has been found in many other settings in regard to care received during and after stillbirth and also in relation to what parents want and need as part of this care [9, 13, 42]. Afghanistan is a conflict-affected country that has been at war for over four decades. Exposure to trauma among women and families is high and mental health issues are widespread[43, 44]. Women face additional challenges in a largely patriarchal society, with restrictions on their movement, access to financial resources and high levels of domestic violence[43]. Data on post-partum depression is limited, but qualitative studies indicate this is very common in Afghanistan[45]. It is, therefore, even more imperative that respectful and quality perinatal bereavement care is provided to not exacerbate the trauma and long-term impacts of perinatal loss on women and families. Afghanistan's National Mental Health Strategy for 2019-2023[46] includes a focus on pregnant and post-partum women and the development of guidelines for maternal mental health screening and psychosocial support. This provides an opportunity to incorporate psychosocial counselling for women who have experienced a perinatal loss. Parents in our study wanted meaningful care where they received sufficient information about what happened, that they and their baby were treated with respect, their grief and loss was acknowledged, and they had adequate time with their baby. With sufficient commitment, such care can be provided using existing guidelines to develop and train care providers and improve outcomes for women and families in Afghanistan.

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Conflict of interests

The authors declare no competing interests.

Ethical approvals

Ethical approval was provided by the institutional review board of the Afghanistan National Public Health Institute/Ministry of Public Health, Afghanistan (no. 43880) and the ethical review committee of the University of Sydney (no. 2017/566). Written permission was provided from participating hospitals and all participants gave written or verbal informed consent. The study was performed in accordance with the Declaration of Helsinki.

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