Original Article

Bereavement Care Practices Following Stillbirths: Health-Care Provider's Perspective

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Abstract

Background: Addressing stillbirth is a difficult task and becomes more challenging with a huge burden and skewed doctorpatient ratio. There is a lack of data regarding the knowledge about the bereavement care practices following pregnancy loss and practices being followed by the health-care providers in the Indian context. The objective of this study is to describe the experience, views, and practices of health-care professionals while managing women with stillbirths. **Design:** Internet-based Monkey Survey. **Methodology:** An on-line self completion questionnaire was shared with various health care providers via emails and whats app groups. **Results:** A total of 281 responses of health-care providers were analyzed, and the majority of them were obstetricians. Almost 90% had managed women with stillbirth, but just a third (38.1%) had provided bereavement care. The majority of them felt the lack of a uniform and comprehensive training model for providing bereavement care to such women. Out of 281 participants, 258 (91.8%) believed that health-care providers should have a bereavement care training and support system, whereas only 23 (8.2%) rejected this idea. **Conclusion:** There is no defined protocol or standards for providing bereavement care to women following stillbirth. Most health-care professionals feel an urgent need for professional training to bridge the gap between the expectations of patients and the care provided.

Keywords: Bereavement care practices, bereavement care, stillbirth

Introduction

Pregnancy is a time of joy and excitement of the newfound blessing in the form of a baby; however, it becomes equally distressing for those who end up in stillbirth. The sudden loss of an unborn child can lead to guilt, anguish, and self-blame. The grief of losing a baby can lead to major mental illnesses such as depression, anxiety, and posttraumatic stress disorder.[1] The impact of stillbirth is not only on the affected parents and the families but also on the communities, and society, health-care system, and providers too. Health-care providers also find it difficult to cope up with the burden of guild despite providing the best care and even considering giving up the obstetrics altogether.[2,3] The response and behavior of health-care providers while delivering care plays a critical role in modifying the stress response of these mothers with loss.[3,4] There is enough evidence that the care received by the women following stillbirth is inconsistent and deficient worldwide.[5,6] There is a huge gulf between the expectations of parents and the options provided to them.[7] There are no comprehensive programs to support these women following loss and to guide the health-care providers except few national guidelines available from High middle income countries. (HMIC).[8] Therefore sensitization and training of health care providers is needed to provide optimal care and support.

Annually, an estimated 2.6 million stillbirths occur worldwide and majority (98%) of them occur in low- and middle-income countries (LMICs). India is among the top ten countries with the highest stillbirth numbers, with stillbirth rate of 23.3/1000 births in 2015.[9] Addressing the stillbirth itself is a difficult task and becomes more challenging in country like India with a huge burden and skewed doctor–patient ratio. There is a lack of evidence-based recommendations

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for providing bereavement care following stillbirth from the Indian setting. There are no data regarding the knowledge about the bereavement care practices following pregnancy loss and practices being followed by the health-care providers.

This study was planned to assess the experiences of health-care providers and the practices in managing women following stillbirth. Furthermore, to find out their views regarding the need for bereavement care practices in existing settings of Northern India.

Methodology

The study was conducted with the approval of the institutional ethical committee from July to September 2020. A prestructured questionnaire was prepared with fixed-choice answers using an online survey development cloud-based software (Monkey Survey). The questions were based on aspects related to women with stillbirths; (1) breaking the bad news, (2) management of women following intrauterine fetal death, (3) intrapartum care of such women, (4) memory-making, and (5) bereavement care practices. To calculate the sample size, initially, a pilot study was conducted to assess the bereavement care practices in existing settings using online questionnaire survey. Out of 30 participants, 12 (40%) responded that they are providing some kind of bereavement care and support to women following stillbirths. Based on the pilot study results, a sample size of 260 was calculated to achieve a 40% response of bereavement care to the women following stillbirths in existing health settings with a 6% absolute margin of error and 95% confidence interval. Anticipating a 10% nonresponse rate of the participants, a sample of 290 participants was finalized. The participants were the health care providers including medical officers, physicians, nursing officers and obstetricians & gynecologists. Snowball sampling technique was used to recruit the participants using WhatsApp groups and through e-mails. The responses were extracted in Microsoft Excel 2010 sheet and analyzed using SPSS version 22 (IBM Corp. Released 2013.IBM SPSS Statistics for Window,Version 22.0. Armonk,NY (USA):IBM Corp).

Results

The response rate to this survey was 38.7%; as it was sent to 800 health-care providers through e-mail and various WhatsApp groups, and a total of 310 (30 for pilot study) health-care professionals participated. The data of 281 participants were analyzed. Majority (83%) of respondents were of the age of 55 years and above who had experience of 25 years or more. Majority of them were female (91.5%) and obstetricians (80.7%). Apart from obstetricians, medical officers, nursing officers, and other professionals such as psychiatrists, radiologists, and ophthalmologists also participated in the survey.

Almost 90% of participants had managed women with stillbirth (87.9%); however, only 38.1% were providing specialized bereavement care. Table 1 depicts the theme-based responses, majority (92%) feel that such women need specialized care, still it is not given. The common reasons

Table 1: Current practices and experience of health-care providers in managing women with stillbirth

Questions and responses	*n* (proportion %)
Management following intrauterine fetal death	
Have you ever managed stillbirth?	
Yes	247 (87.9)
No	34 (12.1)
Have you ever blamed a woman for stillbirth?	
Always	0
Usually	2 (0.7)
Sometimes	25 (8.9)
Rarely	49 (17.4)
Never	205 (73)
How often have you seen such mothers crying/ having anger bursts or blaming themselves?	
Always	36 (12.8)
Usually	109 (38.8)
Sometimes	102 (36.3)
Rarely	33 (11.7)
Never	1 (0.4)
Breaking the bad news	
Do you know how to break the news bad news following stillbirth?	
Yes, confidently	120 (42.9)
Yes, hesitantly	142 (50.8)
No	19 (6.8)
Intrapartum care of such women	
Do you ask such women about the preference of mode of delivery	
Always	64 (22.8)
Usually	70 (24.9)
Sometimes	57 (20.3)
Rarely	49 (17.4)
Never	39 (13.9)
Are you giving liberal labor analgesia to such women at your hospital	
Always	58 (20.6)
Usually	88 (31.3)
Sometimes	67 (23.8)
Rarely	38 (13.5)
Never	29 (10.3)
Are birth companion allowed	
Always	70 (24.9)
Usually	69 (24.6)
Sometimes	77 (27.4)
Rarely	40 (14.2)
Never	25 (8.9)
How often attention is given to emotional needs of such families	
Always	62 (22.1)
Usually	93 (33.1)
Sometimes	86 (30.6)
Rarely	37 (13.2)
Never	3 (1.1)

Contd...

Table 1: Contd...

Questions and responses	*n* (proportion %)
Memory making	
Do you ask the mother her preferences of seeing, holding, or clicking photos of stillborn?	
Always	33 (11.7)
Usually	35 (12.5)
Sometimes	42 (14.9)
Rarely	64 (22.8)
Never	106 (37.7)
No answer	1 (0.4)
Holding or taking pictures of a stillborn baby (memory making) affects the women psychologically?	
Affects positively	48 (17.1)
Affects negatively	117 (4.6)
Cannot say	113 (40.2)
Bereavement care practices	
Are you providing specialized bereavement care?	
Yes, always	107 (38.1)
Yes, sometimes	115 (40.9)
No	59 (21.0)

Table 2: Reasons given by health-care providers for not providing bereavement care in existing settings

Reasons for not providing specialized care	*n* (%)
Overcrowding and shortage of staff	197 (70.1)
Lack of confidence as no formal training is provided	48 (17.1)
It is the duty of psychologist	9 (3.2)
Cultural practices and belief	13 (4.6)
No need of any specialized care as fetus is already dead	5 (1.8)
No answer	9 (3.2)

for not being able to provide special attention are depicted in Table 2. Most of the participants had witnessed such women suffering from self-guilt, despair, self-blame, and having anger outbursts [Table 1]. Participants also responded about their beliefs regarding allowing the woman to see, hold, or take pictures of her dead baby, and only 29.2% feel that such women should be asked for memory making. Most of them admitted that they have never asked the mothers about the preferences of seeing, holding, or clicking photos of their stillborn baby [Table 1]. About 42.1% of health-care providers thought that holding a stillborn baby would have a negative psychological impact on the mother [Table 1]. Majority of the participants (166 [59.7%]) were not aware of the option of donating breast milk to other babies as a measure to help them cope up with their grief [Supplementary file].

Only 42% of professionals feel that they are confident in breaking the bad news following stillbirths. Out of 281 participants, 258 (91.8%) believed that health-care providers should have a bereavement care training and support system, whereas only 23 (8.2%) rejected this idea.

Discussion

This data represent the experiences/practices of health-care professionals and their views regarding bereavement care following a stillbirth which is largely neglected in our country. Attitude and knowledge of health-care providers matters for immediate- and long-term benefit on parents. Majority of our respondents were obstetricians and had the experience of managing stillbirth. Regrettably, most of the participants acknowledged that such women are often neglected in terms of their emotional needs. There is a complete lack of grief support system, and health-care providers are acting based on their personal beliefs and opinions.

Many of them feel that they are empathetic in communicating, but unfortunately, due to overcrowding, shortage of staff and different cultural practice unable to provide the care needed. Even in the RESPECT study for consensus on global bereavement care after stillbirth, the inadequate number of health-care workers was found to be one of the barriers to implement bereavement care in LMICs.[8] Other barriers found in global consensus were lack of supervision of Health care providers (HCP), lack of funding and trainings, staff demotivation, resistant of health-care workers to change, lack of support for HCP, and burnout from huge burden of stillbirths.[8]

Empathy is an essential component of doctor–patient relationship and leads to better clinical outcomes, patient satisfaction, and lower levels of stress.[10] Being empathetic is a learned response, and for an empathetic counseling, specialized training is needed. Many of the health-care professionals are unaware of the strategies to be offered to lower the grief of bereaved mothers.

In our study, there was no consensus on allowing the mother to make mementos, hold the baby, or take pictures. Most respondents either feel that holding the baby has a negative psychological impact, others have no opinion about it. Even available literature did not find enough evidence to support the effect of memory-making on short-term or long-term mental health and well-being of mother.[11] Still, memory-making is practiced worldwide and found to provide satisfaction to bereaved parents and make them happy with their decision of holding the stillborn baby.

Formal training to deal with parents' emotions and doctors own insecurities is lacking in our residency program as in our study, half of the participants admitted that they do not feel confident in breaking the bad news. The mode of delivery is often decided as per the associated obstetrical complications, not on the basis of preferences and vaginal mode is usually preferred in our setup. Only 51.9% are routinely giving liberal labor analgesia to such women. Birth companion is an essential part of respectful maternity care; unfortunately, in our study, only 49.5% are regularly allowing birth companions.[12]

Clinical practice guidelines in the management of women with stillbirth are available for high-income countries; however,

there is a lack of consensus in LMICs.[13,14] The limitation of this study is that it was just an online survey and snowball sampling technique was used for recruitment. Therefore, the actual response rate was not calculated, and the geographical area was also not taken care. The identity of the responders was also not included except the profession and years of experience. However, this study emphasizes the need for specialized training of health-care professionals in providing bereavement care. This would also help to improve their communication skills, behavioral techniques, emotional response, and lead to a good doctor-patient relationship.

Conclusion

Stillbirth is a neglected issue in our setting. There is no defined protocol or standards for providing bereavement care to women following stillbirth. Most health-care professionals feel an urgent need to be offered professional training to bridge the gap between expectations of patients and the care provided. Management of stillbirth and helping them cope up psychologically should be a part of the training curriculum of all health-care providers involved in the field.

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Conflicts of interest

There are no conflicts of interest.

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Supplementary File: Views of health-care professional's regarding the bereavement care following stillbirth	
	***n* (%)**
Do you think women with stillbirth need specialized bereavement care during labor/postpartum?	
Yes, always	257 (91.8)
Yes, sometimes	22 (7.9)
No, usual care	1 (0.4)
Reasons for not providing specialized care to such women	
Overcrowding and shortage of staff	197 (70.1)
Lack of confidence as no formal training is provided	48 (17.1)
It is the duty of psychologist	9 (3.2)
Cultural practices and belief	13 (4.6)
No need of any specialized care as fetus is already dead	5 (1.8)
No answer	9 (3.2)
How often you found yourself or your colleagues empathetic in communicating the news of fetal demise and explaining what will follow?	
Always	149 (53)
Sometimes	115 (40.9)
Rarely	13 (4.6)
Never	2 (0.7)
Are such mothers neglected in labor room and postpartum period?	
Usually	74 (26.3)
Sometimes	127 (45.2)
Rarely	39 (13.9)
Never	41 (14.6)
Do you think stillbirth can cause PTSD/prolonged grief requiring medical help?	
Always	97 (34.5)
Usually	123 (43.8)
Sometimes	56 (19.9)
Rarely	4 (1.4)
Never	1 (0.4)
Do you think they might have physical symptoms such as pain and breast engorgement needing medical attention?	
Always	97 (34.5)
Usually	123 (43.8)
Sometimes	56 (19.9)
Rarely	4 (1.4)
Never	1 (0.4)
Do you think they might face bothering milk let down problem?	
Always	43 (15.3)
Usually	113 (40.2)
Sometimes	107 (38.1)
Rarely	17 (6)
Never	1 (0.4)
Holding or taking pictures of a stillborn baby (memory-making) affects the women psychologically?	
Affects positively	48 (17.1)
Affects negatively	117 (4.6)
Cannot say	113 (40.2)
Do you know about donating breast milk to other babies might help bereaved mothers to cope up with their grief?	
Yes	113 (40.2)
No	166 (59.1)
Is there any need for bereavement care counselors	
Strongly agree	141 (50.2)
Agree	117 (41.6)
Cannot say	22 (7.8)
Disagree	0
Who is the best person to provide bereavement care in the existing settings	
Obstetrician	103 (36.7)

Contd...

Supplementary File: Contd...

	n (%)
Psychologist/counselor	152 (54.1)
Social worker	26 (9.3)
Health-care providers should have comprehensive bereavement care training and support system	
Yes	258 (91.8)
No	23 (8.2)

PTSD: Posttraumatic stress disorder