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"Getting it right when it goes wrong – Effective bereavement care requires training of the whole maternity team"

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ABSTRACT

Stillbirth or neonatal death is one of the most traumatic and distressing life experiences with negative psychosocial effects. Perinatal grief is natural and understandable, and, if not recognized and well supported, may lead to long-term harmful effects. Harm may also be caused to the other surviving siblings, families, and next generation. This can be helped by effective bereavement care. Bereavement care is an area of enormous needs, relatively untraveled road. Though the loss cannot be undone, but a negative impact can be minimized by compassionate supportive care.

This chapter will focus on the need of a trained team for effective bereavement care. Principles of evidence-based best practices from the literature will be reviewed and translated into key practice implications. An emphasis is laid on a structured training involving the whole team. We hope this will help in day-to-day situation handling so as to prevent the harm associated with unaddressed grief. Areas of gap with the further need of research are highlighted.

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"Grief never ends …. But it changes. It's a passage not a place to stay. Grief is not a sign of weakness, nor a lack of faith …. It is the price of Love,"

Introduction

(a) Overview
(b) When it goes wrong
(c) Getting it right
(d) Supportive bereavement care and role of HCPs

Overview

Annually, 2.6 million stillbirths occur globally, and almost the same numbers of neonates die, but stillbirths are not addressed in any of the major global development goals. In the past few years, various international agencies have recognized the devastating effects of stillbirth on parents, caregivers, and health systems.[1, 2] The experience of the bereaved parents has been recognized to be the key factor in trying to bring about improvements in stillbirth [3,4]. The 2016 Lancet series on ending preventable stillbirths placed emphasis on the unidentified psychosocial intangible costs of the stillbirth [2] and called for a "global consensus on a package of care after a death in pregnancy or childbirth in all settings" to reduce the negative effects of stillbirth. The World Health Organization's statement on respectful maternity care also included dignified maternal care to grieving parents [5]. The United Nations Inter-agency Group for Child Mortality Estimation (UN IGME) in its 2020 report has also recommended the highest quality bereavement care by providing comprehensive and ongoing training and support to all members of the team [6]. In spite of all these recommendations, the needs of the bereaved parents' are frequently unmet [7]. Also, the care practices show much variation between HICs and MICs [8].

This chapter will present evidence-based best practices on the need of training and skill development of the entire team for effective bereavement care.

Going wrong: Various stakeholders

Perinatal death is one of the most stressful events with a high emotional and profound impact on women, families, communities, and health care workers. It results in a variety of feelings such as sadness, anger, guilt, helplessness, depression, self-blame, blame game on the mothers, or health professionals. There may be extreme social stigmatization, particularly in LMICs as well as intimate partner violence, loss of self-esteem, and poor quality of life [9,10].

Perinatal grief is universal, and its effects have been reported by almost all parents [2,11]. A paradoxical situation – the occasion expected to be joyful suddenly becomes a period of dreadful silence and everything seems to have gone wrong with a shattering end. Whereas grief is relatively understandable and obvious, its negative long-term effects are complex. Almost two-thirds of the bereaved women in HICs have been shown to have persistent depression after one year which may even continue to four years in half of them [12]. The associated risk is not the grief and distress itself, but the risk of bypassing normal grief, promoting a variety of severe negative psychological complications. If not recognized and acknowledged, grief may result in exacerbation of the deep emotional impact with additional complications like post-traumatic stress disorder (PTSD) [13–17] Moreover, the harm is not merely to the mother but also to her partner, family, her surviving children, and also future pregnancies and offspring [18,19]. This avoidable harm may not be due to staff negligence but due to paucity of training failing good staff [20].

In addition to the parents, health care providers (HCPs) caring for mothers who experience a stillbirth are also significantly affected. They may have psychological and professional burdens along with a feeling of helplessness by not being confident in providing care [21,22]. Stillbirth is among the

most difficult experiences, where providers feel the emotional burden of human response to bereaved parents as well as personal responsibility/guilt [23]. Fear of litigation and disciplinary action is an additional stress. This can influence their attitudes toward the care of the bereaved parents [24,25].

Getting it right: supportive bereavement care

The death of a baby cannot be undone but efforts can be made to support parents. The support received at this time has been shown to be the single most important predictor of the nature of the grief process. This can be provided by bereavement care starting with diagnosis and continuing in the whole postnatal period. Delivering empathic bereavement care can help parents to cope better with their experience and is vital for the prevention of short-term and long-term poor psychological outcomes. This has a profound effect on not only the parents and family but HCPs and communities as well [16,26,27]. Insensitive care can make things worse. Training and education are of paramount importance for both bereaved parents and their providers [28]. Effective bereavement care also holds up the principles of ethics of medical care provision, which is avoiding harm.

Role of the health care providers

Studies show that HCPs play a crucial role during the bereavement period. The profound impacts of their behavior on the overall parental experience at such distressing time cannot be underestimated [13]. Most of the international guidelines have shown the pivotal role played by various HCPs such as sonographers, midwives, obstetricians, nurses, and psychologists in the stillbirth care provision [4,29]. Most guidelines are tailored for specific health systems but share some key points like the use of simple non-judgmental language, continuity of care, help in important decision-making like postmortem (PM) examination, memory making, and follow-up meetings to address unanswered questions and grief [30,31].

Bereavement Care

(a) What's respectful bereavement care?
(b) Global context
(c) Global bereavement care principles

What is respectful bereavement care?

Respectful care and inclusive care are a key element of the provision of quality maternity care. Women who feel safe, supported, respected, and able to participate in shared decision-making (SDM) are likely to have more positive childbirth experiences [32].However, respectful care is more than freedom from mistreatment, and it is care that maintains parents' dignity and control and enables them to engage with health care facilities. This respectful maternity care includes dignified maternal care to grieving parents as well as to the baby who has died [5].

The key principles of respectful bereavement care are as follows:

- Shared decision-making
- Recognition of parenthood
- Good communication
- Effective support

Shared decision-making (SDM)

SDM in the context of stillbirth means that all parents are given information about the options available and are supported in making choices that are consistent with their needs, preferences, and values. Offering practices known to be valued by parents can enable engagement and contribute to family-centered care, which extends the person-centered approach to recognize and respect the care needs of both parents when a baby dies. Many decisions made at the time of stillbirth will have far-

reaching consequences for any sense of regret or emotional closure in the future, for example, their decisions to see or hold their baby or have a PM where available.

Examples of shared decision-making:

1 Mode and timing of the baby's birth and options for management of labor pain are discussed and agreed upon with parents, taking into account both physical and psychological outcomes.
2 How to interact with the parent of the baby and how to spend time with the baby and collect mementoes are supported by trained providers.
3 Decision regarding autopsy and how to arrange the baby's funeral are made jointly and informed by evidence.

Recognition of parenthood

An essential component of bereavement care is the recognition of parenthood.

For bereaved parents, in particular, this is an essential part of bereavement care. It is important to recognize and validate their experience of parenthood which can lead to positive perceptions of body and self [33]. The literature review also reveals parental wishes to have been more involved in decision-making and avail opportunities to spend time with their babies.

Making memories can take many forms like holding the baby, taking photographs, and taking imprints of the hand and foot of the baby. In one study, the majority of parents expressed regrets about decisions about not spending time with or holding their babies [4,13,34]. This is supported by some evidence that shows decreased anxiety, reduced sleep disorders, and physical symptoms. Conversely, one study showed negative consequences [35], but this study has been criticized due to its small sample size. Parents should always be given the opportunity of spending time with their stillborn baby.

For parents, the priority remains their baby, and respectful family-centered care encompasses the care of their stillborn baby. There is a tendency for health care professionals to focus solely on the mother's needs leading to the dissonance between parental and clinical priorities.

Good communication

When a baby dies, parents face many difficult and time-critical decisions at a time of intense loss and grief. Access to appropriately presented evidence-based recommendations can empower people in their interactions with health care professionals and support SDM. Parents often report not receiving adequate information and that they only became aware of options, or of consequences of their decisions, when it was too late [36]. Timely access to evidence-based information is needed to minimize potential regret and missed opportunities.

Effective support

Parents should have access to different forms of support [37]. The role of doctors, nurses, and midwives in some contexts and particularly family is essential to lowering levels of anxiety and depression following a stillbirth [38–40]. Partners, family, and wider social networks may reduce maternal distress in the longer term. The role of support groups is also reported as having a positive effect. Crucially, all individuals involved in supporting bereaved parents should have received training and have robust support systems in place for their own continuous development and support.

As much as possible, partners should have their needs considered and be involved in decision-making and practical tasks. Access to pastoral care and religious rituals (blessing, baptizing, or naming the baby) should also be facilitated.

Continuity of care is particularly important. As far as possible, bereaved parents should be cared for in a private environment away from the sounds of laboring women. However, this separation should not come at the cost of a parents' feeling of abandonment.

Bereaved parents may express a preference for being cared for by the same health care professional. Many parents are reluctant to see the same HCPs if they have had a perceived negative experience and/or blame the HCPs for the death. Many will change providers altogether if possible.

Global context

Bereavement care provision is a highly challenging and emotionally draining area. The present status of the evidence reflects that bereavement care is a global necessity. Despite the knowledge of the development of prolonged and negative psychological responses in the absence of supportive emotional care, this is one area where there is no or little training, neither in the teaching curricula nor pre-service or in-service schedules. A survey from the UK schools revealed only 57% coverage of stillbirth in medical school the curriculum [41]. Or it may be lacking completeness in addressing the emotional demands and personal needs of the providers [42]. Even in countries with available evidence-based specific care pathways, not all HCPs are able to provide useful support. This may be due to a lack of awareness of the framework for grief support or possibly because they have never received appropriate training [43,44].

Recent systematic reviews of care after stillbirth across low-, middle-, and high-income settings have revealed that care immediately after and following stillbirth is inconsistent, variable, and often deficient [36,45]. In some of the high-income countries (HICs), national guidelines and care pathways exist for bereaved women but, paradoxically, hardly any exist in LMICs where the burden is the greatest [46].

Global bereavement care principles

The RESPECT (Research of Evidence based Stillbirth care Principles to Establish global consensus on respectful Treatment) study set out to address the need to establish a global consensus for perinatal bereavement care in an effort to reduce the enormous psychosocial burden on families and to reduce the known inequities in the quality of care received following [47]. A core set of eight evidence-based principles for bereavement care after stillbirth or neonatal death were developed in consultation with frontline care providers from a diverse range of contexts and settings, applicable both to high- and low-resource settings. This study has its own strengths and limitations, and South America, parts of Africa, and the Middle East were under-represented; the survey was only in English. However, it represents a first step toward addressing a largely unmet global need.

The core principles, actions, and expected positive outcomes are listed below [47].

Core principle	Action	Expected positive outcome
Reduce stigma experienced by bereaved women and families by increasing awareness of stillbirth within communities	Engage community leaders for better information and integration of perinatal bereavement into cultural and community awareness	Bereaved parents being able to engage a with wider community for support and access rituals such as naming or baptizing the baby Bereaved parents are not blamed for the death or socially isolated
Provide respectful maternity care to bereaved women, their families, and their babies	Implementing care policies that promote supportive safe and respectful care	Respecting women's dignity and autonomy, leading to positive birth experience, respect for the baby – treated with the same respect that would be given to a live-born baby
Support women and families to make shared, informed, and supported decisions about birth options	Health care professionals being able to appropriately present evidence-based recommendations	Parents feel a sense of autonomy. Minimizing sense of regret and missed opportunities
Offer appropriate information and postnatal care to address physical, practical, and psychological needs, including a point of contact for ongoing support	Having a single point of contact for meeting physical, psychological, and practical needs after bereavement	Parents having the reassurance that they have not been abandoned and having recourse to help and continuity of care
Acknowledge the depth and variety of normal grief responses associated with stillbirth and offer appropriate emotional support in a supportive environment	A number of examples of specialist interventions exist from counseling to specialist referral	Reduce disenfranchised grief. Reduce the effect of stillbirth on parental relationship, other children, wider family, and societal functioning

Provide information for women and their families about future pregnancy planning and reproductive health at appropriate time points throughout their care and follow-up	Offer contraceptive choices	Choice of inter-pregnancy interval allows time to resolve psychological difficulties with reduced impact on subsequent pregnancies
Make every effort to investigate and identify contributory factors and provide an acceptable explanation to women and families for the death of their baby	HCPs to offer investigations that might reveal the cause and time of death and inform discussions of the risk of recurrence	Emotional closure for parents, reducing stigma Data to inform research and changes to policy
Enable the highest quality bereavement care by providing comprehensive, ongoing training and support to all members of the team	Equipping and supporting staff with skills and knowledge to understand parental grief	Reduced burnout and compassion fatigue among staff, leading to better care for parents

Skill development for bereavement care

a) Need for skill development
b) Barriers/challenges in training
c) Training of the whole team
d) Making it effective and supportive.

Need for skill development

The need for education, training, and support has been emphasized [16, 25, 36, 48–52]. Information is relevant for knowledge [53,54]. Specialist bereavement care training is still very limited for the maternity team.[29, 49] Positive effect of care provided by the trained team is stressed [2,4,16,24,26,45,55]. It is extremely important to deal with acute reactions [36,55,56], as it may lead to secondary trauma and long-term consequences [57,58]. Midwives and others have reported both lack of skills and knowledge [42,49,59,60]. The emotional fatigue can deplete resilience significant psychological effects [23,42]. Support and debriefing after an adverse event may be invaluable [11,61].

Evidence from the literature	Parental perspective	Provider perspective
The need for education, training, and support emphasized	The positive effect of care provided by a trained team	Midwives and others have reported both lack of skills and knowledge. The emotional fatigue can deplete resilience significant psychological effects
Limited specialist bereavement care training maternity team	Extremely important to deal with acute reactions that may lead to secondary trauma and long-term consequences	

Challenges/barriers in skill development

1. **Emotional barriers: Mismatch between parental concerns and providers' attitudes** – Parents want staff to demonstrate sensitivity and empathy and validate their emotions, whereas providers may be inclined to focus on the technical aspects of care, causes, and next pregnancy instead of emotional support [33,45,62,63].
2. **Socio-cultural barriers** – Effective bereavement care may not work uniformly across all cultures and societies. Memory making, seeing, and holding the dead baby may not be culturally acceptable in all. In LMICs, family support could be a primary support mechanism instead of professionals [64,65].
3. **Training/system-based barriers** – Skill development in bereavement is usually incomplete. The team may not be adequately represented for all needs. Only a very small percentage of teams are represented by psychologists. This may have a negative impact on other staff members with the feeling of being left alone during the traumatic event.

4. **Evaluation of care challenges** – **The** evaluation of the true benefits of various bereavement interventions is difficult in the absence of high-quality RCTs. Evidence is limited to recommend any particular intervention. Scientifically, rigorous clinical trials are difficult to be carried out due to the small sample size and sensitive nature of the event.

Why is training of whole team required (Box 1)

Box 1: Crossing the borders: Training the whole team

- Behaviors of the providers at all stages could have a memorable effect on parents. Care provision by untrained team may result in negative interaction even at administrative level.
- Since parents may come in contact with different staff members at different timings and places during stillbirth, so everyone needs to be trained for the care to be effective and supportive at each step.
- Multidisciplinary team training in bereavement care has been shown to improve outcomes as warning signs of grief can be picked up early.
- Focused training needs to be given to the whole team who comes in contact with the bereaved parents including obstetricians, sonographers, nurses, midwives, anesthetists, hospital attendants, ward staff, cleaners, clerks, administrative staff, etc.
- Clear pathways must be laid out at primary and secondary care interface.

How to make bereavement care more effective? (Practical tips)

Bereavement care can be made more effective by making it adaptable to different socio-cultural contexts. However, certain principles are common, and care can be made compassionate and customized by improving each of the following steps:

Facilitating the diagnosis: Early, accurate, and properly conveyed

HCPs should be available around the clock who can diagnose the stillbirth confidently. Delay in the diagnosis due to unavailability of trained providers is associated with additional distress [66]. The urgency of initial diagnosis is as important for the parents as the providers. While performing an ultrasound scan, parents must be informed about the procedure and nonverbal suspicious clues must be avoided. Verbal information should be supplemented with a written one. This will ameliorate the additional distress during the waiting period.

Breaking the bad news empathetically

The whole team needs to be trained in breaking the bad news in empathetic, straightforward, and honest but gentle way. The diagnosis should be shared as soon as confirmed. Communication should be non-judgmental and parent led. Warm, open body language should be used like sitting near them, making eye contact, and using touch if culturally deemed appropriate. Use simple clear wording and give them time for the news to sink in. Include both parents, use the word “baby” or address the baby by their name (if the parents prefer so) instead of “fetus.” Be empathic and respectful [51]. It may not reduce the loss but can help in long-term parental experiences. This will help in the recognition of parenthood.

Expecting and managing different grief reactions: Professional training

Grief response reactions should be managed by customized and individualized approach. The team should have structured training to acknowledge and manage different grief reactions (as usually anticipated in the psychological theories). Evidence-based training and skill development are necessary for better care and removing uncertainty. Structured training does help in managing grief [41,66].

A separate place must be available where privacy can be maintained. Every effort should be made to satisfactorily answer the parents' questions.

Helping make decisions: Continuity of care after diagnosis

Shared decisions regarding future management are crucial and may pertain to timing and route of delivery. Timing of delivery may be a paradox as it remains of paramount urgency for the parents, whereas the HCPs may not feel the urgency after the diagnosis and like to wait in anticipation of spontaneous labor. The risk and benefits of waiting versus immediate delivery and of vaginal versus cesarean birth should be discussed in detail with the parents and their choices need to be respected [34]. Parents may request a cesarean delivery for a number of reasons, for example, they may believe the baby can be resuscitated if delivered quickly, or may avoid physical pain in addition to the mental anguish [7]. The physiological advantages of vaginal birth should be carefully weighed against the potential psychological harm of going through a labor. Their fears need to be allayed. Maintaining continuity of care by the same team helps building their confidence.

Respectful care during and after stillbirth

Respectful maternity care is needed for these women. Preferably, these women need to be given separate place from women with live babies during and after labor. But then, a separate place should not give them the feeling of abandonment. Due to additional emotional stress, a birth companion of choice and personalized care may be given wherever possible. There is a tendency on the part of the care providers to shift the focus on to the mother rather than baby. The baby must be handled with respect and dignity. Parents should have the feeling of still being parents. This may be possible by providing them details of the baby weight, length, and hair and eye color. They should be given ample time to spend with the baby, memory making by mementoes, rituals, etc. Care must be provided for physical needs also such as lactation, bleeding, diet, and contraception. Also, in the logistics of finances, burial arrangements need to be discussed and supported. This will facilitate the logistic problems.

Investigations after birth: Postmortem (PM) and placental examination

This has different implications globally as the availability of a PM is very limited in some settings. There are disparities in the availability of pathology services, suitably trained pathologists, and parental acceptability.

Decision-making for PM is an emotionally draining situation. Parents must be clearly informed about the need, various steps of PM, and extra time needed. They should be assured of respectful treatment toward the baby. The possibility of getting to know the cause by PM in cases where there is no obvious cause (for example, congenital heart disease) may help in acceptance. Framing the process of counseling in a positive way helps the parents in taking this difficult decision. They may be able to decide with confidence.

Follow-up

Women discharged after diagnosis (not yet delivered). Follow-up care is mostly neglected. This is of the utmost importance, especially in those where mother is discharged following a diagnosis of stillbirth, and delivery is planned later on. Continuity of care is very important, and so planned follow-up with the same unit and same team is essential where woman has to come for delivery. Proper contact details, date of follow-up, and availability of round-the-clock emergency need follow-up and should be properly provided along with parent-centric information to go through at home.

Women discharged after stillbirth delivery. Follow-up after delivery is also important, and bereaved parents want to know the cause. Hence, the cause of death must be evaluated thoroughly and shared. In the absence of medical cause, supernatural explanations including superstition curses/spirits are

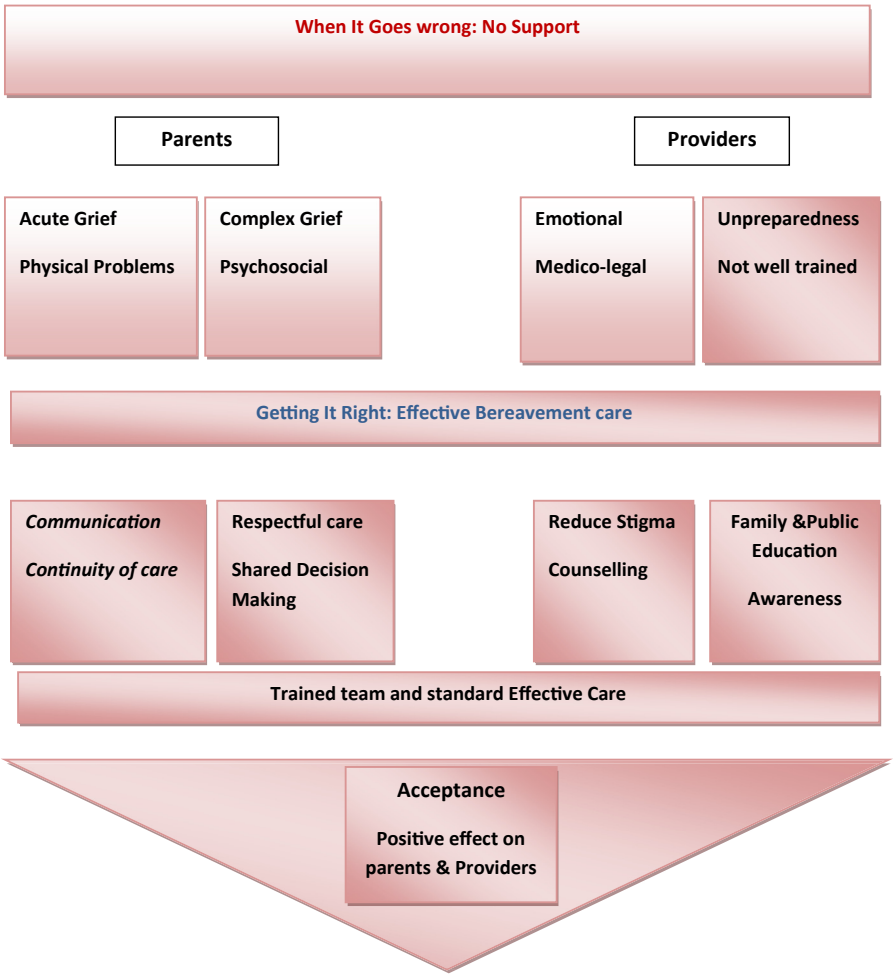

Fig. 1. Effective bereavement care: Getting it right when goes wrong.

believed, especially in LMICs focusing blame on women. Understanding the cause resolves uncertainty [36,66], helps with bereavement, and may also prevent stigma in some settings and reduce the strain of professional and public blame on HCPs. Grief should be assessed, and referrals made if needed.

Health care bereavement programs: Organizational policies

A perinatal bereavement program can help institutions to provide quality care for bereaved families and help them through this difficult experience through supportive discussions and interventions. It should focus on parents, families loss, and grief needs and should be adaptable to different socio-cultural contexts. Staff needs also must be addressed as they have to face a highly demanding emotional paradox [54]. Standard protocols, teams, ongoing training, and support packages for all involved in the care of these women should be in place. Ideally, a psychologist should be included in the team to assist parents as well as debriefing and supervision of other HCPs.

Public education

Public education to reduce stigma and blame and promote respectful maternity care agenda will lead to positive effects. It is important to work with all stakeholders and politicians to implement improvements in bereavement care to reach all families. Educating, investigating, and respecting can help to improve the standards of bereavement care [67]. Sensitizing the society to stillbirths and needs of bereaved parents is still a big unmet issue.

Summary

Stillbirth is one of the most tragic and stressful life events with negative outcomes for the parents. Approximately one in five parents will suffer from intense and prolonged grief. This perinatal grief is natural but can be helped by providing appropriate supportive bereavement care. Bereaved parents never forget the care, understanding, respect, and genuine warmth received at this crucial point of their life. This can become as important and impressionable as any other memories of the lost pregnancy. However, there is a huge unmet need of the parents in getting proper effective bereavement care. Care providers usually feel unprepared to provide care due to unpreparedness and lack of knowledge. Adequate education and training to the whole of the maternity team are required for delivering compassionate care. Adequately developed health systems with trained and supported staff are best equipped to provide support and information. The care package needs to be adaptable to the local socio-cultural needs of the women and the family. Fig. 1 summarizes the theme of doing no harm and how to put things right through training in evidence-based bereavement care.

Key practice points

- Parent-centric compassionate and empathic bereavement care must be provided at the time of stillbirth or neonatal death.
- Care needs to maintain continuity taking into account physical as well as emotional needs.
- Care providers should include not only just the obstetrician/midwife but the whole team including medical students and non-technical staff.
- High-quality bereavement care training of the whole team is needed to deliver the best evidence-based practices like SDM for mode of delivery, memory making, PM, etc.
- All efforts must be done to understand the cause of death as it resolves uncertainty and helps in coping with grief.
- Follow-up must be done to assess grief and make necessary referrals.
- Provision of individualized care during subsequent pregnancy should be available.

Research agenda

1. Multi-centric assessment of the effectiveness of interventions [38,52] and training programs.
2. Assessment of bereavement needs in LMICs.
3. Assessment of the long-term sequel of different choices for mode of delivery and interval between diagnosis and delivery.
4. Extrapolation of simulation training programs for perinatal bereavement from early pregnancy loss study [68].
5. Explore the role of professional and personal needs of providers to improve the effectiveness of care.

Relevant current and appropriate guidelines/statements/policies of professional associations.

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Declaration of competing interest

The authors have no conflict of interest.

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