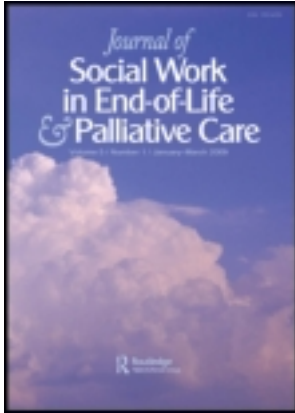


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### “I'll Never Forget Those Cold Words as Long as I Live” : Parent Perceptions of Death Notification for Stillbirth

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## **“I’ll Never Forget Those Cold Words as Long as I Live”: Parent Perceptions of Death Notification for Stillbirth**

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*This qualitative study analyzed stillbirth notification messages recalled by parents who strongly agreed (n = 47) and strongly disagreed (n = 43) that the way news about the death of their infant was delivered negatively impacted their grieving process. Three message elements formed a core stillbirth notification experience (delay of news delivery; expression of sympathy; communication of death), and three additional message elements occurred in both data sets (communication regarding options; expression of uncertainty; exit of health care provider); however, the messages differed in form and frequency between the two groups. Three message elements reflected opposing experiences for the two groups (support of parent emotion; continuity of care; and information provision). Recommendations for stillbirth notification that emphasize acknowledging parent perceptions, clear language and information, empathetic communication, and continuity of care are given.*

**KEYWORDS** *bad news delivery, bereavement, death notification, grief, perinatal end-of-life care, physician/patient communication, stillbirth*

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Walking into her doctor's office for a prenatal visit, a healthy mother-to-be, having experienced no complications in her pregnancy does not expect to hear the words, "Your baby's heart has stopped beating." In the United States, words like these convey the devastating news of stillbirth more than 25,000 times every year (MacDorman & Kirmeyer, 2009). Stillbirth is an emotionally and physiologically painful and traumatic event that occurs suddenly and often without warning (Cacciatore & Bushfield, 2007; Gold, 2007). A deep sense of attachment often develops between a mother and unborn child during pregnancy; thus, she is likely to experience profound psychological distress, including high risk of posttraumatic stress disorder (PTSD) upon the baby's death (Cacciatore & Bushfield, 2007; Trulsson & Radestad, 2004). Mothers' grief experiences following the death of a baby to stillbirth are further complicated by the biological fact of death occurring within the body; cultural discomfort with death, particularly a child's death; and feelings of anxiety, failure, and guilt (Cacciatore, 2010; Condon, 1986; Reddy, 2007).

Because many health care providers (HCPs) are often uncomfortable when a patient dies, particularly when the patient is a baby or a child, support for parents experiencing stillbirth may be compromised (Gold, 2007). Obstetric nurses and physicians receive a dearth of death education, and generally feel unprepared to face the profound losses of a baby's death (Cacciatore & Bushfield, 2007; Chan, Chan, & Day, 2003; Säflund, Sjögren, & Wredling, 2002).

However, parents do report that HCPs' behavior and their handling of stillbirth is important to their experiences of loss (Gold, 2007; Säflund, Sjögren, & Wredling, 2004). When bereaved parents perceive HCPs as dishonest and not forthcoming, they experience increased anxiety and mistrust toward their providers (Schott, Henley, & Kohner, 2007). Parents also report being upset by care provider behaviors perceived as avoidant, insensitive, and lacking in emotional support. Conversely, when medical professionals are perceived as caring and honest, patients report feelings of appreciation despite their tragic circumstances (Gold, 2007).

Physicians have identified conversations with parents experiencing the death of a baby as more serious than conversations with patients about any other condition (Säflund, 2003), and a few studies have examined HCP opinions of, treatment plans for, or conversations with parents experiencing stillbirth (Chan et al., 2003; Kirkley-Best, Kellner, & Ladue, 1984–1985; Robson, Thompson, & Ellwood, 2006; Säflund et al., 2002). However, no studies to date have examined perceptions of death notification in the context of stillbirth. In addition, despite research showing the value of empathy in provider-patient communication and efforts to improve communication during medical training (Ahrens & Hart, 1997; Benenson & Pollack, 2003; Levetown, 2008), there has been little change in patient perceptions of doctors as less supportive than nurses (Gold, 2007). It is critical that health care providers develop a clearer understanding of how death notification can impact a patient's grieving process, both positively and negatively.

## DEATH NOTIFICATION

HCPs describe death notification (i.e., telling persons that their loved one has died) as emotional and indicate that delivering news of a child's death is especially unsettling (Clark & LaBeff, 1982). Ahrens and Hart (1997) found that HCPs believed the experience of communicating the news of a child's death was the most difficult experience in emergency medicine, more difficult than communicating the death of an adult to his or her family. Some HCPs find the death of a baby or child so distressing that they shy away from empathizing with the parent(s) (Leon, 1992). HCPs struggle with how much emotion to show when delivering news of the death, how to deliver the news (e.g., direct telling may be perceived as cold), and how to respond to the family member's reactions (Clark & LaBeff, 1982).

HCPs also report feeling unprepared to engage in death notification due to lack of education or training (Ahrens & Hart, 1997; Benenson & Pollack, 2003; Hobgood, Tamayo-Sarver, Hollar, & Sawning, 2009; Leash, 1996; Smith-Cumberland & Feldman, 2006; Stewart, Lord, & Mercer, 2000). However, when HCPs receive death notification education, the training appears to improve confidence in their ability to deliver news of death (Nordström, 2011; Ponce et al., 2010; Smith-Cumberland, 2006; Smith-Cumberland & Feldman, 2006). However, some assert that death education focused on psychosocial care can be problematic if it encourages adherence to a fixed protocol or sequence of steps that do not account for individual patient responses, nuances, and needs (Cacciatore & Flint, 2012; Villagran, Goldsmith, Wittenberg-Lyles, & Baldwin, 2010).

Little extant research has explored bereaved parents' perspectives about what is helpful during death notification (Gyulay, 1989; Janzen, Cadell, & Westhues, 2003–2004). However, interactions with HCPs do influence bereaved parents. For example, negative interactions exacerbate trauma symptomology while compassionate caring promotes positive outcomes for grieving parents (Janzen et al., 2003–2004). Also, parents whose children die suddenly report wanting their doctors to show compassion, give information, explain procedures, and provide support referrals (Janzen et al., 2003–2004). Parents prefer that HCPs demonstrate a caring attitude and allow them to express their emotions (Gold, 2007; Levetown, 2008). Getting inadequate or poorly delivered information (Levetown, 2008; Schott et al., 2007), receiving conflicting opinions from multiple HCPs (Levetown, 2008), experiencing delay of death notification (Leash, 1996), and hearing jargon-laden or indirect terminology (Prasad, 2010) can negatively impact the way bereaved parents perceive HCP communication.

The literature suggests that interactions with HCPs have a profound impact on parents who experience a perinatal death. Even years after being told that their baby is stillborn, parents are clear that some communication from health care providers helped them and some communication still leaves

them feeling angry and upset (Fallowfield & Jenkins, 2004; Gold 2007). How the death of a baby to stillbirth is communicated may impact satisfaction with care provision, a parent's sense of social support, and the severity of long-term psychological distress (Trulsson & Radestad, 2004). Hence, given the dearth of literature published on this subject, the purpose of this study was to describe how notification following the death of a baby to stillbirth is recalled by patients and how that communication impacted their grieving process. Specifically, the research question guiding this study was: What death notification message elements were recalled by parents with strong feelings about how news of their baby's death to stillbirth was delivered?

## METHOD

A retrospective study, using an IRB-approved questionnaire regarding parent perceptions of perinatal loss diagnosis delivery was administered via an online survey service (SurveyMonkey). Data analyzed in this study are part of a larger project regarding communication in the context of stillbirth. The questionnaire contained open- and closed-ended questions. The first author, having experienced the death of a baby to stillbirth, is active in various support communities for bereaved parents; thus, participants were recruited and contacted through participation and membership in organizations that offer services to bereaved parents of perinatal loss.

### Sample

Anyone who had a perinatal death was allowed to complete the survey, but this study focused only on data collected from participants who reported their diagnosis was stillbirth. This was defined as the intrauterine death of a baby 20 weeks gestation or greater ( $n = 624$ ). Females accounted for 97.4% ( $n = 599$ ) of respondents, with 97.9% ( $n = 597$ ) self-identified as heterosexual, and 83.2% ( $n = 510$ ) self-identified as married.

### Measures and Data Analysis

For the purpose of this study, all surveys of participants who had experienced stillbirth wherein respondents strongly agreed that they recalled the exact words a health care provider used to deliver death notifications were selected ( $n = 222$ ). These data were then sorted on the basis of either strong agreement or strong disagreement with the survey item, "The way I found out about the diagnosis negatively impacted my grieving process." Fifty-one respondents strongly agreed and 47 strongly disagreed.

From the 98 surveys, those in which the participant also responded to the open-ended item "Please write down what the care provider said and/or

did when s/he delivered the news of the diagnosis" were selected (50 of 51 and 45 of 47 respondents, respectively). Upon review, five surveys were eliminated because how the parent was told the baby died was not included or the description indicated that a live birth had occurred. Hence, messages reported by 47 parents who strongly agreed and 43 parents who strongly disagreed that the death notification negatively impacted their grieving process were analyzed.

Data were analyzed using a constant comparison method associated with grounded theory (Glaser & Strauss, 1968). The first step was open coding. This involved the first and second authors independently reading each death notification description, identifying distinct message elements, and then discussing what they had identified in order to achieve negotiated consensus. As in Salander's (2002) research, message descriptions differed in that some participants only provided the words they recalled a HCP using to deliver death notification (e.g., "I'm sorry, both your babies are dead"), while others described a sequence of events constituting the larger process of news delivery (e.g., "The nurse then told me she was going to get another Doppler to find the heart beat maybe this one is broke"). In all cases, what Strauss and Corbin (1990) term discreet incidents or ideas were identified and labeled. For example, "I'm sorry, both your babies are dead" contains two discreet ideas—an expression of sympathy and communication of death.

The second, interrelated step in data analysis was axial coding, which focuses on connections between categories (Strauss & Corbin, 1990). Specifically, subcategories were linked to categories, with particular regard to communication strategies and consequences (Strauss & Corbin, 1990). For example, that communication of death occurred was not surprising, but several distinct ways of communicating (i.e., subcategories) were identified. The authors worked through the data line-by-line, examining discreet message elements and asking, "How are these similar and how are these different?" The result was a detailed description of message elements reported by parents who had strong feelings about whether or not the way death notification was delivered negatively impacted their grieving process. For clarity in reporting findings, the two groups are referred to as parents perceiving HCP communication positively and negatively.

## FINDINGS

A total of 14 message elements were identified in parent descriptions of recalled diagnosis of stillbirth. Six elements occurred in both data sets (i.e., parents perceiving HCP communication positively or negatively), with three of the six elements forming a core death notification experience. The two groups differed in the form and frequency of these message elements. Three additional message elements in each data set formed bipolar opposites in

relation to one another, while five message elements were unique to the group perceiving HCP communication negatively.

### A Core Experience in Death Notification for Stillbirth

Parents in both groups commonly described three message elements at the heart of a diagnosis of the baby's death: delay of news delivery, expression of sympathy, and communication of death; however, there were experiential distinctions between the groups (see Appendix 1 for an overview of key differences between the two groups).

#### DELAY OF NEWS DELIVERY

Following an initial indication of possible death such as a heartbeat not being detected during an ultrasound, a HCP may take additional measures to confirm the diagnosis, thus the process of diagnosing the baby's death is delayed. Both groups reported delay of news delivery due to: (a) multiple diagnostic exams being conducted or additional HCPs being consulted in one location; (b) parent relocation to another exam room or health care facility; and (c) topic avoidance by HCPs. However, topic avoidance distinguished the two groups, with three times as many parents perceiving HCP communication negatively reporting it compared to parents perceiving HCP communication positively.

#### EXPRESSION OF SYMPATHY

Expressions of sympathy, particularly simple statements such as "I'm sorry," were reported by parents in both groups, with some indicating more than one expression of sympathy by HCPs; however, compared to the negative group, parents perceiving HCP communication positively reported far more simple statements with intensifiers, such as "I'm so sorry," and nonverbal expressions of sympathy, such as personal touch and the HCP expressing emotion. Nonverbal expressions of sympathy were rare in the negative group.

#### COMMUNICATION OF DEATH

Communication of death was reported in both groups, generally following a delay in news delivery and, if present, an expression of sympathy. Communication of death varied in that it could be: (a) direct—the parent was told that the baby had died; (b) indirect—HCPs communicated with each other regarding the baby's lack of organ activity within hearing of the parent; (c) implied—a parent must infer a diagnosis from a HCP's comment; and/or (d) nonverbal—a parent sees lack of fetal heartbeat on the monitor or the look on a HCP/family member's face and knows the baby is dead.

Direct death notification was commonly reported in both groups and could be further described as: (a) blunt, using statements like “Your baby is dead”; (b) phrased in the negative, saying things like “There’s no heartbeat”; or (c) using idiomatic phrases like “Your baby is gone.” Indirect communication was rare in both groups. Parents who perceived HCP communication negatively more frequently reported implied statements of death such as, “Sometimes these things just happen,” and parents who perceived HCP communication positively reported more nonverbal communication of death; for example, a HCP asking the parent to look at the monitor as nonverbal reinforcement of verbal communication of death.

### Shared Experiences in Death Notification

In addition to the core experience, three additional themes occurred in both groups: communication regarding options, expression of uncertainty, and noted exit of the HCP.

#### COMMUNICATION REGARDING OPTIONS

Parents perceiving HCP communication positively report being offered delivery options, such as one parent’s report that the HCP “nicely explained the options to me and we opted for an epidural and I gave birth vaginally,” or being given a medical explanation for why options were limited, such as one parent’s explanation that the HCP “told me having a C-section would be ill-advised since they knew the baby was already gone and having one when it wasn’t necessary would only set a precedent for future pregnancies . . . .” In contrast, parents perceiving HCP communication negatively emphasized being told what the next step would be without explanation, such as one parent’s statement that she was “ . . . told [I] will be given pain relief but have to deliver normally.”

#### EXPRESSED UNCERTAINTY BY HCP

Parents from both groups reported that HCPs expressed uncertainty during their diagnosis but the quality of the messages differed. Parents who perceived HCP communication negatively reported that HCPs: (a) expressed uncertainty regarding the physical condition of the baby, with one HCP making a graphic statement regarding the baby’s head possibly detaching in utero; (b) expressed uncertainty regarding examination or treatment, such as one HCP being unsure how to operate the ultrasound machine; or (c) paired uncertainty with hopelessness, such as one HCP saying, “There is a 90% chance your baby is no longer alive.” Parents perceiving HCP communication positively reported uncertainty being paired with hopefulness, such as a HCP saying, “The baby might just be hiding from the monitor”; or reported



that the HCP expressed uncertainty about how to communicate death to the patient, such as one HCP's statement that, "I don't know how to tell you this." Parents in both groups also reported that HCPs expressed uncertainty about why the baby died. However, parents who perceived HCP communication positively reported that the HCP also stated a possible cause or a desire to find a cause of death.

#### NOTED EXIT OF HCP

Parents from both groups noted that a HCP "left the room" following death notification and did not report the HCP's return, but the character of the exit again differed between the groups. Parents who perceived HCP communication negatively noted that the HCP exited immediately following communication of death. According to one parent, "He told me that sometimes these things just happen then left the room." Other parents who perceived HCP communication positively specified that the HCP who gave the death notification stayed with them for a while before leaving.

#### Opposing Experiences in Death Notification

Three message elements in each data set represented opposing experiences for parents. Polar differences in the two data sets were: (a) suppression versus support of patient emotion; (b) lack of versus presence of information provision; and (c) lack of versus presence of continuity of care.

#### SUPPRESSION OF PATIENT EMOTION VERSUS SUPPORT OF PATIENT EMOTION

Parents who perceived death notification more negatively recalled that attempts were made to suppress their emotions. One parent said the HCP told her that someone would call her husband only "after you get control of yourself." Parents with negative perceptions also said that HCPs prevented others from seeing their emotions. For example, one parent noted that she was told to exit through a side door. Although HCPs may have intended to protect the mother, parents in the latter group perceived HCPs as suppressing the public expression of their emotions.

In contrast to emotion suppression, parents who perceived HCP communication positively described support for their emotions. HCP communication took four forms: (a) time/space for feelings, either with the HCP staying with the parent during her emotional reaction or the HCP saying something like "he would let us have a few minutes alone to let this news sink in and that he'd come back and talk about 'getting our little one here'"; (b) enlisting supportive others, such as calling a family member to be with the parent; (c) validation of feelings, such as acknowledging that the death of a baby is emotionally devastating; and (d) relocation, often meaning taking the patient someplace more

private. Relocation was framed as being given the opportunity to grieve and supporting emotion, not a means of hiding the patient, as with emotional suppression.

#### INFORMATION SHARING VERSUS INFORMATION WITHHOLDING

Parents who perceived HCP communication negatively indicated they did not receive information regarding the baby's death or the information they needed to make important decisions. One parent, for example, noted that a HCP told her that her baby would be stillborn but she did not know what that meant for her or the baby. She did not receive any information from the doctor or hospital about what to expect, about her choices for birth, or about social support in the aftermath of her loss. Another parent indicated that her birth choices were not explained, even though the HCP asked her what she wanted to do.

In contrast, parents who perceived HCP communication positively reported information provision that took three forms: (a) explanation, such as, "He answered any questions we had"; (b) information about what to expect or what the next steps were, such as, "The delivery nurse was great at explaining everything that I should expect"; and (c) cause of death, such as, "She explained through the ultrasound, it looked like the baby knotted his cord by turning breech."

#### LACK OF CONTINUITY OF CARE VERSUS PRESENCE OF CONTINUITY OF CARE

Parents perceiving HCP communication negatively reported lack of continuity of care, such as not seeing the HCP who delivered death notification again. In other words, the HCP may have come into the examination room, told the parent that the baby died, exited immediately, and avoided future contact with the parent. However, parents who perceived HCP communication positively reported continuity in their care during the death notification process. According to one parent, "The midwife remained with me at all times." Parents also reported continuity of care into the future. For example, one parent explained, "He gave us his personal pager and told us to ... call him, no matter what time of night."

#### Unique Message Elements

Parents who perceived negative HCP communication reported five unique message elements. Specifically, parents reported: (a) isolation, such as being left alone for a long period of time or being put in an isolated location; (b) blame, with the HCP suggesting the parent caused the baby's death; (c) contradiction of experience, such as being told that what the parent felt was impossible; and (d) the death of the baby to stillbirth being cast as beneficial,

such as one HCP saying he would include the case in a professional publication. The fifth unique message element, reassurance, was reported by one respondent who said an ultrasound technician's reassurance when she began to blame herself for the baby's death contrasted with a physician's "cold" communication. In this case, the contrasting level of empathy between the technician and doctor contributed to negative perceptions.

## DISCUSSION

*"We spend the better part of a decade learning to wield the unwieldy words of medicine, but the final lesson is knowing when to put them away." (Prasad, 2010, p. 885)*

Death notification appears to take many forms after the death of a baby to stillbirth. Even when HCPs utilize similar message elements, such as communication of death, the specific character of the message can differ, such as being told directly or having the death be implied. At the heart of the differences described by the two groups in this study is verbal and nonverbal communication that may or may not convey care, empathy, and understanding (Mager & Andrykowski, 2002; Salander, 2002; Strauss, Sharp, Lorch, & Kachalia, 1995; Yardley, Davis, & Sheldon, 2001). The death of a baby to stillbirth may be the worst news a parent ever receives (Pullen & Nalos, 2009), but how HCPs communicate about the stillbirth can either foster a sense of support for the parent or exacerbate a sense of fragility (Cacciatore & Bushfield, 2007; Trulsson & Radestad, 2004). A HCP's ability and willingness to engage a grieving parent with humility and mindfulness (Cacciatore, 2010; Cacciatore & Flint, 2012; Watson & Gallois, 1998) rather than with detached objectivity appears key to positive perceptions.

A core experience is perceived by both groups in this study, wherein a delay in the diagnosis is followed by an expression of sympathy and communication of death. However, parents who perceived HCP communication negatively were more likely to report death notification delays due to provider topic avoidance. HCPs may operate under a strict protocol regarding who can explicitly confirm the baby's death to a parent (Statham & Dimavicius, 1992), but silence by HCPs when evidence for death is explicit given multiple exams, additional HCPs being consulted, and the inability to find a heartbeat may prolong distress and confusion (Trulsson & Radestad, 2004).

Many parents reporting negative perceptions did not receive a message of sympathy from their HCP and others received only a simple statement of sympathy. Only two of the parents in the negative group reported any nonverbal support, and that nonverbal support was expressed by only one of the multiple HCPs they saw. "I'm sorry," particularly when not accompanied by mindful provider presence, may not be enough to address what more than one parent described as "the worst day of my life." Verbal intensifiers

augment simple statements, and nonverbal expressions demonstrate a level of caring commensurate with the magnitude of the parent's grief. Nonverbal signs of support from HCPs—such as crying, hugging, or holding hands—are highly memorable for parents experiencing stillbirth (Peppers & Knapp, 1980). Parent perceptions in this context appear to mirror health care providers' general reports regarding effective and ineffective bad news delivery experiences, wherein nonverbal behaviors such as eye contact and touch are only described in effective incidents, and expressions of empathy distinguish effective and ineffective incidents (Dickson, Hargie, Brunger, & Stapleton, 2002). However, HCPs also acknowledge that touch is atypical in the delivery of "bad news" (Ptacek & Ellison, 2000).

Although death notification was central in this study, the process took various forms, with implicit statements distinguishing the positive and negative groups. Implied statements of death create potential confusion in that the words spoken, such as, "We missed him by a day," do not clearly relate to death or vital organ functions. HCPs may also minimize the significance of the baby's death for the parent with platitudes such as, "You have another child at home." These types of messages occur more frequently in reports provided by parents linking HCP communication to negative impacts on grieving.

The baby's death was most often communicated verbally to parents, but the frequency with which communication of death was paired with at least one expression of sympathy varied widely between the two groups. Only 18 of 47 parents negatively perceiving HCP communication reported any expression of sympathy in conjunction with communication of death whereas 33 of 43 parents positively perceiving HCP communication reported an expression of sympathy with communication of death. Absence of expressions of sympathy, especially nonverbal expressions, may be highly problematic. Some parents in the negative group characterized HCP behavior as "cold" and "insensitive," while those in the positive group characterized their HCP as "sensitive" and "compassionate." The absence of any expression of sympathy may contribute to a negative perception by the parent. For example, one parent reported the following reaction to a statement made by a doctor called in for a second opinion: "The doctor said, 'I concur the demise of the fetus.' I will never forget those cold words as long as I live." The mere reference to a much-wanted and loved baby as "the fetus" indeed feels "cold" and "detached" and fails to acknowledge the depth of the relationship between a mother and her newborn.

Parents report a desire to express their emotions (as opposed to having emotions suppressed by HCPs), continuity in terms of the HCPs treating them, having their questions answered, and information regarding next steps and cause of their baby's death. These preferences are consistent with past findings regarding effective perinatal end-of-life care from both physician and patient perspectives (Cacciatore & Bushfield, 2007; Dickson et al., 2002;

Ptacek & Ellison, 2000; Salander, 2002; Trulsson & Radestad, 2004; Widger & Picot, 2008).

Finally, messages such as isolation, blame, contradiction of experience, and expressed benefit of the baby's death are solely reported as negative HCP communication. No parent wants to be blamed by her HCP for the tragedy or hear that her baby's death will make an interesting case study.

Based on the perceptions of patients in this study, parents who have experienced stillbirth prefer continuity of care wherein HCPs maintain communication from the moment of suspected death throughout any additional examinations to confirm the death. Parents also desire a clear statement of the baby's death accompanied by verbal and nonverbal expressions of sympathy. Parents prefer that the HCP remain present, allowing time and space for emotions and questions, as well as offering and explaining options. Stillbirth is both a diagnosis for one patient (the parent) that requires subsequent, and often immediate, decision making (e.g., induction of delivery) and death notification regarding a second patient (the child). The traumatic impact of this dual notification requires care and support for the surviving patient in the hours and days following death notification.

Specifically, the findings in this study support many recommendations in competent and compassionate death notification. When a heartbeat is not detected during a routine ultrasound, topic avoidance should not prevail when there are obvious nonverbal signs, such as additional tests and HCPs being consulted, that something is not right. Being aware of the parent's emotional, verbal, and nonverbal response during this time is crucial. If parents are exhibiting signs of anxiety, fear, or a need for information that the technician or nurse cannot provide, rather than ignoring the parent or deflecting the reality of the situation, the HCP can: (a) acknowledge the parent's feeling, perhaps saying, "I can see you are concerned" or "I can image that this might feel stressful"; (b) assure the parent that everything is being done to ascertain the baby's condition by saying something like, "I'm going to get another technician/doctor here to help me interpret what I'm seeing" or "I need to get another machine to get a better look"; (c) confirm that the parent will get the information as soon as it is possible, perhaps saying, "I'm going to step out and talk with the doctor who will back here in just a few minutes to talk with you and answer any questions you have"; and (d) support the parent by asking if there is anything she needs while waiting to get the results of the exam, saying something such as, "Can I call a partner or a friend to wait with you?"

When the baby's death has been confirmed, the expression of heartfelt sympathy, including nonverbal connection, is important. Also vital is the clear communication of stillbirth that is not cloaked in clinical jargon. Spending time with the grieving mother and creating space for emotional expression is recommended. And, when the parent is ready, psychoeducation about the birth process and alerting parents to their options are helpful and may minimize irremediable regret. Continuity of care is also significant to stillbirth

parents. If the clinical setting does not enable the physician determining and/or delivering stillbirth news to remain with the mother, an interdisciplinary approach wherein a bereavement specialist or social worker trained in death notification is present is recommended to provide comfort, answer questions, and address concerns. Even when the physician is able to remain present, it may be advisable to have a bereavement specialist or social worker present to help parents process both the medical information and the emotional trauma of their baby's death. Just as social workers are not trained to provide diagnoses or perform medical procedures, physicians generally are not trained to help parents navigate the profound psychosocial and spiritual issues of stillbirth the way a bereavement specialist or social worker might.

### Limitations and Future Research

In this study, our focus was on parents who strongly agreed or disagreed that the way stillbirth was communicated by HCPs negatively impacted their grieving process. It is possible that focusing on parents with the strongest reactions captures potentially unusual circumstances. Future research can include the parents who did not have such strong reactions about the way stillbirth notification affected their grieving process. A broader look at participant responses might confirm differences and recommendations identified in this research, and also reveal additional strong points of distinction between the groups.

Respondents in this study also provided different types of answers to the open-ended survey item regarding what a HCP said or did during death notification, with some providing the statement of diagnosis and others offering detailed descriptions of events. Future researchers might interview parents in order to derive extended narratives from all participants. This could affirm or extend the findings described in this study, and potentially allow for quantitative distinctions regarding the frequency of message elements experienced by the two groups.

Future research can also build on descriptions of patient perceptions by empirically testing the impacts of message elements. Simulations involving different combinations of preferred and not preferred message elements can be created with observers rating HCPs in terms of empathy, likeability, person-centeredness, and competence. Such research would allow for correlations between specific message elements, or combinations of elements, and perceptions of HCPs and stillbirth notification.

### CONCLUSIONS

Based on the results of this study, a HCP's ability to maintain humility, compassion, and mindfulness in the face of a baby's death may diminish short- and long-term negative consequences for parents (Cacciatore & Flint, 2012).

The death of a baby to stillbirth is a devastating experience that has immediate and ongoing emotional, psychological, and social consequences for a family. While HCPs may not be able to predict or prevent many of these deaths, they have a responsibility to mitigate the trauma around the death notification experience for the grieving mother and her family. Ultimately, the onus of the responsibility to *do no harm* falls upon the HCPs. There may be nothing that can ameliorate a parent's natural grieving process, but HCPs can mitigate psychological damage and avoid further exacerbating the trauma.

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**APPENDIX 1:** Key Distinctions Between Parent Groups

	Parents reporting positive perceptions	Parents reporting negative perceptions
Core stillbirth notification experience (differing in form and frequency between groups)	Delay of news delivery Expression of sympathy <ul style="list-style-type: none"> <li>paired with intensifiers</li> <li>nonverbal expressions of sympathy</li> </ul> Communication of death <ul style="list-style-type: none"> <li>nonverbal coupled with verbal notification</li> </ul>	Delay of news delivery <ul style="list-style-type: none"> <li>topic avoidance by HCP</li> </ul> Expression of sympathy <ul style="list-style-type: none"> <li>simple statements</li> </ul> Communication of death <ul style="list-style-type: none"> <li>implied statements of death</li> </ul>
Shared experiences in stillbirth notification (differing in focus and timing between groups)	Communication re: options <ul style="list-style-type: none"> <li>options offered or limits on options explained</li> </ul> Expressed uncertainty <ul style="list-style-type: none"> <li>expressed uncertainty about how to deliver news</li> <li>uncertainty paired with hopefulness</li> <li>HCP gave, or desired to find, cause of death</li> </ul> Noted exit of HCP <ul style="list-style-type: none"> <li>HCP presence after news delivery</li> </ul>	Communication re: options <ul style="list-style-type: none"> <li>options limited without explanation</li> </ul> Expressed uncertainty <ul style="list-style-type: none"> <li>expressed uncertainty re: baby's condition or how to perform exam</li> <li>uncertainty paired with hopelessness</li> </ul> Noted exit of HCP <ul style="list-style-type: none"> <li>immediate HCP exit</li> </ul>
Opposing experiences in stillbirth notification	Support of parent emotion Information provision Continuity of care	Suppression of parent emotion Lack of information provision Lack of continuity of care