

When a baby dies: Motherhood, psychosocial care and negative affect

Abstract

Background: The process of giving birth to a baby who has died is a significantly traumatic experience for the mother and her family and also for health professionals. Support, or even the perceived lack of support, from professionals often influences whether or not the parents choose to see and hold their baby. Psychosocial clinical care may also affect long-term psychiatric sequelae. The purpose of this study is to explore the lived experiences of mothers following the death of a baby and their interaction with healthcare professionals. **Methods:** Through a web-based survey, a content analysis of this open-ended question was conducted: 'Do you currently feel sad, hurt, or angry for something health professionals did in connection to the birth of your baby?' **Results:** Mothers reported feeling sadness when they perceived too little support from professionals, particularly related to bonding time with the baby. They reported feelings of disappointment when health professionals neither acknowledged nor validated their motherhood. Mothers reported anger in response to professionals they perceived to be indifferent or callous toward their loss. They also reported that they felt hurt when health professionals lacked respect and when they felt abandoned by the personnel. **Conclusions:** There are crucial implications for practice; it is important for women who experience a stillbirth to have their motherhood actively acknowledged and validated and to have the humble, empathic presence of their health professionals.

external influences which might hinder a parent's ability to cope with the death of their child. The psychological milieu in which the death of a child has occurred may influence bereavement outcomes and psychological distress (Cacciatore, 2011). Physicians who experience fear around the death of a baby even if there is no evidence of liability, report higher levels of fatigue and distress. Thus the physicians' psychological state may directly affect their ability to provide compassionate psychosocial care (West et al, 2009), particularly in the aftermath of a baby's death. Kaunonen et al (2000) found that health care providers experience a sense of injustice when a baby dies. Furthermore, their study also revealed that health professionals felt inadequate in their roles as caregivers, and they did not feel supported by their colleagues when a baby died (Kaunonen et al, 2000). Additionally, there is evidence to support that some professionals are detached and reluctant to express sympathy or apology to a patient or a patient's family in the face of trauma or death (Coulehan, 2009). Any instance in which a family feels that health professionals have 'hurried up, disallowed, trivialised or not recognised' them, avoiding their profound sense of grief and loss, seems to exacerbate and prolong their dissatisfaction with care (Neimeyer, 2002).

Indeed, health professionals may be insufficiently trained to provide patient-focused psychosocial care, particularly in the aftermath of traumatic death. This is likely to arouse anxiety and trigger experiential avoidance in the professionals (Reese and Brown, 1997; Neimeyer, 2002; Cacciatore and Flint, 2012). The degree to which a health professional feels attuned to the patient's emotional state can predict their willingness and ability to provide compassionate psychosocial care (Chibnall et al 2004; Kruijver et al 2006; Cacciatore and Flint, 2012). In some fields of nursing, for example, oncology, nurses accept a dual, psychosocially focused role as both a health professional and a therapist for the family (Arving and Holmström, 2011). Peplau's (1997) theory of interpersonal relations proposed that nursing, specifically, is a healing art that is fluid, intuitive, and personalised as opposed to a rigid protocol, and recognised the differing

The death of an infant is one of the hardest losses to bear. Previous research on this subject explores the direct effects that the infant's death had on the parents and the various clinical interventions for coping with the grief. Lang and Goulet (2003) proposed that the ways in which parents coped with their child's death was best predicted by parents' level of hardiness or resilience. This included the extent to which they exercised locus of control, the degree to which a person feels they have control over their experiences, their willingness to seek support, and how they made sense of the event (Lang et al, 2003). Another study showed the same effect in relation to spirituality (Brotherson and Soderquist, 2002). Feeley and Gottlieb (1988) found that mothers use social support, avoidance strategies, and distraction to cope with the deaths of their newborns. They also found that couples who engage in respectful and open communication cope better than couples whose communication was discordant (Feeley and Gottlieb, 1988).

Many studies, however, fail to explore the

Ewa Nordlund
Midwife, Karolinska University
Hospital, Huddinge

Astrid Börjesson
Midwife, Karolinska University
Hospital, Huddinge

Joanne Cacciatore
Assistant Professor, School
of Social Work, Arizona State
University

Carissa Pappas
BSW Student, Arizona State
University

Ingrid Randers
Associate Professor
Sophiahemmet University
College, Stockholm

Ingela Rådestad
Professor Sophiahemmet
University College, Stockholm

roles in the job including that of counsellor, manager of environment, mediator, and technical expert. Particularly when a baby dies, this wide range of role shifts may affect and possibly impede the health professionals ability to provide psychosocial care (Cacciatore and Flint, 2012).

Experiences and expressions of grief may be influenced by character traits, resilience, socioeconomic status, history of loss, education, help-seeking behaviours, partner concordance, and spirituality (Feeley and Gottlieb, 1988; Reese and Brown, 1997; Brotherson and Soderquist, 2002; Lang and Goulet, 2003; Cacciatore et al, 2009). The purpose of this study is to explore the lived experiences of mothers following the death of a baby and the quality of their interactions with health professionals.

Methods

This study emanates from one web-survey question aimed toward women who lost a baby before or during birth. The question asked was: 'Do you currently feel sad, hurt, or angry for something health professionals did in connection to the birth of your baby?' After answering 'yes', 'no', or 'other', respondents were able to expand on their answer. The questionnaire was available through the Swedish National Infant Foundation's website between 27 March 2008 and 1 April 2010. The Swedish National Infant Foundation is an organisation providing support to parents. Information about the survey was available through daily papers and at the Swedish National Infant Foundation's website. The Regional Ethics Committee, Lund, Sweden, approved the study Dnr. 467/2006.

Sample

The women included in this analysis experienced a stillbirth after 22 gestational weeks during the years of 2008, 2009, and the first 3 months in 2010. Eighty-four (39%) of the 213 women who participated in this survey answered the question: 'Do you currently feel sad, hurt, or angry for something health professionals did in connection to the birth of your baby?' The other 129 (61%) had either not answered or replied 'no' to the question or the answers were not related to the birth of the baby.

Data analysis and processing

Content analysis was used to analyse this open-ended question (Elo and Kyngäs, 2008). A systematic review of the responses, line by line, was conducted to identify the meaning bearing units. The units consisted of a single word and/

or cohesive text and were marked in different colours depending on the context it was written. They were placed in emotion-focused categories:

- Sad
- Hurt
- Angry.

Sub-categories were established for each category, these were:

- Lack of support for bonding rituals with the baby
- No acknowledgement of motherhood
- Lack of respect and offending behaviour
- The feeling of being abandoned
- Lack of empathy and understanding.

Direct participant quotes were selected to represent each sub-category.

Results

Sad over something health professionals did during the birth

Lack of support for bonding rituals with the baby

Support and encouragement from professionals were important to mothers when deciding if they would be able to hold and spend time with the baby after birth. Mothers expressed sadness when they felt health professionals did not support them in taking time to bond with their baby. Some expressed regret that they were unable to weigh, measure, clean, or dress their baby, noting that they had not been offered the option to take photographs. Mothers were also sad when staff had mislaid mementos (such as the baby's blanket, cap, and pillow) or when they had to 'argue' with providers to keep mementos of emotional value (such as the baby's blanket) that actually belonged to the hospital.

'When our son was born he was placed in a light-blue blanket that belonged to the delivery ward. When we were going home and had to leave him there, I wanted to take the blanket with me. It was the only thing that was his and that smelled like him. The staff said that I could not have it since it belonged to the hospital. I did get the blanket in the end, but only after an attack of anxiety after returning home, and I had to promise to bring a new blanket to the ward, and so I did.'

'I regret that I never had my son naked on my skin. He was wrapped in a blanket when I got him and it is something I miss that I have never felt.'

No acknowledgement of motherhood

Mothers felt that the birth of their baby was a significant event in their life, even though the baby was born dead. They expressed sadness when their feelings of both loss and motherhood were not acknowledged. They experienced the same sadness when they felt that professionals focused solely on the cause of the death rather than on their emotional distress and grief. Mothers felt disappointment when the physical and emotional strength they had shown during the birth was unrecognised by health professionals. They also expressed deep sadness when they felt professionals did not respect the baby who died in the same way as a live baby, for example, by ignoring the baby or failing to ask the mother to engage with the baby in the same way as they would with a living baby. For example, one mother wished she had been asked to cut the umbilical cord, just as she would have if her baby had been alive, and another mother noted that her baby was not diapered and dressed after birth.

'I wanted to go through the birth with the midwife during my first revisit. The birth was one of the biggest things that had ever happened to me but nobody in my surroundings asked me about it. I never got to compare like other mothers. I just received the autopsy report on my first revisit.'

'A social worker came and talked to us. He did not look at our boys.'

Hurt by something health professionals did during the birth**Lack of respect and offending behaviour**

The mothers felt hurt when professionals touched the baby in a way that they felt was disrespectful. Mothers in this study were also offended when health professionals used minimising language such as referring to the baby who died as a 'miscarriage' or used the pronoun 'it', or 'fetus' when referring to the baby. Mothers felt that their emotional states were disregarded when the professional's primary focus was on practical matters such as death reporting or funeral planning. Mothers also reported feeling hurt when health professionals conversed with one another about irrelevant topics during the birth, interpreting this as a lack of respect and understanding of their tragedies. For example, one mother reported that health professionals were 'telling jokes in the surgical ward'. Mothers reported occasions when they felt that professionals 'hurried' them in their final moments of goodbye.

'A midwife called my baby 'the miscarriage', despite the fact that the baby was born in week 25. She also said 'There are worse things'. It was horrible to hear her say that.'

'The paramedics that had taken me to the surgical ward (operating theatre) when the death of my baby was established. They started to hug, comfort, and feel sorry for each other, something I felt was wrong. They should have shown those feelings and sadness toward me instead.'

The feeling of being abandoned

Some mothers in this study expressed feelings of abandonment and loneliness when being forced to change rooms at the hospital—their care turned over to new staff. Mothers found it difficult to meet new health professionals with whom they did not have a relationship. Some of the mothers described distressing situations where they went to the cafeteria alone and encountered other pregnant women. Death notification was also particularly difficult and mothers perceived professionals to be uncertain, avoidant, and tenuous. Mothers felt ignored in the corridors, noting that health professionals often avoided making eye contact. The intense grief mothers were already suffering was exacerbating by hearing the cries of other newborns in the ward and seeing pregnant women. The hospital discharge process was painful for mothers as they had to leave the baby. One wished that a midwife would have taken her baby out of the room before discharge, as it may have eased her distress during discharge.

'The summer substitute personnel, without experience, could not handle the grief, they avoided eye-contact or took a detour whenever we walked in the corridors.'

'One thing that was extremely tough [sic] was to go down to the maternity care department to take fetal fluid tests among all the 'super' pregnant women. We just cried. To stay in the delivery room was also extremely tough [sic] with all the screams we heard from newborn babies.'

Angry by something personnel did or didn't do during and after the birth**The lack of empathy and understanding**

Some of the women reported that professionals

did not listen well and lacked empathy. This perceived health professional's reaction often provoked a feeling of anger in mothers. The ways in which information about the baby's death was communicated also evoked anger. Some mothers waited extended periods of time for a physician to confirm the baby's death, and others felt that they did not receive appropriate medical care from professionals because their baby was dead. For example, one mother did not receive antibiotics for an increasing fever nor for the pain relief she requested. In another instance, a mother described being very angry that critical information about her baby's death did not reach the surgery ward. This set into motion serious misunderstanding, and professionals were thus unprepared for the birth of a baby who died. Situations also occurred where health professionals did not accept responsibility for their errors including insufficient or inadequate communication regarding the baby's death, a breach of protocol, misplacement of mementos, or overlooking important rituals such as photographing the baby who died. Mothers felt that professionals blamed them for such transgressions, even implicitly, and this also incited angry feelings.

'The physician thought we should go out for dinner and come back the next day. Dinner out?! He said that he and his wife had done that when their daughter was on intensive care unit and they had said to each other 'No matter how disabled she is—as long as she survives'. Our child was dead; we thought he was unethical and that he offended us.'

'I asked when I was going home, if I shouldn't have some of that medicine I got the day before, to prevent the milk from coming. She then told me that I did not need that since it (the milk) was triggered by hearing the baby cry. That felt terrible to hear.'

'I was congratulated for having a baby when I was going to have placenta removed. I told them, before being sedated, that she had died. They should know that before I get there.'

Discussion

The results of this study suggest that grieving mothers often experience negative emotional responses during their interaction with health professionals following a stillbirth. In particular, mothers reported feeling sadness when professionals

offered little support or encouragement to bond with the baby who died. They experienced disappointment when professionals failed to acknowledge their motherhood and their baby. The women in this study felt hurt when professionals were avoidant, detached, and lacked the same respect for the baby who died as they would for a living baby, often reporting feelings of abandonment. They felt angry when professionals were not empathic failed to understand the magnitude of their losses.

The onus of responsibility falls on health professionals and administrators to become trained in dealing with death (Cacciatore, 2011) and thus become more aware of the emotional, relational, and even spiritual aspects of the patient's unique experiences of loss (Chibnall et al 2004; Kiernan, 2010). Health professionals who have received such specialised training are better able to acknowledge the subjectivity, emotional, relationship, and solidarity, and, when applicable, spirituality of each mourning family (Chibnall et al 2004; Coulehan, 2009; Cacciatore, 2011). Often, professionals specifically educated in understanding aspects of human suffering are more empathic listeners and will engage in more approaching techniques with patients facing human suffering. In addition, these professionals tend to be more self-aware and self-compassionate (Coulehan, 2009, Cacciatore, 2011, Cacciatore and Flint, 2012). International leaders in the perinatal bereavement community convened to assess current empirical evidence and practice wisdom in standards of care. In particular, they called on health professionals to engage in compassionate and open ongoing communication, facilitate bonding time with the baby who died based on culturally competent care-giving, collecting mementos when appropriate, and assisting families in plans for final disposition. Of critical import is the health professionals training in bereavement and death studies.

Conclusions and implications for practice

It is important for women who experience a stillbirth to have their motherhood actively acknowledged and validated and to have the full, empathic presence of health professionals. They should approach grieving mothers with compassion, humility, and mindfulness (Cacciatore, 2011). Also, because each patient's needs are unique, a mindfulness-based approach, which includes death education (Cacciatore, 2011), is more likely to ensure the needs of each individual mother are met, consistent with interpersonal relations theory (Peplau, 1997). Death education is critical to helping health professionals feel comfortable in approaching traumatic losses

Key points

- Mothers felt sad when they perceived too little support from their healthcare professionals, particularly related to bonding time with the baby
- Mothers were disappointed when professionals neither acknowledged nor validated their motherhood
- Mothers were hurt when healthcare professionals lacked respect and when they felt abandoned by the personnel. Mothers felt anger in response to professionals they perceived to be indifferent or callous toward their loss
- It is important for women who experience a stillbirth to have their motherhood actively acknowledged and validated and to have the humble, empathic presence of their healthcare professionals

so they are better able to focus on caring for the grieving mother. In addition, this may lessen tendencies toward avoidance and reduce the risk of secondary stress in professionals (Reese and Brown 1997; Cacciatore, 2011; Cacciatore and Flint, 2012). In lieu of a detached protocol, deeply intimate and respectful relationships with professionals may help allay fears that result in irremediable decisions, exacerbating an already excruciating experience for mothers and their families. Mindful psychosocial care, ultimately, fosters a healing environment, which may help diminish unnecessary negative affect when a baby dies.

BJM

- Arving C, Holmström I (2011) Creating a new profession in cancer nursing? Experiences of working as a psychosocial nurse in cancer care. *J Clin Nurs* 20: 2939-47
- Brotherson S E, Soderquist J (2002) Coping with a child's death: Spiritual issues and therapeutic implications. *J Family Psychother* 13: 53-86
- Cacciatore J, Schnebly S, Froen F (2009) The effects of social

- support on maternal anxiety and depression after stillbirth. *J Health Soc Care Comm* 17: 167-76
- Cacciatore J (2011) *Psychosocial Care, in Stillbirth: Prediction, Prevention and Management* Wiley-Blackwell, Oxford, UK
- Cacciatore J, Flint M (2012) ATTEND: Toward a mindfulness-based model of bereavement care. *Death Studies* 36: 61-82
- Chibnall J T, Bennett M L, Videen S D, Duckro P N, Miller D K (2004) Identifying barriers to psychosocial spiritual care at the end of life: A physician group study. *Am J Hospice and Palliat Med* 21: 419-25
- Coulehan J (2009) Compassionate solidarity: Suffering, poetry, and medicine. *Perspect Biol Med* 52(4): 585-603
- Elo S, Kyngäs H (2008) The qualitative content analysis process. *J Adv Nurs* 62: 107-15
- Feeley N, Gottlieb LN (1988) Parents coping and communication following their infant's death. *J Death Dying* 19: 51-67
- Kaunonen M, Tarkka M, Hautamäki K, Paunonen M (2000) The staff's experience of the death of a child and of supporting the family. *Internat Nurs Rev* 47(1): 46-52
- Kiernan G, Meyler E, Guerin S (2010) Psychosocial issues and care in pediatric oncology: Medical and nursing professionals' perceptions. *Cancer Nurs* 33(5): E12-20
- Kruijver I P M, Garssen B, Vissee A P, Kuiper A J (2006) Signalling psychosocial problems in cancer care: The structural use of a short psychosocial checklist during medical or nursing visits. *Patient Educ Couns* 62: 163-77
- Lang A, Goulet C, Amsel R (2003) Hardiness scale: Development and testing on bereaved parents following the death of their fetus/infant. *Death Studies* 27(1): 851-80
- Neimeyer R A (2002) Traumatic loss and the reconstruction of meaning. *J Pall Med* 5(6): 935-42
- Peplau H E (1997) Peplau's theory of interpersonal relations. *Nurs Sci Quart* 10: 162-7
- Reese D J, Brown DR (1997) Psychosocial and spiritual care in hospice: Differences between nursing, social work, and clergy. *Hosp J* 12(1): 29-41
- West CP, Tan A D, Habermann T M, Sloa J A, Shanafelt TD (2009) Association of resident fatigue and distress with perceived medical errors. *JAMA* 302: 1294-300

CALL FOR RESEARCH PAPERS

Do you have a study you would like to write about?

Share your experience by sending your article to the editor: bjm@markallengroup.com

www.britishjournalofmidwifery.com

MA Healthcare Ltd ■ St Jude's Church ■ Dulwich Road ■ London ■ SE24 0PB ■ UK

Copyright of British Journal of Midwifery is the property of Mark Allen Publishing Ltd and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.