Navigating Care After a Baby Dies: Improving Nursing Care for the Bereaved Parents

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Keywords: nursing, perinatal death, parents' experiences, practice recommendations, qualitative research.

INFORMATION SOURCE

This article is based upon two systematic reviews of qualitative research, both evaluating more than 1100 articles from 1966 to 2006. Both of the systematic reviews address parents’ experiences of hospital care surrounding foetal and early infant loss (Gold, Dalton & Schwenk, 2007; Gold, 2007).

The term “perinatal death” will in this article refer to foetal deaths in the second and third trimester of pregnancy as well as “neonatal deaths” occurring in the first 28 days after birth (Gold, Dalton & Schwenk, 2007, p 1157).

BACKGROUND

In 2006, 2258 perinatal deaths were registered in Australia. Even though there has been a reduction in perinatal deaths over the last ten years (9.2 per 1000 births in 1997 to 8.5 per 1000 births in 2006), the number is still significant (Australian Bureau of Statistics, 2008). Losing a child during the late stages of pregnancy or in the first weeks after birth is a devastating experience for most parents (Gold, 2007). For many reasons perinatal loss is different from other losses. As Bennett, Lee, Litz and Maguen, 2005 (p. 181) put it, “When an adult dies, a piece of the past is lost; however, when an infant dies, a piece of the future is lost, or significantly changed forever.” Hopes and expectations are replaced by loss and grief.

Historically, the significance and traumatic nature of these losses were not recognised, and were characterized by a lack of understanding regarding best practice in the hospital setting (Gold, Dalton & Schwenk, 2007). This has changed significantly, and it is clear that the nature of care provided in hospitals can impact on the parents and their ability to handle the grieving process. Parents are in an emotionally aroused state, and what might seem to be harmless missteps or comments from health care workers can cause high levels of distress and anger from the bereaved parents (Gold, 2007). Experiences of this nature can remain in the parents’ memory for decades after their loss. It is therefore vital that all health care workers are acutely aware of how they can best support bereaving parents through specific interventions and behaviours. This article will suggest interventions based on the interview of more than 6000 parents regarding their experiences of hospital care surrounding the time of the death of their child.

FINDINGS

Offering Choice

When parents are faced with the reality that their baby is dead prior to birth, there are several issues that need consideration. Should delivery be induced as soon as possible, should it be postponed days or weeks or should they wait until spontaneous labour occurs? There is no evidence suggesting any of these options delivers a better outcome than others (Gold, Dalton & Schwenk, 2007). Pain control is also an individual choice. It is important that it is adequate, however over-sedation should be avoided (Gold, Dalton & Schwenk, 2007). The question of where post-partum care should take place also needs consideration. Again, parents had different opinions and no clear answer as to what is optimal could be made. Generally, mothers being cared for in the labour and delivery unit described it as emotionally challenging being around healthy infants, and mothers who were moved to general surgical or gynaecology units were generally less satisfied with the staff and quality of care (Gold, Dalton & Schwenk, 2007).

Thus there are no correct decisions regarding timing of delivery, pain control and location of post - partum care. However, what was important for nearly all parents that resulted in higher satisfaction of care was when parents were given a choice regarding these issues (Gold, Dalton & Schwenk, 2007).

Seeing and Holding the Baby

The studies uniformly showed nearly all parents found seeing and holding their baby as a valuable experience and an important part of the grieving process (Gold, Dalton & Schwenk, 2007). Parents who first declined generally regretted their decision and stated they probably would have changed their mind had they been further encouraged. Parents who did see and held their baby often wished they had been offered the option to spend even more time with their baby. (Gold, Dalton & Schwenk, 2007). If the parents initially decline, give them some time and offer again, and explain the possible advantages in their grieving process. With that being said, it is the parents’ decision, and there might be cultural as well as individual reasons the parents choose not to hold or see their baby, and this needs to be respected.

Parents are also acutely aware of how health professionals handle their deceased baby. It can cause high levels of distress if the baby is handled carelessly. Nurses who cleaned and dressed the deceased baby in a respectful manner, as they would have done for a living baby were highly valued and appreciated by the parents (Gold, 2007).

Photos and Mementos of the Baby

Taking photos of the deceased baby is a common practice in most hospitals (Gold, Dalton & Schwenk, 2007). It was clear from the studies that this practice is valued by virtually all parents, and seen as one of the most helpful practices during their hospital stay (Gold, Dalton & Schwenk, 2007). The photographs should be non clinical and taken as soon as possible after birth, after cleaning and dressing the infant. The photos should be offered to the parents, and if that offer is declined the photographs should be kept on file to offer at a later time.

Parents also value other memories of their baby (Gold, Dalton
Communication Between Staff

Poor staff communication can greatly affect bereaving parents. Parents reported episodes where staff made thoughtless comments or came cheerfully into their hospital room apparently unaware of their loss, causing unnecessary distress and trauma (Gold, Dalton & Schwenk, 2007). This might seem like a benign misstep from the health care worker, but can have a far bigger impact than it would under different circumstances. A discrete and effective way of communicating perinatal loss is through using specific symbols on hospital room doors. This way all staff, from nurses to cleaners will be aware of the parents’ loss, and take it into account when entering the room (Gold, 2007).

Emotional Support

Spending extra time with the bereaving parents and showing genuine emotional support is highly valued. Many parents had experienced nurses and doctors avoiding them after their loss, which they found very painful (Gold, 2007). This might be due to the fact that nurses and doctors do not know how to handle situations of this nature and find it confronting. If this is the case, increased level of education and training programs for staff are necessary to ensure better outcomes for both the health professionals and for the parents (Gold, 2007).

Autopsy

Often the cause of the infant’s death is unclear, especially when the infant dies prior to or during birth (Gold, Dalton & Schwenk, 2007). Not knowing what went wrong can be a stressful feeling for many parents, and feelings of guilt can often occur (Gold, Dalton & Schwenk, 2007). It is therefore important that the option of having an autopsy is offered. This can often erase feelings of guilt and can provide comfort to the parents. However, a common complaint was that the results of the autopsy were not provided to the parents, and no information was given as to how they could obtain the results of the autopsy were not provided to the parents, and no information was given as to how they could obtain the records, causing unnecessary frustration and dissatisfaction (Gold, Dalton & Schwenk, 2007). Parents appreciated being given clear and honest information in a way they could understand (Gold, 2007).

Funeral and Memorials

Several qualitative studies showed that many parents felt they had little control over the disposition of their baby, and some did not even know what happened to their infant’s body (Gold, Dalton & Schwenk, 2007). This is a significant source of distress for the parents. Parents should be given information, both oral and written regarding their options for burial or cremation (Gold, Dalton & Schwenk, 2007). They should then be given time to think and discuss their options and be the ones that make the final decision. This is also important in early pregnancy loss. If parents do decide to leave the disposal of the remains to the hospital, oral and written information regarding hospital procedure should provided (Gold, Dalton & Schwenk, 2007).

NATURE AND QUALITY OF THE RESEARCH

Like all research, the systematic reviews this article are based upon also have limitations. Due to the sensitivity of the topic, it is not ethical to conduct randomized controlled studies. This article therefore relies heavily on qualitative studies. However, due to the size of the systematic reviews, they provide rich data regarding parents’ experiences and perspectives with high transferability to nursing practice (Gold, Dalton & Schwenk, 2007). The studies however varied largely in quality, method and reporting. Many lacked information regarding their methods, not many had control groups and the vast majority of the samples were based on convenience and snowball sampling of volunteer participants as opposed to a comprehensive sample (Gold, Dalton & Schwenk, 2007).

It is important to understand that the recommendations in this article are not absolute. There will be individual preferences regarding nursing care based on religion, culture and personality. For example, a 2002 study cited in Bennett, Lee, Litz & Maguen (2005) found that women who held their deceased baby had a higher chance of suffering depression in their following pregnancy. Even though this is only one single study, and the vast majority found different results, it illustrates that there is no absolute right way that fits everyone. Therefore, what can possibly be said to be the most important recommendation in this article is to offer emotional support and give the parents choices regarding their care after providing sufficient information so they can make well informed decisions.

References


