

## Perinatal grief: a poignant form of bereavement

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Perinatal grief is of a different nature to other grief such as that following the death of an elderly parent or a long-term spouse. It is defined as the grief that parents experience after the death of a baby during pregnancy, birth or the first month after their birth, which includes miscarriage, ectopic pregnancy, termination, stillbirth and neo-natal deaths. Each year in Australia perinatal grief may be experienced by thousands of families. The death of a baby is a very stressful event and the bereaved parents will usually experience acute emotional distress. Their initial response to the death of their baby may include emotional numbness, confusion, disbelief and shock which may be a mechanism for them to cope with the overwhelming impact of the death of their baby in the short term.

### Nature of perinatal grief

This is a form of grief that is both 'disenfranchised' as well as complicated because these deaths often occur without warning and are contrary to our expectations about life (Doka, 1989; Zhang, El-Jawahri & Prigerson, 2006). Many times it occurs in circumstances without an explanation for, or cause of, the death. This lack of information about the factors which have led to the death of the baby can create distress for the parents and other family members as they struggle to make sense of their loss. It can be difficult to announce a pregnancy and its demise at the same time to family and friends, as many couples do not mention the pregnancy until after the end of the first trimester. Also for those couples who are struggling with fertility and may have used assisted reproductive technology to achieve conception, deciding whether they have experienced a miscarriage or a 'failed cycle' may influence how they want to express their grief and from whom they seek support.

However, even if the pregnancy has progressed beyond the 20th week of gestation, about 3,000 babies still die each year in Australia before, during or soon after birth (Laws & Sullivan, 2010). While many of the parents of these babies manage their grief within their usual networks, some seek support elsewhere, such as from self-help, peer-based organisations like SIDS and Kids. These organisations usually describe their services as 'bereavement support', not provision of therapy.

As is the case in other forms of grief, perinatally bereaved parents may express their grief in different ways which may range on a continuum from 'instrumental' to 'intuitive' grieving (Doka & Martin, 2010). Instrumental grievers often express their grief by 'doing' something. This may vary from making a memorial garden to setting up a foundation in memory of their baby. Intuitive grievers commonly express their grief in words. They need to talk about what happened and how they are feeling. It can be common for women to express their grief in a more intuitive style and they may complain or express concern about their partners not feeling the same level of grief because they do not express it in the same way. Assisting these parents to understand that the different ways of grieving are not better or worse than each other, just



better suited to different people, may help them to understand each other more and assist them in maintaining their relationship.

### Symptoms of perinatal grief

As this is death at the beginning of life and may be the first death that these parents have experienced, depression can be a common symptom (Winjngaards-de Meij et al., 2005). The parents struggle to come to terms with the loss of their baby and the loss of the life they were expecting to enjoy. It can be a huge existential crisis. The mother is often unsure of what to do as she had planned to be caring for a baby. She may become distressed at having to make decisions about whether she should return to work or become pregnant again. Her partner is often also struggling with these issues, while trying to support her and feeling that his/her situation may be overlooked by family, friends and colleagues.

Anxiety is common in parents experiencing perinatal grief especially if there is no explanation for the cause of the death of their baby. It is understandable that these parents may then blame themselves. They may have a sense that they should have known that something was wrong for their baby and been able to 'fix' it. Some experience posttraumatic stress and need assistance to cope with the symptoms, such as flashbacks (Engelhard, van den Hout & Arntz, 2001).

Approximately 75 per cent of bereaved parents subsequently go on to have another baby (Boyle, Vance, Najman & Thearle, 1996), and these pregnancies are often fraught with anxiety as the parents become aware of many threats to the health of the mother and the developing baby. They are often particularly anxious when approaching the same stage of pregnancy/life of the deceased baby, although there are no guarantees that subsequent babies will not experience similar problems. If a viral or bacterial infection was implicated in the death of the baby, such parents may become overly concerned with cleanliness, sometimes to the point of developing an obsessive compulsive disorder.

Commonly the bereaved parents have friends and family members who are also pregnant or have babies or children at about the same time. This can present difficulties for them as they try to be happy for others who have live, healthy babies, while being in their company reminds them of their own loss. Many bereaved couples express awkwardness about how to be with their friends at these times when it is so painful for them.

Even the birth of subsequent babies can have a negative impact on the emotional balance of these parents. Firstly, many of their family and friends may expect them to be 'better' or to find 'closure' now that they have a live baby, but this expectation fails to understand the lifelong nature of perinatal grief. Modern grief theorists encourage the expression of 'continuing bonds', so that the parents find a way of expressing the place of the deceased baby in their family (Klass, Silverman & Nickman, 1996). However, then the parents may be more likely to make comparisons about what they had been expecting to be doing with their deceased baby whilst caring for their new baby. They may also have difficulty with realising that the subsequent baby may not have been conceived if the other baby had not died. There can be many layers of loss and guilt for these parents (Barr, 2004).

Another difficulty that these couples have to negotiate is the impact of their loss on their relationship, as they often struggle to find the emotional resilience to help each other while



they are individually coping with their own distress about the death. One study has shown that in spite of the pressure on their partnership, most couples who had a mutually satisfying relationship before the death of their baby manage to maintain their union (Najman et al., 1993). Conversely, it is more common for those couples who had already been experiencing problems with their relationship to find that the strain from the death of their baby is so great that they break up.

### Interventions for perinatal grief

Bereaved parents are usually referred for psychological therapy when the way in which they express their grief is seriously interfering with their ability to manage their everyday life. While it is common for these parents to express suicidal ideation, they are also keenly aware of the impact of the death of a loved one and so are often reluctant to inflict this pain on their family members or close friends.

Specialised couple therapy which explores the different ways in which instrumental and intuitive grievers express their grief can be helpful in opening up the conversation between the parents about the impact that the death is having on each of them. This will allow them to appreciate their differences instead of interpreting other ways of grieving as somehow pathological.

Therese Rando, a renowned grief theorist, is about to publish a book about interventions for this type of loss (Rando, in press). Her recommendations for those affected by perinatal grief may be useful (presented in the boxed information). Strategies that have been used for the treatment of acute stress disorder associated with traumatic loss, such as those recommended by Richard Bryant et al. (2008) may also apply.

It is vital when assisting a client who is bereaved through a perinatal death to not simply apply strategies from theories about other forms of grief. This profound experience in the lives of parents needs to be fully explored to identify the particular meaning of the loss for each person, and then to tailor assistance accordingly.

# Treatment Strategies (Rando, in press)

- Exposure strategies reprocess memories and emotions
- Cognitive strategies promote positive self-talk
- Anxiety management address all manifestations of anxiety
- Regulation of affect and cognitions increase positive and decrease negative
- Connect with others meaningfully re-engage and accept support
- Tell the story develop the narrative around the death
- Reconstruct personal meaning revamp disrupted life narrative



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