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Never a simple journey

Pregnancy following perinatal loss

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Abstract: More than half of families who experience the death of an infant, either pre-birth or shortly after, go on to have another pregnancy. But the psychological impact of the previous loss may not be acknowledged by family members, friends and care-givers. Parents may experience symptoms of post-traumatic stress disorder; they may fail to attach to the new child. This article outlines the fears commonly reported by parents who have a second pregnancy after loss, and their struggles to come to terms with the coming birth of the new baby in the shadow of the death of its sibling. It goes on to describe the pregnancy after loss (PAL) group set up by the author and a colleague that uses family education methods to help these parents acknowledge and overcome their fears and build healthy bonds with their new baby.

Keywords: Pregnancy, infant death, sibling, attachment, family education

It is estimated that between half and 86% of families who experience an infant loss have a subsequent pregnancy (Cordle & Prettyman, 1994; Cuisinier *et al*, 1996). When a baby dies, parents suffer the psychological burdens of both trauma and bereavement (Turton *et al*, 2001; O'Leary, 2004). It is not surprising to learn that mothers and fathers alike are vulnerable to case-level symptoms of post-traumatic stress disorder (PTSD) in the next pregnancy, and are often unable to imagine that their baby will be born alive (Côté-Arsenault & Morrison-Beedy, 2001; Côté-Arsenault, Donato & Earl, 2006; O'Leary, 2004). In spite of this, there continues to be discrepancies in how a pregnancy after loss (PAL) is viewed by others, including providers who care for these families, and how they are experienced by the parent(s).

Over the past 20 years, I have had the privilege of working with families where there is a pregnancy after loss. My journey began when a distraught woman, who had attended an infant loss group, wanted support in the first trimester of her subsequent pregnancy. When told there was no group she became very upset, saying: 'I can't go back to the infant loss group. How can you abandon me now when I need you the most?' Hearing her plea, and with no prior experience or special training in infant loss, my nurse colleague and I began a pregnancy after loss group. In retrospect, our lack of training may have been

a benefit, as we were open to whatever was presented.

Four mothers attended the first group: one had experienced three early miscarriages, another had a baby boy with severe abnormalities who lived two hours; the third had given birth to a daughter at 22 weeks gestation, and the fourth had a stillborn baby. Although the losses were different, the women shared common themes: fear and anxiety, mistrust of their body as a safe place for a baby to grow, and wanting the pregnancy to be over. At the end of the session we scheduled the next meeting for two weeks time. There was an outcry from the mothers: 'Two weeks? We can't wait that long. We're way too anxious and need to come back every week!'

After they left we were exhausted. My nurse colleague turned to me and said: 'Did you see all those women with high-risk pregnancies?' She heard the medical implications: mothers who had lost trust in their bodies, putting them at risk for medical complications and pre-term labour symptoms they might ignore. As an early childhood professional, I replied: 'Did you see all those babies with attachment disorders?' I visualised four babies carried by mothers trying to deny a baby within, displaying prenatally Mary Ainsworth's anxious avoidant, anxious resistant attachment behaviours. The joy of pregnancy was over-shadowed by anxiety and fear of loss happening again.

What we learned

Unlike the traditional infant loss model of bi-monthly or monthly meetings, we followed the lead of the parents and began meeting weekly. Over time, we identified five developmental tasks of pregnancy specific to families where there is a pregnancy after loss (O'Leary & Thorwick, 1997). These continue to be supported by research. The frequency of these tasks suggests that either Rubin's (1975) normal developmental tasks are arrested or different developmental tasks are present for these parents.

Fear of another abnormal pregnancy

The PTSD-I interview defines a stressor as something so uncommon and so horrible that it would be very distressing to almost anyone (cited in Turton *et al*, 2001). When birth ends in the death of the child, pregnancy can never be the same again. Parents' innocence and meaning of life have been threatened. Because what happens at the time of loss is remembered (Chez, 1995), it is impossible to repeat the experience of perinatal care without stimulating memories of a painful past. One father told us:

'I don't know how many times I've heard people at the clinic say, "Do not compare this pregnancy to the other one because they'll be different." But... you compare, that's how we make our decisions going forward. The only outcome we have with any child is that he died. So immediately you always think bad things.'

No matter how long families wait, the subsequent pregnancy sets in motion a new layer of grief that cannot be anticipated or fully prepared for until it happens (O'Leary, 2004).

'It was all emotions at once... instant joy but also instant fear. Is this going to be the day that something goes wrong?'

Some parents cope by using denial.

'Around other pregnant people I felt, "Well I'm not really pregnant the way you are. I'm sort of pregnant. I might be having a baby."'

These feelings, when voiced, are often mistakenly viewed by care providers as pathological.

Grief for the loss of self that is parent

When a baby dies, a part of oneself as a parent dies too. Not having been able to prevent their baby from dying can lead to feelings of helplessness, powerlessness and being out of control. A father's role as protector of the family can be shattered (O'Leary & Thorwick, 2006a). People in grief often become anxious about their own humanity, weakness, finiteness and limitations (Attig, 2000). Some women and men are no longer able to imagine the woman's body as a safe place for a baby to grow (Côté-Arsenault, Donato & Earl, 2006; Côté-Arsenault & Dombeck, 2001; O'Leary & Thorwick, 2006b).

'My womb killed my last baby so it's not a comfort for me to know my baby is [in] there.'

Anticipatory grief can occur: the parents cannot trust that they will bring home a live baby this time.

Others may unwittingly negate the parents' identity as parents. In her second pregnancy this mother objected when people spoke of her and her partner as 'parents to be'.

'No, we're parents. Even if this was our first baby, we'd be parents. We already have a baby.'

Avoiding attachment for fear of future loss

Well-meaning people may say: 'You're pregnant again. Focus on this baby now.' There is a lack

of understanding that it takes courage to risk attaching to another baby.

'There's been a hesitancy to become as emotionally attached as I want to be because the pain of loss is deeper in me than I realised.'

It is normal for parents to avoid any preparation for the birth, such as buying baby clothes, setting up the room, wanting any baby showers. Parents need gentle encouragement to embrace the new baby, and to understand that, even if they try not to attach, it will not hurt any less if this baby dies.

Loyalty to the deceased baby

When fetal movement becomes stronger, parents can no longer maintain they are 'just pregnant'. But the baby's movements can re-awaken memories of the deceased baby, bringing up loyalty issues.

'If I begin to love this baby what does that tell my other baby, that I'm forgetting him?'

This misplaced sense of loyalty can hinder parental attachment to the new baby.

'I'd been reading books on the symptoms of pregnancy – you know, trying to do all that cerebral stuff, but the bottom line is I was terrified, scared to attach and fearful about replacing my son.'

Honouring and respecting their continuing parenting role with respect to the deceased baby helps parents recognise they are not replacing one baby for another.

Attaching to the unborn child

Attaching to the babies as separate entities is crucial. Adults who were themselves the subsequent child in a family where there had been a perinatal loss have confirmed that parental fear of attachment can be life-long; they talk of 'feeling

invisible' in their family (O'Leary, Gaziano & Thorwick, 2006). A helpful intervention to support attachment is encouraging parents to writing a journal. Writing has been used by grieving parents since the 1700s, and continues to be found helpful in reducing the physical and mental stress associated with loss (Pennebaker, 1997). Parents often feel they are unable to keep a journal; they say they do not want the new baby to know that grief overshadows their joy. A helpful way for parents to begin is by writing to the deceased baby about the new baby coming. As the new baby becomes more active, parents can change to writing about the baby who is not there to greet their sibling. This builds awareness that the new baby needs them now and that the babies are siblings.

Father/partner issues

Fathers/partners are often the overlooked bereaved parent, both at the time of loss and during the pregnancy that follows, because the focus is on the physical experience for the mother. Fathers often report that no one asks them how they are doing. They too, have heightened fear and anxiety about the safety of the baby, and may need frequent reassurance from the mother that the baby is still alive. If the previous loss put the mother's life at risk, the father/partner may have increased anxiety about her well-being, in addition to the baby's. Some fathers withdraw emotionally, out of fear; others have an intense need to control and monitor closely. Fathers also say their primary source of support is the mother, yet they feel they have to hold back their own fears and anxiety so as to not increase her stress (O'Leary & Thorwick, 2006a).

The pregnancy after loss group

The pregnancy after loss group that I and my colleague began was open-ended, allowing parents to join at any stage in the pregnancy. The theoretical foundation for facilitation and intervention was through the lens of family education, supporting parent's strengths,

Sue and Tom's story

Baby Mary died at 18 weeks gestation, before her mother felt fetal movement. This was Sue and Tom's first pregnancy and, like most young couples, they had no idea that things could go wrong and were in shock when there was no heartbeat at the 18-week ultrasound examination. When Sue became pregnant again, they began our weekly PAL support group and talked about the lack of support from family and friends who told them the pregnancy was too soon when they were still grieving so profoundly. Yet both Sue and Tom believed they were Mary's parents and needed to honour their role. As they struggled to attach to the baby coming in the next pregnancy, they took comfort in knowing that Mary had been a 'person', and knew them as her parents through their voices; that she died cradled in her mother's uterus. Knowing she felt their love and that Sue's heartbeat was one of the last sounds she heard allowed them to have concrete examples of their 'relationship' with Mary. This helped them to embrace their new baby and not feel they were putting Mary aside.

honouring their role as a parent to the deceased baby while keeping them in the present with the new pregnancy and the new baby who needed their attention now. Understanding that child death does not cancel parent status (Rosenblatt, 2000), an attachment-based intervention was used that followed Fraiberg's model (Fraiberg, Edelson & Shapiro, 1975), using the baby to centre work with parents with attachment issues (O'Leary, Parker & Thorwick, 1998). This led to developing an intervention focused on the prenatal relationship, and helping parents understand the developmental age and fetal competencies of their unborn baby. Providing information on fetal competencies also gave parents concrete evidence that their deceased baby knew them as parents during the previous pregnancy, helping validate their need to include the deceased baby in their family. This was something they said other people often did not understand (see Tom and Sue's story).

Parents learned how to trust their intuitive knowing of their body, often destroyed during the previous pregnancy, and their sense that the new baby 'was already here'. They were supported through their fears about death striking again by reframing their subjective experience to one of understanding that to risk loving another baby did not negate parental status to their deceased

baby. They learned ways to cope with their fears and anxieties about the safety of the new baby, and to seek the care they needed for themselves and their baby by asking their care provider to explain the meaning of clinical data: for example, proper size for age implies wellness; amniotic fluid volume indicates good blood flow and kidney function; acceleration of fetal heart rate with movement reflects brain regulatory function.

Preparing for birth

The final trimester brings increased anxiety and a need for the pregnancy to end: to 'get the baby out' while it is still alive. Preparing for birth after a previous loss is difficult. At the time of loss many parents are in shock, the mother may have been heavily medicated, and the birth meant death not life. It is common for parents to avoid birthing classes, as being around naive first-time parents can be too painful (Parker & O'Leary, 1989). This can leave them vulnerable to suffering symptoms of post-traumatic stress, as well as not understanding the physiology of normal labour. Offering a private or small group class that includes touring the birthing area with other parents who have experienced a perinatal loss is an important intervention. Most parents will not want to do this because they are too fearful of the birth process and what may happen. But

Table 1: Birth plan

Background information	What do you want the staff to know about your family that will help you through this birth experience?
History of this pregnancy	How has this pregnancy been for you?
Labour and birth support	What will you and your partner need?
Postpartum?	Any concerns such as help with breast feeding, siblings etc?

Table 2: Important considerations in pregnancy after loss

Review the story of their previous loss(es) and ask about their deceased baby.
Be mindful of factors that can interfere with pregnancy: <ul style="list-style-type: none"> • adverse prior childbearing or child rearing experience • conflicts or defects in the support system • inadequate preparation for childbearing and child rearing • maternal health risks (Cohen, 1979).
Discover how parents feel about this pregnancy.
Provide pregnancy planning. Ask 'What will help you feel comfortable?'
Note anniversary dates that may be more stressful.
Offer extra heartbeat checks in the early weeks for reassurance that all is well. Just knowing they can ask may be enough for some.
Forgotten details of the previous pregnancy may surface. The trauma of the loss often interferes with understanding what happened.
Prepare parents – ultrasound scanning can evoke memories of the past. Staff should find the fetal heartbeat first.
Parents can be vigilant or distant.
Encourage keeping a journal.
Provide information about how the woman's body supports the baby's development.

going to the space where they will give birth helps them process their fears and identify what may trigger flashbacks in a safe setting before they are in active labour. It provides an opportunity for parents to have intentional control of what they can control before they present in active labor for this birth. They can then write a birth plan that reflects their specific needs (see Table 1).

Conclusion

Clinical work and ongoing research with families where there is a pregnancy after loss suggests it is not just what happens at the time of loss that puts them at higher risk for long-term parenting issues but the lack of understanding of what families need in the pregnancy that follows (see Table 2).

This offers an explanation as to why Hughes and colleagues (2002) found increased depression, symptoms of post-traumatic stress disorder and attachment issues in mothers who had another pregnancy following the loss of an infant. The loss of a child changes families fundamentally, making it difficult to compare them with first-time pregnant families. The fear to attach is real and can continue into the postpartum period. The birth of a healthy baby brings the full realisation of what was lost, creating another layer of grief that cannot be anticipated. In the words of one mother:

'I didn't think he would take away my grief but I didn't know he would make it stronger.'

Providing groups during pregnancy for families who have a second pregnancy after loss, and a labour and birth preparation class and continued group support in the postpartum period may have long-term benefits for healthy family development. Clearly there is a need for more community programmes and research with these families. ■

Attig T (2000). *The heart of grief*. New York: Oxford University Press.

Ainsworth M. See: <http://bpc.digitalbrain.com/bpc/web/LearningObjects/Ainsworth/strange/>

Cordle C, Prettyman R (1994). A two-year follow-up of women who have experienced early miscarriage. *Journal of Reproductive and Infant Psychology* 12(1) 37–43.

Chez R (1995). After hours. *Obstetrics & Gynecology* 85(6) 1059–1061.

Cohen RL (1979). Maladaptation to pregnancy. *Seminars in Perinatology* 3(1) 5–17.

Côté-Arsenault D, Donato K, Earl SS (2006). Watching and worrying: early pregnancy after loss experiences. *MCN The American Journal of Maternal Child Nursing* 31 356–363.

Côté-Arsenault D, Dombeck M (2001). Maternal assignment of fetal personhood to a previous pregnancy loss: relationship to anxiety in the current pregnancy. *Health Care for Women International* 22(3) 649–665.

Côté-Arsenault D, Morrison-Beedy D (2001). Women's voices reflecting changed expectations for pregnancy

after perinatal loss. *Journal of Nursing Scholarship* 33(3) 239–244.

Cuisinier M, Kuijper J, Hoogduin C *et al* (1996). Miscarriage and stillbirth: time since the loss, grief intensity and satisfaction with care. *European Journal of Obstetrics and Gynecology* 52(2) 163–168.

Fraiberg S, Edelson E, Shapiro V (1975). Ghost in the nursery: a psychoanalytic approach to the problems of impaired infant–mother relationships. *Journal of American Academy of Child Psychiatry* 14 387–422.

Hughes P, Turton P, Hopper E, Evans CDH (2002). Assessment of guidelines for good practice in psychosocial care of mothers after stillbirth: a cohort study. *Lancet* 360(13) 114–118.

O'Leary J (2004). Grief and its impact on prenatal attachment in the subsequent pregnancy. *Archives of Women's Mental Health* 7(1) 7–18.

O'Leary J, Gaziano C, Thorwick C (2006). Born after loss: the invisible child in adulthood. *Journal of Pre and Perinatal Psychology and Health* 21(1) 3–23.

O'Leary J, Parker L, Thorwick C (1998). *After loss: parenting in the next pregnancy. A manual for professionals working with families in pregnancy following loss*. Minneapolis, MN: Allina Health Systems. Available from: jandj@pro-ns.net

O'Leary J, Thorwick C (1997). Impact of pregnancy loss on subsequent pregnancy. In: Woods jr, JR, Esposito Woods JL (eds). *Loss during pregnancy or in the newborn period*. Pitman, NJ: Janetti Publications, 431–435.

O'Leary J, Thorwick C (2006a). Fathers' perspectives during pregnancy, postperinatal loss. *Journal of Obstetric, Gynecologic, and Neonatal Nursing* 35(1) 78–86.

O'Leary JM, Thorwick C (2006b). *When pregnancy follows a loss: preparing for the birth of a new baby*. Self-published booklet for parents. Available from: jandj@pro-ns.net

Parker L, O'Leary J (1989). Impact of prior prenatal loss upon subsequent pregnancy: the function of the childbirth class. *International Journal of Childbirth Educator* 4(3) 7–9.

Pennebaker JW (1997). *Opening up: the healing power of expressing emotion*. New York: Guilford.

Rosenblatt P (2000). Parents talking in the present tense about their dead child. *Bereavement Care* 19(3) 34–37.

Rubin R (1975). Maternal tasks in pregnancy. *Maternal Child Nursing*, 4(3) 143–153.

Turton P, Hughes P, Evans CD *et al* (2001). Incidence, correlates and predictors of post-traumatic stress disorders in the pregnancy after stillbirth. *The British Journal of Psychiatry* 178 556–560.