Practitioner Perspective

Perinatal Grief – A Profound and Complex Process

By Cathy Quinn

Numerous studies demonstrate that grief following a baby's death is frequently minimised and may go unacknowledged by society. These findings challenge us not only to grasp the significant impact of the sociocultural dynamics woven into perinatal grief but also to create an empathetic therapeutic relationship, wherein bereaved parents are truly understood

"When you are understood, you are at home. Understanding nourishes belonging. When you really feel understood, you feel free to release your self into the trust and shelter of the other person's soul" (O'Donohue, 1997, p. 13-14)

Introduction

Perinatal grief embraces the grief experienced by parents following miscarriage, following a diagnosis during pregnancy of a baby with a life-limiting condition, when a baby is stillborn or when a baby is born alive but dies within the first week of life. The profound grief experienced by parents following miscarriage or the death of their baby is considered a complex emotional response (Fenstermacher & Hupcey, 2013). However, the majority of bereaved parents will experience a normal grief reaction with the support of family and friends (McSpedden, Mullan, Sharpe, Breen, & Lobb, 2017). Additional support may be sought from advocacy groups, while some parents may attend counselling.

This article provides an overview of the multiple facets of perinatal grief and the grieving process. It explores the key concepts of continuing bonds and the complexity of disenfranchised grief. It also reflects briefly on the significance of creating a safe empathetic space.

Perinatal death in perspective

In the past, the predominant culture of maternity hospitals and society in general tended to minimise or even ignore the existence of perinatal grief. Today compassionate approaches to care are slowly but positively transforming the landscape and culture of how we care for this vulnerable group of parents, for example the introduction of the National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death (Health Service Executive (HSE), 2016).

In 2016, a total of 227 babies were stillborn and 124 babies died within the first week of life in Ireland (Healthcare Pricing Office & HSE, 2018). Miscarriage occurs in approximately one-fifth of pregnancies equating to approximately 14,000 miscarriages per year in Ireland (Poulose, Richardson, Ewings & Fox, 2006). Concealed in these statistics are an enormous number of bereaved parents and their families who undeniably will require empathetic care and support.

Multiple facets of perinatal grief

To empathise fully with bereaved parents' experience of perinatal

grief, the counsellor needs to recognise the multiple facets of perinatal death that are woven into the tapestry of grief and undoubtedly impact the parents' grief response.

Perinatal grief is unique given that most mourning is retrospective whereas perinatal grief is prospective mourning i.e. parents have to relinquish hopes, wishes and dreams about a future together with their anticipated baby (Leon, 1990). They grieve for what might have been, a future with their baby suddenly vanishes when unfulfilled dreams and expectations are crushed.

A baby's death goes against the natural sequence of life events, is frequently unexpected and the cause of death may be unexplained. Furthermore, there are no formal funeral or burial rituals for babies usually associated with other deaths which may limit social acknowledgement and support.

Consistent feelings of guilt, shame and failure, combined with self-blame and low self-esteem, may dominate the parents' landscape of grief (Barr & Cacciatore, 2007; Wonch Hill, Cacciatore, Shreffler, & Pritchard, 2017). A study conducted by Meaney, Everard, Gallagher and O'Donoghue, (2017) revealed that bereaved parents experienced a sense of failure which battered their self-esteem and mothers in particular felt guilty and blamed themselves for their baby's death. These complex, intrusive feelings of shame, failure and guilt may impede the grieving process and damage a vulnerable self-esteem, thereby increasing the risk of complicated grief (Markin, 2017). Counsellors should be alert to pathological symptoms of grief that may arise as several studies have reported elevated levels of complicated grief, post-traumatic stress disorder, depression and anxiety symptoms following perinatal death (Blackmore et al. 2011; Cheung, Hoi-yan, & Hung-yu, 2013; Christiansen, Elklit, & Olff, 2013; McSpedden et al. 2017).

Informing parents of the individuality of grief is helpful; although they are both grieving as parents of the same baby, each parent may grieve differently and are rarely synchronised in their grief

Seeing live healthy babies of family and friends may be difficult for parents; particularly in the early stages of grief; they may struggle to cope with painful feelings or avoid situations, which can lead to isolation.

Parents may also be fearful and doubt their ability to have a live healthy baby in the future. Well-meaning family and friends and society in general may sometimes assume that a subsequent pregnancy will instantly heal the parents' grief, resulting in diminished opportunities for parents to share their true feelings (Markin, 2016; Meaney et al. 2017)

In the midst of the parents' grief, the focus of support may be directed solely towards the mother's needs which may lead to the father's grief going unacknowledged by society. Fathers may feel they have to be stoic and society may dictate this. In a study by Meaney et al. (2017) fathers reported that they had to be strong emotionally, at times putting their own grief on hold in order to support their partner. Validation and acknowledgement of the father's grief experiences and his fatherhood is essential (Cacciatore, DeFrain, Jones, & Jones, 2008).

Another challenge that bereaved parents have to negotiate is the impact of their baby's death on their relationship; they may struggle to find the emotional resilience to help each other while they are individually coping with their own grief. Studies have shown that parents who share and communicate their grief report less severe grief reactions and greater partner satisfaction (Cacciatore et al. 2008; Buchi et al. 2009; Avelin, Radestad, S¨aflund, Wredling, & Erlandsson, 2013). In contrast, other studies have identified perinatal death as a risk factor for relationship break-down (Gold, Sen, & Hayward, 2010; Shreffler, Hill, & Cacciatore, 2012). Informing parents of the individuality of grief is helpful; although they are both grieving as parents of the same baby, each parent may grieve differently and are rarely synchronised in their grief. Encouraging parents to share their feelings may help them to understand each other's unique reactions and ultimately avert or lessen tensions that may develop in their relationship. Open, honest, communication with their surviving children is also encouraged.

Grieving the death of a baby of a multiple birth is a complex process for families (Richards, Graham, Embleton, Campbell, & Rankin, 2015). Parents often experience a rollercoaster of conflicting emotions: grief for the baby who has died, as well as hopes and fears for their vulnerable baby/babies who survive. Parents may keep their emotions on hold while caring for the surviving baby and a strong grief reaction may emerge weeks, months or even years later (Richards et al. 2015)

Early and late miscarriage may be experienced as a highly traumatic loss for many women, yet it may be minimised and go unacknowledged by society (Gerber-Epstein, Leichtentritt, & Benyamini, 2009; Murphy & Merrell, 2009; Sejourne,

Callahan, & Chabrol, 2010). Lack of tangible mementos, especially in early pregnancy loss, limited empathy and support from family and friends with few opportunities to engage in culturally recognised mourning rituals, which may lead to social isolation and disenfranchised grief (Kersting, & Wagner, 2012; Bellhouse, Temple-Smith, & Bilardi, 2018).

Parents who decide to terminate their pregnancy when their baby is diagnosed with a life-limiting condition may experience higher levels of self-blame, guilt, and social isolation (Maguire, 2015). They may seek counselling, feeling unsupported or stigmatised and will require an empathetic, non-judgemental, safe space to process their feelings (Markin, 2017).

The grieving process

Stroebe and Schut (1999) developed the Dual Process Model (DPM) of coping which is an extension of the earlier linear models of grief. This model is extremely helpful when working with parents as it considers the uniqueness of each parent's complex and highly individualised experience of grief. The model also recognises the effect of cultural and religious beliefs on the grieving process.

The DPM of coping with significant loss is based on the principle that when people are grieving effectively, there is a natural oscillation between two types of coping. Loss-orientation coping relates to engaging with grief work, whereas restoration-orientation coping relates to adjusting to the changes that occur as a consequence of the death. In loss-oriented coping, parents are confronting the painful reality of their baby's death e.g. painful expression of a range of emotions and talking about their baby. In restoration-oriented coping parents are coping with the changes that occur as a consequence of the baby's death. They are faced with the challenges of readjusting to their changed world without their baby; learning to live with the death in the face of bereavement and rebuilding their lives by creating a new normal. Oscillation between the two types of coping is necessary to grieve effectively; parents need to be able to engage with their grief and also detach from their grief (Stroebe & Schut, 2010). Healthy grieving involves being able to do both and to move from one to the other. Difficulties occur in the grieving process when there is a persistent lack of oscillation between experiencing and detaching from grief. Under such circumstances the parents are either totally overwhelmed by the experience or they systematically repress it. In both situations there is a persistent sense of 'stuckness', a distinct feature of complicated grief.

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Continuing bonds

"We let go the loved one, not the love" (Fallon, 2014)

It is essential that counsellors recognise that for many parents, continuing bonds with their deceased baby, in a manner that maintains a healthy adjustment to grief, is deeply woven into their grieving process. Creating mementos and storing memories become a significant part of the parents' life moving forward without their baby. Historically, continuing bonds with the deceased person was considered a maladaptive grief reaction and an obstacle to successful grief resolution (Klass, Silverman, & Nickman, 1996). The general consensus among grief theorists echoed a belief that in order to resolve their grief, it was necessary for the bereaved to sever bonds by detaching themselves emotionally from the deceased person.

It was Klass (1988) who first reported that bereaved parents maintained a bond with their deceased baby. However, he did caution that it may not be representative of all bereaved parents (Klass, 2006). He supported the theory that a baby's death ended a life but the profound connection lived on. The deceased baby is both present and absent; there is a physical letting go of the deceased baby but at the same time keeping hold of the connection or the bond. The true essence of continuing bonds is captured by baby Laura's mother, "In this unsettled 'after' life with its melee of feelings and words, Laura is a part of our journey onwards. She is in the way we love each other now. She is in how we live. We do not live without Laura. We live with her ever-present absence. And that is not to say our lives are lived with the constant question: What if? What if? What if? It is to say she is present in how we notice each other, how we hear each other. Laura is there in our sadness, but in our happiness too" (O'Connor Foott, 2015, p. 11).

Many bereaved parents integrate the memory of their baby by continuing bonds in various ways:

- Talking about their deceased baby and sharing memories with family, friends, healthcare professionals, within support groups or with their counsellor, enables them to continue their bond with their deceased baby in a way that is meaningful to them

- Sharing linking objects e.g. mementos, photographs. A bereaved father describes the significance of his daughter Matilda's amulets "the things she touched, that were a part of her, are sacred. We hoard them, treat them with the reverence of archivists, and like curators worry uncontrollably that they will be lost, broken, or consumed by a fire" (Weaver-Hightower, 2011, p. 475)

- Choosing a central location in the home to display photos of their baby with other family photos

- Preserving memories e.g. writing their baby's story, a book, personal blog, poems, songs, art and craft work, planting a tree/ flowers, fundraising and donating to support groups or maternity hospitals

- Continuing rituals e.g. visiting the baby's grave or special place. Creating rituals that evoke memories at significant times/ anniversaries e.g. on baby's due date, baby's birthday, date of death or at Christmas time

- Attending the hospital or local remembrance services

- Creating memorials to honour their baby e.g. park bench or memorial garden

- Integrating the people who companioned them on their grief journey into their lives and into their narrative going forward

By continuing bonds the deceased baby is acknowledged, honoured and rightfully occupies a unique place in the family and in society (Côté-Arsenault & Denney-Koelsch, 2016). Bereaved parents delicately weave their deceased baby's memory into the fabric of their altered daily lives, their families lives, extended family, circle of friends and their community, thereby strengthening their support system which may ultimately reduce their risk of social isolation and/or disenfranchised grief.

For many women, advanced scanning technology influences the mother's attachment to her baby in the womb, long before the baby is born

(Atluru, Appleton, Kupesic, Plavsic, Kurjak, & Chervenak, 2012)

Disenfranchised grief

To work empathetically and effectively with bereaved parents and families, counsellors need to be aware of and understand the dynamics of disenfranchised grief. Social support has consistently been shown to provide a buffering effect on the impact of perinatal death, yet this impact can often be minimised, especially following miscarriage, and go unacknowledged by society and sometimes by family and friends (Gerber-Epstein et al. 2009; Bellhouse et al. 2018). As a consequence, bereaved parents are denied the opportunity to publicly mourn their baby and may not have the usual support that is available following the death of an adult which in turn may lead to social isolation and disenfranchised grief. Doka (1989) defines disenfranchised grief as a loss that is not openly acknowledged or visibly supported by society. Grief following perinatal death is particularly susceptible to being disenfranchised, making this an additional burden for parents who are denied a socially recognised right to grieve and this may intensify or impede their healing process (Lang, Fleiszer, Duhamel, Sword, Gilbert, & Corsini-Munt, 2011; Mulvihill & Walsh, 2013). A study by Mulvihill and Walsh (2013) recounted parents' experiences of disenfranchised grief which included insensitive language used by professionals, insensitive comments, avoidance and perceived lack of partner and social support.

Doka (1989) referred to society's grieving rules that attempt to dictate how people should grieve. Society may decide what level of grief should be attributed to a specific death/ loss e.g. the grief of early miscarriage may be viewed as a lesser grief, consequently minimising the loss and negating the grief reaction. For many women, advanced scanning technology influences the mother's attachment to her baby in the womb, long before the baby is born (Atluru, Appleton, Kupesic, Plavsic, Kurjak, & Chervenak, 2012). However, society may not always recognise the significance of this relationship, especially if she miscarries or if her baby is stillborn, resulting in insensitive comments implying she never knew her baby. According to Lang et al. (2011) parents reported that overall, extended family and society failed to understand and acknowledge the significance of their baby's death and its parity with other deaths. Consequently, in the absence of family and social support, parents may seek out support from advocacy groups e.g. A Little Lifetime Foundation, Féileacáin or the Miscarriage Association. Other parents may attend counselling, where the presence of an empathic therapeutic relationship will enable them to explore the impact of disenfranchised grief and re-establish their right to grieve.

Creating a safe empathetic space

Entering the bereaved parents' world challenges counsellors' attitudes and beliefs in relation to perinatal death. Markin, and Zilcha-Mano (2018) suggest that as counsellors "we too are products of our culture and absorb the cultural denial around perinatal grief" (p.24).

Consequently, self-awareness is vital in exploring how counsellors' personal/family stories, culture, beliefs and experiences may impact on the care provided for bereaved parents.

Cacciatore (2017) explored what parents found helpful/unhelpful in relation to counselling they received following their baby's death. Counsellors were deemed most helpful by participants when they were empathetic, non-judgmental, listened attentively, acknowledged parents' feelings and created a space for parents to tell their story and process their emotions. Unhelpful counsellors were reported as lacking empathy, being judgemental, minimising parents' feelings with insensitive comments and attempting to find/force meaning in the baby's death. Cacciatore (2017) proposed that counsellors should integrate mindfulness-based approaches into their practice e.g. compassion, non-judgement and acceptance, to facilitate the creation of a safe empathetic space. Counsellors need to recognise that each circumstance of perinatal death is unique and the intensity and/or duration of the parents' grief reaction is not founded on the number of weeks of pregnancy or how long the baby lived. Irrespective of when or how the baby died, our challenge is to listen with our heart as opposed to analysing with our head, to avoid assumptions and to connect with parents at where they are on their grief journey, not where we want them to be.

A genuine therapeutic relationship and empathetic presence are core healing qualities which have the ability to temper parents' grief and soothe their brokenness. Empathetic engagement respects the parents and their deceased baby, their feelings, their stories and experiences and their unique reaction to their baby's death which ultimately facilitates healing and the process of mourning.

As some parents experience disenfranchised grief, a safe, trusting and empathic space is crucial in giving them a voice to express their hidden grief. It enables the parents to mourn their baby; to tell their story and to express and experience their emotional pain. In this safe space, the counsellor is present in the here and now and comfortable bearing witness to the parents' pain and suffering, is willing to sit with it, by listening intently to understand their story, by acknowledging, validating and normalising their feelings. Wolfelt (2005) reminds us that being fully present to another person's pain is about being still; being comfortable with chaos and profound heartache and avoiding the temptation to impose order and logic.

According to Markin (2017) "emotional experiencing and expression of feelings related to grief and loss are key to successful treatment" (p. 370). Within a safe therapeutic alliance, intense feelings of guilt, anger, shame or failure may emerge during therapy. Self-blame and a crushed self-esteem may also be evident, all of which can impede the grieving process.

Counsellors need to be acutely aware of these feelings and have the competence to recognise and hold the intensity of the parents' emotional experience, without judgement. Counsellors should also be mindful that unresolved losses, which may or may not be pregnancy related, may also be reawakened by the baby's death and will also need to be mourned.

Parents may find that keeping a journal of their feelings or setting up a blog may also help to temper their grief. Other parents may find it difficult to articulate their profound grief and they may grieve and remember their baby by creative expression e.g. through music, song, artwork or poetry.

Conclusion

Bearing witness to bereaved families pain and journeying with them following their baby's death is both challenging and rewarding. An awareness of our assumptions, attitudes and beliefs in relation to perinatal death is crucial for effective empathetic therapy. Counsellors need to be cognisant of the multiple facets of perinatal death and recognise that each parent's approach to grief is unique to them. An empathetic non-judgemental approach to providing support will facilitate the creation of a safe space where parents are afforded the time to express, experience and process their grief; where they are truly heard and their feelings acknowledged and validated. By working in partnership with parents, we enable them to grieve and empower them to rebuild a meaningful life without their baby.

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Cathy Quinn is a registered nurse, midwife and an accredited counsellor with an MSc (Hons) in Counselling. She has over 20 years' experience in working with bereaved parents and their families. Cathy developed an innovative Midwifery-led counselling service in 1991 for bereaved parents - the first to be established in an Irish maternity hospital. She is a contributing lecturer in delivering the MSc Perinatal Mental Health Programme at the University of Limerick; leading the Perinatal Bereavement and Loss Module and lectures at the Graduate Entry Medical School. She also facilitates perinatal bereavement care workshops for healthcare professionals.

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