Complicated grief after perinatal loss

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The loss of an infant through stillbirth, miscarriage, or neonatal death is recognized as a traumatic life event. Predictors of development of complicated grief after prenatal loss include lack of social support, pre-existing relationship difficulties, or absence of surviving children, as well as ambivalent attitudes or heightened perception of the reality of the pregnancy. Risk of complicated grief was found to be especially high after termination of a pregnancy due to fetal abnormality. Studies have revealed that men and women show different patterns of grief, potentially exacerbating decline in a relationship. Although it is clear that prenatal loss has a large psychological impact, it is concluded that there is a substantial lack of randomized controlled studies in this field of research.

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Introduction

The loss of a child is recognized as a very difficult life experience, which can often cause complicated grief (CG) reactions that risk negatively affecting psychological and physical well-being.[1,2] In a population-based sample, bereaved individuals who had lost a child showed the highest prevalence of CG.[3] Perinatal loss is a relatively common occurrence which, in this article, refers to the death of an infant due to miscarriage, stillbirth, and neonatal death. In 2007 in the United States the infant mortality rate was 6.9 deaths per 1000 live births.[4] Miscarriage, generally defined as an unintended termination of the pregnancy prior to 20 weeks of gestation, is the most common type of pregnancy loss. The overall prevalence is 15% to 27% for women aged between 25 and 29, increasing to 75% in women older than 45 years,[5] with elevated risk for women who have lost a previous pregnancy.[6] The death of a fetus after 20 weeks' gestation with a birth weight of over 500 g is referred to as a stillbirth. In these cases, the fetus has either died before or during labour, often unexpectedly or after an uncomplicated pregnancy. A relatively new issue that has emerged in the field of perinatal loss is that continuing development of prenatal diagnostics has increased diagnosis of fetal abnormalities, with relatively high corresponding termination rates. A European survey found average termination rates of 88% for Down's syndrome as well as in cases of neural tube defects.[7] Although parents have not built up a relationship with their infant, grief after pregnancy loss does not differ significantly in intensity from other loss scenarios. As has

been found in bereavement involving first-degree relatives, grief symptoms usually decrease in intensity over the first 12 months.[8,9] Longitudinal studies have demonstrated that in a normal grieving process, grief declines over a period of 2 years after the pregnancy loss.[8,10] Perinatal losses have also been shown to have a substantial psychological impact on parents and families, and are associated with post-traumatic stress, depression, anxiety, and sleeping disorders.[11,12] Overall, high levels of CG are generally associated with a poorer state of mental health.[13]

This article reviews literature on CG reactions to perinatal loss. Typical grief reactions and unique aspects of bereavement after perinatal loss are described, before a summary of the risk factors which influence grief outcome. The specific issue of termination of pregnancy due to abnormality is outlined and gender differences between fathers and mothers after prenatal loss are then addressed. Finally, clinical implications for parents after pregnancy loss are discussed.

Grief reactions after pregnancy loss

Grief is a deeply personal process which nevertheless follows a fairly predictable course. Reactions to the loss of a significant person often include temporary impairment of day-to-day function, retreat from social activities, intrusive thoughts, and feelings of yearning and numbness which can continue for varying periods of time. Although grief is a natural, nonpathological phenomenon, it can lead to CG, where symptoms are more disruptive, pervasive, or long-lasting than in a normal grief response. This is especially likely if the death has occurred in a sudden, violent, or traumatic way. CG (alternatively "prolonged grief disorder"), a descriptive diagnosis developed from two previously proposed diagnostic criteria,[14,15] is still not in the *DSM-IV* or *ICD-10*. It is, however, proposed that CG may be given official recognition in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders*.[16]

Adjustment after bereavement has been empirically shown to occur through a sequence of stages in a longitudinal study of bereaved individuals.[17] This study revealed that in normal grieving, negative grief indicators such as disbelief, yearning, anger, and depression peak within approximately 6 months of loss. Lin and Lasker found a similar grief process in a study that looked specifically at bereaved parents after pregnancy loss.[18] In this study, grief scores were initially relatively high and declined most steeply over the first year. In a 2-year follow-up their evaluation of the grief process showed an interesting result: whilst 41% of participants showed a normal decline of grief scores, the remaining 59% showed different patterns of pervasive presence or delayed resolution of grief.

CG reactions after perinatal loss can be generally specified within the existing diagnostic criteria, but they differ from grief after other significant losses in a number of key aspects. A consistent feeling of guilt is commonly experienced after pregnancy loss and is associated with CG reactions.[8,19,20] Self-blame may prolong the normal grieving process, especially if there was a feeling of ambivalence towards the pregnancy[21] or if the subject perceives having done something wrong (eg, smoking or jogging during pregnancy). Another unique aspect of pregnancy loss is that women feel that their bodies have failed, and that their femininity has been undermined.[20] Women who have already suffered a miscarriage show higher levels of psychological distress than women who have not experienced perinatal loss.[22] Sometimes "child envy"—the feeling of being envious of other people's children—can be an issue for those who have been through perinatal loss. These women often struggle to make contact with friends or family members who have children or who are at the same stage of pregnancy as that at which the loss was suffered. Difficulty coping with these feelings and continuous avoidance often leads to isolation of these mothers.

As pregnancy losses are typically sudden and unexpected, parents usually have no time to anticipate grief or prepare themselves for the change in situation. Unlike the death of other close family members, parents bereaved by a perinatal loss have few or no direct life experiences with the infant. The introduction of imaging techniques such as ultrasound and 3D presentations mean that the fetus is now more likely perceived as a baby than as a fetus,[23,24] but studies evaluating the psychological effect of having viewed ultrasounds have reported discordant results. Whilst some studies report higher levels of grief in those who have seen the ultrasound image of the unborn child, especially in men,[25] others found no relationship.[26]

An additional aggravating factor is that if the loss takes place at an early stage of pregnancy there will usually be no funeral or other rituals of mourning, and the loss may remain unacknowledged by the family and friends.

Generally, the possibility of saying goodbye after the loss of a significant person is assumed to have a positive impact on the bereaved person.[27,28] These issues may complicate the grieving process and increase a sense of isolation for the parents. De Wijngaards and colleagues found in a study of bereaved parents that presenting the body for viewing at home and the feeling of having said goodbye to the child were associated with lower levels of grief.[29] Previously it was common practice to remove a baby quickly after stillbirth, but this policy has been updated in recent years, with the general assumption that seeing and even holding the infant helps the mourning process. Often parents are nowadays encouraged to hold and see their stillborn infant's dead body. There is, however, controversy over this practice and the concept has recently been challenged by recent studies. It has been found that women who hold their deceased infant have significantly higher rates of post-traumatic stress disorder (PTSD), anxiety, and depression even 7 years after the event.[30,31] It has been reported in these publications that women who hold their dead infant have significantly higher rates of depression than those who only looked at them, and the least impact on depression was found in the mothers who did not have any contact with the fetus.[31]

Risk factors of grief reactions

A number of variables predict CG reactions following a perinatal loss; for example it is widely documented that social support plays a large role in adjustment after bereavement. Based on stress theory, social support is thought to have a buffering effect, and poor social support from family and friends is associated with CG reactions.[8,10,13,32] High levels of perceived emotional support from society is consistently associated with lower scores of perinatal grief in all studies examining it.[13] Furthermore, religious communities have been found to be beneficial as another source of social support, as greater religious participation has been related to increased perception of social support contributing to less grief-related distress for parents.[33] Following this argument, lack of support from a partner and poor marital relations have both been described as other strong components associated with more intense grief.[10,32] Projections of guilt and blame as well as angry feelings towards a partner and loss of the vision of a future as a family may put considerable stress on the relationship.

Another important predictor of grief intensity is the presence of living children. Childless women who suffer a miscarriage have significantly higher levels of grief than women who already have children,[34,35] and a number of studies revealed that grief intensity decreases substantially after a subsequent successful pregnancy.[18,36] In the longitudinal study completed by Lin and Lasker, however, grief symptoms in the group of "normal grievers" had still not completely disappeared during the 2-year study period,[18] suggesting that even though pre-existing children or subsequent pregnancies might help to assuage grief, continuing low levels of grief will still be found in most subjects.

Personality has been found to be another significant predictor, with women shown to have a relatively high degree of neurotic personality characteristics before loss being more likely to develop intense grief reactions after the infant's death.[8] These findings are consistent with the study by Toedter and colleagues who evaluated pre-loss mental health[13] and found that pre-event status predicted the likelihood of a persistent intense grief reaction at 2 years of follow-up. Another study, this time examining the reactions to miscarriage of women with a history of major depression, found that 54% of subjects experienced a relapse in their psychiatric symptoms.[34]

As mentioned above, ambivalent attitudes toward the pregnancy were found to be associated with more intense grief reactions, and loss of an unplanned pregnancy was often reacted to in the same way.[37,38] It is thought that these findings might be explained by guilt or blame which these women felt after pregnancy loss. Mothers who had more invested in their pregnancy, for example those who had thought of a name or bought things for the baby, also showed a higher level of grief-related yearning for the loss of the infant,[39] and this was matched by greater grief in women who had experienced the fetus moving inside of them. It is thought, therefore, that the more the mother has experienced or comprehended the reality of the baby the higher the level of grief.[23] Contrary to these findings, however, are a number of studies have evaluated the association between length of gestation and level of distress after perinatal loss, and could not find an increase in psychological distress with higher gestational age.[23,34] Therefore, mothers who have lost their infant at an early stage of pregnancy may be seen to develop similar grief symptoms to mothers in a later stage of pregnancy.

A number of further predictors have been generally associated with psychological morbidity after prenatal

loss, but no specific relationships could be found between grief and maternal age, marital status, or occupational status.[22,37,38]

Pregnancy termination

In contrast to other perinatal losses, the termination of a pregnancy is not an unexpected event. Once a diagnosis of fetal abnormality has been made, parents are confronted with the decision as to whether to continue or to terminate the pregnancy. Factors which contribute to a decision to end the pregnancy are the child's prognosis and future well-being, as well as consideration of the consequences for the family and marriage.[6] There is often little time between diagnosis and termination, which is then completed by either dilation and evacuation or induction of labour. No significant difference in grief intensity at 12 months' follow-up has been found between methods.[40] As with a stillbirth, women who have undergone induced labour must decide if they wish to view or hold the infant. Viewing the fetus, which may have visible evidence of deformity, may be a very traumatic experience, but on the other hand it may provide the couple with the welcome confirmation that they have made the right decision in terminating the pregnancy.[6] After termination, a number of important issues need to be considered before communicating the event to family and friends. As some people may experience condemnation by sections of society that do not approve of the decision to terminate, a number of families decide to pretend that the loss was due to miscarriage.[6]

A number of recent studies have revealed that the loss of an unborn child after discovery during pregnancy of fetal malformation or severe chromosomal disorders can be considered as a traumatic life event with high psychological impact. This is especially relevant if the termination of pregnancy takes place in the 2nd or 3rd trimester of pregnancy.[41-43] PTSD and CG reactions have been documented in parents years after a termination on the grounds of abnormality. In their longitudinal study, Kersting and colleagues found that 14 months post-loss, 14% of women fulfilled full criteria of CG and 17% had been diagnosed with a psychiatric disorder.[42] These findings were confirmed by Korenromp and colleagues, who documented that 20% of the women suffer up to 1 year of CG and psychological consequences after such a procedure.[44] Several predictors of negative long-term outcome after pregnancy termination, including high level of distress immediately after the procedure, low self-efficacy, lack of support from the partner, and high levels of doubt whilst making the decision.[42,44] In spite of changes in mental state following termination, however, only 2.7% of the participants regretted their decision. Interestingly, firmer religious faith, as assessed 14 days after the loss, predicted lower levels of CG 14 months later.[42]

Gender differences

Loss of an infant during pregnancy can clearly deeply distress a woman and put strain on her relationship with the father, but it may also have a distinct psychological impact on the grieving father. Although it may seem predictable that fathers are also affected by the loss, there has only been a limited amount of research in this field. A number of quantitative studies compared the grief responses of fathers and mothers after perinatal loss and found lower levels of grief intensity in the fathers.[45-50] Beutel and colleagues found that men tend to grieve less intensively and for shorter periods than their partners. Symptoms of grieving in men were found to be similar to those of women, except that men report less crying and feel less need to talk about their loss. Similar findings were reported by Stinsons and colleagues, who reported that women already had significantly more intense grief responses at 2 months, and that this trend was still relevant after 2 years of follow-up.[45] The men in this study were also found to internalize and deny their grief, or attempt to distract themselves rather than speaking about their loss.[47] Johnsson and Puddifoot[51] had slightly different findings: they evaluated an all-male cohort and showed that grief responses were at a similar level to those of women after miscarriage. In general, these findings support the idea that fathers also experience grief after perinatal loss, but it is assumed that reactions are generally less intense. Coping mechanisms differ from those of women, it is thought that these differences in grieving may often contribute to misunderstanding and conflicts in the relationship. It would certainly seem that one of the greatest challenges in these situations would be to provide support for a partner whilst trying to cope with grief. In summary, it has been shown that the greatest risk to a relationship is presented by unequal or noncongruent grieving processes between partners.[52,53]

Clinical implications after perinatal loss

Although it is widely recognized that perinatal loss can lead to psychiatric disorders and CG, only a small number of the women who have experienced miscarriage receive routine follow-up psychological support.[54] As interventions typically aim to alleviate depressive symptoms, there seems to be little on offer for the prevention of development of CG.[55] If intervention is offered, it generally begins early, often immediately after the loss when the patient is still under hospital observation. Normally, psychological aftercare will involve programs of counseling, whilst manualized interventions are rare and are seldom based on evaluated intervention programs. The current literature highlights a number of methodical challenges to this system. Reviews and meta-analyses of general bereavement interventions have shown that although effectiveness of bereavement interventions is often assumed, empirical evidence yields inconclusive results. It has even been claimed by some reviewers that there is no strong evidence that these interventions are at all effective.[56,57] Although bereavement interventions appear to be effective if aimed high-risk groups or at those whose grieving process has already complicated,[57-59] interventions aimed solely at preventing grief seem to have inconsistent support.[60]

Only a few randomized controlled studies have been carried out for women after prenatal loss, and most of these have been limited by being aimed at outcomes of depression and psychiatric disorder rather than grief itself.[61-63] One exception to this was an intervention to prevent grief after perinatal loss specifically aimed at women following a stillbirth. This program began before hospital discharge and continued over a period of 4 to 6 months. However, no statistical differences were found in overall grief scores between the treatment and control groups (who received routine hospital care).[64] Lilford and colleagues also compared prenatal bereavement counseling with treatment as usual in a randomized controlled trial but again found no differences between counseling and control groups with respect to grief, anxiety, or depression.[65] Swanson and colleagues evaluated a couple-focused intervention in a randomized controlled trial and found a beneficial impact on grief resolution.[66] In a meta-analysis of 14 studies of intervention in CG, Wittouck and colleagues[60] found that only four studies reported positive results in terms of decreased CG measures. Interestingly, all four of the successful trials were based on cognitive-behavioral techniques.

A further recent study examining the efficacy of an Internet-based cognitive behavioral therapy for mothers after pregnancy loss[67] showed positive treatment effects, with the intervention group showing significantly reduced symptoms of grief, PTSD, and depression after treatment relative to the waiting-list group, and this symptom reduction was maintained at 3-month follow-up.[68,69] The treatment program involved self-confrontation with the most painful memories relating to the loss, social sharing as well as cognitive restructuring with regard to feelings of guilt and blame.[70]

Overall, methodological flaws, the lack of randomized control groups, and the absence of proven efficacy of grief interventions after prenatal loss make it difficult to suggest guidelines outlining which form of intervention may be most beneficial. It may be concluded, however, from meta-analysis of general bereavement interventions that the best treatment outcomes seem to be reached by interventions aimed at a high-risk group or those that include some element of cognitive-behavioral therapy.

Conclusion

The results of this review emphasize that perinatal loss of an infant has the potential to have a large impact on mothers, fathers, and the relationship of a couple. Although not all participants in the presented studies suffer long-term CG, there are still a significant number of women found to be grieving years after loss. This is especially likely if they fulfil criteria for any of the risk factors described above. Pathological grief was found to be particularly high in women after termination of an abnormal pregnancy. The presented studies have also documented the differences in coping styles of women and men, and have highlighted how these can lead to a decline in the quality of a relationship. It is therefore suggested that future intervention approaches should involve male partners, including them in psychotherapy and ensuring an ongoing dialogue between the grieving parents.

While there is a large body of literature on the subject of risk factors and patterns of grieving, very little research exists documenting the efficacy of different interventions. What is clear, however, is that the current

findings indicate the importance of psychotherapeutic monitoring and support. Randomized controlled trials have shown a mixture of results, but this is in line with the findings of meta-analysis of general bereavement intervention. Further research is deemed necessary, and it is recommended that future studies focus on randomized controlled trials, especially in the areas of general prevention of CG development, tackling of high-risk subgroups and possible courses of action to help parents already suffering from CG. ❑

Duelo complicado después de una pérdida perinatal

La pérdida de un bebé por muerte fetal, aborto o muerte neonatal se reconoce como un acontecimiento vital traumático. Entre los predictores del desarrollo de un duelo complicado después de la pérdida prenatal están la falta de soporte social, las dificultades en las relaciones pre-existentes o la ausencia de niños vivos, como también las actitudes ambivalentes o la percepción exagerada de la realidad del embarazo. Se ha encontrado que el riesgo de un duelo complicado es especialmente elevado después del término de un embarazo debido a una anormalidad fetal. Los estudios han mostrado que hombres y mujeres muestran patrones distintos de duelo, los que potencialmente aumentan el deterioro de la relación de pareja. Aunque es claro que la pérdida prenatal tiene un gran impacto psicológico, se concluye que existe una ausencia importante de estudios controlados randomizados en este campo de investigación.

Deuil compliqué après un décès périnatal

La perte d'un enfant mort-né ou par avortement spontané ou mort néonatale est un événement de vie traumatisant. Les facteurs prédictifs d'un deuil compliqué après une telle perte sont l'absence de support social, des antécédents de difficultés relationnelles, l'absence d'enfant vivant ainsi que des attitudes ambivalentes ou une perception aiguë de la réalité de la grossesse. Le risque de deuil compliqué est particulièrement élevé après l'interruption d'une grossesse pour anomalie du fœtus. Des études ont montré différents schémas de réaction psychologique de deuil pour les hommes et les femmes, ce qui peut aggraver une dégradation de leur relation. L'impact psychologique d'une perte prénatale est important, pourtant des études randomisées contrôlées manquent considérablement dans ce domaine de recherche.

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