

The Presence and Predictors of Complicated Grief Symptoms in Perinatally-bereaved
Mothers from a Bereavement Support Organization

Margaret McSpedden MCouns, MSc¹, Barbara Mullan PhD^{1,2}, Louise Sharpe M ClinPsych,
PhD¹, Lauren J. Breen BSc(Hons) PhD², Elizabeth A. Lobb MAppSci, PhD^{3,4,5}

¹School of Psychology, University of Sydney, Sydney, New South Wales, Australia

²Health Psychology and Behaviour Change Research Group, School of Psychology and
Speech Pathology, Curtin University, Perth, Western Australia, Australia

³Calvary Health Care Kogarah, Australia

⁴Cunningham Centre for Palliative Care, Darlinghurst, Australia

⁵University of Notre Dame Australia, Sydney, Australia

Corresponding Author

Correspondence concerning this article should be addressed to Barbara Mullan, School of
Psychology and Speech Pathology, Curtin University, Western Australia, Australia; e-mail:
barbara.mullan@curtin.edu.au; ph: +61 8 9266 2468.

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Disclosures

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Abstract

The present study investigated the presence and possible predictors of complicated grief symptoms in perinatally-bereaved mothers (N = 121) up to five years post-bereavement. The presence of complicated grief scores in the clinical range was 12.4%, which is higher than in many other bereaved populations, and the presence of other living children may protect against the development of complicated grief symptoms. The majority of the women were able to negotiate a perinatal loss without developing complicated grief; however, there remains an important group of women who up to five years later score in the clinical range for complicated grief symptoms.

Key words

Bereavement; Complicated Grief; Perinatal Deaths; Mothers; Children

A small proportion of bereaved individuals experience severe and prolonged grief that has an ongoing, negative effect on their lives. Two main diagnostic criteria for disordered grief have been proposed—Prolonged Grief Disorder (Prigerson et al., 2009) and Complicated Grief (Shear et al., 2011). Both describe intense distress; a range of cognitive, emotional and behavioral symptoms; and functional impairment, all persisting for at least six months. The American Psychiatric Association (2013) drew from both in proposing Persistent Complex Bereavement Disorder, with the criterion that the symptoms must persist for more than one year. Population-based studies reveal the presence of the clinical threshold of complicated grief to be 6.7% in a German sample bereaved on average 8.8 years (Kersting, Braehler, Glaesmer, & Wagner, 2011), 2.4% in a Japanese sample bereaved on average 4.65 years (Fujisawa, Miyashita, Nakajima, Ito, Kato, & Kim, 2010), and 6.4% in a sample of Australians bereaved 6 to 24 months (Aoun, Breen, Howting, Rumbold, McNamara, & Hegney, 2015).

Much of what is known about bereavement experiences is drawn from samples of older women widowed following the deaths their husbands from illnesses and disease; considerably less is known about grief from sudden and untimely deaths, including the deaths of children (Breen & O'Connor, 2007). In Australia, over 2500 babies die within the perinatal period each year (Li, Zeki, & Hilder, 2012), which includes the death of a baby during pregnancy or within a year after birth (Austin et al., 2011). Perinatal bereavement differs from other bereavements in that the death occurs at the beginning of life, is usually sudden, and often unexplained. Unlike most bereavement events, perinatal deaths provide limited experiences and memories of the deceased child upon which parents may reflect and, in the case of miscarriage, there may not be an opportunity to engage in culturally-recognised mourning rituals, including a funeral (Kersting & Wagner, 2012). These factors may increase

the likelihood of complicated grief for bereaved parents (Lannen, Wolfe, Prigerson, Onelov, & Kreicbergs, 2008).

Several studies have investigated the presence and predictors of psychopathology in perinatally-bereaved individuals (primarily mothers), with most indicating elevated levels of depression, anxiety, and post-traumatic stress (Blackmore et al., 2011; Cheung, Hoi-yan, & Hyng-yu, 2013; Christiansen, Elklit, & Olf, 2013). While the association between perinatal bereavement and psychopathology is well-established, the association between perinatal bereavement and complicated grief remains obscured. For instance, Bennett et al. (2008) used the Perinatal Grief Scale ([PGS], Potvin, Lasker, & Toedtler, 1989) and reported that 30% of their sample exceeded the clinical cut-off score of 91 or more. However, while this measure distinguishes between grief and depression, and has subscales for active grief, difficulty coping, and despair, it does not indicate the presence of complicated grief (Ritsher & Neugebauer, 2002).

Several factors are thought to predict psychopathology in perinatally-bereaved parents; however, the evidence for many of these factors is equivocal. One study demonstrated that women who had a previous miscarriage exhibited depression at a rate four times higher than the general population (Friedman & Gath, 1989) whereas another (Bennett, Litz, Maguen, & Ehrenreich, 2008) reported no relationship between previous loss and psychological distress measures. Another study showed that women without children who experience miscarriage were significantly more likely to develop major depressive disorder than women who miscarried and had living children (Neugebauer et al., 1997). While losses further along in pregnancy, or of a neonate, may be more distressing than earlier losses (Lasker & Toedter, 1991; Gaudet, Séjourné, Camborieux, Rogers, & Chabrol, 2010), other studies did not find an association between psychological distress and gestational age

(Bennett et al., 2008; Klier, Geller, & Ritsher, 2002; Neugebauer et al., 1997; Swanson, Connor, Jolley, Pettinato, & Wang, 2007).

While the presence of other children in the family is positively correlated with lower levels of depression, anxiety, and grief symptoms in some studies (Bennett et al., 2008), other studies showed a negative (La-Roche et al., 1984) or no impact (Swanson et al., 2007). Studies examining the effect of a subsequent pregnancy on maternal psychopathology also show mixed results. While some studies indicated an increase in anxiety during the subsequent pregnancies (Conway & Russell, 2000), others demonstrated a decrease in depression and grief (Turton, Hughes, Evans, & Fainman, 2001), and the persisting high levels of anxiety and depressive symptoms following subsequent live births (Blackmore et al., 2011).

The Current Study

While depression, anxiety, and post-traumatic stress symptoms appear elevated in women who have experienced a perinatal bereavement, there remains a lack of studies focusing on the presence and predictors of complicated grief for perinatally-bereaved mothers. Determining the effect of potential moderators, such as the presence of living children, is required in order to understand variables that might be predictive of an unremitting, intense experience of perinatal grief. Further, studies tend to use other measures (e.g., of postnatal depression) as proxies of bereavement distress and overlook measures of complicated grief. These practices may result in perinatally-bereaved mothers being diagnosed with and treated for postnatal depression while their complicated grief remains undiagnosed and untreated, which is highly problematic given that complicated grief is a risk factor for other psychological morbidity, including suicide (Latham & Prigerson, 2004). The aim of this study was to determine the presence and predictors of complicated grief in a sample of perinatally-bereaved mothers.

Method

Participants

SIDS and Kids is a federation of nine independent organisations in Australia which provide bereavement support to families whose baby or child died during pregnancy, birth, infancy and childhood. Seven hundred and fifty bereaved parents who were clients of SIDS and Kids in three regions of eastern Australia were invited by letter or e-mail to complete a questionnaire as part of the review of these services.

Materials

The questionnaire included demographic questions including age, education, employment, household income, time since loss, other perinatal losses, and the presence of other children. The 29-item Inventory of Complicated Grief – Revised ([ICG-R], Boelen, van den Bout, Keijsers, & Hoijtink, 2003) was used to measure complicated grief symptoms. Participants rate the frequency of their experience during the past month from ‘never’ to ‘always’ on some items and the intensity of their experience from ‘no sense of ____’ to ‘an overwhelming sense of ____’. Total scores range from 29 to 145; scores 90 and over indicate the presence of complicated grief (Boelen et al., 2003). A study of the ICG-R’s psychometric properties (Boelen et al., 2003) established the measure’s high internal consistency (Cronbach’s $\alpha = 0.94$); concurrent validity established against the Texas Revised Inventory of Grief (Faschingbauer, Zisook, & DeVaul, 1987; $r = .71$), the Beck Depression Inventory (Beck, Rush, Shaw, & Emery, 1979) and the 90-item Symptom Checklist (Derogatis, 1983); and test-retest reliability of total scores ($r = .92$) over an interval of 9 to 28 days. While there are several versions of the ICG, the 29-item version is the most comprehensive in the suite of ICG measures (Sealey, Breen, O’Connor, & Aoun, 2015). The questionnaire included other questions related to the service review but as unrelated to this study are not reported here.

Pilot testing demonstrated three items in the ICG-R—items 12 (identification with symptoms of the deceased), 15 (hearing the voice of the deceased), and 16 (seeing the deceased)—are not relevant to most perinatal deaths. As such, and due to these items being weaker indicators of overall complicated grief severity (Boelen & Hoijtink, 2009), the responses to these items were removed. The revised 26-item scale demonstrated robust internal consistency reliability (Cronbach's $\alpha = .95$). Following removal of the three items, the possible range of scores was adjusted from 29-145 to 26-130 and the cut-off score indicating complicated grief was adjusted from 90 to 81.

Procedure

Participants completed the online questionnaire either via Survey Monkey or the equivalent paper copy, which they returned to SIDS and Kids using reply-paid postage.

Statistical Analysis

All analyses were conducted using the statistical package for the social sciences (SPSS) version 21.0 (SPSS Inc., Chicago, IL, United States). The presence of complicated grief was determined using the cut-off score described above. The effect of previous perinatal loss, type of perinatal loss, and presence of other living children in the family on complicated grief scores was investigated with a series of independent-samples t-tests. Effect sizes were calculated and interpreted according to Cohen's (1988) conventions.

Results

A total of 154 parents completed the questionnaire (response rate = 21%); however, 23 were excluded from analyses due to not being bereaved in the perinatal period, which was defined as death of the child during pregnancy, at birth, or within one year of birth. Additionally, the 10 fathers who responded were removed because fathers mourn a perinatal loss differently to mothers (Lok & Neugebauer, 2007) and the small number of them precluded quantitative comparisons with mothers, leaving a sample of 121 (16%; see Figure

1). At the time of completing the questionnaire, the mothers were aged between 23 and 52 years of age. A summary of the demographic characteristics of the participants is provided in Table 1.

There were insufficient numbers in some groups of perinatally bereaved mothers to investigate the impact of all types of loss on symptoms of complicated grief. However, we did determine that there was no difference in ICG-R scores between women whose infants were stillborn and women perinatally bereaved through other causes, $t = 0.83$, $p = 0.41$. Therefore, the full sample was used for subsequent analyses.

Presence of Complicated Grief

The adjusted total scores on the ICG-R ranged from 26 and 115 ($M = 56.04$, $SD = 19.57$), with 12.4% ($N = 15$) of the sample indicating the presence of complicated grief. The rate when adjusted for time since loss of five years or less (Bennett et al., 2008) was almost identical at 12.2%. The data was analysed to fit the duration criteria for Persistent Complex Bereavement Disorder by excluding those who were within one year of their loss ($N = 15$), which resulted in 11.7% of mothers scoring in the clinical range.

Predictors of Complicated Grief

There was no significant difference in ICG-R scores for mothers who had not had a previous loss ($M = 56.95$, $SD = 18.74$) and those who had ($M = 52.60$, $SD = 18.83$), $t = 1.25$, $p = .22$, $\eta^2 = .008$. Calculations to determine whether ICG-R scores were related to marital status could not be performed because most participants (93%) were in a committed relationship. Similarly, calculations to determine whether ICG-R scores were related to loss type were not able to be performed as there were insufficient participants in the sub-groups other than stillbirth. There was no significant difference between the mothers who experienced a stillbirth ($M = 56.93$, $SD = 19.14$) and those who experienced other perinatal losses ($M = 55.21$, $SD = 18.52$) $t = .50$; $p = .72$, $\eta^2 = .002$. There was a medium, significant

difference in ICG-R scores between mothers with no living children ($M = 66.33$, $SD = 21.88$) and those with living children ($M = 53.86$, $SD = 17.39$), $t = 2.85$; $p = .01$, $\eta^2 = .06$.

Discussion

The presence of complicated grief (12.4%) in this sample of perinatally-bereaved mothers drawn from a bereavement support organization is considerably higher than in population-based general bereaved samples (Aoun et al., 2015; Fujisawa et al., 2010; Kersting et al., 2011). The adjusted presence at one year or more post-bereavement was 11.7%, which is much higher than the reported presence for Persistent Complex Bereavement Disorder of 2.4-4.8% (APA, 2013). However, the rates of complicated grief are similar to those described in other samples of parents who have lost children to illness, such as cancer (McCarthy, Clarke, Ting, Conroy, Anderson, & Heath, 2010) and lower than in subsample of bereaved parents within Kersting and colleague's (2011) study where 23.6% met criteria for complicated grief. It may be that the loss of a child is a particularly important risk factor for the development of complicated grief compared to other losses.

Support was found for the absence of living children as predictive for complicated grief; previous perinatal loss and type of loss were not significant. The non-significant results may be due to less than 20% of the sample having experienced multiple losses, and hence it is unlikely that there was sufficient variance in this characteristic. However, Swanson et al.'s (2007) sample had a higher proportion of mothers with other perinatal losses and also reported no association between this variable and self-reported grief distress one year post-miscarriage. While some mothers may find the presence of living children assists them in managing their grief (Toedter, Lasker, & Alhadeff, 1988), having to support the siblings after the death may contribute to emotional distress in others (Lannen et al., 2008). However, the presence of other children has been found by some researchers to have had no impact on the grief of the women who experienced miscarriage (Swanson et al., 2007). It is possible that

whether the other children were born before or after (or both) may make a difference, but we did not have the power to examine this.

Limitations and Future Research

The cross-sectional nature of this study, the sample size, the response rate, potential influence of confounding variables, and the convenience sample drawn from a bereavement support organisation reduced the possibility of identifying all factors that may increase perinatally-bereaved mothers' susceptibility to develop complicated grief or to generalise the results to all mothers bereaved in the perinatal period. Although the response rate is low, it is comparable to other surveys of bereaved people (Aoun et al., 2015; Mayland, Williams, & Elershaw, 2012). Most participants were in committed relationships with high socio-economic capacity and all were clients of a grief support service for families affected by the death of a child. It is possible that the sample might be a highly distressed subgroup of perinatally-bereaved mothers. Significantly higher grief scores (as measured by the PGS-33) have been found in study samples derived from support groups and self-selected populations (Toedter, Lasker, & Janssen, 2001). However, it is also possible that mothers who were coping relatively well were more likely to take part or that mothers from low socioeconomic background and/or who did not have access to support services were doing less well and less likely to take part. Additionally, any mothers who may have at one time met clinical thresholds for symptomatology, but not at the time of data collection, would not be included in the estimations. Hence, this figure is likely to be an underestimate.

With a few modifications, the ICG-R was accepted by the mothers and allowed the investigation of complicated grief symptoms in this sample. The two items in the ICG-R with the highest mean scores were items 5 (yearning) and 26 (impairment); high levels of yearning and impairment are consistent with diagnostic criteria for complicated grief (Prigerson et al., 2009; Shear et al., 2011) and provide evidence for the utility of the measure in assessing

complicated grief in perinatally-bereaved women. However, the ICG-R requires the summing of item scores, which implies that each item is weighted equally and overlooks the likelihood that the strength of endorsement of each item may differ according to severity of complicated grief and type of loss (Boelen & Hoijtink, 2009). The latter may be the case for perinatally-bereaved mothers where three items on the ICG-R are inappropriate for perinatal grief and published results for this instrument with this population are lacking. More research needs to be conducted to compare the ICG-R with other more specialised perinatal instruments, such as the PGS-33, to optimise the identification of complicated grief in perinatally-bereaved mothers. Relatedly, the predictors investigated in this study were demographic, rather than psychological in nature. Future studies could investigate the ways in which symptoms of depression, anxiety, stress, and post-traumatic stress predict complicated grief over and above the socio-demographic variables. Finally, these findings underscore the need for a formal epidemiological study of prevalence and predictors of complicated grief symptomatology in perinatally-bereaved mothers, using a measure validated for this population.

Conclusions

The proportion of mothers who experienced complicated grief was higher than in many other bereaved samples. The presence of other living children may have a protective effect against the development of complicated grief. The data show that the majority of women were able to negotiate a perinatal loss without developing complicated grief; however, there remains an important group of women who even up to five years later score in the clinical range for complicated grief symptoms. The symptomatology of perinatally-bereaved mothers should be routinely monitored so that they may be referred for treatment when indicated.

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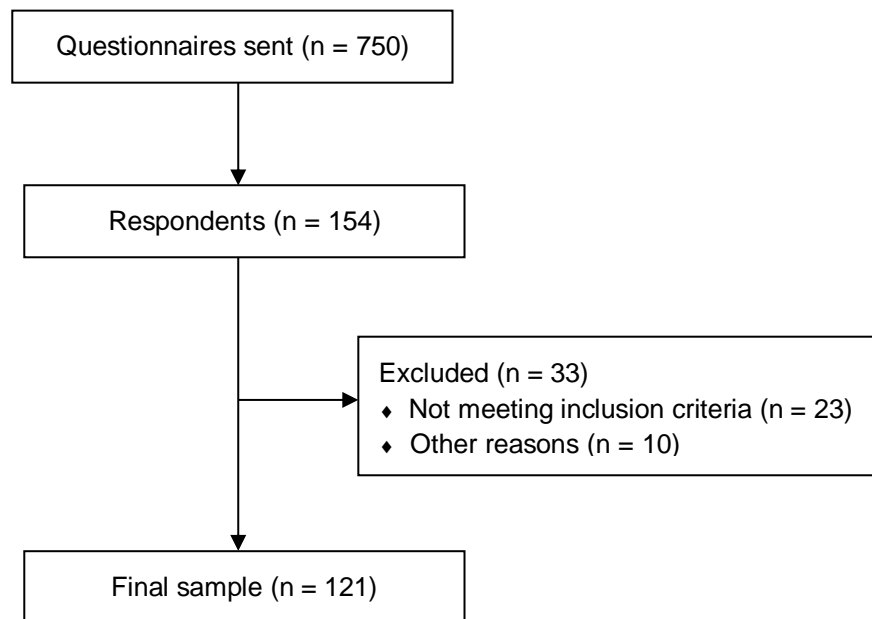


Figure 1. Adapted CONSORT diagram depicting participant recruitment.

Table 1

Demographic and Loss-related Characteristics (N = 121)

	N	%
Marital Status		
Single	2	1
Married/de Facto	114	92
Separated/divorced	5	7
Nationality		
Australian – Aboriginal and/or Torres Strait Islander	2	1
Australian – Non-Indigenous	111	92
Other	8	7
Education		
≤ 10 years	14	12
Completed school	13	11
Trade qualification	22	18
University degree	72	59
Employment status		
Maternity leave/Home duties	48	40
Part-time work	44	36
Full-time work	14	12
Combined family income		
Up to \$29,999	6	5
Up to \$49,999	12	10
Up to \$74,999	20	16
Over \$75,000	77	64

Time since loss		
Up to 6 months	0	0
6–12 months	14	12
1–2 years	22	18
2–3 years	32	25
3–4 years	12	10
4–5 years	18	15
5+ years	22	18
Loss type		
Miscarriage	6	12
Termination	15	14
Stillbirth	59	47
Neo-natal death (birth to 1 month)	19	15
1 month to 1 year	13	11
Over 1 year	9	7
Other babies died		
No	96	79
Yes, before	14	12
Yes, after	11	9
Living children		
No	21	17
Yes, younger	31	26
Yes, older	28	23
Yes, both older and younger	41	34
