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Death Studies

ISSN: 0748-1187 (Print) 1091-7683 (Online) Journal homepage: https://www.tandfonline.com/loi/udst20

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To cite this article: Leoniek Wijngaards-de Meij , Margaret Stroebe , Wolfgang Stroebe , Henk Schut , Jan Van Den Bout , Peter G. M. Van Der Heijden & Iris Dijkstra (2008) The Impact of Circumstances Surrounding the Death of a Child on Parents' Grief, Death Studies, 32:3, 237-252, DOI: 10.1080/07481180701881263

To link to this article: https://doi.org/10.1080/07481180701881263

Death Studies, 32: 237–252, 2008

ISSN: 0748-1187 print/1091-7683 online
DOI: 10.1080/07481180701881263

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THE IMPACT OF CIRCUMSTANCES SURROUNDING THE DEATH OF A CHILD ON PARENTS' GRIEF

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A longitudinal study was conducted among bereaved parents to examine the relationship between the circumstances surrounding the death of their child and psychological adjustment. Two hundred nineteen couples participated at 6, 13, and 20 months post-loss. Examination was made of two categories of factors: those that were determined by the particular death circumstances (e.g., whether the parent was present at the death) versus those over which parents themselves could have influence (e.g., choice of cremation or burial). Results indicated that some but not all factors were related to adjustment over time. Importantly, the feeling of having said goodbye to the child and presenting the body for viewing at home were associated with lower levels of the parents' grief. Implications for supporting bereaved parents are discussed.

The thought that one might lose one's child through death is a terrifying one for parents. If the unthinkable actually happens and a child dies, parents are confronted with a world that has fallen apart. Their life's hopes and expectations are thrown into complete disarray (Rubin & Malkinson, 2001). Indeed, prior research has shown that bereaved parents are a highly vulnerable group.

Received 26 December 2006; accepted 5 May 2007.
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Bereaved parents have a higher relative risk than non-bereaved controls of being hospitalized for affective disorders in particular (Li, Laursen, Precht, Olsen, & Mortensen, 2005) and even have higher mortality rates than parents who have not lost a child (Li, Precht, Mortensen, & Olsen, 2003). Nevertheless, there are likely to be individual differences among bereaved parents in the course of grief and in ways of coming to terms with a loss. In general, it has been shown that certain individual and interpersonal characteristics influence adjustment to loss (for a review, see M. Stroebe, Folkman, Hansson, & Schut, 2006). These characteristics can be seen as risk factors, to assist in identification of bereaved persons vulnerable to poor adjustment. However, surprisingly little empirical research has been conducted specifically on the impact of the circumstances surrounding a death (i.e., those associated with the actual time of loss and during the days following the death) on the grief process. And yet it is likely that these events are critically important. For example, it is generally believed that being present at the sickbed when a child dies has a beneficial effect for the bereaved.

In investigating the impact of circumstances surrounding a death, it seems useful to distinguish two types of factors: First, there are those factors that are usually dictated by the circumstances (e.g., cause and location of the death)—which we label *unchangeable*. Second, there are those aspects to do with the death that require a decision to be made by the bereaved, or an action to be taken (e.g., presenting the body for viewing)—which we will label *changeable* events.

With respect to our first category, several potentially important factors can be identified that are unchangeable, that are "givens" , determined by the situation. These include cause and unexpectedness of the death; location of the death; being present at the death; way of finding out about the death. Again these aspects seem particularly salient in the case of the loss of a child, but to our knowledge empirical evidence is either scarce or completely absent. Differences in outcome related to causes of death of a child have been examined in detail (e.g., Dyregrov, Nordanger, & Dyregrov, 2003; Murphy, Johnson, Wu, Fan, & Lohan, 2003). However, these studies concentrated on unexpected and/or violent causes of death and did not compare the impact of these with other causes of death. In our earlier article, in the context of examining a broader range of risk factors, such as characteristics of the parent (e.g., age, gender,

education) and of the child, we included cause and unexpectedness of the death of the child (Wijngaards-de Meij et al., 2005). Cause of death and the unexpectedness both contributed to the prediction of grief symptoms of the parents. However, apart from the effect of cause of death, we did not look at more specific circumstances surrounding the death in this earlier analysis. Again very few studies have been conducted on the impact of location of the death or being present at the death. Christakis and Allison (2006) found that spouses of persons who were hospitalized had higher mortality rates than those whose partners were not hospitalized for the same illness. One small study of parents, conducted in Greece, examined the experiences of mothers who had cared for their child at home versus in the hospital but did not relate these to the adjustment of the mothers after death (Papadatou, Yfantopoulos, & Kosmidis, 1996). Finally we have only found qualitative accounts relating to aspects to do with learning about the death, but these reports have focused on guidelines on how to tell the news to bereaved parents (Cook, White, & Ross-Russel, 2002).[1]

As noted above, there is little scientific evidence causally linking circumstances surrounding the death of a child with outcome variables among their parents (see Rubin & Malkinson, 2001, for a review of risk and mitigating factors in parental response to loss of achild). With respect to the category of changeable events: Regarding the funeral, there are several aspects that have received attention in the bereavement literature. With respect to participation in the planning of the funeral, in Gamino, Easterling, Stirman, and Sewell's (2000) study there was no (significant) relationship between participating in the planning andgrief symptoms. This is in line with results of studies by Doka (1984–1985) and Bolton and Camp (1987), who found that participation in funeral rituals was not related to adjustment. There is a large body of research on cultural differences on rituals and funerals (e.g., Hockey, Katz, & Small, 2001), but to our knowledge there has been no published[2] research connecting the form of the funeral (burial or cremation) to the psychological adjustment process of bereaved persons.

[1]Clearly it is necessary to consider the interdependency of the above factors in discussing their relationship to outcome.

[2]An unpublished study in the Netherlands found no differences in grief symptoms for bereaved persons following cremation versus burial (Borst & Brusik, 2006).

We know of no scientific studies on the impact of caring for the body or presenting the body for viewing at home.

In this context, another important feature is whether parents have, according to their own personal evaluation, said goodbye to their child. There are clearly several ways to say goodbye, either before, at the moment of death, or in a symbolic way after the loss. There have been surprisingly few studies on the impact of saying goodbye, although in two studies bereaved persons (but not specifically parents) were found to have better adaptation if they had said goodbye to their loved ones (Gamino, Sewell, & Easterling, 2000; Schut, de Keijser, van den Bout, & Dijkhuis, 1991).

With respect to these changeable factors, parents have to make several decisions. One important decision is about the funeral: Do they want their child to be buried or cremated? And Do they choose to take care of the body themselves? Do they want to present the body for viewing at home? And also, although on a somewhat different level: Did they find a way to say goodbye to their child? "Saying goodbye" may have been carried out in words to the dying child or it may have been done symbolically afterwards, for example, planting a tree or reciting a poem. In raising these issues, it is important to ask whether these aspects actually make a difference to the adjustment of the parents.

It is important to note that some of the choices that are mentioned above are culturally bound. Our study was conducted in the Netherlands. In this country, the possibility to present the body of the deceased at home is a common option, as is presenting the body for viewing in the funeral home or at the church. Although this procedure is quite common in Europe, in other countries such options might differ substantially.

The purpose of this investigation was to clarify whether differences in parents' adjustment to the death of their child were related to the changeable and unchangeable circumstances described above. Both depression and grief were included as dependent measures, given that previous research has shown these to be distinct syndromes in response to bereavement (see Prigerson & Jacobs, 2001). In addition to adding to scientific knowledge on individual differences in adjustment to bereavement, our goal was clinically oriented: to gain understanding about how the direct aftermath of the loss of a child may be related to the psychological symptoms of the parents. Clearly, without being prescriptive, the changeable

factors are particularly important in practice (e.g., for funeral directors), because establishing their relationship to adjustment might help to provide guidance for bereaved parents having to make decisions at a time when they are grieving intensely.

Method

Our study was longitudinal, consisting of three points of measurement at 6, 13, and 20 months after the death of the child. The attrition rate was 17.8% over this 14-month period. At 6 months after the loss information on the biographical data about the parents, the child and circumstances surrounding the loss were gathered during an interview with the couple. At all three moments in time, parents were asked to fill in a set of questionnaires separately. In total, 463 Dutch couples who had lost a child were contacted via obituary notices in local and national newspapers. Bereaved parents who were grandparents (i.e., those parents whose deceased child was a parent him/herself) were not included in this investigation, given that they are likely to experience additional difficulties. Single parents were also excluded, because the current article is part of a study that was designed to investigate individual variables as well as variables shared by the parents as predictors of grief (see also Wijngaards-de Meij et al., 2005).

In total, 219 parent couples (47%) agreed to participate. Informed consent procedures were used. The parents who participated ranged in age from 26 to 68 years ($M = 42.2$, $SD = 9.1$). Thiry-one percent of the parents indicated that they were not religious, 38% were Roman-Catholic, 26% were Protestant, and 5% belonged to another religion. The age of the deceased child ranged from stillborn to 29 years with a mean age of 10.2 years ($SD = 9.8$). A total of 68.7% of the deceased children were boys. The causes of death varied from neonatal death (including stillborn;16.3%), through illness (47.7%), to accident, SIDS, suicide, or homicide (36.1%).

Independent Variables

UNCHANGEABLE VARIABLE

Unchangeable variables were cause of death (three categories [see above] made into two dummy variables: neonatal death is the

reference group and the first variable is 'illness' and, the second variable 'accidental' death); (un)expectedness (5-point scale) of the death; location of the death (home, hospital, else); present at the moment of death (yes/no); and discovered the death him or herself (yes/no).

CHANGEABLE VARIABLES

Changeable variables included presenting the body of the child at home (yes/no), funeral (cremation or burial), taking care themselves (i.e., personally) of the body after death (yes/no), and saying farewell to their child (yes/no).

CONTROL VARIABLES

To exclude possible gender effects and effects of age of the child (see Wijngaards-de Meij et al., 2005), all analyses were controlled for these variables.

Dependent Variables

Depression was measured using the subscale of the Symptom Checklist-90 (SCL-90, Derogatis, 1977; Dutch translation by Arrindell & Ettema, 1986). The subscale depressive symptomatology consists of 16 items. Answers are given on a 5-point scale, ranging from 1 (*not at all*) to 5 (*very much*). In our study, Cronbach's alpha ranged from .92 to .94. Grief reactions were measured using the Inventory of Complicated Grief (ICG, Prigerson et al., 1995; Dutch version by Dijkstra, Schut, Stroebe, Stroebe, & van den Bout, 2000). The ICG consists of 19 items covering psychological aspects of grief (e.g., "I yearn for our deceased child" and "I feel that it is unfair that I should live when our child died"). The answers are given on a 5-point scale ranging from 1 (*never*) through 3 (*sometimes*) to 5 (*always*). In our study the Cronbach's alpha ranged from .90 to .92.

The dependent variables were transformed to a scale 0–100 to facilitate comparison between the predictors and between the predictive value for depression and grief.

Analysis

Multilevel regression analyses are appropriate for having several predictors in a dependent structure (Hox, 2002). A unique feature

of multilevel analysis is that it works with a specific statistical model designed for nested data. In our data there is a nested structure captured by a three-level hierarchy. The three measurement moments in time are nested in one person—the father or mother. The measurements of the father and mother are dependent and are thereby nested in a couple. Therefore time since death is the lowest level (1st level), nested in the individual (2nd level). The parents (2nd level) are nested in a couple (3rd level). Each independent variable varies only at one specific level. Time since the loss of the child varies only at the lowest level, the time level (1st level). The individual factors of the two parents differ at the individual level (2nd level). The remaining factors are the same for the parents in a couple, but these factors do vary between the couples at the couple level (3rd level).

For each of the two dependent variables (grief and depression) a multilevel regression analysis was performed with MLwiN (Rasbash et al., 2000). In Model 1, the factors time, gender and age of the child were included (curvilinear for grief). In Model 2, the unchangeable variables were introduced—cause, (un)expectedness and location of the death, being present, and being aware of the moment of death. To test whether the circumstances around the death that require a decision predicted the level of grief of the parents, the variables 'presenting the body of the child at home' , kind of funeral, cared for the body after death, and 'saying farewell to their child' were introduced in Model 3.

Results

Differences Between Causes of Death (in Circumstances)

UNCHANGEABLE VARIABLES

Of the children who died before or at birth, most died in the hospital (see Table 1). The majority of the parents whose child died in an accidental death were not present at the death. In contrast, of the parents of whose child died because of an illness or disorder, the majority was present at the moment of death. Although these parents were present, only one out of three discovered the death in the group of neonatal deaths, which equals the percentage of parents who did so within the accidental group. Among the parents

TABLE 1 Unchangeable Variables Differentiated by Cause of Death

	Location of death			Parent present		Death discovered	
Cause	Home (%)	Hospital (%)	Other (%)	Yes (%)	No (%)	Self (%)	Other (%)
Neonatal	12.1	87.9	—	79.1	20.9	35.4	64.6
Illness	35.1	59.6	5.3	69.2	30.8	53.2	46.8
Accidental	10.3	35.2	54.4	18.2	81.8	36.4	63.6

whose child died of an illness or disorder, half was aware of the moment of dying him or herself.

CHANGEABLE VARIABLES

Parents whose child had died of an illness were twice as likely to present the body for viewing at home as parents whose child had died in an accident or from other violent causes (Table 2). Most parents did not or could not take care of the body after the death. In cases of accidental deaths less than 4% of parent did so, and among the other parents one third took care of the body of their child themselves. In all groups the majority of the children were buried, only one of four couples chose a cremation. When asked whether they had said farewell to their child, almost all parents in the neonatal death group indicated that they had. After an illness or disorder of the child, the majority of parents also indicated that they had said farewell. After an accidental death more than half of the parents said farewell, but not as many as in the other groups of parents.

TABLE 2 Changeable Variables Differentiated by Cause of Death

	Presented body		Funeral		Cared for body		Farewell	
Cause	Yes (%)	No (%)	Burial (%)	Cremation (%)	Yes (%)	No (%)	Yes (%)	No (%)
Neonatal	32.5	67.5	72.5	27.5	33.8	66.3	92.4	7.6
Illness	42.1	57.9	77.9	22.1	35.8	64.2	88.8	11.2
Accidental	18.7	81.3	72.0	28.0	3.9	96.1	71.7	28.3

Grief

Model 1 consisted of the predictors time, gender of the parent, and age of the child (curvilinear; see Wijngaards-de Meij et al., 2005). Women had higher grief scores than men. Although the grief scores were high for all the parents over the period of the study, through time the grief decreased slightly for both men and women (Tables 3 and 4). There was a curvilinear relationship between grief and the age of the child (up to the age of 17 the grief increases, after the age of 17 the grief decreases).

In Model 2 the unchangeable variables were introduced. The results showed that grief was predicted by cause of death and the (un)expectedness of the death and being present at the moment of death (Table 4). Parents who lost their child through an accident or a violent death had the highest grief scores, followed by the parents who lost their child after an illness or disorder. The parents who lost their child by stillbirth or neonatal death had somewhat lower scores (but still high) than those of the other two groups of bereaved parents. Furthermore, the more the parents expected

TABLE 3 Means and Standard Deviations of Grief and Depression by Gender and Cause of Death

	Grief time 1		Grief time 2		Grief time 3	
	M	*SD*	*M*	*SD*	*M*	*SD*
Gender						
Men	40.86	18.90	39.82	17.90	37.80	45.62
Women	49.34	19.46	45.90	18.62	45.63	16.93
Cause						
Neonatal	36.21	16.00	33.04	16.87	31.15	16.08
Illness	43.08	19.50	40.88	17.85	40.30	18.00
Accident	54.64	18.71	52.75	16.54	50.92	15.99
	Depression time 1		Depression time 2		Depression time 3	
Gender						
Men	17.66	15.48	16.37	15.76	15.60	15.60
Women	29.97	21.21	28.20	20.12	25.87	18.82
Cause						
Neonatal	19.62	16.58	16.37	15.30	14.42	12.96
Illness	21.69	18.56	21.23	19.26	19.67	18.41
Accident	30.72	22.71	29.18	20.18	26.72	19.48

TABLE 4 Multilevel Regression Analyses for Grief and Depression

	Grief						Depression					
	Model 1		Model 2		Model 3		Model 1		Model 2		Model 3	
Variable	B	s.e.	B	s.e.	B	s.e.	B	s.e.	B	s.e.	B	s.e.
3rd level												
Age child (in yrs)	0.814*	0.102	0.718*	0.160	0.677*	0.155	0.486*	0.097	0.289*	0.144	0.283*	0.143
Age child (square)	−0.037*	0.015	−0.024	0.017	−0.024	0.016						
Cause of death (0 = neonatal)[a]												
Illness			4.205*	3.523	3.960*	3.206			1.942	3.384	0.823	3.335
Violent/accident			10.105*	4.467	9.803*	4.283			8.613	4.166	8.482	4.185
Expectedness			−2.414*	0.879	−2.164*	0.863			−0.131	0.893	−0.032	0.888
Location of death (0 = home)[a]												
Hospital			−1.392	2.858	−3.200	2.869			−0.805	2.906	−2.421	2.971
Somewhere else			−4.670	3.846	−5.890	3.908			−4.976	3.864	−5.993	4.002
Laid in state at home (0 = no)					−4.925*	2.391					−3.276	2.463
Cremation/burial					−1.135	2.319					0.496	2.372
2nd level												
Gender (0 = male)	8.069*	1.062	8.424*	1.179	7.692*	1.210	12.138*	1.285	12.848*	1.480	12.399*	1.532
Present (0 = no)			−5.551*	2.570	−4.872	2.562			−1.826	2.747	−1.754	2.787
Discovered (0 = self)			4.216	2.365	2.708	2.376			4.819	2.502	3.628	2.549
Cared for the body (0 = no)					−3.011	2.230					−1.952	2.505
Farewell (0 = no)					−7.454*	2.554					−4.078	2.773
1st level												
Time	−2.162*	0.280	−2.139*	0.315	−2.104*	0.320	−1.562*	0.309	−1.587*	0.346	−1.529*	0.354

[a] The variables cause of death (neonatal, illness and violent/ accident) and location (home, hospital, elsewhere) were both tested with a χ^2 test.
*$p < .05$.

the loss, the less grief they experienced. Parents who were present at the moment of the death of their child experienced less grief that those who were not. In Model 3 the changeable variables were introduced. Of the changeable variables, two of the four variables did predict the grief of the parent. Whether the body of the child was presented at home for viewing affected the level of grief of the parents. Parents who were able to present the body of their child at home experienced somewhat less grief than those who were unable to do so. Saying farewell also influenced the grief of a parent. When a parent had (to his or her own idea) said farewell to the child, he or she had less grief than a parent who did not or could not do so. In contrast, whether the child was cremated or buried or whether parents were able to take care of the body of their child did not affect the extent of their grief. In Model 3 the variable "being present at the moment of death" was not significant anymore.

Depression

For depression the models were built in the same order. In Model 1 there were main effects for time, gender, and age of the child; through time the grief symptoms decreased and women had higher levels of grief than men (Tables 3 and 4). The higher the age of the child, the higher the levels of depression of the parents. In Model 2, in contrast to predicting grief, none of the unchangeable variables were predictors of the level of depression of the parent. In Model 3, the changeable circumstances were added. Here again, none of the added variables were significant predictors of the depression of the parent.

Discussion

It has long been assumed, in popular culture at least, that, even though the loss of a child is a devastating blow for all parents, the circumstances surrounding the death can aggravate or ameliorate the loss experience. And yet, apart from the expectedness of the loss (for overview, see W. Stroebe & Schut, 2001), the impact of the circumstances surrounding the loss on grief and depression have been little studied. To fill this lacuna in our knowledge, the current investigation focused on the relationship between

the circumstances surrounding the loss of a child and levels of psychological adjustment of the parents. We made a distinction between factors that are unchangeable, determined by the situation and those that need a decision (i.e., changeable factors). Of the so-called changeable factors, two factors were related to parents' levels of grief. One of these was whether parents had said farewell to their child. Parents who had said farewell had lower levels of grief during the first two years after the death. These results are in line with findings in the general bereavement research literature showing that saying goodbye is beneficial (Gamino, Sewell, & Easterling, 2000; Schut et al., 1991). In our study, most of the parents reported at the first point of measurement (at six months after the loss) that they had said goodbye to their child. However, we have no further information on the manner of saying goodbye. It might be that this occurred immediately before or just after the death of the child. But it is also possible that parents said farewell in a symbolic way in the weeks or months after the death. Either way, to have said farewell seems to have had some healing effect.

Quite soon after the child has died, parents have to decide whether or not they want the body of their child presented for viewing at home. Our data revealed that parents whose child was laid out at home had less grief in the two years following the death than those who did not (controlling for other relevant factors). For some parents, presenting the body may not have been possible, for example when the child had been in a violent accident and the body was too badly damaged. One possible interpretation is that when parents present the body at home, it helps them to confront the child's death and that the process of recognizing (and accepting) that the child has died is thereby furthered. More specifically, the parents will (have to) experience for some days in their own home, that their formerly living child is now cold and without motion. In addition, presenting the body at home might permit more contact with the deceased child at self-chosen moments on which they feel the urge to do so, thereby facilitating acceptance of the enormity of the fact that their child has died.

There are also decisions that do not appear to influence parents' levels of grief. For example, the decision whether to bury or cremate the body was unrelated to parents' level of grief, suggesting that neither of the two ways needs to be promoted as the better choice for parents. So parents who chose for cremation

adjusted as well as parents who chose for burial. Nor were any differences found between parents who did or did not take care of the body themselves after the loss.

On a more general level and in line with previous research (see Prigerson & Jacobs, 2001; Wijngaards-de Meij et al., 2005), the present analysis revealed clear differences in the impact of the circumstances surrounding the loss on grief versus depression. Whereas most of the circumstances of the death assessed in our study seemed to predict parents grief, depression was only related to the time since the loss, the gender of the parent, and the age of the child (women had more depression than men; through time the level of depression decreased slightly; the higher the age of the child, the more depression the parents had). Neither the factors that were unchangeably connected to the situation, nor the variables that require a decision, were related to the levels of depression of the parents.

The results of our study also have potentially important clinical implications. In the early days after the child has died, it is hard to support parents in the decisions that have to be made involving the procedures around the death. Even though the relevance of the decisions depends on the situation of the loss, the results of this article may offer some guidelines. First, because parents who presented the body of their child for viewing at home had less grief during the two years following the loss, one could consider recommending this. However, caution is needed: Although our findings suggest that it is helpful to present the body for viewing at home, this might not be true for all parents (in our study the parents made their own decision). The second variable related to adjustment was whether the parents felt they had said goodbye to their child. It might be recommended to the parents to find their own way to say goodbye. If there was no possibility to do so before or at the moment of the death, after the loss parents might be encouraged to find a symbolic way to say farewell. It is also important to note that some difficult decisions that had to be made by the parents were not related to their psychological adjustment (e.g, such as whether to care for the body of their child themselves, or whether to have their child cremated or buried). For caretakers in the early days of bereavement, these results may provide relevant information for forming guidelines, although caution is needed because no causal relationship was tested in our study.

Some remarks need to be made about limitations of our study. For ethical reasons, our first measurement moment was at six months after the loss of the child. This implies that the information on the circumstances around the moment of death was gathered retrospectively. Although, given the critical nature of the loss experience, parents are likely to have a clear memory of the circumstances surrounding this event, it could be argued that our design does not really provide a strong basis for causal conclusions with regard to the impact of the changeable variables on grief and depression. But even if one were able to measure at the time of the death, one could not have ruled out the possibility that parents who were more depressed were less likely to say farewell or to present the body of their child for viewing. Furthermore, the distinction made in this study between changeable and unchangeable variables is not always as clear as it might seem. Future studies could incorporate more fine-grained measures of the changeable and unchangeable variables to further examine the relationships with adjustment of parents (or other bereaved samples).

Our study has not only shown the importance of some decisions that have to be made by the parents in the aftermath of the loss of their child, but also that some decisions are not related to the psychological adjustment of the parents. As discussed above, this is of relevance to those supporting the bereaved in the early days of their loss.

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