Shared or discordant grief in couples 2-6 years after the death of their premature baby: effects on suffering and posttraumatic growth

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Abstract

BACKGROUND: The loss of a baby causes severe short- and long-term distress to parents and their marital relationship, but little is known about how this distress is shared between spouses. The authors hypothesized that the grief-related concordance within a couple 2 to 6 years after the loss of a premature baby could be an indicator of shared emotional distress within a couple. OBJECTIVE: The authors investigated the long-term grief experience among couples. METHOD: A group of 44 parents (22 couples) were assessed by questionnaire regarding grief, suffering, posttraumatic growth, and affective symptoms, and semistructured interviews with 6 couples added qualitative information about processes within couples. RESULTS: The extent of grief concordance was found to be related to different patterns of suffering and posttraumatic growth within couples. CONCLUSION: The emotional exchange between partners after the loss of the child appears to be crucial for a process of concordant grief, which in turn is associated with a more synchronous process of individual posttraumatic growth.
Shared or discordant grief in couples 2-6 years after the death of their premature baby – effects on suffering and posttraumatic growth

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Keywords: couples, grief, prematurity, posttraumatic growth, PRISM

Running title: Effects of shared or discordant grief in couples after the death of their baby

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Abstract:
The loss of a baby causes severe short- and long-term distress to parents and their marital relationship but only little is known how this distress is shared between spouses. We hypothesized that the grief-related concordance within a couple two to six years after the loss of a premature baby could be an indicator of shared emotional distress within a couple and tested effects of concordance on parents’ suffering and posttraumatic growth. The extent of grief concordance was found to be related to different patterns of suffering and posttraumatic growth within couples.

Introduction

Bereavement – the loss of a loved one through death – is a universal human experience. Research on bereavement has burgeoned in the last 20 years and has brought some insight into processes of short- and long-term effects of loss. Three main types of factors have been identified as potentially affecting risk for outcomes of bereavement\(^1\). Person factors include gender and characteristics prior to the death such as emotional stability, religious belief and self-esteem. Situational factors related to the death include whether the death was sudden or anticipated. Interpersonal factors are also important, such as the availability of social and emotional support from partner, family and friends. Although it is well known that in bereavement in general, support from one’s partner is one of the most important factors protecting against enduring grief and distress, most research to date has focused on factors related to the person or the situation causing bereavement\(^2\)-\(^5\).

After the loss of a child, several adverse effects on the parents’ relationship have been described, like increased emotional distance between partners, or even separation\(^6\). However, little is known about patterns of distress within couples\(^7\). It has been suggested that problems may arise when grieving is incongruent between partners – one partner is less affected by the death, or is at least perceived to be so by the other partner\(^8\). Specifically, the partner who is more affected by the death (typically the mother) attributes the other partner’s response as indicating indifference, thus exacerbating her distress, while the less affected partner becomes increasingly frustrated or angry. To date, there has been no empirical support for this suggestion. However, it is consistent with several studies which have reported that better communication between parents after the loss of a child is associated with more favourable outcomes. For example, it has been reported that couples who have more positive attitudes to communicating about their grief show less severe grief reactions in the longer term than do other couples, and also report greater marital satisfaction\(^9\).

The grief of parents in the aftermath of the death of their child is considered as an archetypal example of human suffering. Suffering is a uniquely individual experience, but it can be shared with
others which is expressed in proverbs like “suffering shared is suffering halved”. We have developed and validated a novel non-verbal measure of suffering called the Pictorial Representation of Illness and Self Measure (PRISM)\(^{10,11}\) which was detected to assess relevant aspects of suffering like intrusion or loss of control in patients with physical illness, alcohol dependence\(^{12}\) as well as in parents after the death of their baby\(^{13}\). In this study PRISM was used for the first time to assess interactive effects on suffering within couples after the loss of a child.

Although the death of a child is devastating, many parents report also positive aspects of this experience. In a cross sectional study of 109 Australian women who experienced stillbirth or neonatal death of a baby, 91 per cent saw the death of their baby as the worst thing that had ever happened to them. However 68 per cent also reported that they were also able to attribute something positive to the experience. In recent years, there has been an increasing interest in systematically evaluating positive aspects of the aftermath of a trauma. An example is the concept of posttraumatic growth, and of instruments to measure this\(^{14,18}\). Most research on posttraumatic growth has focused exclusively on individuals without considering the impact of their social supports. This lack of a systemic perspective has been criticized by several experts\(^{19,20}\). Few studies\(^{21}\) have focused attention on the impact of social support between marital partners on the development of posttraumatic growth. Personal growth among partners of women with breast cancer correlated with the depth of marital commitment and the extent of posttraumatic growth of the wife\(^{21}\). In a study assessing 67 parents after the loss of a child, most parents reported an increase of personal growth due to the loss of the baby\(^{18}\). The longer the time since bereavement, the more perception of benefit was reported; no gender differences were found. How are these positive experiences in response to loss of a baby transmitted between the spouses? The current literature reveals very little. To the best of our knowledge interactive effects on posttraumatic growth between partners after death of a child have not been studied to date.

This study was part of a larger project involving 92 parents of prematurely born children, some of whom died\(^{22}\). We recently published results examining how parents respond to the death of a premature baby, emphasizing similarities and differences between mothers and fathers\(^{13}\). Based on the background just described, our aim in this study was to examine how distress after the loss of a baby was shared within a couple two to six years after the loss. We assumed that where couples were discordant in their grief, this was likely to reflect less emotional exchange between the partners. We hypothesised that such couples who were discordant in their grief would, relative to those who were concordant in their grief, also show greater differences in affective disturbance, suffering and posttraumatic growth.
Materials and methods

Sample

The study was approved by the Institutional Review Board of the University Hospital of Zurich, Switzerland. The sample was derived from that collected for a wider study of neonatal bereavement and was drawn from parents who had given birth to a baby at 24-26 weeks gestation between 1.1.1998 and 31.12.2002 in the neonatology clinic at the Zurich University Hospital. All parents (mothers and fathers) with sufficient command of German to fill in a questionnaire were contacted by mail. Of a total of 72 parents who had lost their premature baby, 54 filled in and returned the questionnaire (response rate 75%). Non-participants did not differ from the study sample regarding sex, age, or time since loss of their baby. Of the 54 respondents, 10 had no partners and were therefore excluded from the present study, leaving 22 couples. All couples were married and lived together at the time of assessment. Characteristics of the parents are presented in Table 1. Of the 22 pregnancies, four were twin pregnancies and one was a triplet. Parents in the sample lost a total of 28 babies, whose mean duration of gestation was 25.3 weeks (SD=0.9) and mean birthweight was 699 grams (SD=132, range= 450-1080).

Table 1

Instruments

Parental grief was assessed using the Münchner Trauerskala (MTS), developed from the short form of the Perinatal Grief Scale (PGS). The MTS is the best validated German questionnaire for assessment of perinatal grief. The scale has 22 items, scored on a 1-5 Likert scale, giving a score range of 22-110. It has five subscales but because the scores on each of these was highly correlated with the total score, only the latter is reported in this paper.

Suffering through loss of the baby: This was assessed using a modified version of PRISM (Pictorial Representation of Illness and Self Measure). In the original test, applied with people who have an illness, subjects are shown a white A4-size metal board with a fixed, yellow disk 7 cm in diameter at the bottom right-hand corner. Subjects are asked to imagine that the board represents their life as it was currently, and the disk represents their “Self”. Subjects are then handed a red disk, 5 cm in diameter, asked to imagine the red disk represents their illness and asked, “where would you put the Illness disk, to show its importance in your life at the moment?” The main quantitative outcome measure is the distance between the centres of the two disks representing “Self” and Illness (for ease of description, this measure is called the Self-Illness Separation (SIS)). A modified, paper-and-pencil
version of the PRISM task, designed for unassisted completion, has recently been validated. This modified version of PRISM was used in the present study. A rectangle 10cm x 7cm, marked out in the questionnaire pack, was labelled “Your life” and a circle, 2cm in diameter in the bottom right corner, was labelled “Self”. Parents were asked to place a cross in the rectangle to express the place of their dead baby in their lives. The distance between the “Self” circle and the cross representing the baby was termed the “Self-Baby Separation” (SBS) and as with the original version of PRISM, smaller SBS, was taken to indicate greater suffering. SBS could range between 0-8.7cm.

Posttraumatic Growth: This was assessed by the German version of the Posttraumatic Growth Inventory (PTGI), which is the most used and best validated questionnaire to assess posttraumatic growth. It consists of a global score (PTGI-tot) with 21 items which are rated on a Likert scale from 0 (not true) to 2 (completely true), the total score range is 0-42. There are five subscales but because each of these correlated highly with the total score, further calculations were performed using only the total score (PTGI-tot).

Depression and Anxiety: The Hospital Anxiety and Depression Scale (HADS) was used as a valid and reliable measure of depression (7 items) and anxiety (7 items). The range for both scales is 0-21. Following the standard convention, scores 7-10 on each subscale were taken to indicate a possible clinical depression or anxiety, and scores > 10 were taken to indicate probable caseness.
Statistics

With the exception of the descriptives and intercorrelations of relevant parameters for all parents, the analyses were performed on a paired-samples datafile. The calculations were done using SPSS Version 12. Two groups were identified based on the extent to which partners in each couple differed in their grief scores, based on a median split of the difference between partners’ MTS scores. Couples with a MTS-difference >8 fell into the Discordant (D) group (n=10) whereas the other couples fell into the Concordant group (C) (n=12). The group sizes differ since three couples had the same MTS difference of 8. Analyses of variance with repeated measures on PRISM, PTGI, and HADS scores for gender (within couple’s effects) and comparison between groups of different grief concordance were performed, including interaction effects between gender and grief concordance. To further assess adaptation within couples of different grief concordance, paired samples correlations were calculated separately for the two groups for PRISM, PTGI and HADS.

Results

A. Descriptives for all parents (n=44)

Two to six years after death of their premature baby, MTS bereavement scores of the whole sample were still high (mean 57.5, range 33-82, SD 12.5). Mean PRISM distance between Self and baby (SBS) was 4.3cm (range=0-8.7cm, SD 2.1) indicating that for most parents, the baby still had a central place in their life parents. Nine parents (20%) had a SBS of less than 2cm indicating substantial suffering.

The mean total PTGI score was 22.8 (range 9-41, SD 7.4). Mean HADS depression score was 3.3 (range=0-11;SD 2.7); three (7%) parents scored > 7 indicating a possible depressive disorder. Mean HADS anxiety score was 5.7 (range=1-12; SD 2.9); 9 (20%) parents scored >7 pointing towards possible anxiety disorder. A HADS-score >10, indicative of probable anxiety disorder, was seen in three (7%) parents.

No effects of time since loss of the baby and MTS, PTGI, HADS and PRISM-SBS were found.

B. Sociodemographic differences between couples with concordant (C) and discordant (D) grief

No differences were found between the C and D groups in sociodemographic variables, and average time since death of the baby was similar for both groups. Relative to the Concordant group, the Discordant group showed a tendency to have no other children (D=5, C=1, Fisher’s exact test, p=0.06).

C. Effects of gender and grief concordance on suffering (PRISM), posttraumatic growth (PTGI) and affective symptoms (HADS)
Overall, suffering did not differ between mothers and fathers or between the Concordant (C) vs. Discordant (D) group. However, there was a significant interaction between gender and grief concordance group. In couples with discordant grief (D), mothers’ suffering was rated as greater than that of fathers, while the opposite was found in the concordant grief (C) group (Fig. 1).

Mothers showed greater posttraumatic growth than fathers. As with suffering, PTGI scores did not differ overall between the C- and D-groups. However, there was again a significant interaction between gender and C and D groups. In the Concordant group, there was little difference between male and female partners in their PTGI scores. By contrast, when compared with the Concordant group, PTGI scores in the Discordant group were significantly higher for mothers but significantly lower for fathers. In Discordant couples higher differences in posttraumatic growth were found than in Concordant couples (Fig. 2).

**Fig. 1, Fig. 2**

For HADS-depression and HADS-anxiety, no significant effects were found of gender, couple’s grief concordance, or the interaction between these.

**D. Adaptation within couples with concordant (C) and discordant (D) grief**

If couples were concordant for grief (C), they were also concordant for posttraumatic growth, suffering, depression and anxiety. Couples discordant in grief (D) were also less concordant in suffering, depression and anxiety. PTGI scores for mothers and fathers in the Discordant group were negatively correlated (Tab. 2)

**Table 2**

**Qualitative interviews**

Semi-structured interviews were conducted with 12 parents (6 couples). The interviews focused on the development of partnership, suffering and processes of growth. All interviews were audio taped and analysed using qualitative techniques. The results will be presented in detail elsewhere. To illustrate processes associated with discordant and concordant grief, two short narrative case histories - one of the couple that showed greatest concordance in their grief scores, and one of the couple that showed the greatest discordance - are presented.

**Discordant couple** (mothers MTS-score=73, fathers MTS-score=33)
George and Hanna lost their premature baby, Luca, 3 years ago. At the time of the birth, both parents were 27, were married for two years and it was Hanna’s first pregnancy as well as the couple’s first baby. During the pregnancy, Hanna developed a severe form of pre-eclampsia. At the time of the interview Hanna was pregnant for the second time. Hanna is a midwife and was extremely happy when she became pregnant for the first time. Not only professionally but also from a personal and even a philosophical perspective, birth was a major topic in her life. During her pregnancy she enjoyed an intensive relationship with her baby and had planned early on in the pregnancy to give birth at a clinic specialised in underwater delivery. Her husband George was a successful banker. During Hanna’s pregnancy, he changed his job and was very absorbed in his work. Hanna’s pre-eclampsia was an enormous strain on both partners. Within 2 days of the onset of symptoms, a caesarean section had to be done to save Hanna’s life. Luca died 14 hours after birth. George and Hanna wanted to participate in the burial, and, out of keeping with normal procedures, even carried Luca’s dead body out of the hospital themselves in a coffin. For the first week after Luca’s death, the bereaved parents were supported only by George’s parents. They buried Luca alone, and explicitly specified on the obituary notice that they did not wish to receive any cards or letters of condolence. While George returned to work after three days without telling anybody what had happened, Hanna had very strong feelings of grief and sadness for many months. The main ruminating question was: Why did this happen to me? Even at the time of the interview, 38 months after Luca’s death her level of suffering was still very high. Since Luca’s death, she had suffered from several physical problems like chronic pain from a herniated disc of her back, together with fatigue and extremely irregular periods. The couple talked very little about Luca’s death. During their interviews, both mentioned that they were used to solving problems alone and felt embarrassed to talk about their private problems with other people. Six to nine months after Luca’s death, George started to get annoyed when Hanna still ruminated about the circumstances and the meaning of Luca’s death. From time to time, George also thought about Luca, but he “could put this aside”. Both parents were anxious about the second pregnancy but felt positive that things would develop better this time than three years ago.

Concordant couple (mothers MTS-score=66, fathers MTS-score=62)

Jessica and Marco, the twins and first babies of Antonio and Andrea died five years ago, at 24 weeks’ gestation. When Andrea got pregnant, her 3 year-relationship with Antonio was in severe crisis, and they had been making plans to separate. Due to the unexpected pregnancy the couple finally decided to stay together. At only 23 weeks’ gestation, the obstetrician detected a problem with perfusion of the placenta, and sent Andrea as an emergency to the university hospital. Eight days later, a caesarean section had to be performed. Marco died immediately after birth, but Jessica survived five more days. In the first days and weeks after the deaths, Andrea and Antonio had a lot of support from their families. Eighty-five relatives and friends participated in the funerals of Jessica and Marco. Both partners felt much grief, but while Andrea felt the need to talk about her grief,
Antonio tried at first to hide his deep sadness, trying to be a “strong” and supportive husband. However, Andrea perceived her husband as distant and unemotional, and three months after the death of the twins, she confronted him with her feelings of that she was having to grieve alone. This led to an emotional outburst by Antonio, who cried in front of Andrea for the first time. After this, the couple started to exchange feelings regularly about the death of their children. For both partners, the deaths led to enormous changes in their personal relationships. With many friends, emotional exchange and closeness increased, while other relationships became more distant. Both partners mentioned separately that they feel much closer to their spouse than before the death of their twins. Interestingly each partner seemed to have tried to find meaning in the deaths in a similar way – that the deaths had brought them closer as a couple, and had made relationships even better for the children that followed. Although the couple now has two boys aged two and four years, the dead twins remain very much part of their family.

Discussion
The present study examined effects within couples of grieving on patterns of suffering and posttraumatic growth of parents after loss of a baby. To our knowledge this is the first paper to test empirically the so-called “incongruent grieving” hypothesis which postulates dyadic problems due to marked differences in couples’ grief after the loss of a child. In contrast to most studies of bereavement in parents after the loss of a baby, our analysis have been done with the pair of the parents as the relevant unit of analysis, rather than comparing groups of mothers and fathers. Also, as far as we are aware, this study is the first in which suffering has been directly quantified.

However, the present study has also several limitations, that must be considered when interpreting the results. The sample size of 22 couples is relatively small, and selection bias is possible because this represents 61% of the 36 couples who were contacted. No information is available on the couples who declined to participate. It is possible that those couples who chose to take part in the study had more stable relationships, or a more positive outlook. However, the study sample yielded a wide range of distress in terms of grief scores, and considerable variation in congruity of scores between partners.

Our results support the “incongruent grieving” hypothesis, formulated by Peppers and Knapp. Two to six years after the loss of a baby, couples who were more discordant in their grief were also more discordant in depression and suffering (Table 2). It has been suggested that fathers are less affected than mothers by the death of a baby. In our study, this finding applied to discordant couples, but not to the concordant ones, where fathers suffered more than mothers (Fig. 1). Interestingly the global burden of suffering for concordant and discordant couples is similar, but depending on the emotional exchange of grief the burden of suffering is shared differently between the partners. These results indicate that suffering is determined by social interaction as well as by biological factors (the latter predominantly affecting mothers). Where couples differ
considerably in their grief, it may be that the father is less likely to acknowledge the extent of his
distress, perhaps aiming to appear ‘strong’, as in the first case vignette above.

Posttraumatic growth is commonly greater in women than men and this was also the case in the
present study. This was also detected in our sample were mothers had higher growth than fathers.
However, comparing Concordant and Discordant groups, there were substantial differences
between posttraumatic growth of mothers and fathers, resulting in a significant group by gender
interaction (Fig 2). This suggests that the quality of a couple’s grief process has marked effects on
individual parents’ posttraumatic growth. In concordant couples as illustrated in the second case
vignette, both partners share a process of growth. In discordant couples process of growth are not
connected so that the loss of the baby triggers processes that separated the individual world of
both partners and might give rise to low satisfaction with relationship or even separation.

Earlier studies have reported positive effects on couples’ grief after the loss of a baby of having other
children, or becoming pregnant fairly soon. Our own findings are consistent with this although
failed to reach statistical significance, most likely due to small sample size – only one (8%) Concordant
couple was childless at the time of assessment, compared with 5 (50%) Discordant couples. Having other children might have positive effects in terms of distracting parents’ from
ruminating about the dead baby towards the living children. Also women who show intense grief
may have more difficulty conceiving than those experiencing less grief due to psycho physiological
factors. In addition, among Discordant couples, differences in grief and emotions are likely to
result in less frequent sexual intercourse.

In conclusion, the results of our study with a relatively small sample of parents indicate that among
couples whose prematurely born baby has died, the way that the partners experience and share
their grief can profoundly influence not only their suffering but also their posttraumatic growth.
From a systemic perspective, emotional exchange between partners about the loss of the child
appears to be crucial for a process of concordant grief, which in turn is associated with a more
synchronous process of individual posttraumatic growth. Clinicians treating parents in the aftermath
of the loss of a baby should be aware of the importance of shared emotions between spouses after
the loss of a baby. Further studies with larger study samples and with preferably longitudinal design
are needed to investigate in depth the significance of shared grief within couples after the loss of
their baby.


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Table 2  Differences and associations of grief (MTS), affective symptoms (HADS), posttraumatic growth (PTGI) and PRISM within couples (N=44)

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* $p < 0.05$, *** $p < 0.001$

MTS = Münchner Trauerskala  
PTGI = Posttraumatic Growth Inventory  
HADS = Hospital Anxiety and Depression Scale  
PRISM = Pictorial Representation of Illness and Self Measure
Fig. 1  Posttraumatic growth (PTGI) in couples with Concordant- \(n=12\) and Discordant- \(n=10\) grief

![Graph showing Posttraumatic Growth (PTGI) in Concordant and Discordant grief types for Mothers and Fathers.](image)

### Analysis of Variance

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Fig 2. Suffering (PRISM) in couples with Concordant- (n=12) and Discordant-(n=10) grief

![Graph showing suffering (PRISM) in couples with Concordant- and Discordant grief]

Analysis of Variance

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