

faith, and assumptions about life. A complicated grief reaction (also called *morbid grief* or *pathological grief*) has been reported in about 20–40% of parents, although usually only mothers have been studied (Cullberg, 1966; Hunfeld, Wladimiroff, & Passchier, 1997; Jensen & Zahourek, 1972; LaRoche et al., 1982; Nicol, Tompkins, Campell, & Syme, 1986; Rowe et al., 1978; Tudehope, Iredell, Rodgers, & Gunn, 1986). Sample bias (i.e., selective attrition and subjective outcome criteria) make these estimates questionable, and there is a tendency to classify intense grief as pathological or deviant too soon after infant losses instead of understanding it as one of a broad range of normal responses (see Leon, 1992). Some of the parents in the above studies were diagnosed as having morbid grief within the first year following their loss. Most studies have focused on grief reactions and, to a lesser extent, have mapped traumatic effects of sudden infant death on the parents.

Studies that have followed families over time after the loss of a child have researched the effects of losing an older child, especially children with cancer (Fish, 1986; Lehman et al., 1987; Martinson, McClowry, Davies, & Kuhlenkamp, 1994; McClowry, Davies, May, Kulenkamp & Martinson, 1995; Rando, 1983), and some have focused on the death of infants (Boyle, Vance, Najman, & Thearle, 1996; Hunfeld et al., 1997; Rubin, 1982). Lehman et al., (1987) found that 96% of bereaved parents had memories, thoughts, or mental pictures of the dead come to their mind 4 to 7 years after an accidental death. Rando (1983) found that bereavement reactions intensified in the third year after parental bereavement (death due to cancer), and she questioned the common sense notion and belief that the passage of time “heals” grief. Miles (1985) also found that time did little to alleviate the risk of emotional symptoms through the first 30 months after a child’s death. Rubin (1991–1992) found relatively limited group differences between parents bereaved 4 and 13 years earlier and states that this “suggests that by four years post-loss, a number of the responses to loss appear to have stabilized” (p. 196).

Four years after the loss of a child, Hunfeld et al. (1997) found that 11 out of 29 women (38%) displayed general psychological distress indicative of the need for psychological support (as defined by the GHQ [General Health Questionnaire]-28). Boyle et al. (1996) followed a group of 194 mothers at 2, 8, 15, and 30 months

post-loss (stillbirth, neonatal death, and sudden infant death syndrome [SIDS]) and found that the bereaved mothers, as a group, manifested significantly higher rates of psychological distress than mothers of living infants. They also found that mothers who were not distressed soon after the loss (2 months) were unlikely to become so later, whereas those who were still distressed at 8 months were likely to remain so subsequently. Mothers in the SIDS group manifested the highest rate of anxiety and depression, and 1 in 4 SIDS mothers met the study's criteria for mental health problems. Though families have been followed for several years, they have not been followed beyond the first decade after the death.

Parents are believed to work consciously to maintain an inner representation of their child (Klass, 1993). Contrary to earlier beliefs when theorists understood the purpose of grief as relinquishing the lost object to form new attachments, continued relationships with a transformed inner representation of the child are now seen to be a healthy form of adaptation and change (Klass, 1993). Klass maintained that difficulties may arise when the inner representation is not shared by the parents' natural support system, or the inner representation becomes intertwined in individual or family pathology.

Previous studies have generally found that mothers react more intensely and over a longer time period than fathers (Bohannon, 1990–1991; Dyregrov & Matthiesen, 1987b; Moore, Gilliss, & Martinson, 1988; Lang & Gottlieb, 1993; Zeanah, Danis, Hirshberg, & Dietz, 1995), although some studies have found comparable levels of grief (Hoekstra-Weebers, Littlewood, Boon, Postma, & Humphrey, 1991; Rando, 1983). A substantial group of fathers (around 20%) show grief or distress that exceeds that of their partners (Benfield, Leib, & Vollman, 1978; Dyregrov & Matthiesen, 1987b; Zeanah et. al., 1995).

It cannot be ruled out that part of the differences found between mothers and fathers may be due to the measurements involved. Vance, Boyle, Najman, and Thearle (1995) found significantly more psychological distress among mothers than fathers, as well as significantly more symptoms in bereaved mothers than control mothers over the 30 months following an infant loss. However, when they included the excessive use of alcohol as an additional

reaction to stress, the difference in responses between men and women became much smaller, or non-existent. Those authors propose that increased alcohol use and less psychological distress in fathers may be a manifestation of a different way of coping with such stress than in mothers (i.e., a way of hiding feelings). Instruments that measure grief among parents usually focus on emotional reactions and generally women score higher than men on such measures (see Dyregrov, 1990, for a review), whereas behavioral indicators such as the one used by Vance et al. (1995) are seldom used. The full range of men's grief reactions may thus not be tapped.

Fathers have been found to keep their feelings more to themselves, avoid talking about the child (Schwab, 1996), and cry less than mothers, as well as seek less emotional support outside the marriage or relationship (Carroll & Shaefer, 1993–1994; Smart, 1992). Initially fathers feel an obligation to be “strong” for their partners and cannot break down and cry (Kachoyeanos & Selder, 1993; Helmrath & Steinitz, 1978; Smart, 1992). It has been proposed that fathers appear to recover quicker than mothers do because this is a father's role in society, and he therefore must appear healed (DeFrain, Martens, Stork, & Stork, 1990–1991). The father is usually afforded less support from the environment (Bohannon, 1990–1991; Zeanah et al., 1995), and he is more critical at the help offered by hospitals (Dyregrov & Matthiesen 1987b). Rubin (1991–1992) found that bereaved mothers whose loss occurred 4 or 13 years previously had a dramatic improvement at follow-up, compared with the first year of loss. The men did not match this improvement. Their initial response was less pronounced and so the measured decline was less marked. However, the initial response was based on their recollected experience of the first year following their loss.

An increased ability to relate their problems to others, being more compassionate and caring, being more aware of the importance of other loved ones, and having a greater understanding of life and death are among the positive outcomes noted following a child's death (Martinson et al., 1994; Miles & Crandall, 1983). However, these positive changes are often paralleled by vulnerability consisting of apprehensions about new disasters (Dyregrov & Matthiesen, 1987a).

The present study concerns a group of parents who lost a child in SIDS between 1981 and 1984. Data from these parents collected 1½ years following the loss were compared with data collected 12 to 15 years later (in 1996). Answers to the following questions were sought: (a) In what way and to what degree has there been a change in reactions over the 12 to 15 years? (b) Do gender differences usually found in the first years following the death continue over a longer time period?

Method

Participants

The sample of the original research project on parents' reactions after SIDS consisted of 18 couples. Four of these couples were divorced. Twenty-five individuals (13 women and 12 men), participated in the follow-up study (69% of the original sample). This was nine couples and seven single parents who had lost a child 12 to 15 years ago. The mean age of the informants was 41.7 years (range = 33–55). Of the parents representing the original 13 couples, 7 had lost boys and 6 had lost girls; 5 had lost their first child and the number of children currently in the family varied between 1 and 4 ($M = 2.6$). All participants were Norwegian and middle class. Eight lived in rural districts and the remaining 17 lived in cities on the western coast of Norway. Nine women and 6 men were members of the SIDS Society in Norway. One couple and a single mother (partner had died) were unreachable. Three couples and one single man did not want to participate in the study. One of the unwilling couples stated that they had experienced other losses besides the SIDS death and could not stand the pain of talking about this.

Instruments

Questionnaires and interviews were used. In the follow-up survey, the respondents were first asked to respond to some background items (gender, age, education, marital status, participation in support groups, city/rural life).

The Impact of Event Scale (IES; Horowitz, Wilner, & Alvarez,

1979; Zilberg, Weiss, & Horowitz, 1982) was used as a measure of traumatic aftereffects. The inventory consists of two subscales; one that measures intrusive images (Intrusion; IES-I), and the other that measures the amount of avoidance of thoughts, places, etcetera, associated with the traumatic event (Avoidance; IES-A). A sum score (IES-Total) provides a measure of total psychological distress in relation to the event. Horowitz (1982) established a criteria for low (< 9), medium ($\geq 9 < 19$), and high (≥ 19) distress for each of the two subscales (IES-I and IES-A) separately. A clinical cut-off point is usually set at 30, with those who score above 30 comprising those at high risk for having a posttraumatic stress disorder (Yule, 1992, 1998). Cronbach's alpha for IES-I was .91 and .77 for 1981–1984 and 1996, respectively; for IES-A Cronbach's alpha was .80 and .94, and for IES-Total it was .89 and .91 for the two time points.

The 20-item version of the GHQ (Goldberg, 1978) was used to measure general psychological well being. This scale originally was developed to detect psychiatric impairment among the general population. Goldberg suggested a clinical cut-off point of 4 when using Likert scoring. Cronbach's alpha was .91 in 1981–1984 and .97 in 1996.

The State version (STAI-X1) of the State Trait Anxiety Inventory (Spielberger, Gorsuch, & Luchene, 1970) was used to measure the degree of state anxiety present. Cronbach's alpha was .94 in 1981–1984 and .96 in 1996.

The Bodily Symptom Scale (BSS; Person & Sjöberg, 1981) was used to measure somatic complaints. This scale was developed to investigate the relationships between mood and the experience of different bodily states in normal adults. Cronbach's alpha was .93 in 1981–1984 and .95 in 1996.

The short form of the Beck Depression Inventory (BDI; Beck & Beck, 1972) was used to measure depression. Beck and Beck recommended a cut-off score of 4 to designate those with a high likelihood of suffering from depression. Cronbach's alpha in 1981–1984 was .76 and in 1996 it was .84.

To understand the parents' subjective feelings, experiences, and understanding connected to the loss of an infant child over time, we used semi-structured, in-depth interviews. An interview guide containing the following four main themes was developed.

First, a general question was asked about the experience of the cot death, followed by a series of more specific questions as to how they were met by family, friends, colleagues, official aid agencies, etcetera. The parents were also asked about their relationships with their remaining children, if they let them join the funeral, if they were able to assist them in their grief, and how their reactions close to the death could have influenced the children over the years.

Second, the second main topic dealt with their communication about the lost child over the years. The parents were asked about how they had talked about and memorialized the child over the years (i.e., pictures, the grave, and celebration of birthdays), and if anyone in the family needed or wanted to talk about the dead child more than others and how did the rest of the family meet these demands?

Third, specific questions dealt with their subjective meaning regarding the effects the loss of their child had had over the 12–15 years (on physical and psychological health, religious questions, marriage, remaining children, quality of life, the effect of media reports on research about SIDS, etc.). Questions concerning any traumatic aftereffects of persistent images and pictures from the time they found the dead child and how these may have bothered and affected their life over the years were also included. The parents were asked about the quality and quantity of any help or support received over the years, and what they had found to be of greatest help to them. Possible positive outcomes (i.e., on life values) were also covered.

Fourth, the last main topic dealt with their experience of the interview. The intention was to illuminate ethical questions of this kind of research, through their evaluation of the effect of recapitulating their sad story so many years later.

Procedure

Following the approval of the Medical Ethical Research Committee and the Data Inspectorate of Norway, A. Dyregrov contacted families who took part in a previous study in 1981 to 1984.

Contact was made by telephone, where parents were informed about the project and were told that they would receive a written request for participation. On return of the request, which included a written consent, the family was contacted to arrange a time and place for the interview. The interviews were conducted in June and July of 1996. Couples chose to be interviewed together and divorced parents were interviewed separately (16 interviews). Each interview lasted for 2–5 hours. Because of the sensitive topic, K. Dyregrov used time to create a favorable interview situation. The informants usually chose to be interviewed in their homes. After the interview, the parents were given the phone number of the psychologist of the project and invited to call if they had questions or concerns. At the end of the interview the questionnaires were left with the parents to be returned by post. They were asked to fill in questionnaires to allow for comparison between their present responses and their responses to the same questionnaires in 1981–1984. Siblings above 16 years of age were also asked to fill in questionnaires as well as being interviewed in depth. This article will focus on the parental reactions.

Of the 25 parents who were interviewed, 23 completed the questionnaires. A few questionnaires were incomplete, reducing the N for some analyses.

Data Analysis

Questionnaires were coded and entered on a permanent data file together with data from the questionnaires that the parents filled in during the first years after the death ($M = 17.6$ months; range = 9–38 months). CSS:Statistica (1991) was used for statistical analysis.

The interviews were recorded and then transcribed by the interviewer. The meanings in the transcriptions were condensed after a 5-step empirical phenomenological mode of analysis (Kvale, 1996). The method involved a condensation of the expressed meanings into more and more essential meanings of the structure and style of the impact of grief over time. The condensed material was categorized on dimensions in line with the quantification tradition in the social sciences (Kvale, 1996).

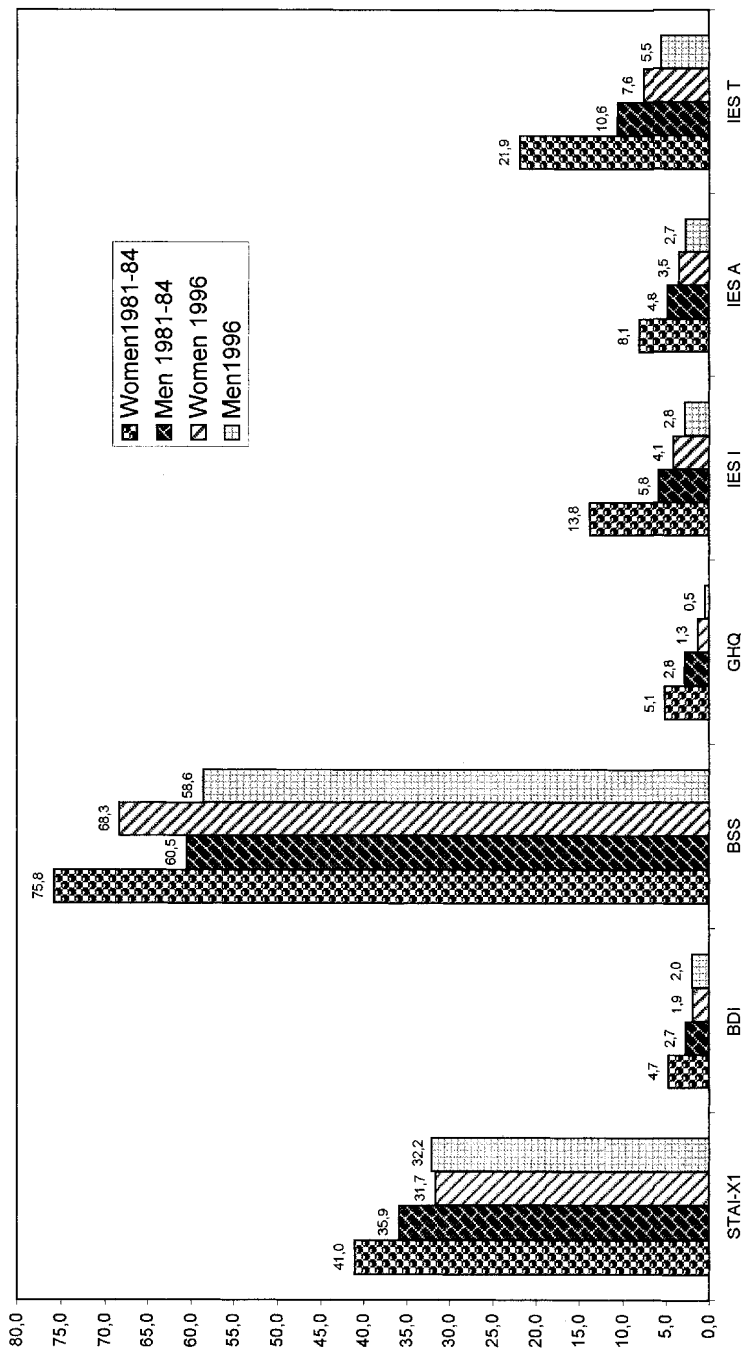


FIGURE 1 Mean scores for different inventories.

Results

Quantitative Results

Mothers' and fathers' scores on different inventories are shown in Table 1. A visual representation is found in Figure 1. Whereas mothers had a mean score that was higher than fathers on all inventories in 1981–1984, in 1996 it was reversed, except for BSS and IES-I. From then to now, all women's mean scores showed a significant reduction (*t* tests for related samples) except for bodily complaints. For fathers, only the IES-I showed a significant decline. In 1996, fathers' mean scores were higher than in 1981–1984 on five of the inventories, though the differences were minimal.

TABLE 1 Number of Respondents, Mean Scores, and Standard Deviation for the Different Inventories, and *T* Test for Dependent Samples

Participants and inventory	1½ year			12–15 year			<i>t</i> test
	<i>N</i>	<i>M</i>	(<i>SD</i>)	<i>N</i>	<i>M</i>	(<i>SD</i>)	
Women							
STAI X-1	12	41.3	(13.2)	12	31.8	(9.3)	3.16**
BDI	12	4.7	(3.5)	12	1.9	(2.3)	2.22*
BSS	11	75.9	(19.0)	12	68.3	(21.7)	1.11
GHQ	11	5.1	(5.4)	12	1.3	(2.5)	3.19**
IES-I	12	13.8	(8.0)	12	4.1	(4.1)	4.41***
IES-A	12	8.3	(7.5)	12	3.5	(5.1)	3.57**
IES-T	12	22.1	(13.8)	12	7.6	(7.0)	4.76***
Men							
STAI X-1	12	35.9	(8.9)	11	35.5	(13.5)	0.38
BDI	12	2.8	(2.3)	10	2.3	(3.6)	–0.24
BSS	12	63.7	(18.8)	11	61.9	(18.8)	0.22
GHQ	12	3.3	(4.8)	11	2.3	(5.9)	0.87
IES-I	12	6.7	(6.0)	11	3.7	(3.3)	2.68*
IES-A	12	4.9	(3.4)	11	5.4	(9.6)	–.10
IES-T	12	11.6	(8.1)	11	9.1	(12.5)	1.18

Note. STAI X-1 = State Trait Anxiety Inventory, State version; BDI = Beck Depression Inventory; BSS = Bodily Symptom Scale; GHQ = General Health Questionnaire; IES-I = Impact of Event Scale, Intrusion subscale; IES-A = Impact of Event Scale, Avoidance subscale; IES-T = Impact of Event Scale, Total subscale.

* $p \leq 0.05$. ** $p \leq 0.01$. *** $p \leq 0.001$.

Table 2 gives more specific information about the scores within the couples. In 1981–1984, there were more mothers who had higher score than fathers within couples on all inventories. In 1996, there were more fathers than mothers that scored higher within the couple on three inventories (STAI, IES-I, IES-A), and on one inventory (BDI) there were as many mothers as fathers who held the higher score. In addition, the numbers of mothers and fathers who had the highest score were more equal for the rest of the inventories. Because of the low number of participants there were only two statistically significant differences. There were significantly more women with the higher score on IES-I and IES-T in 1981–1984.

TABLE 2 Comparison of Parent’s Grief Reactions 1½ and 12–15 Years after the Loss

Inventory	Direction of differences			Wilcoxon Z
	Fathers’ highest score	Mothers’ highest score	Equal score	
1½ years				
STAI	5	7	0	1.26
BDI	3	7	2	1.53
BSS	4	8	0	1.51
GHQ	3	7	1	.92
IES-I	1	10	1	2.22*
IES-A	5	6	1	6.51
IES-T	2	9	1	2.40*
12–15 years				
STAI	7	4	0	.49
BDI	5	5	0	.20
BSS	5	6	0	.31
GHQ	2	3	6	.40
IES-I	6	5	0	.36
IES-A	4	3	4	.59
IES-T	7	4	0	.13

Note. Differences in inventories tested for significance by the use of Wilcoxon matched-pairs signed ranks test for related samples.

STAI = State Trait Anxiety Inventory; BDI = Beck Depression Inventory; BSS = Bodily Symptom Scale; GHQ = General Health Questionnaire; IES-I = Impact of Event Scale, Intrusion subscale; IES-A = Impact of Event Scale, Avoidance scale; IES-T = Impact of Event Scale, Total subscale.

* $p \leq 0.05$.

Table 3 depicts the percentage of men and women that scored above the recommended cut-off points on the following inventories: BDI, GHQ, IES-I, and IES-A. From Table 3 it is evident that there was a decline in the percentage of both mothers and fathers who scored above the cut-off score, except for the BDI (depression) and IES-A (avoidance) where more men scored above the cut-off point after 12 to 15 years compared with one and a half years following the loss. Because of the low N , caution must be taken when viewing the percentages. Still, in 1996 only a few mothers fell into the risk groups as defined by the cut-off score, whereas relatively many fathers were in the depression risk group.

Discussion of Quantitative Results

The most interesting finding from the quantitative data is the decline in mothers' score from the 1980s to the 1990s. When reviewing the mean scores of mothers and fathers, 12 to 15 years after the death, these scores were similar for the two genders. This similarity was remarkable, because women in general usually report more and different psychological complaints and distress than men (see Dyregrov, 1990, for a review). One should thus expect that more complaints would be reported among women than men. If anything, this was reversed in our data. There are

TABLE 3 Percentages of Men and Women Above the Recommended Cut-off Points^a at 1½ and 12–15 Years Following the Loss

Inventory ^b	1½ years		12–15 years	
	Men	Women	Men	Women
Depression (BDI)	25 (3)	58 (7)	40 (4)	18 (2)
General health (GHQ)	33 (4)	42 (5)	9 (1)	17 (2)
Intrusion ^c (IES-I)	33 (4)	75 (9)	9 (1)	17 (2)
Avoidance ^c (IES-A)	17 (2)	50 (6)	18 (2)	17 (2)

Note. BDI = Beck Depression Inventory; GHQ = General Health Questionnaire; IES-I = Impact of Event Scale, Intrusion subscale; IES-A = Impact of Event Scale, Avoidance subscale.

^aFor BDI and GHQ the recommended cut-off score is 4. For the IES the low distress score is less than 9, medium distress score from 9 to 19, and a high distress score is above 19. ^b N for the different time points are found in Table 1.

^cHigh and medium distress levels combined.

several possible explanations for this relationship, such as (a) that mother's higher scores close to the death have forced them to confront and work through what happened more than fathers—something that helps mothers over time; (b) that fathers in the beginning are taking the role of the “strong” one who supports their partner, and are developing mechanisms that effectively stop emotional pain, but these mechanisms continue to prevent them from working through the reactions in a thorough fashion; (c) that men who have experienced the loss of a child are more expressive or acknowledge their reactions more openly than other men, and thus fewer differences are found between them and their female partners after some years (the usual underreporting believed to be present in men is reduced). This study does not allow for testing of these different explanations, which should be subjected to future research.

In a prospective study conducted among parents who lost children to SIDS, stillbirth, and neonatal death in the 1980s (Dyregrov & Matthiesen, 1991), where parents were followed over the first year after the death, both fathers and mothers showed a decline in grief scores. They were measured after 1, 6, and 13 months. If the scores from the last measuring point in this prospective study (13 months) are compared with the mean scores from one and a half years in Table 1 of the present study, the scores from the present study are somewhat higher. This is probably because only SIDS parents are included in the present study, whereas the prospective study included parents following other infant deaths as well. SIDS parents evidence the strongest reactions among parents who experience infant death (Boyle et al., 1996; Dyregrov & Mathiesen, 1987c). If the results from the prospective study are seen in relation to the present results, the following picture emerges: Fathers report less strong reactions than mothers 1 month after the death of an infant child and seem to have “normalized” their scores with few changes over the first year. For mothers, there were some declines in reactions over the first years, but the greatest decline in their reactions took place later. When studied 12 to 15 years after the death, mothers did not differ much from fathers. When this decline in mothers took place is difficult to know because there were no measurement points in between. The qualitative interviews, however, suggest a gradual decline, more than a sudden shift.

For mothers it was only the score for bodily complaints that did not show any significant decline. For men also, this score was almost equal at the two measuring points. Bodily complaints may increase with age in such a manner that any decline in scores on bodily complaints will be outweighed by a natural increase in such problems with age. In a study looking at parents' reactions 2 to 4 years after their infants' death and then 24 months thereafter (Lang, Gottlieb, & Amsel, 1996), it was found that all scores except for somatization showed a significant decline. In Lang et al.'s study, a normal control group was used, and the somatization score in the group of bereaved was not significantly higher than in the normal group.

There is no simple explanation for what led to the decline in scores over time. Besides professional help, the parents mention that the presence of other children or the birth of a new child was of help. Parents also strongly emphasize the importance of talking with their partner over time, and it seems like this was both protecting against further difficulties and important for healing. On the basis of impressions from interviews, it seems like time in itself had been a friend as feelings of grief and longing became less intense and bothersome over time. Although they experienced time as a healing factor, other people hurt the parents by saying "Time heals every wound." Although the mental wounds seemed to heal over time, they easily could be opened again (e.g., by media reports).

The mean reactions in Table 1 show that most mothers and fathers do not have major psychological problems such as anxiety, depression, intrusive images, and thoughts, and that their psychic well-being is similar to "normal" populations in 1996. If we compare the data in Table 1 with data from various Scandinavian studies, mothers in the present study are within the normal range when studied in 1996 on both the STAI (Weisæth, 1984) and the BSS (Person & Sjøberg, 1981). Fathers had a somewhat elevated STAI score in 1996. If the 1996 IES scores are compared with the scores from a study by Malt (1986), where persons injured in accidents were studied two and a half years following the accident, the 1996 scores for SIDS parents were lower than the accident sample.

Despite this "normalcy," for each inventory there was a smaller group that evidenced an increase in sum score from 1981–1984 to

1996. This was masked by the tendency for the total group. For most persons this increase was moderate, or limited to one inventory, but for four persons (3 men, 1 woman) there was an increase on four of the seven sum scores from 1981–1984 to 1996. Lin and Lasker (1996) showed, in a comparable study of parents who had lost their child, that grief patterns are complicated. Though a large group of parents show a decline in scores over time, there were subgroups of parents experiencing an increase in scores, or showing little change over time.

When looking at the individual pairs, the differences between the partners have equalized from the 1980s to the 1990s, and there were even more fathers in each couple who scored higher than mothers on STAI, IES-I, and IES-A. Most striking was the reversal on the IES-I in Table 2 indicating that mothers were more bothered by intrusive images and memories in the 1980s than fathers, whereas this was reversed 12 to 15 years later. In the interviews, parents stated that the father was supporting the mother and did not seem to experience the same intensity or allow grief to appear until the mother grieved less. This social pressure could have led men to use more avoidance strategies that, when they first were in use, were difficult to “turn off.” Although this may have functioned well at the time, it might not have been beneficial over time.

To explore why so many were showing more than normal distress, cut-off scores for the different inventories were used. A few women and some more men fell into the risk groups (see Table 3). Depressed fathers comprised the largest group after 12–15 years. A closer inspection of the data shows that the high-risk persons were found mainly among couples who had separated. Almost all of these persons were already above the cut-off values when measured after one and a half years, before the separation/divorce had occurred. Although this does not say anything about the direction of the causal relationship, it highlights the need to identify high-risk persons early, not only to provide individual help, but also to prevent problems in the couple relationship. The use of cut-off scores is therefore recommended in the first year(s) following a child’s death to identify people at risk who should be followed more closely to offer extra help and support.

We also looked at the parents who scored very low on the differ-

ent inventories after one and a half years. Specifically, parents who simultaneously scored low on the IES (sum score < 9 on the subscales Intrusion and Avoidance), GHQ (sum score < 3), and BDI (sum score < 3) were identified. Four people, two mothers and two fathers (among them a couple) fulfilled these criteria. All of them were still below the same criteria 12 to 15 years later. This means that there was a small group of parents for whom the situation had already normalized during the first 18 months and who still seemed to function well 12 to 15 years later. The risk for so-called "delayed grief reactions" seems low in this group, but the numbers involved in this study are too low to be certain of this finding. Our findings were similar to those of Boyle et al. (1996) who also found little evidence for delayed mental health problems. Such problems usually manifest early, and if parents have not developed problems during the first years, it is unlikely that they will appear later as a consequence of the loss.

One should be careful in drawing conclusions with so few people in each category, but the results may indicate that more fathers than mothers experience depression 12 to 15 years following the loss. Close to one-fifth of the women had scores reflecting lower general health, continued intrusive images, and avoidance reactions. Boyle et al. (1996) found that 1 in 5 mothers were anxious and about 1 in 6 were depressed 30 months following the loss of an infant to SIDS. Hunfeld et al. (1997) found that a quarter of the mothers who experienced a perinatal loss 4 years earlier scored at a level indicating a high level of distress when using the IES-I subscale score. Although the present sample is small, taken together with Boyle et al. (1996) and Hunfeld et al. (1997) results, it provides a clear indication that parents who lose children should be followed over time, and help should be provided for those who are at risk for developing psychiatric complications.

Qualitative Results: Grief and Communication within the Marriage

Mothers and fathers state that they reacted differently to the loss of their child, especially during the first year. Mothers experienced heavier grief with the strongest and most long lasting reactions. Four fathers said that they hid their tears to be able to be strong and help their partner. One of these wives said about her husband,

“After half a year you were sure you were ill too [his wife felt physically and psychologically ill from grieving] and went to the doctor. Before that you had to be strong, supporting me and taking care of the children, so maybe, when I started to recover, you started” There were misunderstandings and blaming between half of the partners. It was especially mothers who had been with the child and found their child on the day of death, that either blamed themselves or felt their partner’s blame. An innocent remark could trigger feelings of guilt, most often in mothers, a feeling that many still harbored. During the interview one wife said to her husband “When your mother always repeats that he was lying on his stomach, I really get hurt.” Surprised, her husband replied “Oh, I was not aware of that.” Few partners had talked openly about blame and self-blame, and for some couples long years of misunderstandings were cleared during the interviews as partners talked for the first time at length about the death. When one father told how he had fled from their home shortly after the death because his grief was unbearable, his wife jumped up screaming, “Was *that* the reason why you went away, I thought you hid because of that stupid law suit we were in. I always wanted to hear how sorry you were, but you did not seem to grieve!”

Only three couples felt that they were not able to discuss the loss, neither during the first period following the loss nor in the years after. Two of these couples are divorced today. They did not feel that a lack of openness was the direct cause of the divorce but more a result of the fact that the couple never had the trust needed in a good relationship. They thought that the relationship would have ended anyway. These parents felt the grief more heavily today, either as psychosomatic complaints or because they had suppressed or encapsulated their grief. Four fathers said that it was hard to understand that the grief could be so strong so many years afterwards. Although the other 8 fathers still experienced difficult moments, they had consciously thought of other things and tried to be engaged in their work or hobbies throughout the years. A father who thought his wife still was too preoccupied with the dead child said, “I feel that the more she talks about it, the more she thinks about it. It is better to think of other things, because we cannot get him back.” Another father stated, “I think that her grief is kept

alive because she nurses it in a way, as she continues to help other parents in the grief groups.”

Traumatic Reactions

Traumatic after-reactions and the feeling of imminent disaster were evident among many parents. In the interviews they talked about their strong fear of something happening to their living children. This was worse closer in time to the loss and following the arrival of a new child. However, even in 1996, two-thirds of the mothers said they had continuing thoughts of disaster. In the interviews, fathers to a much higher degree than mothers stated that they had been able to remove such thoughts over time. They told about a gradual decline that had taken place in this area. One father put it this way; “The feeling of insecurity was present for many years, but now I am more calm.” Five mothers (and one father) still harbored disaster thoughts but tried to hide this from their spouses and children. While talking about this in the interviews, several fathers were surprised that this was still bothering the mothers. One mother described her way of thinking, “I am very afraid that it is something catastrophic when something happens. The fear results in very bothersome thoughts. I do not have the feelings that others have, such as ‘it will not happen to me again.’ Today when I met an ambulance in my neighborhood, I immediately thought that my daughter could be dead, and I hurried home.” A father said, “I get such a lump in my stomach all the time, a feeling of disaster and anxiety that something will happen. I fantasize about all different risks to my loved ones, whether they are at sea, on a motorcycle, in a car, etc.”

From the interviews it was apparent that around one-fourth of the parents had been, and still were, bothered by the intrusive images from finding the dead baby. It was mostly mothers who still harbored such images, as they were the ones who most often found their baby. Self-reproach was something that most parents had harbored over the years and many still experienced. Different thoughts such as, “If we had let the baby sleep in the same room as us,” “let it sleep on its back,” “had the child indoors and not outdoors,” “had taken the child up from his/her bed earlier,” “had more knowledge of life-sustaining maneuvers,” “had better air in

the room,” “had not smoked during pregnancy,” etc., “then maybe the child could have been saved,” had been, and for some still were, present. These reactions had been stimulated and reinforced through media stories over the years. As new theories about SIDS were launched, often presented in a sensational form, feelings of guilt and blame were reactivated.

Five fathers and 10 mothers characterized themselves as more sensitive following the death. They said they cried more easily than before, especially if something reminded them of the child they lost. Several viewed this as a positive thing because it was under their control.

Grief at the Present Time

All the parents felt that they were still marked by their loss, but it varied how much this affected their present functioning. Half the group claimed to have “worked through the loss,” whereas the other half said they had tried to suppress it in many ways and nobody had forgotten. More mothers than fathers claimed to be affected by their grief 12 to 15 years after the death. However, although most mothers felt only slightly affected, a few fathers felt more heavily affected. A mother expressed the long-term impact in the following way, “I remember my neighbor who lost her child 20 years ago. She talked to me about this before I lost my own baby. I can remember that I thought ‘incredible, how can she think so much about this so many years later.’ Now I know this surely is possible. I can vividly understand these parents now.” Another mother said, “After fifteen years you would have thought that it had ‘faded,’ but it feels like it just happened.” A father stated the importance of his child’s death in the following way: “It is obviously the most tragic event of my life, and the event that has affected me the most, both when it happened and over time.” This father had an academic career before the death of his child changed his whole life and he started abusing alcohol. He stated, “Though it is many years ago, it is still difficult to talk about. I have tried to suppress it, not think about it, but it still has great consequences, even today.” Another father who initially did not want to talk about the loss with anybody and is divorced from the child’s mother said, “It has been suppressed the whole time. But

when I see something, that is, a film about children, I get strong feelings. Then it hurts, and I cry. The grief has always been there. Though you do not feel it during the day, it is there. I think it will take another 10 years before it is gone." One dialogue between a couple reflecting on the change over time as they had worked through the loss went like this, "I do not want to forget him" [father] . . . "When so many years have passed it is easy to talk about it" [mother] . . . "Yes, time heals every wound" [father].

Fathers and mothers appeared to handle questions about how many children they had in a similar way. A mother illustrated this by saying, "My answer will depend on who is asking, and what relationship I think I will have to the person in the future. If I believe it will become a close relationship, I include and talk about the child, if not, I don't mention it. I decide this for myself." The threshold of when they will tell others about the SIDS baby seemed lower for mothers. Five fathers, but only 1 mother, said they never counted the SIDS child. Some parents would not include the child because of the reactions it might trigger in others when they talked about it.

Regarding communication about the baby today, parents can be divided into three groups. The two largest groups contain parents who either had a great need to talk about the child today or they had had such a need, but now it was less. The third group did not talk about the child at all or only minimally, as they for different reasons were not able to. There were obvious gender differences in this area, with more mothers saying they still talked about the dead child today. Most fathers said they were through talking about the child, regardless of whether they talked or not during the first years. The small third group that had problems with talking about the child consisted solely of men. Two of the three men in this group were divorced from the child's mother, both expressing that they still struggled with talking about the death because they did not challenge themselves enough to talk about it earlier.

All parents, except for three divorced fathers, had pictures of the dead child. Those who were divorced said they knew their ex-wives had pictures of their child, but they had never got around to getting copies. All the others, except one couple, had a picture of their child on the wall. These parents said it had been important

for them to let younger siblings know that they had had a brother or sister who was dead. Three quarters of the parents kept photo albums and two mothers still kept clothes from their child. The same parents said they remembered the child on the day of birth and death and around major holidays and that they regularly visited the child's grave.

Grief and longing for the dead child were present to varying degrees in all parents. Some reactions intensified around anniversaries, with mothers more frequently mentioning the child on these special days than fathers. This longing had become milder over the years. Most parents related their longing to milestones in other children's development. When children who would have been the same age as their own reached school age, or were approaching other milestones, the longing had been especially strong.

Changed Ways of Thinking

All the parents felt that the death had had an impact on their perspective on life. Many used expressions like "more awe toward life," "a larger perspective on life," or "totally different values after what happened to us." They believed the change would affect them for the rest of their life. They especially mentioned a heightened priority on human rather than on material values. The parents stated that the appreciation of their living children was especially strong, as they had lost one. It was important for them to transfer these values to their "surviving" children. One mother stated, "I think that maybe we have got our four children to see that life is more important than a nice car." Other parents emphasized that they had grown as persons and felt better equipped to help others in similar situations.

Reactions to the Interview

At the end of the interview, the parents were asked for their experience of the interview. Although the parents had very diverse views on other matters throughout the interview, the answers to this last question were almost unanimous. Only two couples stated that they had talked about the cot death "all the time" during the years, so it made no difference talking about this in the interview.

The rest of the parents were more emotional, claiming that the interview had been both painful and good. It was painful because it activated feelings and many details were brought to memory. One mother stated, "It was tough, but I would not have been without it." Two-thirds of the group said they had a lump in their throat, had to cry, and felt sad, but they knew that these were passing feelings. One mother said, "I know I will think a little extra of him in the following days, but I am not afraid of it. I will soon be back to normal." All the parents were glad they had participated, although they had discussed in detail whether they should say yes to the request for being interviewed. A mother, representative of more than half of the group, said, "A great reason for my decision to participate was the wish to help parents in the same situation in the future."

One mother reflected on the possibility of opening old wounds by saying, "You cannot open an old wound, because you are living with it all the time." Half of the parents viewed the interview as helpful for gaining insight and mentioned the therapeutic value of talking. Eight parents (3 men and 5 women) mentioned spontaneously that they had talked about important aspects concerning the loss that they never had talked about before. Two men, who were divorced from the mother and had talked very little about their lost children over the years, cried while saying they should have talked about the child like this many years ago. The interview seemed like therapy for them.

Discussion of the Qualitative Results

On the basis of data from the interviews, two-thirds of the parents reported that the death of their child was affecting them 12 to 15 years after the loss. The dead children continued to live in their parents' memory, some with a strong presence. The loss was there as a background, causing returning pain at anniversaries, more than as an event that overshadows their day-to-day existence. Some had great problems even today, with reminders easily triggering intrusive images of what happened that in turn activated periods of strong feelings.

The qualitative data reflected clear gender differences with mothers evincing more grief at the time of the interviews than

fathers. Mothers also had a greater need to talk about the child and their loss. This need probably also reflected a greater ability and permission in the female culture of talking about emotional issues. The majority of fathers stated that they were through talking about the death, and a small group of fathers continued to have problems talking about the loss. Rubin (1989–1990) stated that losing a small child means losing a potential relationship with hope and expectations about the future, whereas losing an older or adult child means losing a relationship where much energy has been used and a high emotional investment has been made. He expected that the grief over the loss of an expected relationship such as the loss of an infant would be shorter but more intense in the beginning, whereas the loss of an older child would result in a grief of longer duration. The qualitative data do not seem to support such a view. Following the loss of an infant, the parents' grief lasts into the second decade. The nature of parents' responses makes it natural to expect that the grief and longing over the loss of an infant for many parents will continue throughout their life span, perhaps in a milder manner.

Parents seemed to hold on to an inner representation of the dead child, where associations, memories, and anniversaries helped in the continuation of this inner image of their child. Such inner representations are a natural side of grief (Silverman, Nickman & Worden, 1992) and were present in parents who were psychologically well functioning.

While most parents functioned normally in their everyday life, and few outside the closest family knew of the parents' grief, parts of the inner grief continued. Feelings had become milder over the years and intensified when passing anniversaries.

All parents felt that the death had an impact on their perspective on life, usually in the form of a heightened priority on human closeness. A sensitization to nonmaterialistic values and a perception of an increased ability to understand and help others in similar situations, as described by Martinson and coworkers (1994), appeared to go hand in hand with an increased vulnerability and feelings of imminent disaster.

Regarding talking about the loss, fathers felt they were through talking about the death when interviewed in the second decade after their loss. Some fathers still found it hard to talk, in line with

Rubin (1989–1990) who wrote, “the loss of a child, at any age, was a permanently painful topic” (p. 333). Although this was true for some men, most parents were able to talk about their loss without feeling severe pain.

General Discussion

Although there was a clear overlap in the results from the qualitative and quantitative part of this study, it also showed the advantage of using both methods. The standardized inventories gave a useful and important indication of symptoms and complaints and their development over time, but they did not catch the finer nuances in parents’ experience of grief and longing into the second decade after their child’s death. The qualitative interviews provided richness to the understanding of parental reactions that could not be achieved through the inventories. The inventories on their side clearly illustrated how symptoms and complaints that parents experienced declined over time, especially for mothers. They were sensitive enough to reflect the changes that happened over time and the scores showed that though parents subjectively had their child close in their memory and could harbor longing, the psychological balance was re-established for most parents. Finally, this study adds to a number of studies showing that, when sensitively and appropriately carried out, studies on bereaved populations can have beneficial effects not only for the research. The bereaved seem to be able to achieve some meaning from their plight, as the data gathered could improve the situations for others and provide an opportunity for systematically recapitulating the whole story.

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