

Anxiety and vulnerability in parents following the death of an infant

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Empirical data on the subjectively reported anxiety reactions of 117 parents who lost an infant at birth or during the first year of life are presented. From a retrospective survey conducted 1 to 4 years after the death it was evident that parents experienced a great deal of anxiety following the death of their child. Parents who experienced a sudden death in the home reported the strongest anxiety, but other parents who lost their child in hospital at birth or thereafter also experienced strong anxiety. The anxiety for surviving children and later-born children was extensive. In all areas mothers experienced more anxiety than fathers. More intense and longer grief in one's partner, the perceived lack of support from others, being older, and being a female were significantly correlated with anxiety. The results are interpreted as a confirmation that parents who lose their children experience a fundamental change in their beliefs about their family's future security. Better training of health personnel is required to secure an adequate follow up of families that lose a child.

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A sharp increase in fear and anxiety is one of the most common and distressing consequences of a post-traumatic stress disorder (PTSD, American Psychiatric Association; Diagnostic and Statistical Manual of Mental Disorders, 1980). A high level of fear and anxiety has been reported among survivors of concentration camps (Niederland, 1968), rape victims (Scheppelle & Bart, 1983), victims of torture (Allodi & Cowgill, 1982), assault victims (Krupnick & Horowitz, 1980), and hostage victims (Ochberg, 1978).

The increase of fear and anxiety has been linked to a loss of the illusion of invulnerability (Janis, 1969; Janoff-Bulman & Frieze, 1983; Scheppelle & Bart, 1983). This illusion refers to the inclination in people to look at themselves as less vulnerable than others (a review of research is given by Perloff, 1983). This strategy results in a sense of control which allows them to cope with their daily activities. However, a person can no longer hold on to a fundamental belief in his future safety after an extremely stressful event (Janis, 1969).

Several studies have reported an increased anxiety in parents following the death of a child (Clyman et al., 1980; DeFraim & Ernst, 1978; Cornwell et al., 1977; Lewis, 1981). Few authors have looked at anxiety and fear from the perspective of vulnerability. In this paper we will examine parental anxiety from the perspective of vulnerability and explore several aspects of the anxiety which parents experience following the death of their child.

The following questions will be addressed: 1) To what degree do parents react with anxiety following their child's death? 2) Is there any difference in the amount of anxiety reported among parents who experienced different types of loss (stillbirth, neonatal death, Sudden Infant Death Syndrome)? 3) Will the death of a child lead to increased anxiety for surviving and later born children? 4) To what extent do parents experience anxiety during a new pregnancy and birth? 5) What psychosocial conditions show the strongest relationship to anxiety? Finally in the discussion we will address the question: Does the death of a child lead to a loss of the sense of invulnerability in parents?

METHOD

Subjects

The study was carried out at The University Hospital of Bergen. This hospital provides services to families living on the western coast of Norway. At the Department of Obstetrics there are around 4000 deliveries per year, and the Department of Pediatrics treat 3600 inpatients and 15000 outpatients annually. All families who lost their child due to stillbirth or neonatal death (a living child transferred to the Neonatal Intensive Care Unit who later died) at the Department of Obstetrics and the Department of Pediatrics within a 3-year period were included in the study. In addition Sudden Infant Death Syndrome (SIDS) families that came in contact with the Department of Pediatrics in relation to the death were included. This group constituted around 80% of all families in the region that lost a child in SIDS during the time period covered (based on data from the birth register). A total of 28 families were excluded when other types of crises made it ethically and clinically difficult to subject them to the investigation, such as an extremely adverse family situation, or the expectation of a new child in the near future.

A total of 214 parents who lost a child received a questionnaire. Of these, 117 parents who had lost a child 1 to 4 years previously ($M=27.02$ months, $SD=9.20$) returned the questionnaire. The group consisted of 55 couples and 7 mothers, and the respondents' age ranged from 19 to 49 years ($M=29.1$, $SD=5.79$). 62% of the parents were younger than 30 years. 56% lived in urban areas. All the fathers and 95% of the mothers were married. Regarding education, 23% had primary school as their highest level of education, 55% had junior college or correspondingly, and 22% had university or high school background.

The sample consists of three groups of bereaved parents. These three groups were 1) a stillbirth group ($N=31$), 2) a neonatal group ($N=57$), and 3) a SIDS group ($N=29$).

All parents were offered assistance after the investigation. An intervention program was started at the same time as this investigation. Except for 6 SIDS families, none of the parents had received any systematic help prior to the investigation. Qualitative data from the intervention program have been used to illustrate some of the quantitative observations. The psychologist's role allowed access to information not available through a questionnaire study.

Measures

The parents were asked to complete a written questionnaire. The questionnaire contained three parts designed to provide 1) sociodemographic information, 2) data related to the loss itself including the family reactions to the loss, and 3) data on psychic and somatic discomfort.

Questions for the instrument were adapted from the literature on family reactions to the death of a child (Kennell et al., 1970; Cullberg, 1966; Rowe et al., 1978; Benfield et al., 1978; Cornwell et al., 1977; Mandell et al., 1980), and from exploratory interviews and meetings with parents who had lost a child. Subsequent revisions were made. From the more extensive questionnaire only data pertaining to anxiety was used (see Table 1 for specific questions answered by the parents regarding the time period following the loss (question A) and later (questions B and C)). Qualitative information collected through the intervention program gave additional information on the different types of anxiety experienced by the parents.

In addition the questionnaire also included Spielberger's STAI Form X-1 (Spielberger et al., 1970). In the state version of the State-Trait Anxiety Inventory subjects indicate the intensity of their feelings of anxiety at a particular moment in time. The parents were asked to report how they felt now. Cronbach's alpha was 0.94.

Procedure

One week prior to sending the questionnaire, a letter was sent informing the parents of the main objectives of the study; to increase health professionals' knowledge of family reactions after the loss of a child, and to improve support for such families. Three weeks after receiving the original questionnaire, non-responding families were sent a follow-up letter requesting their response. In all communications parents were offered the assistance of a pediatrician and a psychologist (the first author) if they felt the need for asking questions, or for discussing thoughts or feelings concerning the loss.

Mothers and fathers received almost identical questionnaires, and they were requested to fill them out separately. The mother's questionnaire contained questions about sibling reactions, and factual questions that required answers from only one of the parents. The length of the questionnaire was thus 18 pages for mothers, and 15 pages for fathers.

Statistics

The data from the 117 questionnaires were coded and entered on a permanent data file. SPSS (Nie et al., 1975) was used for the statistical computations.

RESULTS

About half (54.7%) of the parents returned the questionnaire (53% of the respondents were women). Based on hospital records, responding and non-responding mothers were compared on the child's weight at birth, the child's life-span, the mother's age, and whether the family lived in rural or urban areas. There were no significant differences between the groups ($t > 0.05$, two-tailed test).

The amount of subjectively reported anxiety varied with the child's type of death.

There was a significant group effect ($F = 10.76$, $df = 2/107$, $p < 0.001$), with the parent's

Table 1. *Frequency of anxiety reactions in parents who lost a child*
Split in three groups according to type of death. Tested for significance between the groups

Question	Stillbirth		Neonatal death		SIDS		F ^a
	N	%	N	%	N	%	
A. To what degree did you react with anxiety following the death?							
1. Not at all	9	33.3	18	32.7	1	3.6	
2. Some	14	51.9	22	40.0	7	25.0	
3. Much	2	7.4	8	14.5	13	46.4	
4. Very much	2	7.4	7	12.7	7	25.0	
Non responders	4		2		1		
Mean	1.89		2.07		2.93		10.76*** df=2/107
B. Are you more anxious for your other children now than before the death?							
1. No	4	17.4	4	8.7	0	0.0	
2. To some extent	10	43.5	25	54.3	8	33.3	
3. To a large extent	9	39.1	17	37.0	16	66.7	
Non responders	8		11		3		
Mean	2.21		2.28		2.67		3.90* df=2/90
C. To what extent were you anxious during a new pregnancy?							
1. Not at all	2	6.9	2	5.9	0	0.0	
2. Very little	3	10.3	7	20.6	2	10.0	
3. Some	9	31.0	10	29.4	10	50.0	
4. Very much	15	51.7	15	44.1	8	40.0	
Non responders ^b	0		0		3		
Mean	3.28		3.12		3.30		0.37 df=2/80

^a One way analysis of variance.

^b The non responders are those who indicated that they either expected or had got a new child following the loss, but did not answer this question. * $p < 0.05$ for stillbirth versus SIDS, and neonatal versus SIDS, using a range-test (lsd-procedure), *** $p < 0.001$ for stillbirth versus SIDS, and neonatal versus SIDS, using a range-test (lsd-procedure).

subjective experience of anxiety in the period following the loss significantly higher in the "cribdeath" or SIDS (Sudden Infant Death Syndrome) group, than in both the stillbirth and the neonatal group (Table 1 A). Although not included in the table, women reported more anxiety than men in all three groups. The percentage of women versus men who reported 'much' and 'very much' anxiety was for the stillbirth group; 23.1% vs. 7.1%, for the neonatal group; 40% vs. 12%, and for the SIDS group; 92.9% vs. 50%.

The question A in Table 1, did not specify the kind of anxiety that the parents felt. Qualitative information from the intervention program indicated that the anxiety was both of an unspecified kind, the parents felt another disaster was imminent, and more specific, as fear of the dark, fear of being alone etc.

Clinically, parents often expressed anxiety for their partner. This anxiety took the form of needing reassurance of he or she being well or safe. Fear of oneself having a life-threatening disease, most often cancer, was also reported, together with the fear of own death. "I am afraid of being seriously ill, having to die and not being with the others. I think of illness and death nearly every day" (mother, neonatal death).

Parent's anxiety were often triggered by intrusive images of the death. Sleep disturbances frequently followed periods of increased anxiety.

"After I have gone to bed I frequently see images—just like slides being turned on and off on a screen. I can't stop them when I want to, and that's why I lose control. Everything feels dark and suffocating in my bedroom, my heart starts beating faster and I get difficulties breathing. I want to get out of bed, but it feels like being tied to the bed, and I can't move" (mother, neonatal death).

Parents also reported fear of something happening to surviving or later born children. SIDS parents reported significantly higher levels of anxiety for their surviving children than the other two groups ($F=3.90$, $df=2/90$, $p<0.05$, see Table 1 B).

One father who lost his child in cribdeath said that his fear for their surviving child could be compared to clinging to two ropes up in the air. If one rope broke, he would desperately cling to the other.

A majority of the couples tried to conceive a new child soon after the death of the child. In our sample 78% of the parents either had or expected a new child at the time of study (1 to 4 years following the loss). Parents frequently reported anxiety in relation to a new pregnancy and birth, as indicated in Table 1 C. When the percentages for the categories for "some" and "very much" were taken together, SIDS parents reported more anxiety than the other two groups of parents. However, in the category "very much", stillbirth parents had the largest numbers of responders (51.7%), followed by neonatal death parents (44.1%) and the SIDS parents (40%). No significant group differences were observed. For the categories "some" and "very much" taken together, the percentages for women versus men on this question (question C) were respectively: stillbirth group 86.7% vs. 78.6%, neonatal group 77.7% vs. 68.8%, and SIDS group 100% vs. 77.7%.

Qualitative information indicated that the anxiety sometimes was extremely high, and experienced simultaneously with sleep disturbances, nightmares, and intrusive, compulsive thoughts. If something was physically wrong with the new child, the anxiety rose sharply. If the child was admitted to the Pediatric ward it was not uncommon to find that the mother expected a message about the child's death every time someone came through the door to her room. The fear of reoccurrence was increased by similarities with the original traumatic situation, i.e. the new child was of the same sex as the deceased, if there was physical similarities between the two children ("God, I hope it will not be a girl that looks like her"), or the new child was born at the same time of year as the deceased child.

STAI-X (sumscore) showed state anxiety (how the parent felt *now*, 1 to 4 years following the death) to be highest in the SIDS group ($M=36.78$, $SD=10.97$), and the

stillbirth group ($M=36.28$, $SD=12.01$) while the neonatal group had a lower mean score ($M=33.71$, $SD=10.12$). No significant group effect was observed.

Table 2 provides an overview of some psychosocial conditions that are believed to be of importance in grief reactions. The relationship between these psychosocial conditions and state anxiety for the whole sample is presented.

A total of 5 out of 16 psychosocial conditions showed a significant relation to state anxiety (using product moment correlation). The more difficult it was to communicate with the spouse following the death, and the stronger or longer grief the informant felt he/she experienced compared to his/her spouse, the more anxiety he/she experienced at the time of study. More anxiety was also related to an experienced lack of support from others. There was also a positive correlation between anxiety and age. No relationship between state anxiety and the number of children in the family was observed.

As the interval between the actual loss and the time of participation in this research varied as much as 1 to 4 years, a partial correlation was computed to control for this interval. As evident from Table 2, whether the parents answered early or late in this time period had only minor influence.

Fig. 1 illustrates a multiple regression analysis that shows the relative relationship between state anxiety (dependent or criterion variable) and some of the psychosocial/demographic conditions (independent variables or predictors) listed in Table 2. Relative

Table 2. *Demographic/psychosocial variables, and their correlation and partial correlation (controlled for the interval between death and participation in this research) with state anxiety (Pearson product-moment correlation)*

Question	The whole group		State anxiety ($n=117$)	
	M	SD	r	pr
1. Age (years)	29.17	5.79	.19*	.18*
2. Education	-	-	.01	.02
3. Number of children	1.51	0.78	.04	.04
4. Sex	-	-	.23*	.24*
5. Interval between death and participation in research (months)	27.02	9.20	-.12	-
6. Better/worse relationship to partner	1.62	0.84	.07	.09
7. More difficult to talk with partner	1.65	0.71	.18*	.17
8. Informant felt partner reacted with more intense grief than him/herself	2.04	0.86	.30**	.30**
9. Informant felt partner's grief reaction was of longer duration than his/hers	2.07	0.89	.24*	.25*
10. Informant experienced partner's reaction as different from his/hers	1.87	0.69	.07	.06
11. Family avoided death in conversations	1.87	0.78	.12	.10
12. Friends avoided death in conversations	2.14	0.78	.10	.10
13. Lacked support from others	2.32	0.92	.35***	.34**
14. Post-loss contact with hospital	1.36	0.48	-.03	.02
15. Support from hospital	2.69	1.05	.02	.02
16. Satisfaction with information	1.83	0.84	.16	.18

Note. Questions 6-12, and 16 are trisected, with the value 1 defined as a positive value, value 2 defined as neither positive nor negative, and value 3 defined as negative. Questions 13 and 15 are listed with four values, where value 1 denotes very good support and value 4 very little support. In question 14 value 1 is defined as the existence of post-loss contact with the hospital, while value 2 denotes no such contact. * $p<0.05$, ** $p<0.01$, *** $p<0.001$.

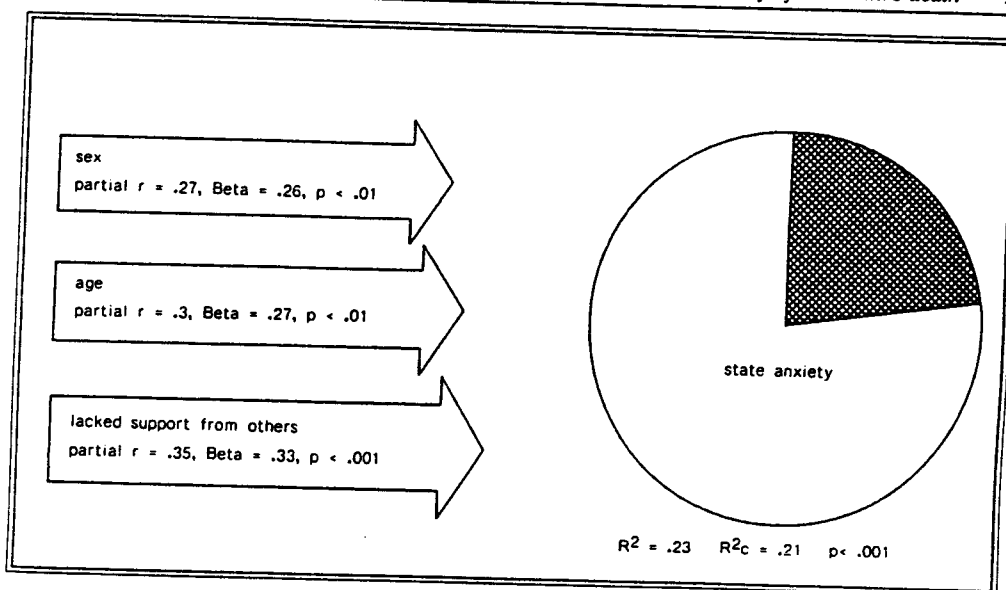


Fig. 1. Psychosocial variables with the strongest predictor contribution to explained variance of state anxiety in parents who have lost a child. The relative contribution of each variable is given in partial correlations (partial r) and beta. The significance level for each predictor-contribution is also listed (p). The circle represents the variance in the criterion variable or the predicted index. The shaded part of the circle denotes variance explained by the predictors. Total explained variance is listed as the squared R^2 .

relationship is explained as the unique contribution the different predictors give to explain observed variance in the criterion variable, when the other predictors are held constant.

Different combinations of the psychosocial conditions listed in Table 2 were utilized in several regression models. In trying to isolate the demographic/psychosocial variables that would yield the optimal prediction equation, the cutoff point was determined by statistical criteria (Nie et al., 1975): 1) that the overall F ratio of the equation be significant, and 2) that the unique contribution (partial correlation and beta-weight) of each predictor in the final regression model be significant at 5% level. The regression model in Fig. 1 illustrates the psychosocial conditions which best predicted state anxiety. Non-significant ($p > 0.05$) predictors were excluded from the model (beta-weights for the excluded predictors vary between 0.20 and -0.06 , using a backward exclusion paradigm). The psychosocial conditions included in this model predicted 23% of the variation in state anxiety ($R = 0.48$, $R^2 = 0.23$, $R^2_c = 0.21$, $F = 11.14$, $df = 3/113$, $p < 0.001$). The strongest predictors in explaining variations in anxiety were the predictors' "lack of support from others", "age", and "sex", in their respective order.

DISCUSSION

The results showed that subjectively reported anxiety was very common in parents following the death of their child. This was especially so with parents who experienced a sudden death in the home (SIDS), but also following death at birth and thereafter. The anxiety for surviving and later-born children was even more extensive. Anxiety was also present during a new pregnancy and birth, and in the time following the birth. In all these

areas women experienced more anxiety than men (see Dyregrov (1985) and Dyregrov & Matthiesen (1987) for more extensive data and discussion relating to parental sex differences in grief.

Anxiety was related to problems of communication among the two partners, to differences in their respective grief reactions, to the perception of others as unsupportive, to increasing age, and to sex.

During the clinical intervention program many forms of anxiety have been noted, such as anxiety for one's spouse and for one's own health. Often the anxiety was felt as an everpresent, gnawing insecurity. Our results confirm those of others (Clyman et al., 1980; DeFrain & Ernst, 1978; Cornwell et al., 1977; Lewis, 1981) showing increased anxiety in parents following the death of a child. Parents who experienced SIDS reported more anxiety on all questions than the other two groups. Our material shows that as many as 50% of the fathers and 93% of the mothers who experienced a SIDS death reported strong to very strong anxiety after the death. A SIDS death gives no time for preparation, as in most perinatal and neonatal deaths. Most SIDS deaths occur in the home, with the parents finding their baby. Many parents developed aversive reactions towards their apartment or house where the death took place. "I felt it smelled of corpse inside. I did not dare walk into the house for days afterwards, and it took several weeks before I could enter the room where I found her. I shivered" (mother, SIDS). SIDS represents a highly unpredictable event, it occurs without warning or a clear explanation, and it is difficult to guard against reoccurrence.

The sex differences in anxiety reported here also confirms the general impression from other studies where mothers have been found to experience more intense and long-lasting grief than fathers (Clyman et al., 1980; Helmrath & Steinitz, 1978; Wilson et al., 1982; Walwork, 1985). See also Dyregrov & Matthiesen (1987) for further analysis.

We found a relationship between anxiety expressed at the time of study and the difficulty the parent felt communicating with one's spouse following the death. Anxiety was also related to the perception of one's spouse reacting longer and more strongly than oneself. Although the correlation does not imply any causal direction, it seems justifiable to believe that the intrafamilial communication will affect one's emotional reactions. Communication seems necessary in securing support and care from one's spouse, and lack of such support makes one prone to more anxiety. Being unable to exchange information about one's reactions and seeing the partner react differently than oneself, probably adds to feelings of isolation and diminishes the chance of mutually reducing insecurity and anxiety.

The death of a child leads to a strong increase in parental fears regarding their other children, as evidenced in other studies (DeFrain & Ernst, 1978; Clyman et al., 1980; Kennell et al., 1970). The unpredictability of the SIDS deaths render these parents especially vulnerable. In our intervention program parents have reported overprotection of their other children, in an effort to assure that nothing will happen to them, (see also DeFrain & Ernst, 1978; Cornwell et al., 1977; Clyman et al., 1980; Kennell et al., 1970). Others reported the need to be physically closer to their children for comfort (as also reported in Mandell et al., 1983). These changes in "parenting" may hamper the identity development of the child, and it is reasonable to think that the parents' anxiety lead to increased anxiety in the children.

The parents' fear was also present through a new pregnancy, with SIDS parents reporting the most fear. Again, the unpredictability of these deaths must bear the responsibility for this. This fear has been noted in many SIDS studies (cf. Blueglass, 1981; Lewis, 1981), and the anxiety of SIDS mothers has been found to be more than a transitory phenomenon (Lewis, 1981). But although SIDS parents generally experienced most anx-

iousness during a pregnancy, the stillbirth group reported "very much" anxiety most frequently. This was to be expected, as the death took place during their last pregnancy. Regarding both surviving and later-born children, parents seemed to develop an anxiety-preparedness; thus being ready for the worst to happen. To some extent this characterizes all three groups.

Multiple regression analysis showed that anxiety to a relatively high degree could be predicted from psychosocial conditions such as the parents' age, the perceived lack of support from others, and the sex of the parent. Anxiety increased with advancing age, and this could not be explained by having more living children. Our finding was in opposition to Benfield et al. (1978) who found no relationship between age and parental grief score. In their study, however, they did not focus on anxiety specifically. In the clinical follow-up we noted that younger parents more often than older seemed more "carefree", more apt to take the view that the future was ahead of them, and less willing to dwell on the negative impact of the event.

It should be emphasized that a relatively large part of the variance in anxiety was not predicted from the psychosocial variables utilized. It must also be emphasized that multiple regression analysis is a method expressing degree of covariance between variables, and it does not imply any causation. The method is descriptive or an interpretation tool (Kim & Kohout, 1975). Dependent and independent variables are chosen from rational considerations.

Our results confirm the mitigating effects of social support in loss situations, where lack of social support is found to be related to more adaption problems in both widowers and widows (Vachon et al., 1982; Cobb, 1976), and in parents following the death of a child (Klaus & Kennell, 1970; Laurell-Borulf, 1982; Spinetta et al., 1981). As parents in this study received very little follow up care and support from health professionals, it is not unexpected that their perception of support from the hospital shows little relationship to later experienced anxiety. The reaction of the parent's closest social surroundings (spouse and close family) was more important for long-term anxiety than the support and care received from health professionals.

Do parents lose their sense of invulnerability as a consequence of the loss? The results from the questionnaire as well as clinical observations document the heavy impact the loss of a child had on the parents' assumed feelings of security in the world. Especially following SIDS loss the parental reactions paralleled those reported following other extreme life events (Niederland, 1968; Scheppele & Bart, 1983; Allodi & Cowgill, 1982; Krupnick & Horowitz, 1980; Ochberg, 1978). From a relatively uncomplicated view of the world as a "safe" place to live, the world was turned into a place full of uncertainty, insecurity and fear. The cognitive frame for the experienced anxiety seemed to be an apprehension about a new disaster; "it has happened once and it can happen again". A mental "set" for experiencing even highly safe situations as unsafe was often evident. For many this implied a thorough change in their beliefs about the world and the future; "The truth is that life is on loan, even my own. This is increasingly clear to me. I am cautious, and do not plan a long time ahead" (father, neonatal death).

The quantitative data is gathered retrospectively. The human mind seems to forget the painful and remember the pleasant (see Ericsson & Simon, 1980). Thus one may expect an underreporting of painful feelings in a retrospective account of the loss experience. Although many parents failed to return the questionnaire, our response rate was similar to other studies conducted several years following the loss of a loved one (see Shanfield, Benjamin & Swain, 1984). Despite the relative high anxiety reported by the parents in this study, there is reason to believe that the anxiety level is even higher if non-responders are taken into account. Other studies have shown that non-responding parents are more

emotionally affected following the loss than responding parents (Clarke & Williams, 1979; Cooper, 1980).

All in all this indicates that our estimates of emotional reactions probably are lower than the true prevalence of reactions among parents who have lost their child.

CONCLUSION

From the results of this study it is evident that parents experience a great deal of anxiety following the death of their child. Parents who experience a SIDS death report more anxiety following the death than parents experiencing neonatal death and stillbirth. Regarding anxiousness for other children, and anxiousness during a new pregnancy, there is no over all group effects. A multiple regression analysis show "sex", "age", and "lack of support from other" to be the strongest predictors in explaining variations in state anxiety (STAI).

The results illustrate that anxiety experienced following the death of a child in many respects is comparable to the reactions shown to other traumatic life events. The illusion of invulnerability is very often badly shaken. While we have focused on anxiety, this is true regarding other reactions as well, such as sadness and intrusive thoughts (see Dyregrov & Matthiesen, 1985). The anxiety was not just a transitory phenomenon but continued over time, and was prominent in relation to a new pregnancy and birth.

In the literature on follow up of bereaved parents anxiety reactions aspects have received little attention. Health personnel are often inadequately and insufficiently trained to understand and handle the increase in vulnerability and anxiety among parents. To prevent the post-traumatic anxiety problems from turning into more permanent problems, it is important to have better trained health personnel, to provide families with adequate follow-up from hospitals, primary health providers and others. From a therapeutical viewpoint it seems well advised to use therapeutic techniques and working methods devised in relation to other traumatic life crises (as coherently presented by Horowitz, 1976, and Schrignar, 1984).

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