Anxiety and depression in parents 4–9 years after the loss of a child owing to a malignancy: a population-based follow-up

ULRIKA KREICBERGS*, UNNUR VALDIMARSDÓTTIR, ERIK ONELÖV, JAN-INGE HENTER AND GUNNAR STEINECK*

Clinical Cancer Epidemiology, Department of Oncology and Pathology, Karolinska Institutet Z6:01, Karolinska Hospital, SE-171 76 Stockholm, Sweden; Childhood Cancer Research Unit, Karolinska Hospital, Department of Women and Child Health, Karolinska Institutet, Q6:05, Karolinska Hospital, SE-171 76 Stockholm, Sweden; Stockholms Sjukhems Foundation, Mariebergsgatan 22, SE-122 35 Stockholm, Sweden; Oncologic Centre, M8, Karolinska Hospital, SE-171 76 Stockholm, Sweden

ABSTRACT

Background. Some consider the loss of a child as the most stressful life event. When the death is caused by a malignancy, the parents are commonly exposed not only to their own loss, but also to the protracted physical and emotional suffering of the child. We investigated parental risk of anxiety and depression 4–9 years after the loss of a child owing to a malignancy.

Method. In 2001, we attempted to contact all parents in Sweden who had lost a child due to a malignancy during 1992–1997. We used an anonymous postal questionnaire and utilized a control group of non-bereaved parents with a living child.

Results. Participation among bereaved parents was 449/561 (80%); among non-bereaved 457/659 (69%). We found an increased risk of anxiety (relative risk 1·5, 95% confidence interval 1·1–1·9) and depression (relative risk 1·4, 95% confidence interval 1·1–1·7) among bereaved parents compared with non-bereaved. The risk of anxiety and depression was higher in the period 4–6 years after bereavement than in the 7–9 years period, during which the average excess risks approached zero. Psychological distress was overall higher among bereaved mothers and loss of a child aged 9 years or older implied an increased risk, particularly for fathers.

Conclusions. Psychological morbidity in bereaved parents decreases to levels similar to those among non-bereaved parents 7–9 years after the loss. Bereaved mothers and parents who lose a child 9 years or older have on average an excess risk for long-term psychological distress.

INTRODUCTION

The loss of a child is often referred to as the most stressful life event possible and it entails a major change for the parents (James & Johnson, 1997). A recent Danish follow-up study of parents who had lost their child owing to various causes showed an increased risk of mortality from both unnatural and natural causes, especially during the first 3 years of bereavement (Li *et al.* 2003). Although not always fatal, psychological complications may greatly affect the parents' and their families' life and well-being. The duration of parental psychological morbidity after the loss of a child has not yet been established and it is not known when and if bereaved parents' mental health ever reaches the levels of the non-bereaved.

* Address for correspondence: Dr Gunnar Steineck or Ulrika Kreicbergs, Clinical Cancer Epidemiology, Z6:01 Karolinska Hospital, SE-171 76 Stockholm, Sweden.
 (Email: Gunnar.Steineck@onkpat.ki.se)
 (Email: Ulrika.Kreicbergs@onkpat.ki.se)

Parental grief

A number of studies have considered parental grief. Middleton *et al.* (1998) followed 44 bereaved spouses, 40 adult children and 36 parents for 13 months; and found the parents to have the most intense grief reaction measured by the Bereavement Questionnaire. Lundin (1984) came to a similar conclusion after an 8-year follow-up of bereaved persons in Sweden. Murphy *et al.* (2002) investigated 173 parents who had lost a child in a violent death 4–60 months earlier. Mental distress in bereaved parents was found to decrease over time without any distinct turning point. In a 12–15 years follow-up of 26 parents who lost a child to sudden infant death, Dyregrov & Dyregrov (1999) reported that most parents still considered the death of the child to affect their daily life but few parents were at risk of psychological complications at the time of follow-up.

Loss owing to malignancy

When the death is caused by a malignancy, the parents – in addition to suffering loss – are commonly exposed to the protracted physical and emotional suffering of the child (Wolfe *et al.* 2000). On the other hand, the opportunity to prepare for the impending loss of their child may be adaptive. However Meert *et al.* (2001) studied 57 parents shortly after, and 2–5 years after the death of their child and found that parents whose child died acutely showed greater grief (Texas Revised Inventory of Grief) than parents whose child died from chronic illness. Anxiety and depression was not reported. The duration of psychological morbidity of parents who have lost a child owing to a malignancy is not yet known. Sirki *et al.* (2000) interviewed one or both parents of 86 children 1·3–7·9 years (mean 4·4 years) after the child's death due to a malignancy. The parents' self-reported 'recovery time' after the loss was less than 2 years. The self-reported recovery was related to depression but not anxiety and no control group was used. Shanfield *et al.* (1984) studied 24 parents who lost an adult child to cancer 2 years previously and found that parents differed from a normative population in terms of symptoms of obsessive–compulsive disorder and psychoticism (Brief Symptom Inventory). Rando (1983) followed 54 parents from 2 month to 3 years after the loss of their child from malignancy and found an intensification of grief in the third year. In a study of 45 parents 2 and 7 years after the loss of a child owing to a malignancy, Martinson and co-workers (1991) found no difference in depression from year 2 to year 7.

Other potential risk factors

In addition to the cause of death, other factors may affect bereavement adjustment after the loss of a child. The literature indicates that the affectional bond between child and parent – suggested in Bowlby's attachment theory (1980) – may be of primary importance. Shanfield *et al.* (1984) found that emotional closeness to the child predicted bereavement outcome. The parent's gender is another factor; mothers have been found to have more difficulties in adjusting after the trauma than fathers (Vance *et al.* 1995; Schwab, 1996). Also, the child's age at death – which may reflect the amount of time for the affectional bonds to develop – seems to affect bereavement outcome. Some studies indicate that the loss of an older child may entail a longer grief process (Rubin, 1993; Sirki *et al.* 2000).

Another important predictor of parents' adjustment after the loss of a child may be religious faith. Religious faith in bereaved parents has been suggested to increase after the loss (Shanfield *et al.* 1984) and parents with strong faith appear to resolve their grief more rapidly than others (Walsh *et al.* 2002).

From the existing evidence, it is difficult to conclude if and when the risk of anxiety and depression in a group of parents who have lost their child to a malignancy returns to the risk levels of non-bereaved parents. Conclusions from the few previous studies are hampered owing to small series, short follow-up, varying measures of dependent variables, lack of control of confounding factors, large number of drop-outs, but mainly due to the lack of controls. Furthermore, the generalizability of previous findings on the risk factors of parental bereavement outcome is a subject of continuous investigation.

The loss of a child to malignancy in Sweden – hypotheses

With population-based registers, Sweden has excellent conditions for research in this field.

The Swedish National Register of Cancer comprises, on the whole, all incidental cases, and the Swedish National Register of Causes of Death includes virtually all who have died of cancer, providing means for establishing cohorts without selection problems. Through a national registration number, unique for each citizen in Sweden, a child can be linked to his or her parents, and through the Swedish Population Register parents can be followed for as long as they live in Sweden. Utilizing these sources, we traced all parents in Sweden who had lost a child owing to a malignancy during the period 1992–1997 and assessed their risk of psychological morbidity. Our hypothesis is that bereaved parents' psychological morbidity in terms of anxiety and depression declines with time. Further, we hypothesize that parents who lose an older child, who are less religious or who are mothers have an increased risk for long-term psychological morbidity compared to others.

SUBJECTS AND METHOD
Subjects

We identified 368 children who were diagnosed with malignancies before the age of 17 years and who died before the age of 25 years in Sweden during 1992–1997, in the Swedish National Register of Causes of Death linked with the Swedish National Register of Cancer. The children's parents were identified in the Swedish Population Register; a parent was defined as being the guardian of the child at the time of the child's diagnosis. Parents were eligible if they (1) were born in one of the Nordic countries, (2) had a non-confidential phone number, (3) understood Swedish and (4) were guardians of the child. Guardians not biologically related to the child are also included, and are referred to below as parents. In the case of bereaved parents, we required a verification of the child's diagnosis, and permission from the child's former physician to contact the family; permission was given for all families. We found 561 bereaved parents meeting the criteria and randomly selected 368 children matched to the deceased children for date of birth, sex and region of residence and identified their parents in the Swedish Population Register as a control group. Altogether 659 non-bereaved parents were identified.

Data collection

Between August 2001 and October 2001, we sent 561 bereaved parents (mothers and fathers) an introductory letter explaining the objectives of the study and invited them to participate. Thereafter we telephoned the bereaved parents and asked if they would like to see the questionnaire; 531 agreed and received it. To safeguard parental anonymity also *vis-à-vis* the researchers, the questionnaire was returned (non-coded) in one envelope and a card notifying the investigators that this had been done was returned separately. Ten days after the questionnaire was sent out, it was followed by a combined thank you note/reminder card. An interviewer called the parents who did not return the notifying answer card. Between November and December 2001, 659 non-bereaved parents (mothers and fathers) were sent an introductory letter explaining the objectives of the study and were sent a questionnaire a week later if they did not contact us in between. Except for the initial telephone call the same procedure concerning the questionnaire was used for non-bereaved and bereaved parents. The method has been developed during investigations of mothers who have experienced stillbirth, cancer survivors and women who have lost their husband to cancer (Rådestad *et al.* 1996; Bergmark *et al.* 1999; Henningsohn *et al.* 2001; Valdimarsdottir *et al.* 2002). The study was approved by the Regional Ethical Committee of the Karolinska Institute.

The questionnaire

The questionnaire was developed on the basis of seven successive in-depth interviews with bereaved parents. Face-validity was performed with 15 bereaved parents; an investigator accompanied these parents when they completed the questionnaire, observing whether or not the questions were understood correctly. In a pre-study of 22 bereaved parents as well as 23 non-bereaved parents, means for collection of data were tested, and this prompted some final changes in the questionnaire. The questionnaire for bereaved parents included 129 questions with a total of 365 items and the one for the non-bereaved had 39 questions with 148 items including current anxiety, depression, psychological well-being and self-assessed quality of

life. The questionnaire assessed the symptoms of the parent's anxiety, depression, psychological well-being and self-assessed quality of life on a 7-point visual digital scale using, for example, the following wordings: 'Have you been anxious during the past month?' (the scale was anchored with 'Never' to 'All the time'), 'How would you describe your quality of life during the past month?' (the scale was anchored with 'Worst possible quality of life' to 'Best possible quality of life'). The respondents were asked about sleep disturbances and intake of sleeping pills and tranquillizers during the previous month and the response categories were: 'No, never', 'Yes, once or twice', 'Yes, regularly (1–2 times per week)', 'Yes, frequently (about 3–4 times per week)' or 'Yes, nearly every night'. For anxiety and depression-related symptoms, Spielberger's Trait measure from the State-Trait Anxiety Inventory (STAI-T; Spielberger *et al.* 1983) and the Centre for Epidemiological Studies Depression Scale was used (CES-D; Radloff, 1994). We summarized the responses on the STAI-T and CES-D respectively by giving a score on a scale of 1–4 (1 = least severe symptoms, 4 = most severe symptoms) for each answer and dividing the sum of these scores by the number of questions answered (all responders that had more than three missing values were excluded). For the summary average score on STAI-T and CES-D we used a cut-off point at the 90th percentile among non-bereaved parents for a reference of levels of anxiety and depression reaching clinical significance. We studied the proportion of bereaved and non-bereaved parents above this cut-off point. The visual digital scale is a simple and quick method for measuring the respondent's subjective evaluation of their anxiety and depression (as well as for self-assessed quality of life and psychological well-being). This method and the accompanying scales have been tested for face-validation and used in previous investigations including approximately 10 000 individuals and carried out by the Clinical Cancer Epidemiology group (e.g. Rådestad *et al.* 1996; Bergmark *et al.* 1999; Henningsohn *et al.* 2001; Steineck *et al.* 2002*a, b*; Valdimarsdottir *et al.* 2002). Visual digital scales correlate with the other validated scales used in our study: STAI-T Spielberger Anxiety scale and CES-D (Valdimarsdottir, 2003).

Statistics

The results are presented as relative risks (RR), calculated as the proportion of bereaved parents reporting a particular symptom divided by the proportion of non-bereaved parents reporting it. We adjusted relative risks and associated 95% confidence intervals (CI) for demographic factors with Mantel–Haenszel's method. *p* values were calculated with Fisher's exact test.

RESULTS

Subjects

Among 561 eligible bereaved parents, information was supplied by 449 (80%) and among the 659 eligible non-bereaved parents 457 (69%) supplied information. Demographic factors were similarly distributed between the two groups, except that the age was lower and more of the parents were married in the bereaved group (Table 1).

Bereaved/non-bereaved

When compared with non-bereaved parents, the bereaved parents were more likely to report anxiety (RR 1·5, CI 1·1–1·9), depression (RR 1·4, CI 1·1–1·7) low or moderate psychological well-being (RR 1·3, CI 1·1–1·5) and a low or moderate self-assessed quality of life (RR 1·1, CI 1·0–1·3) (Table 2). Parents bereaved for 4–6 years were more likely to report anxiety (RR 1·7, CI 1·3–2·3) and depression (RR 1·7, CI 1·4–2·3) on the visual digital scale compared to non-bereaved parents. The corresponding figures for parents bereaved for 7–9 years were RR 1·2, CI 0·9–1·7 for anxiety and RR 1·0, CI 0·7–1·3 for depression. The overall observations based on the visual digital scale were similar to those obtained with Spielberger's Trait measure from the State-Trait Anxiety Inventory and the Centre for Epidemiological Studies measure of depression (Table 2, Fig. 1).

Gender differences

Overall (irrespective of time since loss), bereaved mothers were more likely to report anxiety (RR 1·6, CI 1·1–2·3) and depression (RR 1·5, CI 1·1–2·0) on the visual digital scale compared to non-bereaved mothers. Bereaved fathers (overall) did not report statistically

Table 1. *Characteristics of parents who have lost a child to malignancy and controls*

Characteristics	Controls	Bereaved parents
Identified eligible in registries (*n*)	659	561
Reasons for no participation [*n* (%)]		
Declined to participate	50 (8)	30 (5)
Agreed but did not participate	25 (4)	59 (11)
Not reachable	39 (6)	23 (4)
Unknown or other causes	88 (13)	
Total non-participation	202 (31)	112 (20)
Providing information [*n* (%)]	457 (69)	449 (80)
Relationship [*n* (%)]		
Biological parent of the child	453 (99)	438 (98)
Non-biological parent	4 (<1)	9 (2)
Not stated	– (–)	2 (<1)
Sex [*n* (%)]		
Man	191 (42)	191 (43)
Woman	266 (58)	251 (56)
Not stated	– (–)	7 (2)
Age [*n* (%)]		
26–41 years	90 (20)	139 (31)
42–49 years	175 (38)	160 (36)
50–69 years	189 (41)	146 (33)
Not stated	3 (<1)	4 (<1)
Marital status [*n* (%)]		
Married or living with the child's other parent	312 (68)	329 (73)
Married or living with another partner	40 (9)	51 (11)
Has a partner but lives alone	35 (8)	17 (4)
Single	68 (15)	45 (10)
Not stated	2 (<1)	7 (2)
Number of children today [*n* (%)]*		
1	41 (9)	32 (7)
2	203 (44)	144 (32)
3	135 (30)	161 (36)
4 or more	75 (16)	107 (24)
Not stated	3 (<1)	5 (1)
Level of education [*n* (%)]		
Primary school	107 (23)	83 (18)
Secondary school	192 (42)	215 (48)
University	156 (34)	141 (31)
Not stated	2 (<1)	10 (2)
Employment status [*n* (%)]		
Employed	376 (82)	370 (82)
Unemployed	20 (4)	10 (2)
On sick leave/retired	37 (8)	36 (8)
Housewife/husband	13 (3)	5 (1)
Home with children	2 (<1)	8 (2)
Student	7 (2)	14 (3)
Not stated	2 (<1)	6 (1)
Residential region [*n* (%)]		
Rural	90 (20)	99 (22)
Small village/town	268 (59)	273 (61)
City (>500 000 pop.)	97 (21)	68 (15)
Not stated	2 (<1)	9 (2)
Religiousness [*n* (%)]		
Not religious at all	206 (45)	185 (41)
A little religious	127 (28)	155 (35)
Quite religious	95 (21)	68 (15)
Strongly religious	23 (5)	25 (6)
Not stated	6 (1)	16 (4)

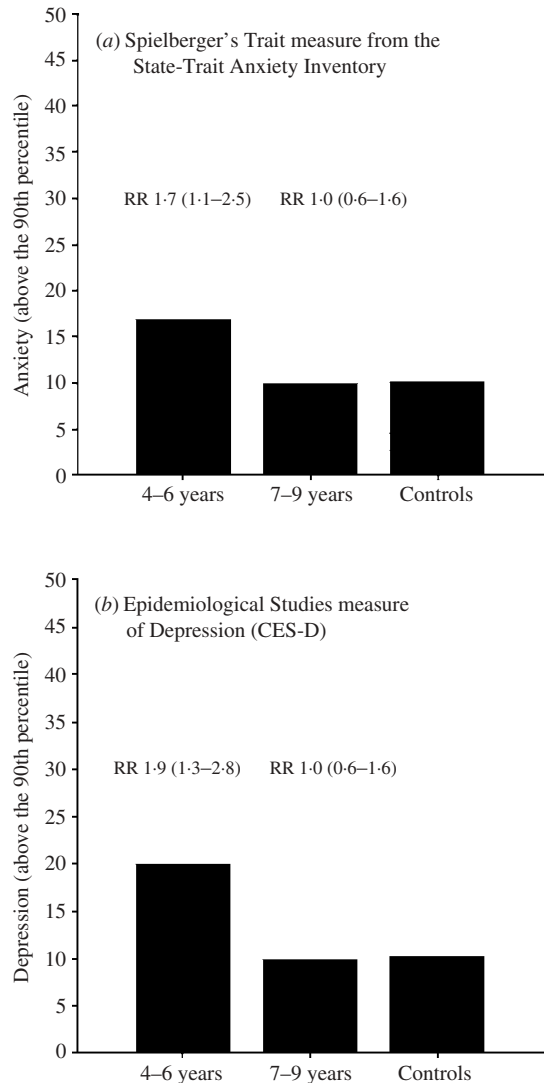* Including the dead child of bereaved parents.

Fig. 1. The responding parents' self-assessed mental health. (*a*) Anxiety measured with Spielberger's Trait measure from the State-Trait Anxiety Inventory. (*b*) Depression measured with the Centre for Epidemiological Studies Depression Scale.

significantly more anxiety or depression on the visual digital scale compared to non-bereaved fathers. At 4–6 years after the loss, both bereaved mothers (RR 1·8, CI 1·2–2·6) and fathers (RR 1·7, CI 1·1–2·7) scored themselves higher than non-bereaved on the visual digital scale. Also depression differed statistically significantly between bereaved mothers (RR 1·8, CI 1·3–2·5) and fathers (RR 1·6, CI 1·1–2·5) 4–6 years after

Table 2. *Morbidity in parents who have lost a child due to malignancy and control*
[*no./total no. (%)*]

Psychological outcome	Controls	All bereaved parents	RR (95% CI)	4–6 yr since loss	RR (95% CI)	7–9 yr since loss	RR (95% CI)
(1) Self-assessed anxiety							
(Visual digital scale 3–7/7)	75/455 (16)	106/438 (24)	1·5 (1·1–1·9)*	63/221 (28)	1·7 (1·3–2·3)*	42/210 (20)	1·2 (0·9–1·7)
Man	32/190 (17)	41/185 (22)	1·3 (0·9–2·0)	27/92 (29)	1·7 (1·1–2·7)*	13/89 (15)	0·9 (0·5–1·6)
Woman	43/265 (16)	65/249 (26)	1·6 (1·1–2·3)*	36/127 (28)	1·8 (1·2–2·6)*	29/119 (24)	1·5 (1·0–2·3)*
(2) Anxiety-related symptoms							
(above the TRAIT 90th percentile)	46/454 (10)	58/439 (13)	1·3 (0·9–1·9)	37/220 (17)	1·7 (1·1–2·5)*	21/212 (10)	1·0 (0·6–1·6)
Man	13/190 (7)	23/187 (12)	1·8 (0·9–3·4)	15/92 (16)	2·4 (1·2–4·8)*	8/91 (9)	1·3 (0·6–3·0)
Woman	33/264 (12)	35/248 (14)	1·1 (0·7–1·0)	22/126 (17)	1·4 (0·9–2·3)	13/119 (11)	0·9 (0·5–1·6)
(3) Self-assessed depression							
(Visual digital scale 3–7/7)	93/454 (20)	122/439 (28)	1·4 (1·1–1·7)*	79/221 (36)	1·7 (1·4–2·3)*	41/211 (19)	1·0 (0·7–1·3)
Man	35/189 (18)	42/186 (23)	1·2 (0·8–1·8)	28/92 (30)	1·6 (1·1–2·5)*	12/90 (13)	0·7 (0·4–1·3)
Woman	58/265 (22)	80/249 (32)	1·5 (1·1–2·0)*	51/127 (40)	1·8 (1·3–2·5)*	29/119 (24)	1·1 (0·8–1·6)
(4) Depression-related symptoms							
(above the CES-D 90th percentile)	46/446 (10)	64/434 (15)	1·4 (1·0–2·0)*	43/215 (20)	1·9 (1·3–2·8)*	21/212 (10)	1·0 (0·6–1·6)
Man	16/185 (9)	26/185 (14)	1·6 (0·9–3·0)	14/90 (16)	1·8 (0·9–3·5)	12/91 (13)	1·5 (0·8–3·1)
Woman	30/261 (11)	38/245 (16)	1·3 (0·9–2·1)	29/123 (24)	2·1 (1·3–3·3)*	9/119 (8)	0·7 (0·3–1·3)
(5) Difficulty falling asleep at night past month							
(at least 1–2 times/week)	54/456 (12)	65/441 (15)	1·2 (0·9–1·7)	41/221 (19)	1·6 (1·1–2·3)*	24/213 (11)	1·0 (0·6–1·5)
Man	23/190 (12)	28/188 (15)	1·2 (0·7–2·1)	16/92 (17)	1·4 (0·8–2·6)	12/92 (13)	1·1 (0·6–2·1)
Woman	31/266 (12)	37/249 (15)	1·3 (0·8–2·0)	25/127 (20)	1·7 (1·0–2·7)*	12/119 (10)	0·9 (0·5–1·6)
(6) Waking up at night with anxiety							
(at least 1–2 times/week)	37/457 (8)	42/442 (10)	1·2 (0·8–1·8)	23/222 (10)	1·3 (0·8–2·1)	19/213 (9)	1·1 (0·7–1·9)
Man	16/191 (8)	18/189 (9)	1·1 (0·6–2·2)	12/93 (13)	1·5 (0·8–3·1)	6/92 (7)	0·8 (0·3–1·9)
Woman	21/266 (8)	23/249 (9)	1·2 (0·7–2·1)	11/127 (9)	1·1 (0·5–2·2)	12/119 (10)	1·3 (0·7–2·5)
(7) Intake of sleeping pills past month							
(at least 1–2 times/week)	16/457 (3)	12/441 (3)	0·8 (0·4–1·6)	6/221 (3)	0·8 (0·3–2·0)	6/213 (3)	0·8 (0·3–2·0)
Man	5/191 (3)	4/188 (2)	0·8 (0·2–3·0)	1/92 (1)	0·4 (0·0–3·5)	3/92 (3)	1·2 (0·3–5·1)
Woman	11/266 (4)	8/249 (3)	0·8 (0·3–1·9)	5/127 (4)	1·0 (0·3–2·7)	3/119 (2)	0·6 (0·2–2·2)
(8) Intake of tranquillizers past month							
(at least 1–2 times/week)	11/457 (2)	8/440 (2)	0·8 (0·3–1·9)	5/222 (2)	0·9 (0·3–2·7)	3/211 (1)	0·6 (0·2–2·1)
Man	3/191 (2)	3/186 (2)	1·0 (0·2–5·0)	2/92 (2)	1·4 (0·2–8·1)	1/90 (1)	0·7 (0·1–6·7)
Woman	8/266 (3)	5/250 (2)	0·7 (0·2–2·0)	3/128 (2)	0·8 (0·2–2·9)	2/119 (2)	0·6 (0·1–2·6)
(9) Low or moderate psychological well-being							
(Visual digital scale 1–5/7)	191/454 (42)	235/439 (53)	1·3 (1·1–1·5)*	132/221 (60)	1·4 (1·2–1·7)*	99/211 (47)	1·1 (0·9–1·3)
Man	78/190 (41)	85/187 (45)	1·1 (0·9–1·4)	47/92 (51)	1·2 (1·0–1·6)*	36/91 (40)	1·0 (0·7–1·3)
Woman	113/264 (43)	149/248 (60)	1·4 (1·2–1·7)*	85/127 (67)	1·6 (1·3–1·9)*	62/118 (52)	1·2 (1·0–1·5)
(10) Low or moderate self-assessed quality of life							
(Visual digital scale 1–5/7)	207/457 (45)	228/440 (52)	1·1 (1·0–1·3)	128/221 (58)	1·3 (1·1–1·5)*	96/212 (45)	1·0 (0·8–1·2)
Man	85/191 (45)	89/185 (48)	1·1 (0·9–1·3)	48/91 (53)	1·2 (0·9–1·5)	39/90 (43)	1·0 (0·7–1·3)
Woman	122/266 (46)	138/251 (55)	1·2 (1·0–1·4)*	80/128 (62)	1·4 (1·1–1·6)*	56/120 (47)	1·0 (0·8–1·3)

RR, relative risk; CI, 95% confidence interval.
* Denotes statistical significance at 5%, Fisher's exact test.

bereavement compared to non-bereaved. The only disagreement between measurements was that bereaved mothers reported statistically significantly higher levels of anxiety (RR 1·5, CI 1·0–2·3) using the 7-point visual digital scale 7–9 years after bereavement compared to non-bereaved mothers while this was not obtained using the STAI-T measure.

As previously mentioned, moderate or high level of depression were more prevalent among bereaved mothers (80/249, 32%) than among bereaved fathers (42/186, 23%), $p = 0.03$. Similarly, gender differences were found for psychological well-being; 149/248 (60%) of bereaved mothers and 85/187 (45%), $p = 0.003$ of bereaved fathers reported low or moderate psychological well-being

Table 3. *Certain psychological and social variables for parents who lost a child to malignancy and controls*

Low or moderate satisfaction according to Tibblin scale	Controls No./total no. (%)	Bereaved parents No./total no. (%)	RR (95% CI)*
(1) Relationship with family	146/451 (32)	133/436 (31)	0·9 (0·8–1·1)
(2) Social involvement/activities	217/453 (48)	217/438 (50)	1·0 (0·9–1·2)
(3) Economy	257/456 (56)	237/438 (54)	1·0 (0·9–1·1)
(4) Health	200/456 (44)	213/440 (48)	1·1 (1·0–1·3)
(5) Appetite	148/455 (32)	128/437 (29)	0·9 (0·7–1·1)
(6) Mood	225/456 (49)	241/439 (55)	1·1 (1·0–1·3)
(7) Energy	277/455 (61)	286/438 (65)	1·1 (1·0–1·2)
(8) Self-esteem	220/454 (48)	225/437 (51)	1·1 (0·9–1·2)
(9) Sleep	203/451 (45)	202/437 (46)	1·0 (0·9–1·2)
(10) Meaningfulness and appreciation outside the home	205/452 (45)	205/439 (47)	1·0 (0·9–1·2)
(11) Relationship with the child's siblings	71/428 (17)	57/421 (14)	0·8 (0·6–1·1)
(12) Relationship with the child's other parent	161/439 (37)	139/424 (33)	0·9 (0·7–1·1)

* RR denotes relative risk for bereaved parents *v.* controls; 95% CI denotes 95% confidence interval.

well-being. Gender differences for these variables were small among the non-bereaved parents. Among bereaved mothers 221/237 (93%) had spent more than 12 h with the child during the last week of the child's life, and 141/177 (80%) of the fathers had done so.

'The Göteborg quality of life instrument'

No statistically significant differences were observed when the psychosocial variables of the two groups were compared using the 'The Göteborg quality of life instrument' (Tibblin *et al.* 1990) (Table 3). High satisfaction (6–7/7 scale) with the relationship with the dead child's sibling 4–6 years after loss was reported by 177/213 (83%) and at 7–9 years by 182/202 (90%) which gives a relative risk of being highly satisfied of 1·0 (CI 0·9–1·1) at 4–6 years and 1·1 (CI 1·0–1·2) at 7–9 years compared to controls. Figures for low or moderate satisfaction were consequently 17% at 4–6 years and 10% at 7–9 years, giving a relative risk of 1·7 (CI 1·0–2·8), $p = 0.04$. No statistically significant difference was noted between bereaved and non-bereaved mothers and fathers at 4–6 years post-loss for bereaved parents, but at 7–9 years after bereavement, bereaved mothers were statistically significantly more likely to be satisfied with the sibling or siblings than non-bereaved mothers (RR 1·1, CI 1·0–1·2). With regard to the relationship between bereaved parents at 4–6 years after the loss, 140/214 (65%) of parents

reported high satisfaction with the other parent and at 7–9 years 140/204 (69%) report the same, giving a relative risk of 1·0 (CI 0·9–1·2) for 4–6 years and 1·1 (CI 1·0–1·2) at 7–9 years compared to controls. Figures for low or moderate satisfaction were consequently 35% at 4–6 years and 31% at 7–9 years, giving a relative risk of 1·1 (CI 0·8–1·4).

Grief

We asked bereaved parents 'Do you think that you have come to terms with your grief?' At 4–6 years after bereavement 71/221 (32%) answered 'No, not at all' or 'Yes, a little', and 7–9 years after bereavement 42/212 (20%) answered 'No, not at all' or 'Yes, a little' giving a relative risk of 1·6 (CI 1·2–2·3) at 4–6 years when the two periods are compared. Among those who indicated that they had not at all or only slightly worked through their grief, 51/112 (46%) reported moderate or high anxiety (3–7/7 on the visual digital scale) compared to 55/322 (17%) among those who replied 'Yes, fairly much' or 'Yes, completely' giving a relative risk of 2·7 (CI 1·9–3·7) for anxiety in the former group compared to the latter. Corresponding figures for depression were 59/113 (52%) and 63/322 (20%), giving a relative risk of 2·7 (CI 2·0–3·5) for depression in the first group. No marked gender differences were noted, except that a lower number of fathers had worked through their grief ('Yes, fairly much' or 'Yes, completely') at years 4–6 compared to mothers.

Other predictors for anxiety and depression

For parents who lose a child aged 9 years or older the risk of anxiety is statistically significantly higher (RR 1·8, CI 1·3–2·4) compared to non-bereaved parents with a child the same age. The corresponding analysis for children younger than 9 years showed no statistical significance. For depression, parents having lost a child aged 9 years or older also showed statistically significant difference (RR 1·8, CI 1·4–2·3) compared to non-bereaved parents. Non-bereaved parents with a child younger than 9 years were more likely to be depressed than bereaved parents, although *not* statistically significantly (RR 0·7, CI 0·4–1·2). Within the bereaved group, the parents' anxiety as well as depression differed statistically significantly according to the age of the child they lost: losing a child aged 9 years or older gave higher levels of anxiety (RR 1·5, CI 1·0–2·1) and depression (RR 1·6, CI 1·2–2·2) compared to losing a child less than 9 years old. The increased risk owing to older age of the child applied particularly to fathers: RR 1·9 (CI 1·1–3·3) for anxiety and RR 2·1 (CI 1·2–3·7) for depression. The corresponding figures for mothers were: RR 1·2 (CI 0·8–1·9) for anxiety and 1·4 (CI 1·0–2·1) for depression. In the non-bereaved group parents with a child aged 9 years or more are less likely to be anxious (RR 0·9, CI 0·5–1·7) or depressed (RR 0·6, CI 0·4–1·1) than parents of a child less than 9 years of age, although *not* statistically significantly so.

Among a little, quite or strongly religious subjects we found higher levels of anxiety (RR 1·5, CI 1·1–2·2) among bereaved than among non-bereaved. Absence of religious belief was also associated with higher levels of anxiety in bereaved compared to non-bereaved, although the difference was not statistically significant (RR 1·3, CI 0·9–2·0). Comparison of the two relative risks gives a *p* value of 0·56.

Demographic variables

Nine demographic variables were studied among non-bereaved parents to explore whether they were associated with anxiety or depression (all presented in Table 1). Age was associated with being bereaved as well as anxiety and depression. The relative risk among bereaved for depression (as measured with visual digital scale) changed from 1·4 (1·1–1·7) to 1·3 (1·0–1·7) when

adjusting for age. The corresponding figures for anxiety was a change from 1·5 (1·1–1·9) to 1·4 (1·1–1·9). Marital status was also a potential confounder; adjusting the relative risk among bereaved for this variable gave a change from 1·4 (1·1–1·7) to 1·4 (1·2–1·7) for depression and 1·5 (1·1–1·9) to 1·5 (1·3–1·9) for anxiety.

DISCUSSION

We found the risk of anxiety and depression to be increased among parents who had lost their child owing to a malignancy 4–6 years earlier. A gradient was seen, with lower risks of anxiety and depression 7–9 years after the loss than 4–6 years after the loss. It appears that the average risk of psychological morbidity in bereaved parents decreases to levels similar to those among non-bereaved parents 7–9 years after the loss. Low or moderate well-being and self-assessed quality of life follow the same temporal course. The loss of a child aged 9 years or older implies an increased risk for the bereaved, particularly fathers, and overall mothers exhibit a greater risk of long-term anxiety and depression.

To our knowledge, this is the first nationwide study, with controls, to address long-term psychological morbidity in parents who have lost a child to a malignancy. We know of no other controlled study that assesses an excess risk of anxiety, depression, low or moderate well-being or self-assessed quality of life 4–9 years after losing a child in this way.

Among the studies conducted in this area there are contradictory observations regarding the temporal course of the psychological morbidity of bereaved parents. The grief process after the loss of a loved adult has been suggested to take about 2 years (Hansson *et al.* 1993) while grief and psychological morbidity after the loss of a child is suggested to be more intense and long-lasting. Our findings support that notion: although bereaved parents on a group level do not appear to differ in anxiety or depression levels from non-bereaved parents 7 years after bereavement, there is an obvious difference during years 4–6 after bereavement. Our intention was to study parents' psychological morbidity rather than their grief; hence our choice of method, we measured psychological symptoms (instead of grief) and included a non-bereaved control group. We have studied the

temporal course of psychological symptoms after the loss of a child in a population-based setting and cannot rule out the possibility that the long-term effects may be due to some abnormality in the grief process of some parents. If only natural predictors such as gender or the child's age are responsible for the increased morbidity, one has to conclude that the long-term morbidity reflects normal grief. However, if either some predisposition (psychiatric) or 'avoidable factors' (such as specific health-care procedures) are responsible for the morbidity, then it may be viewed as an indication of abnormality.

A recent report indicates that bereaved subjects with strong spiritual beliefs resolve their grief more rapidly than others (Walsh *et al.* 2002). However, our results indicate that religious faith does not protect bereaved parents from psychological symptoms as it does in non-bereaved parents. Another study indicated that parents after the loss have become more religious (Shanfield *et al.* 1984). Our findings do not support that notion – the data indicate that the intensity of religious faith is quite similar in the bereaved and non-bereaved population.

The age of the child at the time of death was found to be of importance for bereavement outcome; parents who had lost a child 9 years of age or older showed an increased risk of anxiety and depression compared to parents who had lost a younger child. This finding is in agreement with the observation of Sirki and co-workers (2000), who reported that a longer time was needed for recovery after loss of an adolescent than after a younger child. One explanation might be that the communication is more demanding and complex with older children, especially those in puberty, for example during the farewell process before death. Also, our findings may suggest that the affectional bonds between parents and child grow with time, and the loss of an older child therefore becomes more difficult due to the breaking of these more established affectional bonds. Notably, in support of this notion, fathers, who may have needed more time to establish an emotional bond with their child, have a markedly increased risk of long-term morbidity after the loss of a child 9 years or older. In our study, anxiety and depression was somewhat lower among non-bereaved parents with a child aged 9 years or older compared to non-bereaved parents with a child younger than 9 years.

Our findings suggest that mothers are more likely than fathers to suffer from long-term anxiety and depression after loss. The affectional bonds (suggested in the attachment theory) may grow stronger with time spent together with the child; mothers are more often than not the primary caregiver. Another reason for the difference in long-term psychological morbidity between mothers and fathers may be that mothers spend more time bedside with the child, which entails closer witnessing of the child's suffering. Sirki *et al.* (2000) found a tendency towards more mental problems among bereaved mothers than fathers.

Interestingly, we found no difference between bereaved and non-bereaved parents using the Tibblin and co-workers' quality-of-life instrument (1990). But when using the visual digital scale for measuring low to moderate self-assessed quality of life we obtained statistically significant difference between bereaved and non-bereaved parents. In contrast to the visual digital scale, the factors in the Tibblin quality-of-life instrument have a built-in value preconception of what aspects constitute the respondent's life's quality. Thus, the Tibblin measure does not grasp the bereaved parents' subjective feeling of life quality, which is apparently affected by their loss and psychological morbidity.

Overall, a higher percentage of bereaved than non-bereaved parents were satisfied with their relationship with the child's sibling(s) and with their spouse, although the difference was not statistically significant, and this percentage increased over the time studied, especially the relationship with the dead child's sibling(s). Notably, bereaved mothers were statistically significantly more satisfied with their relationship to the dead child's sibling or siblings than were non-bereaved mothers with their living child's sibling or siblings. This might be due to new values in life after such a trauma (Rådestad *et al.* 1997).

Parental age and marital status are potential confounding factors (being associated with being bereaved as well as anxiety and depression). We adjusted the statistically significant relative risks for demographic factors and certain other potential confounders, and the results only changed by a small degree, if at all.

We used an anonymous questionnaire that was answered at home. This method probably results in fewer investigator-derived errors than, for example, a personal interview or an identifiable questionnaire (Steineck & Ahlbom, 1992; Steineck *et al.* 1998). Moreover, Sweden maintains population-based registers that allowed us to avoid potential problems of selection. In addition, our study was national, and an effort was made to minimize non-compliance. Nonetheless, parents who lost their child in 1996 are over-represented among the non-responders in the bereaved group. We have previously found that attrition among the bereaved can be associated with psychological problems (Valdimarsdottir *et al.* 2002), thus the attrition among parents bereaved for 5 years may affect observed anxiety and depression levels in this group.

Our data indicate that on average the excess risk of anxiety and depression, if any, 7 years after loss is small. This cannot be said for the first 6 years, however. Our findings warrant a search for avoidable factors during care that may increase the long-term risk of anxiety and depression (Whittam, 1993; Hilden *et al.* 2001). Such factors may include parental time with awareness of the child's impending death (Valdimarsdottir, 2003) and also exposure to the suffering of the child (Wolfe *et al.* 2000). Identification and elimination of such stressors may decrease the risk of anxiety and depression during the first 6 years after the trauma. It appears that the loss of a child aged 9 years or older implies an increased risk for the bereaved, particularly fathers, but overall, mothers exhibit a greater risk of long-term anxiety and depression; thus, it may prove fruitful to tailor support for these parents. Finally, an important message from our data is that – although it may take some time – most parents resolve their psychological complications after the loss of their child and continue life without excess psychological morbidity.

ACKNOWLEDGEMENTS

DECLARATION OF INTEREST

None.

REFERENCES

Bergmark, K., Åvall-Lundqvist, E., Dickman, P. W., Henningsohn, L. & Steineck, G. (1999). Vaginal changes and sexuality in women with a history of cervical cancer. *New England Journal of Medicine* **340**, 1383–1389.

Bowlby, J. (1980). *Loss: Sadness and Depression*. Basic Books: New York.

Dyregrov, A. & Dyregrov, K. (1999). Long-term impact of sudden infant death: a 12- to 15-year follow-up. *Death Studies* **23**, 635–661.

Hansson, R., Carpenter, B. & Fairchild, S. (1993). Measurement issues in bereavement. In *Handbook of Bereavement: Theory, Research, and Intervention* (ed. M. Stroebe, W. Stroebe and R. Hansson), pp. 62–74. Cambridge University Press: New York.

Henningsohn, L., Wijkström, H., Dickman, P. W., Bergmark, K. & Steineck, G. (2001). Distressful symptoms after radical cystectomy with urinary diversion for urinary bladder cancer: a Swedish population-based study. *European Urology* **40**, 151–162.

Hilden, J. M., Emanuel, E. J., Fairclough, D. L., Link, M. P., Foley, K. M., Clarridge, B. C., Schnipper, L. E. & Mayer, R. J. (2001). Attitudes and practices among pediatric oncologists regarding end-of-life care: results of the 1998 American Society of Clinical Oncology survey. *Journal of Clinical Oncology* **19**, 205–212.

James, L. & Johnson, B. (1997). The needs of parents of pediatric oncology patients during the palliative care phase. *Journal of Pediatric Oncology Nursing* **14**, 83–95.

Li, J., Precht, D. H., Mortensen, P. B. & Olsen, J. (2003). Mortality in parents after death of a child in Denmark: a nationwide follow-up study. *Lancet* **361**, 363–367.

Lundin, T. (1984). Long-term outcome of bereavement. *British Journal of Psychiatry* **145**, 424–428.

Martinson, I. M., Davies, B. & McClowry, S. G. (1991). Parental depression following the death of a child. *Death Studies* **15**, 259–267.

Meert, K. L., Thurston, C. S. & Thomas, R. (2001). Parental coping and bereavement outcome after the death of a child in the pediatric intensive care unit. *Pediatric Critical Care Medicine* **2**, 324–328.

Middleton, W., Raphael, B., Burnett, P. & Martinek, N. (1998). A longitudinal study comparing bereavement phenomena in recently bereaved spouses, adult children and parents. *Australian and New Zealand Journal of Psychiatry* **32**, 235–241.

Murphy, S. A., Chung, I. J. & Johnson, L. C. (2002). Patterns of mental distress following the violent death of a child and predictors of change over time. *Research in Nursing & Health* **25**, 425–437.

Rådestad, I., Sjögren, B., Nordin, C. & Steineck, G. (1997). Stillbirth and maternal well-being. *Acta Obstetrica et Gynecologica Scandinavica* **76**, 849–855.

Rådestad, I., Steineck, G., Nordin, C. & Sjögren, B. (1996). Psychological complications after stillbirth – influence of memories and immediate management: population based study. *British Medical Journal* **312**, 1505–1508.

Radloff, L. (1994). A self-report depression scale for research in the general population. *Applied Psychological Measures* **1**, 385–401.

Rando, T. A. (1983). An investigation of grief and adaptation in parents whose children have died from cancer. *Journal of Pediatric Psychology* **8**, 3–20.

Rubin, S. (1993). The death of a child is forever: the life course impact of child loss. In *Handbook of Bereavement: Theory, Research, and Intervention* (ed. M. Stroebe, W. Stroebe and R. Hansson), pp. 285–299. Cambridge University Press: New York.

Schwab, R. (1996). Gender differences in parental grief. *Death Studies* **20**, 103–113.

Shanfield, S. B., Benjamin, A. H. & Swain, B. J. (1984). Parents' reactions to the death of an adult child from cancer. *American Journal of Psychiatry* **141**, 1092–1094.

Sirki, K., Saarinen-Pihkala, U. M. & Hovi, L. (2000). Coping of parents and siblings with the death of a child with cancer: death after terminal care compared with death during active anticancer therapy. *Acta Paediatrica* **89**, 717–721.

Spielberger, C., Gorusch, R., Lushene, P., Vagg, P. & Jacobs, G. (1983). Manual for the State-Trait anxiety inventory (form Y). Consulting Psychologists Press: Palo Alto.

Steineck, G. & Ahlbom, A. (1992). A definition of bias founded on the concept of the study base. *Epidemiology* **3**, 477–482.

Steineck, G., Bergmark, K., Henningsohn, L., al Abany, M., Dickman, P. W. & Helgason, A. (2002*a*). Symptom documentation in cancer survivors as a basis for therapy modifications. *Acta Oncologica* **41**, 244–252.

Steineck, G., Helgesen, F., Adolfsson, J., Dickman, P. W., Johansson, J. E., Norlen, B. J. & Holmberg, L. (2002*b*). Quality of life after radical prostatectomy or watchful waiting. *New England Journal of Medicine* **347**, 790–796.

Steineck, G., Kass, P. H. & Ahlbom, A. (1998). A comprehensive clinical epidemiological theory based on the concept of the source person-time and four distinct study stages. *Acta Oncologica* **37**, 15–23.

Tibblin, G., Tibblin, B., Peciva, S., Kullman, S. & Svardsudd, K. (1990). 'The Göteborg quality of life instrument' – an assessment of well-being and symptoms among men born 1913 and 1923. Methods and validity. *Scandinavian Journal of Primary Health Care* **1** (Suppl.), 33–38.

Valdimarsdottir, U. (2003). The loss of a husband to cancer: additional and avoidable psychological traumata. Thesis. Karolinska Institutet, Stockholm, May 2003.

Valdimarsdottir, U., Helgason, A. R., Furst, C. J., Adolfsson, J. & Steineck, G. (2002). The unrecognised cost of cancer patients' unrelieved symptoms: a nationwide follow-up of their surviving partners. *British Journal of Cancer* **86**, 1540–1545.

Vance, J. C., Boyle, F. M., Najman, J. M. & Thearle, M. J. (1995). Gender differences in parental psychological distress following perinatal death or sudden infant death syndrome. *British Journal of Psychiatry* **167**, 806–811.

Walsh, K., King, M., Jones, L., Tookman, A. & Blizard, R. (2002). Spiritual beliefs may affect outcome of bereavement: prospective study. *British Medical Journal* **324**, 1551.

Whittam, E. H. (1993). Terminal care of the dying child. Psychosocial implications of care. *Cancer* **71**, 3450–3462.

Wolfe, J., Grier, H. E., Klar, N., Levin, S. B., Ellenbogen, J. M., Salem-Schatz, S., Emanuel, E. J. & Weeks, J. C. (2000). Symptoms and suffering at the end of life in children with cancer. *New England Journal of Medicine* **342**, 326–333.