Original Article

Anxiety and Depression in Bereaved Parents After Losing a Child due to Life-Limiting Diagnoses: A Danish Nationwide Questionnaire Survey

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Abstract

Context. Losing a child is the most burdensome event parents can experience involving risks of developing anxiety and depression.

Objectives. To investigate anxiety and depression in bereaved parents during their child's life-limiting illness and imminent death and three to five years after the loss to target future interventions.

Methods. A Danish nationwide cross-sectional questionnaire survey. From 2012 to 2014, a register-based study identified causes of deaths of 951 children aged zero to 18 years. Potential palliative diagnoses were classified according to previously used classification. A total of 402 families were included. A modified version of the self-administered questionnaire "To lose a child" was used. Non-response surveys identified reasons for lack of response.

Results. In all, 136 mothers and 57 fathers completed a questionnaire, representing parents of 152 children (38%). Sixty-five percent of mothers and 63% of fathers reported moderate-to-severe anxiety during the child's illness. However, three to five years after their loss anxiety had decreased markedly. Thirty-five percent of mothers and 39% of fathers reported moderate-to-severe depression during the child's illness; three to five years after the loss they were suffering equivalently from depression. The Center for Epidemiologic Studies Depression Scale indicated that severe depression was significantly associated with lower education and being unmarried.

Conclusion. The reporting of anxiety during the child's illness and prolonged depression in bereaved parents three to five years after the loss indicates a potential need for psychological interventions. In the process of implementing specialized pediatric palliative care in Denmark, our findings should be considered for future treatment programs. J Pain Symptom Manage 2019;58:596–604.

Key Words

Anxiety, depression, pediatric, bereavement, parents, palliative care

Introduction

Losing a child is considered the most burdensome event parents can experience and the risk of developing anxiety and/or depression may be expected to be high. Previous Danish studies found an increased risk of psychiatric hospitalization and mortality in bereaved parents.[1,2] A review focusing on the association between losing a child and the subsequent health status of parents found in nine of 17 studies an increased risk of developing anxiety and depression.[3] Thus, psychological distress in terms of anxiety and

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depression seems to have high impact on suffering in bereaved parents.

Since 2015, specialized pediatric palliative care has been a priority in Denmark, which includes establishment of both hospices and hospital-based teams. Palliative care in this study are based on the World Health Organization's (WHO) definition of pediatric palliative care[4] and specialized palliative care is based on the Recommendations from the European Association for Palliative Care.[5] To target future interventions for parents during their child's life-limiting illness and after their loss, it seems highly relevant to investigate bereaved parents' experiences including anxiety and depression. We hypothesized that anxiety and depression would decline over time and that potential risk factors as the child's age and diagnosis, the parents age, civil status, education, and religious belief could influence anxiety and depression.[6] Potential risk factors impacting parental bereavement outcomes after the death of a child with a life-limiting disease have previously been studied[7] and the findings indicated that the child's age and diagnosis,[6] the educational level of parents,[8] and their religious belief[9] may influence anxiety and depression, which seemed to decline over time.[6] Thus, the aim of this study was to investigate anxiety and depression in bereaved parents during the child's life-limiting illness and imminent death and three to five years after the loss to target future interventions in specialized pediatric palliative care.

Methods

Participants and Settings

In a recent nation-wide study, we investigated the mortality rate, causes, and places of death for children less than 18 years of age, who died in Denmark in the period 1994 to 2014.[10] The data were obtained from the Danish Register of Causes of Death, which covers all deaths of citizens in Denmark.[11] The classification of the primary causes of death during the study period was performed in accordance with guidelines from the WHO; and since 1994, the Register has used the International Classification of Diseases, Tenth Revision.[12,13] From the Danish Register of Causes of Death, 951 children, who died in Denmark in the period 2012 to 2014, were identified. A directory of life-limiting conditions elaborated in Wales were used to identify those children, who could benefit from specialized pediatric palliative care. The directory was recorded through diagnoses of patients under the care of five children hospices and a tertiary specialist palliative care service in the U.K.[14] As specialized pediatric palliative care is a new clinical discipline in Denmark, the directory was used to identify Danish children, who potentially could benefit from the intervention. The diagnoses in the directory were matched with the causes of death in the Danish Register of Causes of Death and 402 children were identified. In Denmark, individuals with residence permit have a unique civil registration number stored in the Danish Civil Registration System.[15] This register contains information on, for example, date of birth and death, sex, identity of parents, municipality of residence, and civil status. Through this register, we identified the parents of the 402 children. Parents were eligible if they had a Danish civil registration number and a Danish non-protected postal address. Of 804 eligible parents, contact information was reachable for 743 and they were invited to participate. Contact information was not available for 61 parents due to, for example, death of the parents, unknown paternity, protected address, or emigration from Denmark.

Data Collection and Assessment

As we wanted to investigate bereaved parent's experiences during the child's illness, imminent death and at present, a modified version of the comprehensive questionnaire "To lose a child" was chosen. The questionnaire has been face-to-face validated and formerly been used in parents, who lost a child because of malignancies in Sweden.[16] The fact that Sweden and Denmark are very similar in culture, language, and health care systems as well as the fact that the content could be easily be modified to comprise parents who lost a child to life-limiting diseases influenced our choice of this questionnaire. The original questionnaire contains 129 questions, which are divided into three parts. The first part covers demographics and the parent's views on the care given during the child's illness, the second part includes the parents' views of the professional care received by themselves after the child's death, and the third part covers the parent's well-being at present. We translated the questionnaire from Swedish into Danish according to a revised version of the manual of European Organization for Research and Treatment of Cancer.[17] Independently, a health care professional and a non-professional translated the questionnaire from Swedish into Danish. A discussion and adjustment of the translation was made by our research group. The wordings of some of the questions were changed in the forward translation, for example, each time "last month" during the child's illness was used, it was changed to "end-of-life time," because other life-limiting diagnoses in children than cancer may often have more unpredictable trajectories. Finally, specific questions related to cancer trajectories, for example, "Did your child's illness reappear (recur) after having disappeared" were deleted. As the questionnaire was modified, a back-ward translation according to the translation

manual was not made. The final version included 122 questions. This study presents the demographics of the parents and their responses to questions assessing anxiety, depression, and psychological well-being.

To identify depression-related symptoms, the Centre for Epidemiological Studies Depression (CES-D) Scale was used. The CES-D Scale is a well validated 20-item measure using a four-point Likert scale, where 1 is "never" and 4 is "most of the time."[18] The CES-D Scale responses were summarized according to the guidelines by giving a score of 0 to 3. A score of 16 or more reflects risk of clinical depression. More specifically, a score of 16 to 23 indicates moderate and 24 to 60 indicates severe depression.[18] Responders with missing values on more than four items were excluded.

In addition, the single-item, seven-point Visual Digital Scale (VDS) was used to measure the parent's subjective evaluation of anxiety and depression at present and during the child's illness and death according to their memory. The VDS for anxiety and depression has been thoroughly tested for face validity and has been used in several research projects by the research group of Clinical Cancer Epidemiology.[19–23] Furthermore, the VDS of depression has been shown to correlate well with the CES-D Scale.[21,24,25]

The VDS was also used for measuring the bereaved parents self-assessed well-being. Cut-off scores for VDS were used; 1 to 2 indicates "no or mild," 3 to 5 "moderate," and 6 to 7 "severe" anxiety or depression. Questions referring to the parents' well-being were categorized as 1 to 2 "worst," 3 to 5 "moderate," and 6 to 7 "best."[24,26]

A pilot survey and in-depth interviews with tree bereaved parents focusing on comprehensibility and usability were performed before the questionnaire was finally approved. No further adjustments were made after pilot testing.

At least one representative parent for each child was preferred and, therefore, the questionnaire was sent to mothers and fathers separately. The questionnaire and an introductory letter, which briefly explained the objectives of the study were sent including a folder explaining the study in more depth. Parents not responding within three weeks received one reminder. All parents were invited to fill the questionnaire between April and June 2017. After receiving and analyzing the responses of the first 20 questionnaires, which did not give rise to further revision, they were included in the total sample.

Other Variables of Interest

The Nordregio classification of urban and rural areas was used to divide the 98 Danish municipalities into the following four types of municipalities: urban, intermediate, rural, and peripheral. The classification is based on 14 indicators as population per square kilometer, population in rural areas and towns with less than 1000 inhabitants, percentage of the workforce with basic education, and average distance to motorway.[27] Finally, information on education, status of employment through the child's illness, loss of more than one child, and religiousness were self-reported in the present study.

Statistical Analyses

Descriptive statistics included percentages for categorical variables and means, SDs, and medians for continuous variables.

The associations between the potential risk factors (parental sex, civil status, education, primary causes of death, and age of the children) and severe depression (CES-D Scale >23) were assessed by a logistic regression model using a Generalized Estimating Equation, with allowance for clustering within each child. The effect of clustering has to be taken into account to allow for the likelihood that parents of the same child could respond similarly, because they have been exposed to the same experience. However, we found it interesting to divide the results into mothers and fathers in the results section, as we assumed that there might be differences. Data on potential risk factors (parental sex, civil status, primary causes of death, and age of the children) were obtained from the Danish Civil Registration System and education was reported by the parents in the questionnaire.

The association between potential explanatory factors (sex, age of the parents and the child, primary causes of death of the child, and the residential area of the parents) and non-response were assessed by logistic regression analysis. The results from the logistic regression models are presented as odds ratios with 95% CIs. All *P*-values were adjusted for clustering within the child. The Statistical Application System, version 9.4 (SAS Institute Inc, Cary, NC) was used to perform all the analyses.

Results

Characteristics of the Sample

In all, 136 mothers and 57 fathers completed a questionnaire, representing parents of 152 children (38%). There was an equal distribution between boys and girls (Table 1).

In all, 99.5% were biological parents, 87% were married, and 90% shared the custody at the time of the child's illness. Eighteen percent of the parents had divorced after the child's death. Sixty-seven percent had higher education than upper secondary or vocational school and 68% stated to be religious. Bereaved

Table 1
Characteristics of the Children

N (%)	Children
Identified children	402
Number of children represented	152 (37.8)
Children represented by both parents	41
Age	
0–31 days	72 (37.3)
32–364 days	36 (18.7)
1–3 yrs	14 (7.3)
4–7 yrs	21 (10.9)
8–10 yrs	11 (5.7)
1113 yrs	18 (9.3)
14–17 yrs	21 (10.9)
Sex	
Girls	96 (49.7)
Boys	97 (50.3)
Death causes	
Neoplasms	41 (21.2)
Diseases of the nervous system	24 (12.4)
Congenital malformations, deformations, and chromosomal abnormalities	46 (23.8)
Conditions originating in the perinatal period	55 (28.5)
Other	27 (14.0)

parents to children with congenital malformations, deformations and chromosomal abnormalities, conditions originating in the perinatal period, and cancer were more likely to participate (Table 2).

Anxiety and Depression

During the child's illness, 65% of the mothers and 63% of the fathers according to their memory scored moderate-to-severe anxiety using VDS. At the time of the survey (three to five years after the loss), 24% of mothers and 16% of fathers scored moderate-to-severe anxiety (Fig. 1). There were no statistically significant differences in anxiety between mothers and fathers (Table 3).

During the child's illness, 35% of mothers and 39% of fathers according to their memory scored from moderate-to-severe depression using VDS. At the time of the survey (three to five years after the loss), still 34% of mothers and 35% of the fathers scored moderate-to-severe depression (Fig. 1). There were no statistically significant differences between mothers and fathers with regard to self-reported depression neither during the child's illness nor at the time of the survey (Table 3).

At the time of the survey, 61% of the parents scored moderate-to-worse mental well-being and nearly 52% assessed their overall quality of life as moderate-to-worst possible using VDS (Fig. 2).

At the time of the survey, mothers had lower prevalence of moderate-to-severe depression (33%) than fathers (44%) according to the CES-D Scale (Table 4). No statistically significant association between depression and religious belief in the parents was found. Furthermore, there were no statistically significant associations between the parent's sex, the child's death cause, the age of the child, and severe depressive symptomatology (CES-D Scale >23). However, results from multiple logistic regression analysis showed that parents with lower education (i.e., basic, upper secondary, or vocational school) had 6.92 (95% CI: 2.74 to 17.47) times higher odds of having severe depressive symptomatology than parents with higher education. Furthermore, married parents (at the time of the survey) had 0.29 (95% CI: 0.11 to 0.78) times lower odds than unmarried parents of having severe depressive symptomatology (Table 5).

Finally, 71% of the mothers and 66% of the fathers reported that their mental health has deteriorated after losing a child and 49% of the mothers and 54% of the fathers answered that they never had had access to psychological support during their child's end-of-life time (data not shown).

Non-response

The associations between diagnosis, sex, and age of the child and age and residential area of the parents and non-response were analyzed. The non-responder

Table 2
Characteristics of Bereaved Parents After Losing a Child due to Life-Limiting Diagnoses

N (%)	Mothers	Fathers
Number of invited parents	391	352
Number of respondents	136 (34.8)	57 (16.2)
Age		
<35 yrs	35 (25.7)	10 (17.5)
35–44 yrs	63 (46.3)	23 (40.4)
≥45 yrs	38 (27.9)	24 (42.1)
Civil status today		
Married	103 (75.7)	46 (80.7)
Not Married	31 (22.8)	9 (15.8)
Not answered	2 (1.5)	2 (3.5)
Education level		
Basic, upper secondary, or vocational school	29 (21.4)	19 (33.3)
Higher education	95 (69.9)	37 (64.9)
Not answered	12 (8.8)	1 (1.8)
Status of employment through the child's illness[a]		
Employed	36 (26.7)	34 (59.7)
Leave	97 (71.7)	24 (42.2)
Unemployed, studying, or other	18 (13.2)	3 (5.3)
Residential area		
Countryside and small town	79 (58.1)	35 (61.4)
Medium to large sized city	56 (41.1)	22 (38.6)
Not answered	1 (<1)	0 (0)
Lost more than one child		
Yes	17 (12.5)	5 (8.8)
No	118 (86.8)	51 (89.5)
Not answered	1 (<1)	1 (1.8)
Religiousness		
Religious	100 (73.5)	32 (56.1)
Not religious	36 (26.5)	24 (42.1)
Not answered	0 (0)	1 (1.8)

[a]Can give more than one answer in the same question.

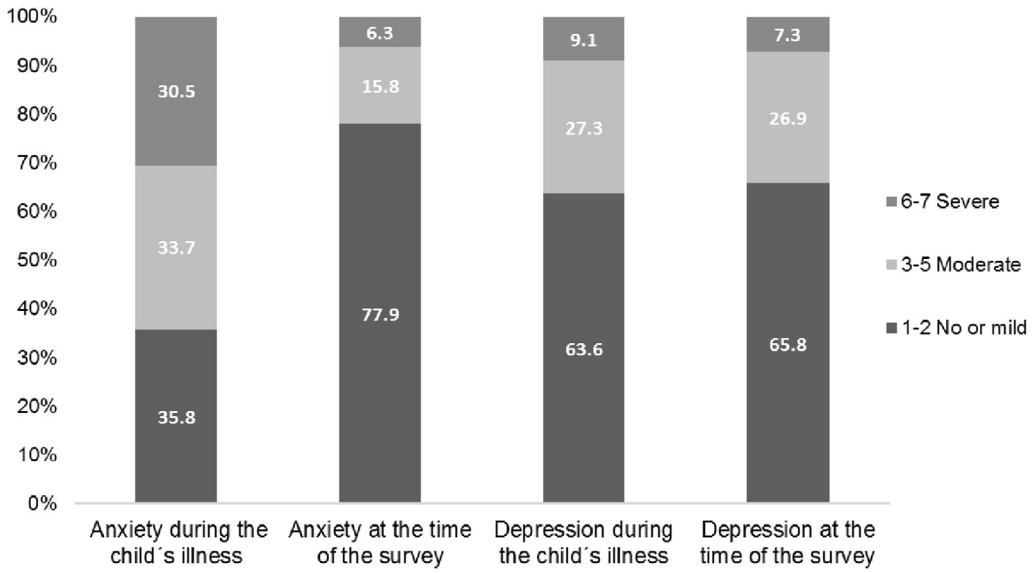

Fig. 1. Anxiety and depression in bereaved parents during the child's illness and after the loss according to VDS, %. VDS = Visual Digital Scale.

analysis revealed a significant association between mothers' age and non-response. Mothers less than 35 years of age had 1.56 (95% CI: 0.94 to 2.57) times higher odds of non-response than mothers aged 35 to 44 years. Furthermore, mothers aged 45 years or older had 0.45 (95% CI: 0.22 to 0.94) times lower odds of non-response than the reference group. The same tendency was observed in fathers, but the association was not statistically significant.

Furthermore, because of the low response rate, a post-hoc non-response survey to identify reasons for lack of response was performed. First, a self-administered questionnaire with 14 short questions based on reactions from participating parents was constructed. The questionnaire was pilot-tested by 15 bereaved parents, who all provided written feedback. The questionnaire was sent to all non-participating parents. For ethical reasons, no reminders were sent. Fifty-one parents participated in the questionnaire survey. Fifty-one percent of these parents "completely or partly agreed" that the questionnaire was too extensive, 63% "completely agreed" that they did not have energy, and 67% "completely or partly agreed" that it was emotionally too hard to participate. However, 51% "completely agreed" that the survey was important and 40% "completely disagreed" that they received the help they needed during the illness and after the child's death (data not shown).

Table 3
Anxiety and Depression According to VDS

	Mean (SD)	*N*	*P*-value
Feelings of anxiety during your child's illness (1 = never and 7 = always)			
Fathers	3.6 (2.06)	57	0.246
Mothers	4.0 (2.38)	130	
Feelings of anxiety at the time of the survey? (1 = never and 7 = always)			
Fathers	1.7 (1.31)	55	0.138
Mothers	2.1 (1.66)	135	
Feelings of depression during your child's illness (1 = never and 7 = always)			
Fathers	2.5 (1.78)	57	0.952
Mothers	2.5 (1.84)	130	
Feelings of depression at the time of the survey? (1 = never and 7 = always)			
Fathers	2.5 (1.74)	57	0.630
Mothers	2.4 (1.70)	136	

VDS = Visual Digital Scale.

Discussion

To our knowledge, this is the first study to investigate anxiety, depression, and well-being in a national sample of parents, who lost a child due to life-limiting diagnoses. Our study indicated that the parents reported to recall high levels of anxiety and/or depression during the child's illness and still reported prolonged depression three to five years after their loss.

Previous studies have found that most anxiety disorders are more prevalent in women than in men.[28,29] However, no statistical sex differences in anxiety were observed in our study. Recall bias may, of course, influence reliability of reporting from an incomprehensible, devastating and chaotic period of life after three to five years;[30,31] however, the reported

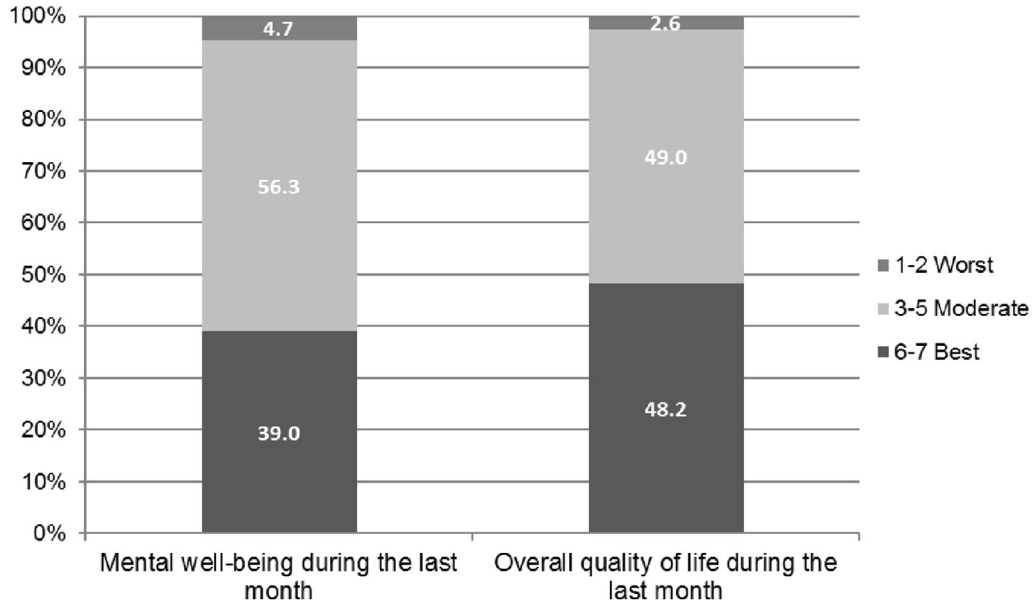

Fig. 2. Mental well-being and quality of life in bereaved parents at the time of the survey according to VDS, %. VDS = Visual Digital Scale.

high prevalence of anxiety may likely be associated with increased distress because of the child's end-of-life trajectory.[32] Some of the parents may even have developed posttraumatic stress disorders,[33,34] which depending on their psychological resilience may be either significantly reduced on a sustained basis or making them even more vulnerable to stressors and crises later in life, that in turn may be associated with long-standing depressive disorders many years after the traumatic and distressing period has ended.[35] Thus, these findings may indicate that anxiety and depression in the aftermath of trauma may be conceptualized as a general traumatic stress construct. In Denmark, depression is mainly diagnosed by a physician based on the WHO's International Classification of Diseases, 11th Revision, criteria.[34] The parents in this survey were not clinically diagnosed, but exclusively screened for depression based on self-report. According to the median prevalence of 8.8% in the general population using the CES-D Scale,[36] we found high levels of moderate-to-severe depression in the bereaved parents. However, another aspect in this context is conceptually to distinguish prolonged grief disorder from depression. A key consideration is the extent to which certain symptoms are specifically about the loss of the child vs. more generalized depression. Diagnostic Criteria for International Classification of Diseases, 11th Revision, Prolonged Grief Disorder and Diagnostic and Statistical Manual of Mental Disorders (Fifth Edition) Persistent Complex Bereavement-Related Disorder are available; however, our study is not designed to discriminate between depression and prolonged grief according to these concepts and definitions.[37]

We found based on recall that the reported anxiety scores for both mothers and fathers were considerably higher than their depression scores during the child's illness. However, anxiety was reduced substantially at the time of the survey, whereas depression remained unchanged. Although populations, settings and designs differ between a previous study found that anxiety and depression in bereaved parents decreased to levels similar to non-bereaved seven to nine years after losing a child.[6] However, another

Table 4
Depression of the Parents According to CES-D

	Mothers, $n = 136$	Fathers, $n = 57$	*P*-value
Total scores mean (SD)			
CES-D (score range 0–60)	14.1 (12.7)	13.8 (10.1)	0.867
Cut-off scores *n* (%)			
0–15, No to mild depressive symptomatology	89 (66.9)	32 (56.1)	
16–23, Moderate depressive symptomatology	17 (12.8)	14 (24.6)	
24–60, Severe depressive symptomatology	27 (20.3)	11 (19.3)	

CES-D = Center for Epidemiologic Studies Depression.

Table 5
OR for Severe Depression (CES-D >23) in Bereaved Parents Three to Five Years After Losing a Child With a Life-Limiting Diagnose

	Crude OR (95% CI)	*P*-value	Adjusted[a] OR (95% CI)	*P*-value
Sex	1.00 (0.51–1.96)	0.994	1.93 (0.76–4.91)	0.157
Women vs. men (ref)				
Child's age	1.04 (0.99–1.10)	0.089	1.08 (1.02–1.15)	0.019
Education				
Basic, upper secondary, or vocational school vs. higher education (ref)	5.50 (2.50–12.1)	<0.001	6.92 (2.74–17.47)	<0.001
Civil status				
Married vs. not married (ref)	0.25 (0.11–0.58)	0.001	0.29 (0.11–0.78)	0.028
Death causes				
Certain conditions originating in the perinatal period	0.22 (0.06–0.75)	0.217	0.59 (0.14–2.43)	0.805
Congenital malformations, deformations, and chromosomal abnormalities	0.40 (0.13–1.27)		1.15 (0.24–5.64)	
Diseases of the nervous system	0.38 (0.09–1.48)		0.60 (0.11–3.39)	
Neoplasms	0.58 (0.18–1.86)		1.04 (0.20–5.30)	
Other	Ref		Ref	

OR = odds ratio; CES-D = Center for Epidemiologic Studies Depression Scale.
[a]ORs adjusted for variables shown in the table.

study found that 18 years after the loss, bereaved parents reported more depressive symptoms and poorer well-being than non-bereaved parents 18 years after the loss.[38]

At the time of the survey, it is likely that the high score of depression found in our study may be associated with low ratings of well-being and quality of life in the parents. A systematic review of psychosocial comorbidities among bereaved parents of children with cancer found that the parents had elevated rates of anxiety, depression, prolonged grief, poor psychological well-being, poor physical health, and poor quality of life.[39] Although, the particular psychosocial comorbidities assessed in the studies of the review were diversely defined and assessed the bulk of suffering including the low levels of quality of life was in line with our findings. However, in our study, it may be noted that the reported lack of psychological support both during the child's illness and after the child's death could have contributed to some of the parents deteriorated condition. Previous studies have shown positive effects of cognitive behavioral therapy for treating[40] and preventing depression[41] and anxiety.[42–44] Thus, depending on the clinical diagnosis, both pharmacologic and non-pharmacologic interventions or a combination of both may be beneficial before and after loss.

We did not find any association between the level of depression and religious belief. A systematic review has formerly concluded that religious beliefs can be helpful in the process of coping with loss,[9] and reported that bereaved parents attending church regularly had less anxiety and depression after loss.[45] However, another study was more consistent with our findings indicating that religious beliefs were not associated with the risk of developing high levels of anxiety and depression.[6] The study found that the loss of a child aged 9 years or older implied an increased risk of anxiety and depression, especially in fathers.[6] Our study could not confirm this finding as we did not find any association between the diagnosis and age of the child and the parents' levels of anxiety and depression. However, lower education and being unmarried were found to be associated with more severe depression. Socioeconomic and marital status have not been studied widely in parental bereavement. However, a recent questionnaire survey from the U.S. found in consistency with our study that mothers with lower education appeared to report more anxiety and depression and had lower capability to access support after their loss.[8] Although the socioeconomic environment in the U.S. is highly different from Denmark, it is obvious even in a welfare state like Denmark that parents with lower levels of education associated with lower levels of household income may have greater risk of comorbid problems.

Finally, the higher odds in unmarried parents for depressive symptomatology could also be explained by marital disruption as our study showed that 18% of the parents got divorced between the death of the child and time of the survey. However, our study could not identify whether the loss of the child caused the divorce. On the other hand, a mixed-methods study demonstrated that dyadic coping between couples after the death of a child due to a life-limiting illness seemed to be helpful for the parents to work through their grief—not only as a couple, but also individually.[46]

Strengths and Limitations

The data of the children and their parents were acquired through national registers. The strength of the registers is the unique opportunity to combine data of decreased children and surviving parents.[47]

The relatively low response rate may preclude the ability to generalize the study's findings as it is possible that the most vulnerable parents may be the ones who declined to participate. Further to study a nationwide sample of parents, who lost a child due to life-limiting diagnoses is a sensitive task and, indeed, ethical concerns are prevailing. However, previous researches have demonstrated that most bereaved parents felt positively affected by their participation, both personally and for the opportunity to help others after losing their child.[16,48,49] Finally, it is well known that females are more likely to participate in questionnaire surveys.[50,51] This finding was also reflected in the present survey, which involved an over-representation of mothers.

Conclusion

Parents losing a child with life-limiting diagnosis recalled high levels of anxiety and/or depression during the child's illness and death. Three to five years after the loss, the self-reported level of anxiety decreased markedly, whereas the level of depression remained unchanged. Especially, unmarried parents and parents with lower education were associated with reporting more severe depression. The reported experience of anxiety and prolonged depression years after loss indicates the need for interventions to support and treat parents during their child's life-limiting illness and after the loss. Future studies should inform who is at risk and may identify resilience factors that protect parents from psychosocial comorbidities and potential family disruption.

Disclosures and Acknowledgments

The authors have no financial or other conflict of interest to disclose.

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Ethical approval: Caused by the emotive nature of this questionnaire, contact information for counseling was given to the parents before participation. To ensure anonymity for anyone other than the research group, all questionnaires carried a serial number. The study protocol was approved by the Danish Data Protection Agency (2012-58-0004) and the Danish Ethics Committee (H-16021831).

References

1. Li J, Precht DH, Mortensen PB, et al. Mortality in parents after death of a child in Denmark: a nationwide follow-up study. Lancet 2003;361:363–367.

2. Li J, Laursen TM, Precht DH, et al. Hospitalization for mental illness among parents after the death of a child. N Engl J Med 2005;352:1190–1196.

3. Hendrickson KC. Morbidity, mortality, and parental grief: a review of the literature on the relationship between the death of a child and the subsequent health of parents. Palliat Support Care 2009;7:109.

4. World Health Organization (WHO). WHO definition of palliative care for children 1998. Available from https://www.who.int/cancer/palliative/definition/en/. Accessed October 11, 2017.

5. European Association for Palliative Care (EAPC). White Paper on standards and norms for hospice and palliative care in Europe: part 1. Eur J Palliat Care 2010;17.

6. Kreicbergs U, Valdimarsdóttir U, Onelöv E, et al. Anxiety and depression in parents 4–9 years after the loss of a child owing to a malignancy: a population-based follow-up. Psychol Med 2004;34:1431.

7. Jaaniste T, Coombs S, Donnelly TJ, et al. Risk and resilience factors related to parental bereavement following the death of a child with a life-limiting condition. Child (Basel) 2017;4:E96.

8. Cacciatore J, Killian M, Harper M. Adverse outcomes in bereaved mothers: the importance of household income and education. SSM Popul Heal 2016;2:117–122.

9. Becker G, Xander CJ, Blum HE, et al. Do religious or spiritual beliefs influence bereavement? A systematic review. Palliat Med 2007;21:207–217.

10. Lykke C, Ekholm O, Schmiegelow K, et al. All-cause mortality rates and home deaths decreased in children with life-limiting diagnoses in Denmark between 1994 and 2014. Acta Paediatr 2018;107:1781–1785.

11. Juel K, Helweg-Larsen K. The Danish registers of causes of death. Dan Med Bull 1999;46:354–357.

12. Helweg-Larsen K. The Danish register of causes of death. Scand J Public Health 2011;39:26–29.

13. World Health Organization. International Statistical Classification of Diseases and Related Health Problems 10th Revision, version 2015. 2015. Available from http://apps.who.int/classifications/icd10/browse/2010/en. Accessed July 9, 2018.

14. Hain R, Devins M, Hastings R, et al. Paediatric palliative care: development and pilot study of a 'Directory' of life-limiting conditions. BMC Palliat Care 2013;12:43.

15. Pedersen CB. The Danish civil registration system. Scand J Public Health 2011;39:22–25.

16. Kreicbergs U, Valdimarsdóttir U, Steineck G, et al. A population-based nationwide study of parents' perceptions of a questionnaire on their child's death due to cancer. Lancet 2004;364:787–789.

17. Koller M, Aaronson NK, Blazeby J, et al. Translation procedures for standardised quality of life questionnaires: the European Organisation for Research and Treatment of Cancer (EORTC) approach. Eur J Cancer 2007;43:1810–1820.

18. Radloff LS. The CES-D Scale: a Self-Report Depression Scale for research in the general population. Appl Psychol Meas 1977;1:385–401.

19. Rådestad I, Steineck G, Nordin C, et al. Psychological complications after stillbirth–influence of memories and immediate management: population based study. BMJ 1996; 312:1505–1508.

20. Bergmark K, Åvall-Lundqvist E, Dickman PW, et al. Vaginal changes and sexuality in women with a history of cervical cancer. N Engl J Med 1999;340:1383–1389.

21. Valdimarsdɔttir UA. The loss of a husband to cancer: additional and avoidable psychological traumata. Institutionen för onkologi-patologi/Department of Oncology-Pathology, 2003. Available from https://openarchive.ki.se/xmlui/handle/10616/39396. Accessed January 15, 2018.

22. Valdimarsdóttir U, Helgason AR, Fürst C-J, et al. The unrecognised cost of cancer patients' unrelieved symptoms: a nationwide follow-up of their surviving partners. Br J Cancer 2002;86:1540–1545.

23. Steineck G, Bergmark K, Henningsohn L, et al. Symptom documentation in cancer survivors as a basis for therapy modifications. Acta Oncol 2002;41:244–252.

24. Onelöv E, Steineck G, Nyberg U, et al. Measuring anxiety and depression in the oncology setting using visual-digital scales. Acta Oncol (Madr) 2007;46:810–816.

25. Steineck G, Helgesen F, Adolfsson J, et al. Quality of life after radical prostatectomy or watchful waiting. N Engl J Med 2002;347:790–797.

26. Kreicbergs U. To lose a child To cancer: A nationwide study of parental experiences. Stockholm, Sweden: Karolinska Institutet; Repro Print, 2004.

27. Nordregio. Official definitions of Nordic rural areas. J Nord 2010;10:4–7.

28. McLean CP, Asnaani A, Litz BT, et al. Gender differences in anxiety disorders: prevalence, course of illness, comorbidity and burden of illness. J Psychiatr Res 2011;45: 1027–1035.

29. Kessler RC, McGonagle KA, Zhao S, et al. Lifetime and 12-month prevalence of DSM-III-R psychiatric disorders in the United States. Results from the national comorbidity survey. Arch Gen Psychiatry 1994;51:8–19.

30. Lalande KM, Bonanno GA. Retrospective memory bias for the frequency of potentially traumatic events: a prospective study. Psychol Trauma Theory, Res Pract Policy 2011;3: 165–170.

31. Coughlin SS. Recall bias in epidemiologic studies. J Clin Epidemiol 1990;43:87–91.

32. Darlington A-SE, Korones DN, Norton SA. Parental coping in the context of having a child who is facing death: a theoretical framework. Palliat Support Care 2017:1–10.

33. American Psychiatric Association. Diagnostic and statistical manual of mental disorders (DSM-5 (R)). 5th Revise. American Psychiatric Publishing, 2013.

34. World Health Organization (WHO). ICD-11 for mortality and morbidity statistics 2018. Available from https://icd.who.int/browse11/l-m/en#/http://id.who.int/icd/entity/399670840. Accessed October 3, 2018.

35. O'Donnell ML, Creamer M, Pattison P. Posttraumatic stress disorder and depression following trauma: understanding comorbidity. Am J Psychiatry 2004;161:1390–1396.

36. Vilagut G, Forero CG, Barbaglia G, et al. Screening for depression in the general population with the Center for Epidemiologic Studies Depression (CES-D): a systematic review with meta-analysis. PLoS One 2016;11:e0155431.

37. Mayou R, Bryant B. Outcome in consecutive emergency department attenders following a road traffic accident. Br J Psychiatry 2001;179:528–534.

38. Rogers CH, Floyd FJ, Seltzer MM, et al. Long-term effects of the death of a child on parents' adjustment in midlife. J Fam Psychol 2008;22:203–211.

39. Rosenberg AR, Baker KS, Syrjala K, et al. Systematic review of psychosocial morbidities among bereaved parents of children with cancer. Pediatr Blood Cancer 2012;58: 503–512.

40. Cuijpers P, Berking M, Andersson G, et al. A meta-analysis of cognitive-behavioural therapy for adult depression, alone and in comparison with other treatments. Can J Psychiatry 2013;58:376–385.

41. van Zoonen K, Buntrock C, Ebert DD, et al. Preventing the onset of major depressive disorder: a meta-analytic review of psychological interventions. Int J Epidemiol 2014; 43:318–329.

42. Hofmann SG, Wu JQ, Boettcher H. Effect of cognitive-behavioral therapy for anxiety disorders on quality of life: a meta-analysis. J Consult Clin Psychol 2014;82:375–391.

43. Cuijpers P, Sijbrandij M, Koole S, et al. Psychological treatment of generalized anxiety disorder: a meta-analysis. Clin Psychol Rev 2014;34:130–140.

44. Coffey SF, Banducci AN, Vinci C. Common questions about cognitive behavior therapy for psychiatric disorders. Am Fam Physician 2015;92:807–812.

45. Thearle MJ, Vance JC, Najman JM, et al. Church attendance, religious affiliation and parental responses to sudden infant death, neonatal death and stillbirth. OMEGA J Death Dying 1995;31:51–58.

46. Bergstraesser E, Inglin S, Hornung R, et al. Dyadic coping of parents after the death of a child. Death Stud 2015;39:128–138.

47. Erlangsen A, Fedyszyn I. Danish nationwide registers for public health and health-related research. Scand J Public Health 2015;43:333–339.

48. Dyregrov K. Bereaved parents' experience of research participation. Soc Sci Med 2004;58:391–400.

49. Hynson JL, Aroni R, Bauld C, et al. Research with bereaved parents: a question of how not why. Palliat Med 2006;20:805–811.

50. Christensen AI, Ekholm O, Glümer C, et al. The Danish National Health Survey 2010. Study design and respondent characteristics. Scand J Public Health 2012;40:391–397.

51. Markanday S, Brennan SL, Gould H, et al. Sex-differences in reasons for non-participation at recruitment: Geelong Osteoporosis Study. BMC Res Notes 2013;6:104.