

# Parental well-being and quality of life after losing a child due to a life-limiting diagnosis: A nationwide survey in Denmark

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## Background

- Losing a child is probably the most burdensome event parents can experience and following the loss, parents may suffer from enduring grief and distress (1).
- Previous research has identified risk factors that might contribute to the development of distress in bereaved parents (2, 3, 4, 5, 6).
- The first children's hospice in Denmark was established in 2015.
- In 2016 all five public healthcare regions in Denmark were upgraded with specialized paediatric palliative care teams in order to strengthen the capacity.

1. Lykke C et al. Anxiety and depression in bereaved parents after losing a child due to life-limiting diagnoses: a Danish nationwide questionnaire survey. *JPain Symptom Manage*, 2019.  
2. Li J et al. Mortality in parents after death of a child in Denmark: a nationwide follow-up study. *Lancet* 2003.  
3. Kreicbergs UC et al. Parental grief after losing a child to cancer: impact of professional and social support on long-term outcomes. *J Clin Oncol*, 2007.  
4. Jalmsell L et al. Anxiety is contagious-symptoms of anxiety in the terminally ill child affect long-term psychological well-being in bereaved parents. *Pediatr Blood Cancer* 2010.  
5. Wu L et al. Pre-bereavement meaning and post-bereavement distress in mothers of children who underwent haematopoietic stem cell transplantation. *Br J Health Psychol* 2008.  
6. Lykke C et al. End-Of- Life communication: a nationwide study of bereaved parents' perceptions. *BMJ Support Palliat Care* 2019.



The aim of this study was to identify associated factors for poor well-being and poor quality of life in bereaved parents 3–5 years after losing a child with a life-limiting diagnosis



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# Methods

## Register-study

- Nation-wide 1994-2014
- Danish Register of Causes of death

## Participants

- 951 children who died in the period 2012-2014
- “Directory of life-limiting conditions”
- 402 children were identified
- Danish Civil Registration System identified 743 parents

## Nationwide cross-sectional questionnaire survey

- Modified version of “To lose a child”

### 3 Sections:

- Care during the child's illness
- Care after the child's death
- The parents' well-being today

## 7-point Visual Digital Scale

### Cumulative symptom index

- ‘Have you felt anxiety during the last month’?
- ‘Have you felt depression during the last month’?
- ‘How satisfied are you with your current sleep pattern’?
- ‘How would you rate your physical health during the last month’?

REGULAR ARTICLE

### All-cause mortality rates and home deaths decreased in children with life-limiting diagnoses in Denmark between 1994 and 2014

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REVIEWAL  
 Why and where do children die?

Child mortality and mortality have changed for the better in most industrialized countries. This can mainly be explained by screening programmes, improved paediatric care and preventive measures such as reducing accidents and providing vaccination programmes. But child death remains a reality that can never be totally avoided. In reality, life-limiting conditions will always pose medical and ethical challenges. When and where to offer treatment and on palliative care is debated. The Nordic countries offer



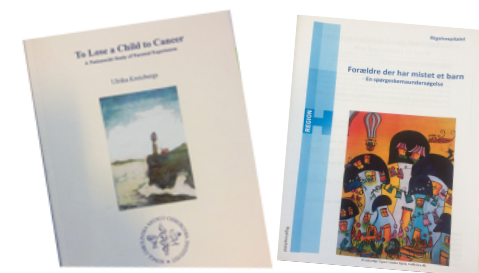
Hain et al. BMC Palliative Care 2013, 12:43  
<http://www.biomedcentral.com/1472-684X/12/43>



RESEARCH ARTICLE

### Paediatric palliative care: development and pilot study of a ‘Directory’ of life-limiting conditions

Richard Hain<sup>1,2,3\*</sup>, Mary Devins<sup>4</sup>, Richard Hastings<sup>5</sup> and Jayne Noyes<sup>2</sup>



### A population-based nationwide study of parents' perceptions of a questionnaire on their child's death due to cancer

Ulrika Kristberg, Ulrika Våldmanstätt, Gunnar Stenck, Jan-Inge Hentzer

Lancet 2004, 364: 292-89



## Results

### Characteristics of the children

<i>N (%)</i>	<b>Children</b>
Identified children	402
Total number of respondent parents	193
Number of children represented	152 (37.8)
Children represented by both parents	41

### Characteristics of bereaved parents after losing a child due to life-limiting diagnoses

<i>N (%)</i>	<b>Mothers</b>	<b>Fathers</b>
Number of invited parents	391	352
Number of respondents	136 (34.8)	57 (16.2)

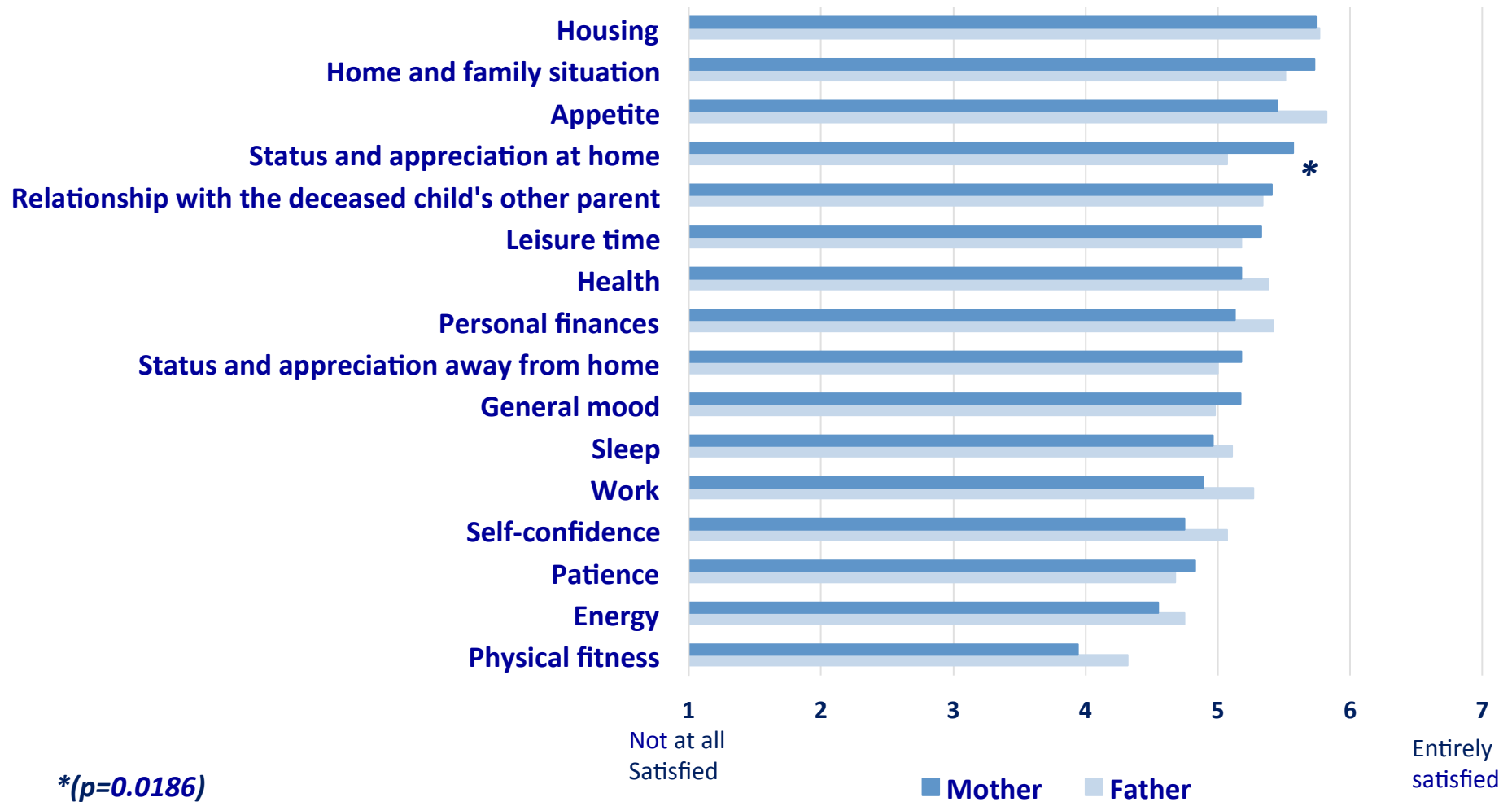
### Deaths causes of the children

<b>Neoplasms</b>	41 (21.2)
<b>Diseases of the nervous system</b>	24 (12.4)
<b>Congenital malformations, deformations and chromosomal abnormalities</b>	46 (23.8)
<b>Conditions originating in the perinatal period</b>	55 (28.5)
<b>Other</b>	27 (14.0)

# Results



Mean scores of health and vitality in bereaved parents 3-5 years after losing a child due to life-limiting diagnoses by parental gender.





## Number of symptoms three to five years after the loss

	0	1	≥2	Total	No. of respondents
<b>All</b>	65.8	17.6	16.6	100.0	193
<b>Parent</b>					
Mother	64.7	17.6	17.6	100.0	136
Father	68.4	17.5	14.0	100.0	57
<b>Married</b>					
Yes	70.5	17.4	12.1	100.0	149
No	52.5	20.0	27.5	100.0	40
<b>Education</b>					
Basic school, upper secondary or vocational education	52.1	22.9	25.0	100.0	48
Higher education	73.5	13.6	12.9	100.0	132
<b>Age of child at death</b>					
0 years	64.8	21.3	13.9	100.0	108
≥1 years	67.1	12.9	20.0	100.0	85

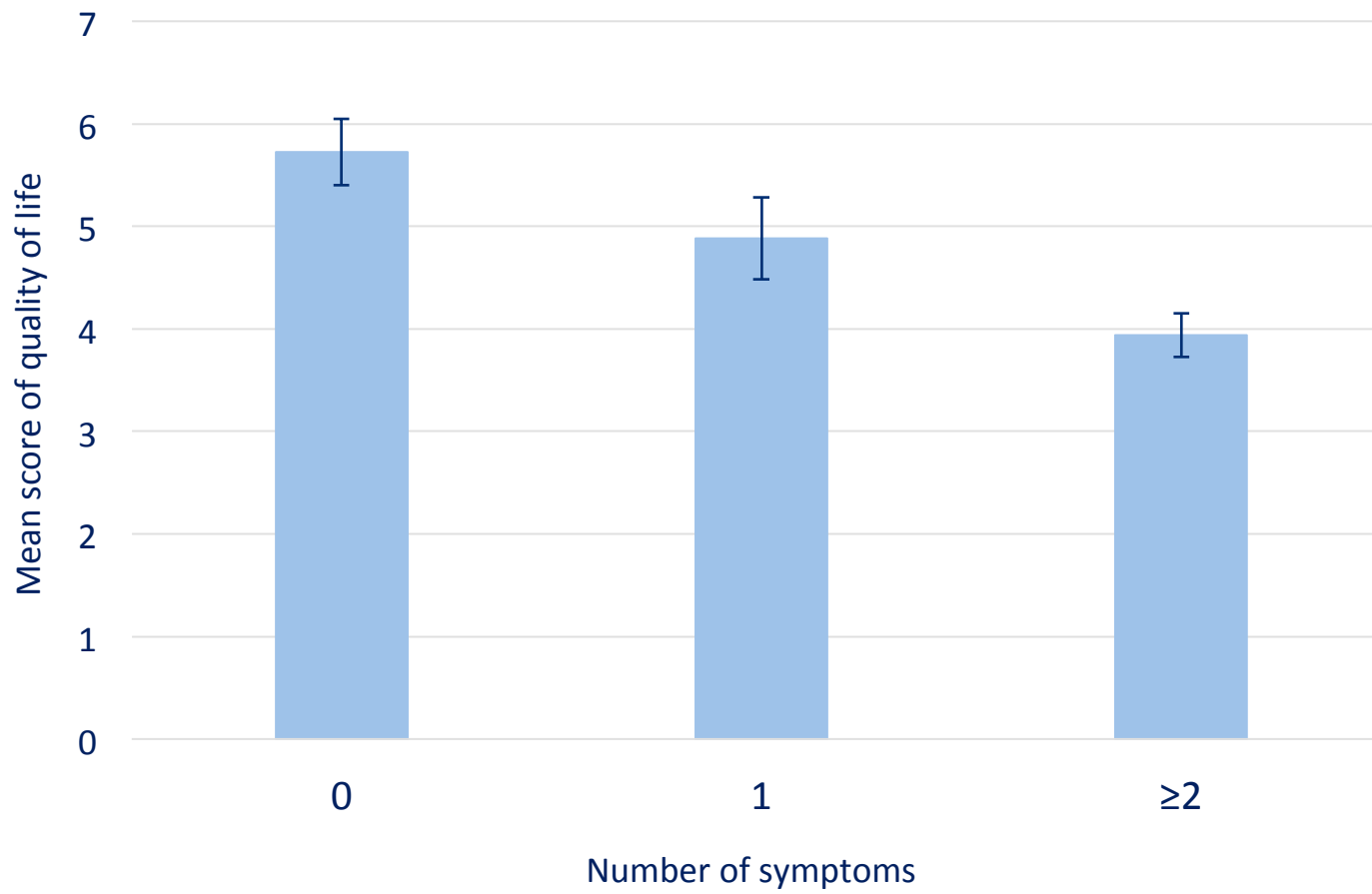


**The association between the various sociodemographics (age, education and marital status) and the symptom index**

	Crude			Adjusted		
	OR	(95% CI)	P-value	OR	(95% CI)	P-value
<b>Parent</b>						
Mother	1.21	(0.64-2.25)	0.5597	1.28	(0.64-2.59)	0.4846
Father	1			1		
<b>Married</b>						
Yes	1		0.0208	1		0.0405
No	2.31	(1.14-4.71)		2.14	(1.03-4.42)	
<b>Education</b>						
Basic school, upper secondary or vocational education	2.47	(1.22-5.00)	0.0121	2.11	(1.01-4.40)	0.0465
Higher education	1			1		
<b>Age of child at death</b>						
1	1.01	(0.95-1.07)	0.7479	1.02	(0.96-1.09)	0.4760
1	1			1		



## Mean score of quality of life and 95% CI by number of symptoms





## Take home messages

- Every sixth of the bereaved parents had  $\geq 2$  symptoms
- 1 out of 10 bereaved parents continued to experience poor well-being and overall quality of life several years after the loss
- Associated factors for poor parental well-being and quality of life suggest attention to particularly unmarried parents and parents with lower education
- Supportive interventions during the child's illness and after the loss may be considered
- Future research should achieve a more detailed and systematic identification and thorough understanding of the parents' needs for interventions during their child's illness and after their loss



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# Thank you for your attention

