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Børn og unge med livstruende og livsbegrænsende sygdomsdiagnoser

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Eventyrlige Upser vender hjem, Gallericc.dk

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ACTA PÆDIATRICA
NURTURING THE CHILD

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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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Keywords
Cause of death, Diagnoses, Location of death, Paediatrics, Palliative care

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ABSTRACT

Aim: Specialised paediatric palliative care has not previously been a priority in Denmark. The aim of this study was to support its development and organisation, by examining why and where children died using official national data for 1994–2014.

Methods: We obtained data on 9462 children who died before the age of 18 from the Danish Register of Causes of Death. The causes of deaths were listed according to the codes in the International Classification of Diseases.

Results: The all-cause mortality rate decreased by 52% over the study period, and infants below one year accounted for 61% of all deaths. The decline in primarily reflected fewer deaths due to congenital malformations abnormalities (68%) and perinatal deaths (30%). In children age the substantial decrease (65%) was due to external causes (75%). The relative proportion of hospital deaths increased, while home

Conclusion: All-cause mortality rate decreased markedly, and the hospital deaths increased. The results may reflect more aggressive attempts to save lives, but some terminally ill children may be de dying at home.

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Acta Pædiatrica ISSN 0803-5253

EDITORIAL

DOI:10.1111/apa.14389

Why and where do children die?

Child morbidity and mortality have changed for the better in most industrialised countries. This can mainly be attributed to screening programmes, improved paediatric care and preventive measures such as reducing accidents and providing vaccination programmes. But child deaths remain a reality that can never be totally avoided. Incurable, life-threatening conditions will always pose medical and ethical challenges. When and where to offer treatment and, or, palliative care is debatable. The Nordic countries offer high-quality paediatric diagnosis and treatment, as shown by registry data, but data on palliative care at hospital or at home are sparse, as is our knowledge on the preferred location of death.

These issues are addressed in an interesting study by Lykke et al. (1) in this issue of *Acta Paediatrica*. The authors analysed why and where children died in Denmark from 1994 to 2014. They identified 9462 children who died before the age of 18 from the Danish Register of Causes of Death and found a 52% decrease in child mortality during

palliative care facilities, as this would provide a more accurate reflection of policies and practice. The high rate of hospital deaths in Denmark could be attributed to a strong intent to cure, as well as the statistical inclusion of infants under one year, who were excluded from a similar study of 11 countries by Hakanson et al. (2). The ample availability of high-tech equipment managed by skilled staff in specialised neonatal and intensive care units may reinforce the intent to cure and offer the prospect of therapeutic

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Formål studie 1:

- at undersøge hvilke dødsårsager der findes i Danmark hos børn og unge i alderen 0 og optil 18 år fra 1994-2014 og identificere deres dødssted.

Metode:

- et registerstudie (DAR)

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Fordeling dødsfald 0 år-18 år

Antal døde pr. år	Total
1994	619
2011	346
2012	309
2013	321
2014	321

Pr. 100.000 børn

1994: 57.1

2014: 27.4

52%

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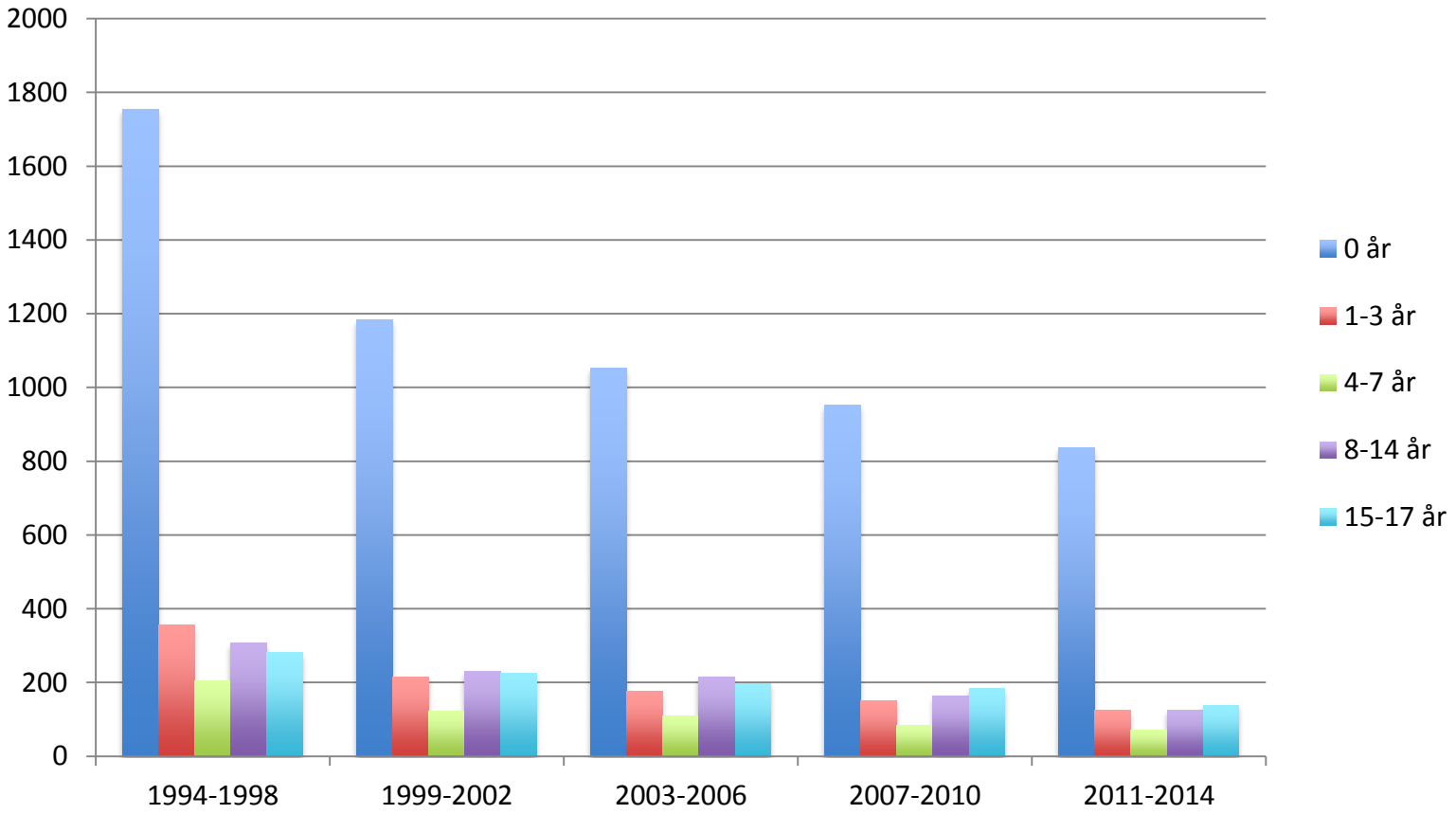
9.462 dødsfald inddelt i år



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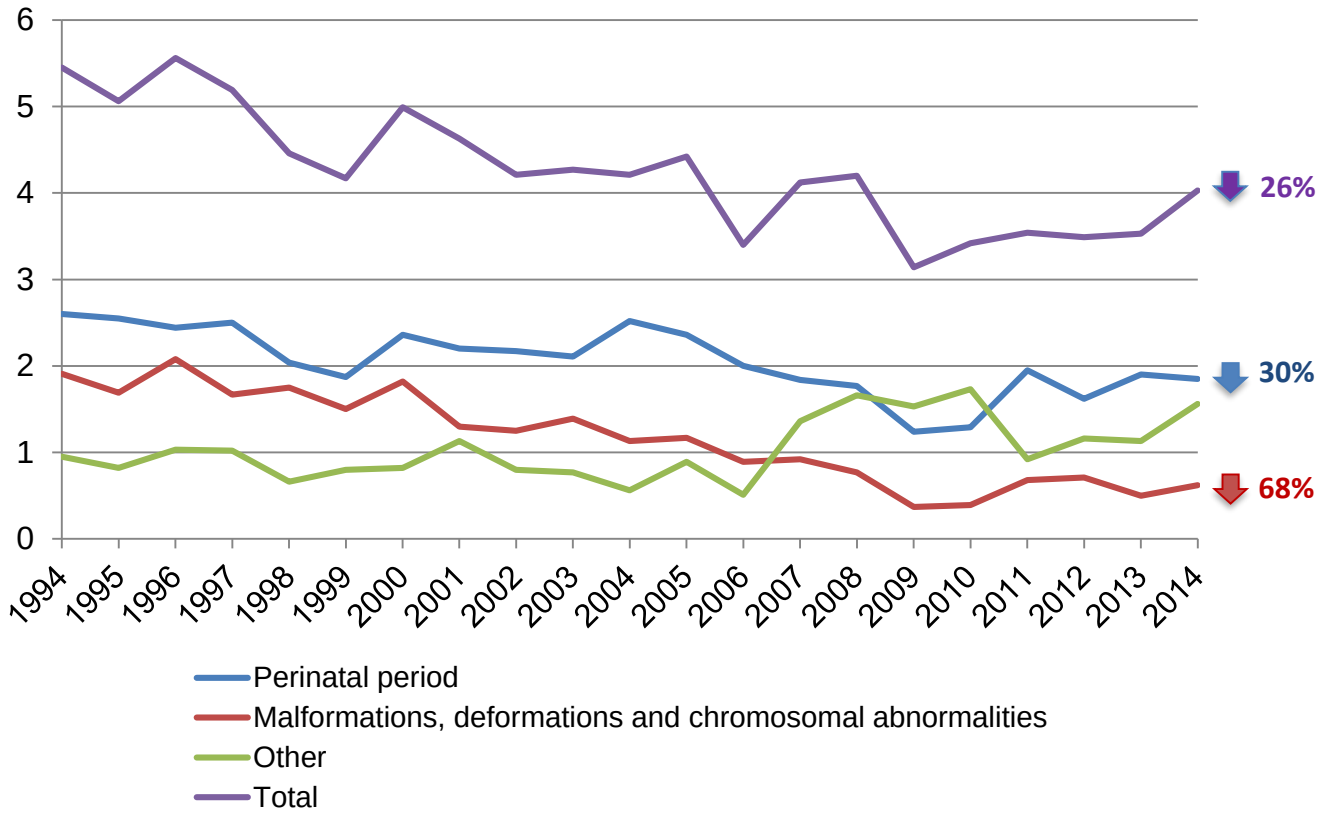
Dødsårsager 1994-2014 (under 1 år) pr. 1.000 børn



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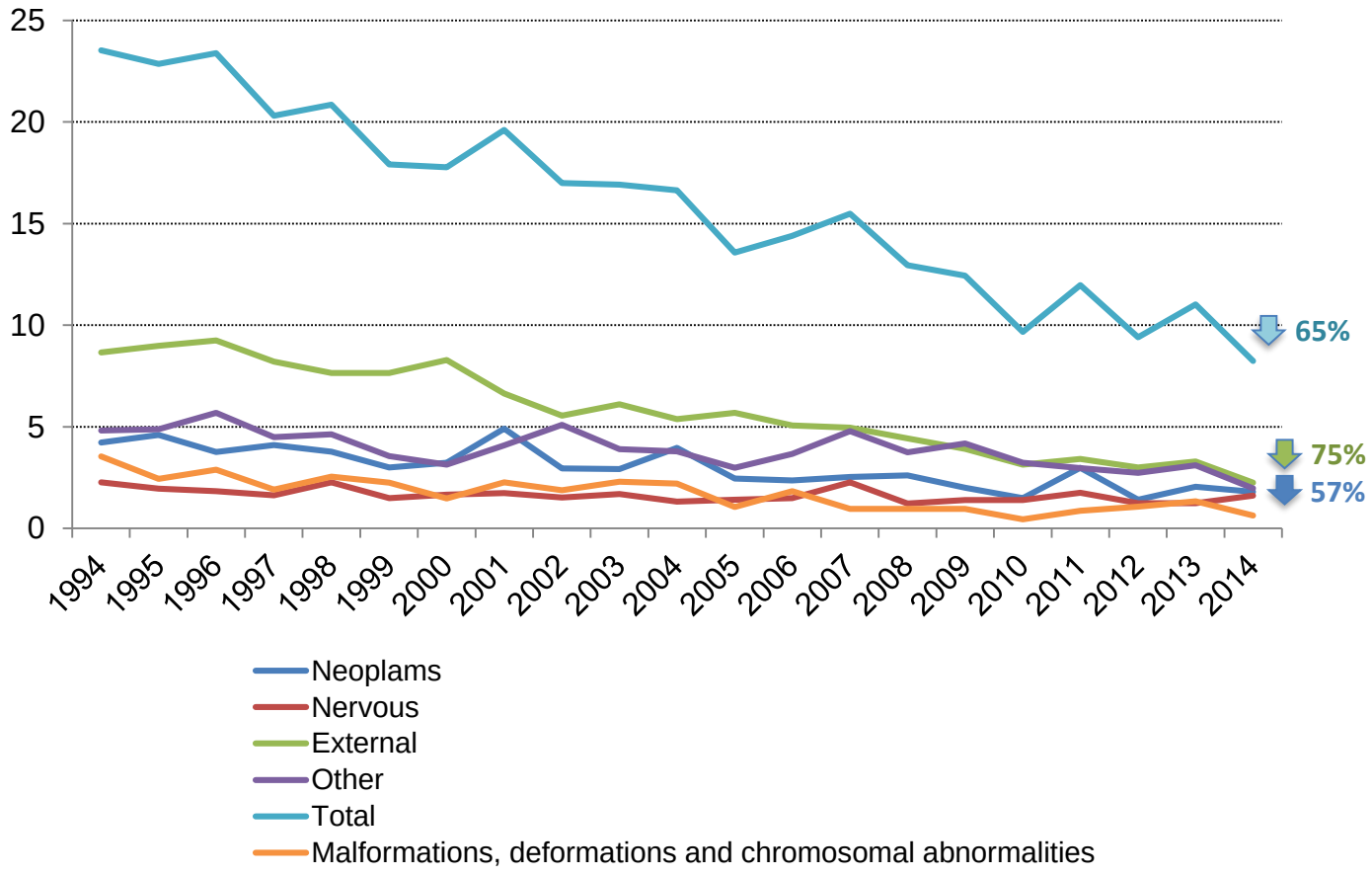
Dødsårsager 1994-2014 (1-17år) pr. 100.000 børn



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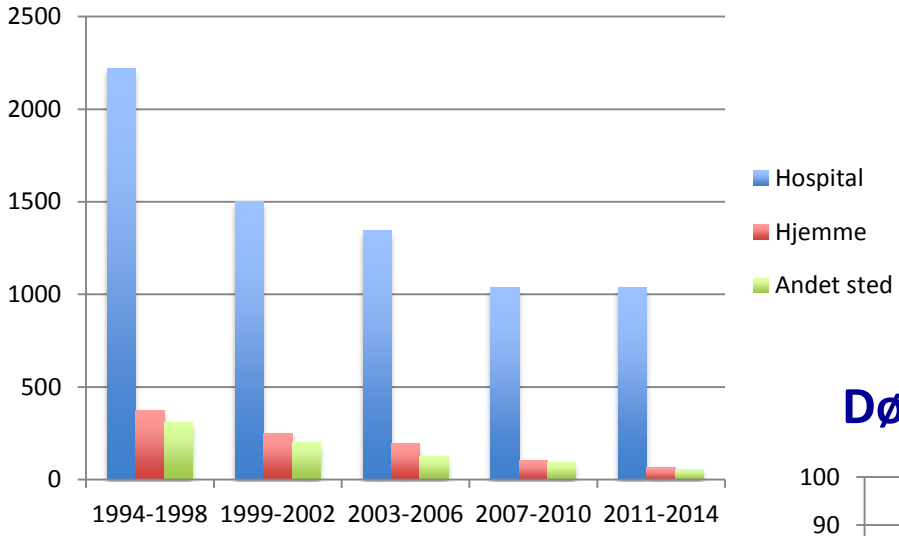
Dødssted

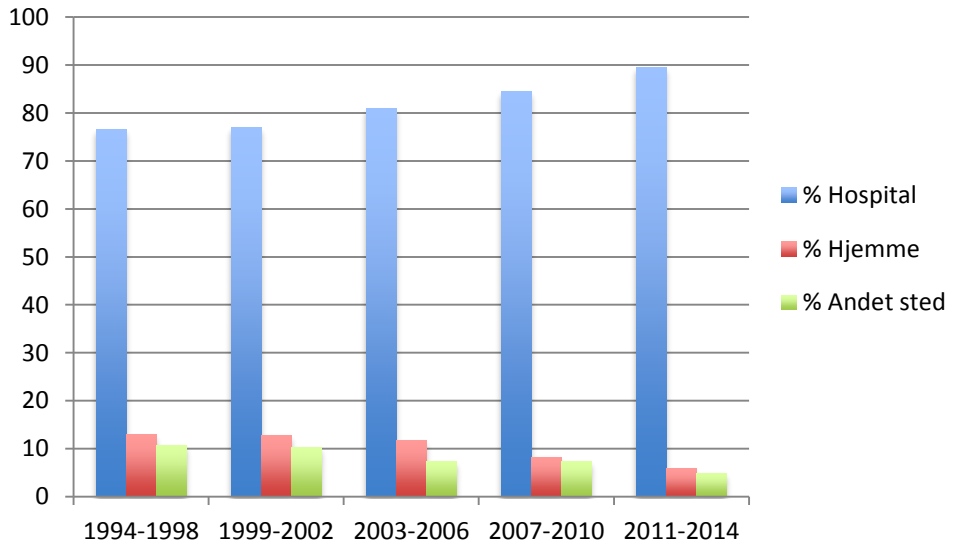


↓52 %

↑17 %

↓50%

Dødssteds procentvise andel



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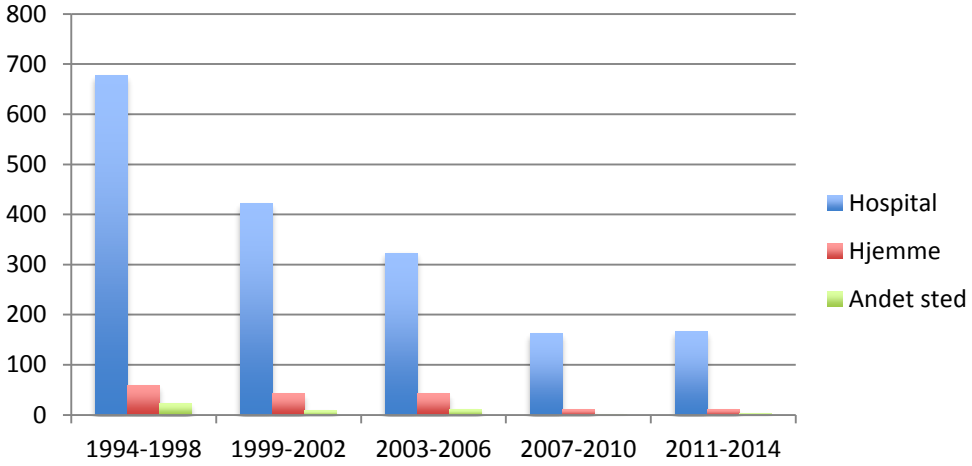
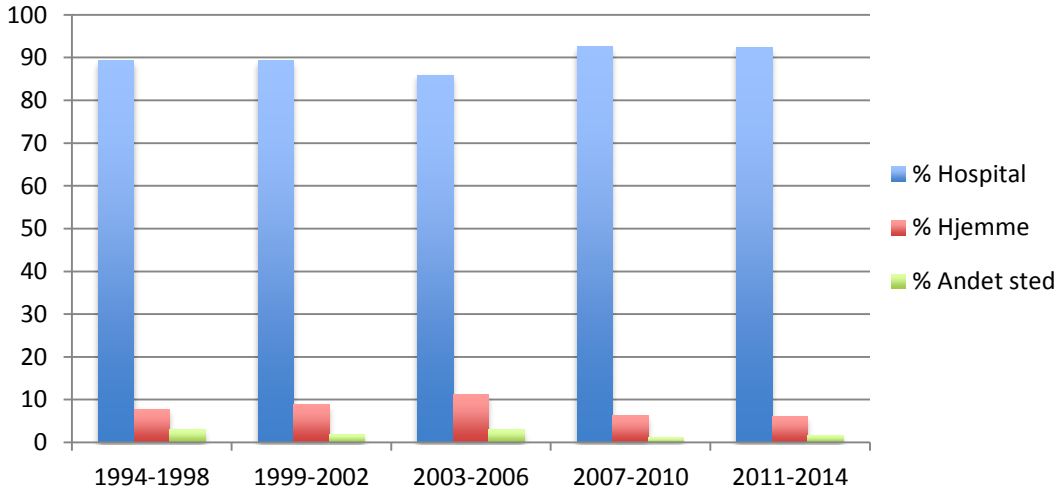
Medfødte misdannelser og kromosomanomalier



↓76 %

Medfødte misdannelser og kromosomanomalier



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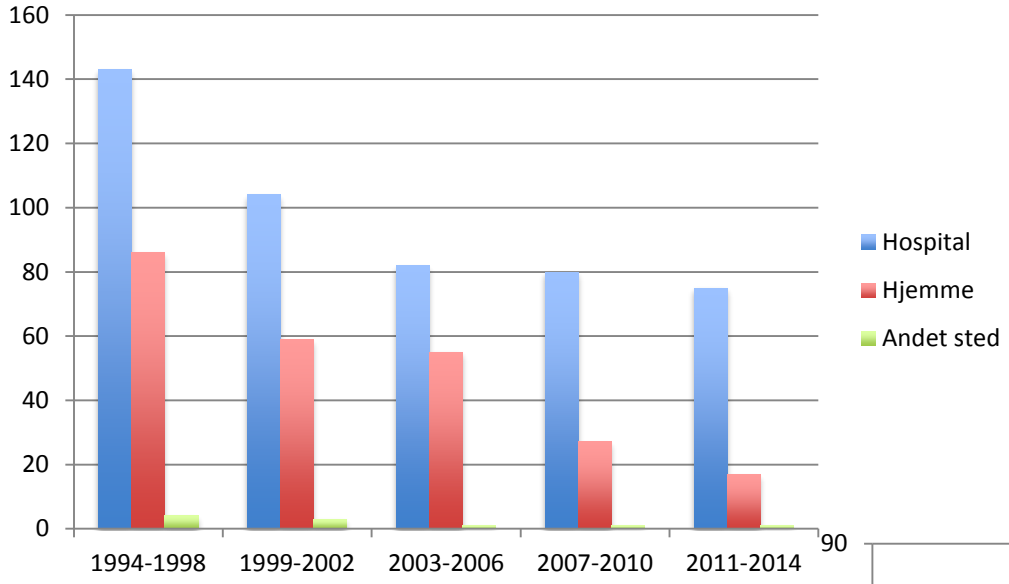
Cancer

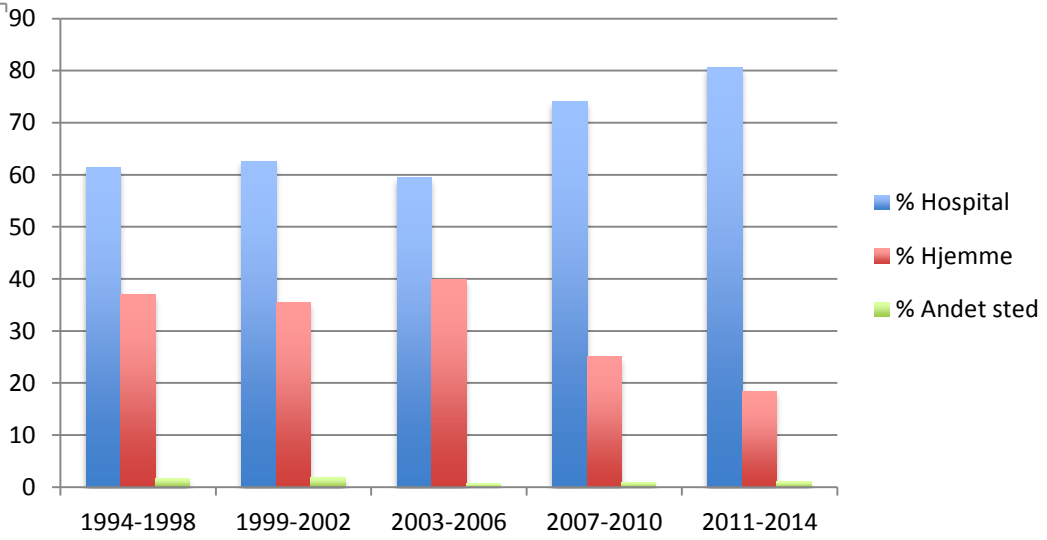


↓60 %

↑24 %

↓50%

Cancer



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- Dødelighed på hospital var generelt højest hos børn under 1 år
- Den største forskel blev fundet hos 4-7 år, hvor hospitals død steg 52% fra 56-85%
- Hjemmedød mest hyppig og faldt mindst i gruppen 8-14 år

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Take home message studie 1

- Dødeligheden faldt markant
- Over halvdelen af børnene døde indenfor det første leveår
- Den relative andel af hospitals dødsfald steg og hjemmedød faldt

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Anxiety and depression in bereaved parents after losing a child due to life-limiting diagnoses: A questionnaire survey

Camilla Lykke[a], Ola Ekholm[b], Kjeld Schmiegelow[c], Marianne Olsen[c], Per Sjøgren[a]

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Formål studie 2:

- at identificere sygdomsdiagnoser hos danske børn og unge, som potentielt kunne profitere af specialiseret palliativ indsats.
- at undersøge niveauet af angst og depression hos forældre, der har mistet et barn, som har været igennem et basalt palliativt forløb.

Metode:

- Register (DAR+CPR)/Tværsnitsstudie (Spørgeskema)

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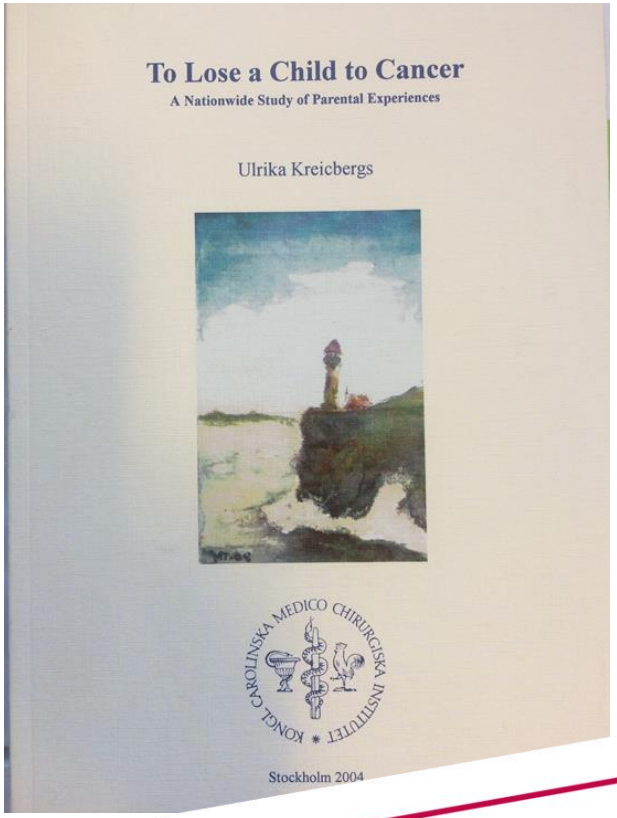
Hain et al. BMC Palliative Care 2013, 12:43
http://www.biomedcentral.com/1472-684X/12/43

BMC Palliative Care

RESEARCH ARTICLE Open Access

Paediatric palliative care: development and pilot study of a 'Directory' of life-limiting conditions

Richard Hain[1,2,3*], Mary Devins[4], Richard Hastings[5] and Jayne Noyes[2]



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

Lancet 2004; 364: 787–89

Ulrika Kreicbergs, Unnur Valdimarsdóttir, Gunnar Steineck, Jan-Inge Henter

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- **Første del:** Spørgsmål om forældrene, barnet og den information, pleje og omsorg de modtog under sygdomsforløbet.
- **Anden del:** Spørgsmål om den omsorg de modtog efter barnets død.
- **Tredje del:** Spørgsmål om hvordan forældrene har det i dag

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Characteristics of the children

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

Causes of deaths

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)

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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 years	35 (25.7)	10 (17.5)
35-44 years	63 (46.3)	23 (40.4)
≥45 years	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)
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)

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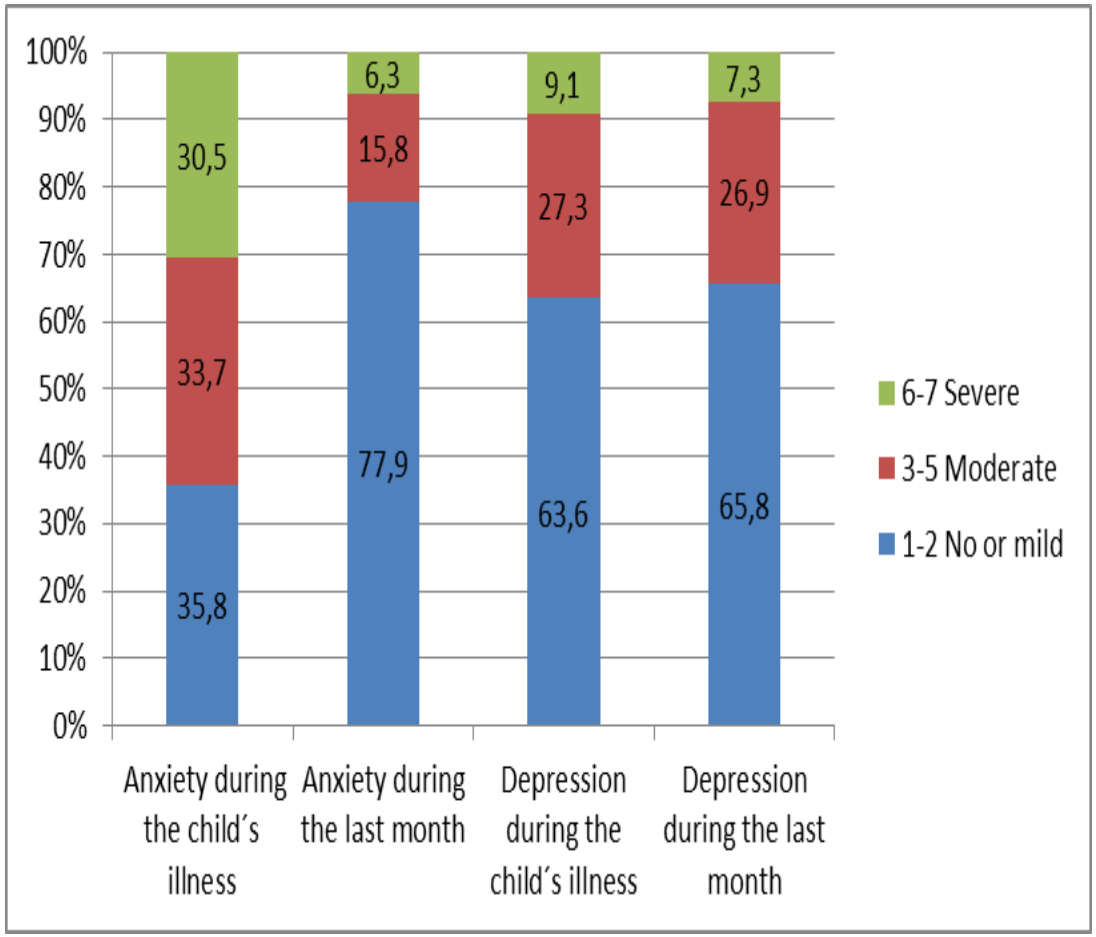
Anxiety and depression in bereaved parents during the child´s illness and after the lost. Percentage



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Psychological outcomes of the parents according to the CES-D scale

	Mothers n = 136	Fathers n= 57	P-value
Total scores mean (SD)			
CES-D (score range 0-60)	14,09 (12,7)	13,8 (10,1)	0,867
Cut-off scores n (%)			
0-15 No to mild depressive	89 (66,9)	32 (56,1)	
16-23 Moderate depressive	17 (12,8)	14 (24,6)	
24-60 Severe depressive	27 (20,3)	11 (19,3)	

Risk of major depression (CES-D>23)		
		OR 95% CI P-value
Education	Basic, upper secondary or vocational school vs. higher education	6.92 2.74-17.47 0.001
Civil status	Married vs not married	0.29 0.11-0.78 0.018

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Non- response 1

Mulig sammenhæng mellem køn, alder, boligområde, diagnose og alder på barn.

Mødre ↓ 35 år 1.56 højre odds for non-response (ref. 35-44)

Mødre ↑ 45 år 0.45 lavere odds for non-response (ref. 35-44)

Sammen tendens ses hos fædre men ikke statistisk signifikant.

Ingen øvrige sammenhænge

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Non- response 2

Jeg havde ikke overskud til at deltage
- 63% helt enig

Det er for hårdt følelsesmæssigt at deltage
- 67% helt eller delvist enig

Spørgeskemaet var for langt og for omfattende
- 51% helt eller delvist enig

Jeg mener, at denne undersøgelse er vigtig
- 51% helt enig

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Take home message studie 2

- **Efterladte forældre er en meget udsat gruppe med forøget risiko for at udvikle angst og længerevarende depressive symptomer**

- **Angst niveauet falder med tiden mens niveauet af depressive symptomer ses stort set uændret**

- **Forældre som er ugifte eller har en lav uddannelse er i øget risiko for at udvikle svære depressive symptomer**

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Formål studie 3:

- At undersøge forladte forældres opfattelse af kommunikation med sundhedspersonale under deres barns livsbegrænsende sygdom og forestående død.

Metode:

- Tværsnitsstudie (Spørgeskema)

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Primære outcomes

- At udarbejde national kortlægning over dødsårsager og dødssteder for børn og unge i alderen 0 og optil 18 år i perioden 1994-2014.
- At identificere de børn og unge, som potentielt kunne profitere af SPI.
- Identificere niveauet af angst og depression hos efterladte forældre.
- At undersøge forladte forældres opfattelse af kommunikation med sundhedspersonale under deres barns livsbegrænsende sygdom og forestående død.

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Perspektiver

- At den specialiserede palliative indsats nationalt målrettes de børn og familier som har brug for den.
- At indsatsen tilrettelægges ud fra de behov som familierne har.

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Stor tak til Børnecancerfonden som finansierer projektet.

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Stor tak til Rigshospitalet for donation til projektet

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Stor tak til Christina Christiansen, Gallericc.dk, for brug af billeder

You can do it, Gallericc.dk

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