

Dynamics of grief in parents during their child's end-of-life: A grounded theory study.

ne Kochen
-candidate

Center of Expertise Palliative Care Utrecht,
UMC Utrecht

kia CCM Teunissen
l A Boelen
rtha A Grootenhuis
ria-Luisa Tataranno
rienne C Fahner
os R. de Jonge
chiel L Houben
rijke C Kars

 **ZonMw**
Projectnr: 844001506



growing attention for parental bereavement and
bereavement care – mostly after the death

parents face incremental losses during their child's end-of-life

how parents experience grief during the end-of-life and
their needs remain unclear

HCPs* recognize parental hardship but are unsure how to
provide optimal preloss care



Research question:

How do parents experience and cope with loss and grief during their child's EOL?

Design:

Explanatory qualitative research design – grounded theory study

Sample:

Purposive sample of parents (≥ 18 y) of children (0-18y) during EOL and recently deceased children was included.

- **Maximum variation** with regard to diagnosis and age of the child

Exclusion criteria

Not referred for complex grief

Data collection:

Semi-structured interviews

Background questionnaire

Data analysis:

Grounded theory approach

Analysis in a multidisciplinary team

Open coding

• Identifying meaningful fragments, discussing interpretations

Constructing narratives

• Overview of topics per case, discussing interpretations and defining categories

Axial coding

• Categorizing in Nvivo, organizing data

Selective coding

• Establishing relations among categories

Participants

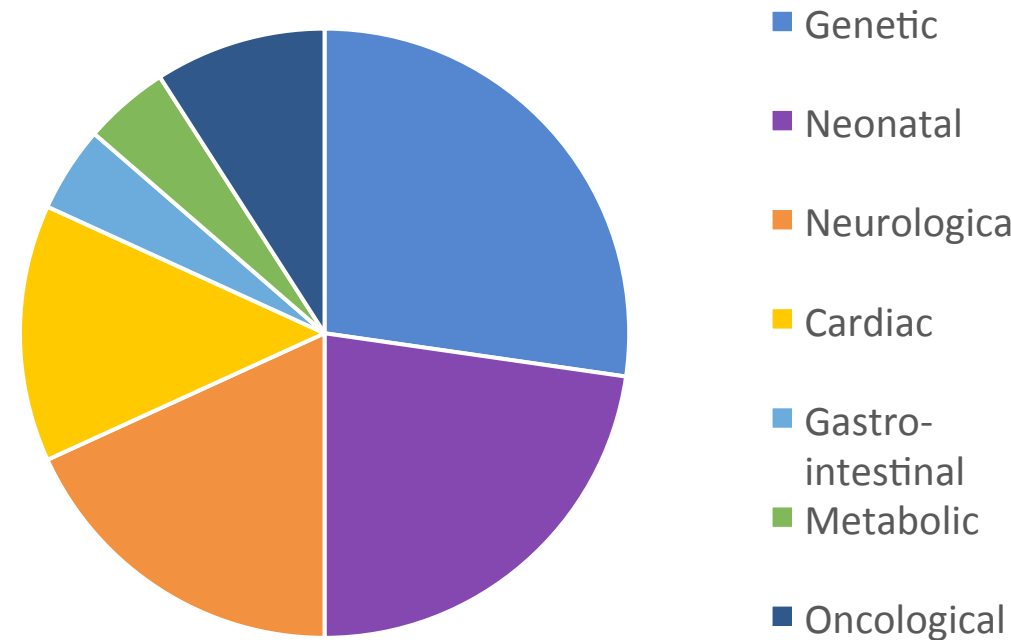
38 parents (21 female) of 22 children

Moment of interview:

- 13 parents of 8 children during the EOL
- 25 parents of 14 children after passing

Age of child	n=
<6 Months	9
6-12 Months	4
1-5 Years	4
6-10 Years	1
>10 Years	4

Diagnosis/disorder of child, N= 22



Sustaining family life and holding parenting goals:

Enacting meaningful parenthood
Ensuring their child could live a full life

Everyday life

Confrontation with triggers of loss:

- Announcement of the loss
- The immensity of the loss

Keeping going to fulfill goals

Grief triggered by experienced losses

Coping with grief

Downregulating feelings of grief

Enduring
Fragmenting
Postponing grief
Rationalizing
Positive thinking
Hoping

Experiencing grief

Being forced by pangs of grief
Allowing to connect with grief

Creating emotional space

Most theories on bereavement emphasize the need to oscillate between loss- and restoration oriented coping – yet performing loss oriented coping is increasingly strained during the EOL

leads to two practical implications:

1. Triggers of loss are more intertwined with daily life than HCPs are aware of
 - Parents' hypervigilance towards these triggers limit their emotional space
 - HCPs should be aware of these triggers and try to minimize/share openly about uncertainty

2. HCPs should be aware that parents tend to downregulate their grief in conversations with them
 - Does not mean that parents do not understand the prognosis
 - Demarking the nature of conversation might benefit parents in their coping

gths

Parents were included during the EOL

Wide range of diagnosis and ages

ations

Lack of diversity in religious and cultural background

line Kochen, PhD-candidate
m.kochen@umcutrecht.nl

 **ZonMw**
Projectnr: 844001506

of Expertise Palliative Care Utrecht

 **emBRACE**

