



Western Norway  
University of  
Applied Sciences

# **Understanding understudied and underserved bereavement**

Drug Death Related Bereavement - The END project

Faculty of Health and Social Sciences

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Photo: Pexels photos

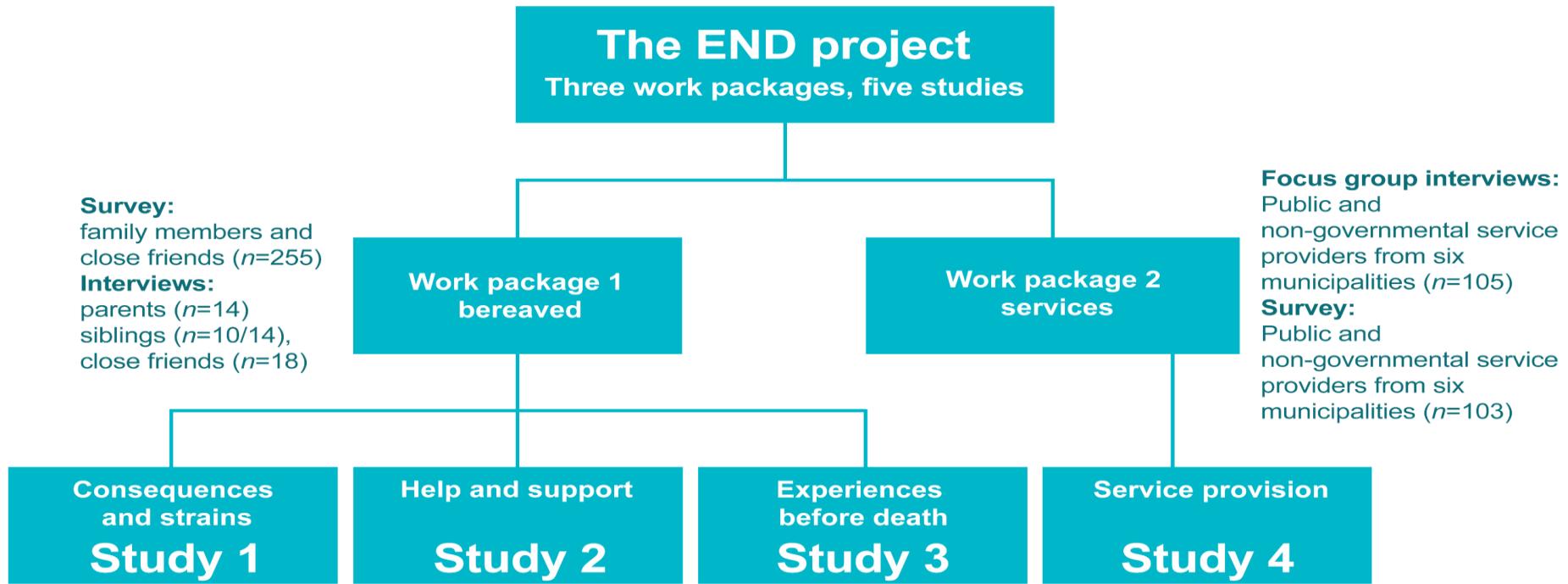
# Drug-related death? Isn't that a narrow focus in a family therapy conference?

- Yes!  
But... By studying one form of unnatural death, we can reflect on other forms of little-acknowledged grieving processes in families, and maybe also grief and families in general.
- By studying different roles, positions and dynamics in families in grief after DRD, we can spot phenomena that many families may experience.
- Bereaved after DRD need family therapists



# Unnatural deaths, drug related deaths

- An unnatural death results from an external cause (homicides, suicides, accidents, medical errors, alcohol intoxication and drug overdose, sudden infant death)
- Often sudden, unexpected, difficult to understand
- Drug-related death is understood as overdoses, mortality associated directly or indirectly with illicit drug use



**Research circle:**  
bereaved ( $n=2$ ), professional helpers from municipalities ( $n=3$ ), non-governmental service providers ( $n=2$ ), and researchers and teachers from HVL ( $n=4$ )

**Work package 3  
knowledge translation  
and implementation**  
**Study 5**

# Mothers story



# The special grief

The special grief. A theoretical model by professor Kari Dyregrov  
(ResearchGate 2019).

Problematic  
drug use

Anticipatory  
grief

DEATH  
stigma

Conflicting  
feelings

Complicated  
grief

Disenfranchised  
grief

# Demanding life situation for families

## Problematic drug use

### An unknown invisible intrusion

Taking over the family life	Family survival	An invisible family
<ul style="list-style-type: none"><li>• overwhelming problems</li><li>• exhausted family members</li><li>• messy lives and broken relations</li></ul>	<ul style="list-style-type: none"><li>• trying to understand</li><li>• hoping for change</li><li>• endlessly adapting</li></ul>	<ul style="list-style-type: none"><li>• a family matter</li><li>• family secrets</li><li>• a professional blind spot</li></ul>

# Anticipatory grief

## Anticipatory grief

- the substance-using family member lives risky life and behaves very differently from the person the family knew earlier.
- Family members could feel loss, grief, and need for distance due to a despairing situation

# DEATH stigma

“Nothing to mourn, He was just a drug addict”

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- as many as 57% of bereaved got negative comments from close and extended family and friends.
- Dehumanizing labeling, unspoken and implicit stigma, blaming the deceased, the only and the best outcome
- A mother wrote about what had been said about her 20-year-old deceased daughter:
  - I was told she was a fucking junky and a fucking whore who had not deserved to live. She should have been taken on the day she was born; she had no right to life, and she used others' tax money to get drugs, tricked men into giving her money by selling herself. Girls like that should die.

(Dyregrov&Selseng, 2022)

# Conflicting feelings

Complex emotions

- anger, guilt, relief, shame
- anger, especially anger toward different health and welfare services
- Guilt and shame were commonly described, for failing as a parent, as a brother or sister, or as a friend.
- Relief: behalf of the deceased, relief for others or relief on their own behalf. (Titlestad et al, 2021)

# nfranch grief

## Disenfranchised grief and grief hierarchy

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- Disenfranchised grief (Doka 1989) - grief that is not acknowledged, either by one's own network or by society in general.
- Disenfranchised grief can also be self-imposed
- Death and grief have different statuses in society, described as grief hierarchy (Peskin, 2019).
- The hierarchy of expressed grief roughly follows the generational family order of spouse and parent before the child and sibling, and family before friends.



# Complicated grief

## Prolonged grief

- Characteristics of PG include a strong denial of the loss, difficulty adapting to life without the deceased, and an inability to form new bonds or relationships with others (Prigerson et al., 2009).
- High levels of PG symptoms after several months since the loss, several years after, also shown as isolation and suicidal thoughts.
- Time does not always heal all wounds, (Titlestad & Dyregrov, 2022)

# Parents

Sounds of Silence



# Parents silent grief

- While other parents often experienced their child becoming independent, these parents have experienced extended parenthood because their child's need for support intensified.
- Bereaved parents after drug death (Titlestad et al., 2019; Titlestad et al., 2020; Titlestad et al., 2021) describe shame and guilt for failing as a parent
- The parents who struggled the most have often a low belief in their coping, they isolate themselves and have a risk for prolonged, complicated grief.

# Siblings

The family story

# Siblings

- Sibling relations can be the longest-lasting relationships in an individual's life, starting from birth and continuing until death (Seltzer et al., 1991).
- That means that siblings may have witnessed more of the changes made across the life course than most other family relations (Connidis, 1992, p. 972).





# Troubled families

- *It's all about the big picture. There is a reason that my sisters started taking drugs, which I understand completely. I think a lot about whether things could've been different. I survived just fine and have become who I am today because of or in spite of it, and I'm quite happy with that. But I think a lot about my sisters, especially the oldest one who died. I can't visit her grave without crying – not so much because she died, but more because of the life she led. The worst part is that my mum is buried in the same grave. Her being dead isn't the sad part, but rather that she was never really a mother to us.*



# Troubled families

- The family burdens could continue for generations (Lindeman et al., *in press*)
- The sibling who had experienced familial problems in childhood continued to help their drug-using siblings' children and grandchildren.
- These siblings' situation requires attention and sensitivity from professionals.
- Siblings' own experiences of lacking help in childhood could result in scepticism towards and distrust of professional services.

# siblings try to keep balance

- *I wasn't able to live my own life because there was always someone, I felt guilty about or needed to help or offer support to. In the end, I felt suffocated, like I couldn't breathe. I can't save either my brother or my parents. They actually have to save themselves. It took a long time for this to fully sink in. I had a poor self-image for many years.*
- The relationship between the participants and their parents change
- Siblings have to be strong, not by choice but because they got that role. (Løberg et al., 2022; Lorås et al., in press)

# Grief hierarchy

*It's Worse for the Parents...*

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"there's a difference between mom and me because he was her baby  
while I am a brother"

## *‘We’ as a Synonym for the Family*

- *What happened was just horrible and threw the whole family into a crisis, but at the same time, when I look back on it now, I see how it drew our family closer.*

*There is a sense of solidarity between the three of us who are still here, as well as my significant other, and we always give each other a hug when we meet and we don’t take each other for granted because we know all too well that things can turn upside down in a matter of moments.*



# Barriers for social support for the siblings

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- complex family relations
- different grief reactions
- shame, blame, and devaluation.

Dyregrov et al (in press). Why informal support fails for siblings bereaved by a drugrelated death: A qualitative and interactional perspectives

Close friends,  
intimate partners,  
ex-partners

**No obvious or clear place for bereaved friends**

**Depending on that, the nearest mourners give them space to be seen as mourners and  
to participate in grief rituals**

# He wasn't that different to me

- *He wasn't that different to me, he was a year younger than me, and we had quite a similar upbringing. I have two brothers, he had a brother, and parents who lived together, we had similar activities and went to quite similar education, that's the way it is in Norway.*
- *And maybe there's something about it, too, that you're kind of losing someone who might as well be ourselves.*

# Bereaved with problematic substance use

**Not acknowledged as bereaved in need of help.**

# Guilt, after twenty years

- *I was the first of us who started with needles right? So, in that way, I have... You inevitably have a level of responsibility. [...] I feel guilty that I started with that first, and then he followed me, right. [...] In the aftermath of the death, in their grief, his parents, his siblings and others close, they blamed me because I was the first to start injecting, of him and me. And he followed right after. One day, I just sat up there in his shed, and then I just picked up the syringe and then, not only do I pick it up, but I get him to help me stick it in me... And that's a bloody heavy load to have.*

# Bereaved with problematic substance use

- Not acknowledged as mourners in need of help
- Substance use hinders social contact
- Help received was related to drug use - substance use as a coping strategy is not accepted
- In need of help that can reach the mourner
- A fundamental lack of help and support when bereaved with their own substance use problems face a DRD.

A photograph of a person's hand holding a clear glass jar with a black lid. Inside the jar, there is a bright, glowing light that resembles a small fire or a celestial body like a planet or star. The background is a soft-focus landscape of trees and a sky transitioning from orange to dark blue at sunset. The overall mood is peaceful and contemplative.

# Working with families in grief

Call for family therapy and  
relational perspectives

Integrated work – both  
individual and relational  
level

## Loss-orientation

Cognitive and emotion regulating strategies about the loss

New knowledge (e.g., about DRD, the death circumstances)

## Restoration-orientation

Dealing with changed life circumstances (e.g., by giving and receiving support)

Reorientation:  
Working toward getting back to "normal" life



*Figure 2 Illustration of how the parents oscillated between LO and RO strategies as they adjusted to life*

# Dual Process Model, loss-orientation Individual- and Family-Level Coping (Stroebe & Schut, 2015)

## Individual level

Accept the reality of loss

Experience pain of grief

Adjust to life without the deceased

Relocate deceased emotionally and  
move on

## Family level

Family acceptance of the reality of  
loss

Share pain of grief with family  
members

Adjust as a family to a world without  
the deceased

Relocation of deceased within a  
family context

# Dual Process Model, Restoration-orientation Individual- and Family-Level Coping

## **Individual level**

Accept reality of changed world

Take time off from the pain of grief

Master the changed (subjective) environment

Develop new roles, identities, and relationships

## **Family level**

Accept the changed family world

Family-level distraction and non-grief-related interaction

Family adjustment: Make changes in ongoing family life and relationships

Move on as a family with new roles

Family therapy  
competencies  
are needed...

- The experience of living with problematic substance use and experiencing DRD and bereavement as a family is complex, diverse and relational.

# ...to facilitate family conversations

- The awareness that family members may not have talked about traumatic experiences earlier and that the stories can be overwhelming, shameful, and broken calls for a competent listener.
- Facilitating circular interactions between family members may provide understanding and acknowledgement and possibilities for meaning-making, both at the individual and family level
- That is what we do – isn't it?

# Literature from the END project

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- Titlestad, K. B., Schmid, M. T., Dyregrov, K. (2021). Prevalence and predictors of prolonged grief symptoms among those bereaved from a drug-related death in a convenience sample of Norwegian parents: A cross-sectional study. *Death Studies*, 1-10. <https://doi.org/10.1080/07481187.2020.1867255>
- Titlestad, K. B., Stroebe, M., Dyregrov, K. (2020). How do drug-death bereaved parents adjust to life without the deceased? A qualitative study. *OMEGA - Journal of Death and Dying*, 82(1), 141-164. <https://doi.org/10.1177/0030222820923168>

# Follow us!

- <https://www.facebook.com/ENDprosjektet/>
- <https://www.hvl.no/end>
- <https://www.hvl.no/forsking/konferanse/end-2021/>
- ENDkast, is now on Spotify:
- 
- <https://open.spotify.com/show/4ZEblfYoi4B4mWB2Ze7aSH?si=51fc4916d7a74d99>

The screenshot shows the Facebook group page for 'END-prosjektet'. The group has 64 members. A post from Kristine Berg Titlestad is visible, and there are sections for new members and a general introduction.

**Gruppeinnsikt:**

- Lukket gruppe
- Om
- Diskusjon
- Medlemmer
- Arrangementer
- Bilder
- Gruppeinnsikt
- Administrer gruppe

**Søk i denne gruppen:**

**Medlemmer:**

- Andrine Konfirmasjon
- Italia 2017
- Thailand 2016
- Villajoyosa
- Kleppestø Ungdomssko...
- KBP, kull 2011
- Vernepleier
- "RØST" - Brukerkonf...
- Oppslagstavle for Fol...
- Kråkestolsveien - "velfo...
- Se flere

**FESTET INNLEGG:**

Kristine Berg Titlestad har oppdatert beskrivelsen.  
2. februar kl. 18:38  
Etterlatte ved narkotikarelatert død» (END) er et nyoppstartet forskningsprosjekt ved Høgskolen på Vestlandet bestående av fire studier. Hvert år dør ca. 250-300 mennesker i Norge som følge av narkotikabruk. Prosjektet vil fremskaffe kunnskap for å belyse etterlates situasjon etter

**LEGG TIL MEDLEMMER:**

+ Skriv inn navn eller e-postadresse ...

**MEDLEMMER:** 64 medlem

Du har 51 nye medlemmer denne uken. Skriv et innlegg for å ønske dem velkommen.

**BESKRIVELSE:** Etterlatte ved narkotikarelatert død» (END) er et nyoppstartet f... Se mer

**TAGGER:** Legg til tag Legg til noen beskrivende nøkkelord.